Exploring the lived experience of control and well-being of older people living with frailty within the healthcare service provision in southern England

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Abstract

The high prevalence of frailty among the older population in the UK presents a critical policy challenge. Frailty is characterised by reduced functional capabilities and an increased risk of sudden health decline, resulting in significant personal and social limitations. To address this issue, it is crucial to enhance our understanding of the experiences of older people, as this facilitates a more humanising approach to healthcare. Central to this exploration is the concept of a sense of control—a vital element for older people within health and social care systems. A sense of control is intrinsically linked to their ability to influence their environment and achieve desired outcomes, both of which are fundamental for maintaining agency, dignity and well-being. Yet, there exists a gap in existing literature regarding the lived experiences of a sense of control and well-being among older people living with frailty, particularly in the context of healthcare utilisation.

This study employed a hermeneutic phenomenological approach to explore the lived experiences of control and its impact on well-being among older people living with frailty. Additionally, it incorporated perspectives from Day Hospital staff on factors that enhance control and well-being for older people living with frailty within healthcare services. Utilising a lifeworld theoretical framework, the research obtained insights through semi-structured interviews with 20 older people and 10 Day Hospital staff, who were purposefully selected. The analysis of the interviews with older people, guided by van Manen's principles of hermeneutic phenomenological reflection, revealed essential themes that were further enriched by insights drawn from the staff interviews.

The findings indicate that older people living with frailty often experience a gradual decline in bodily function, leading to a diminished sphere of influence. This challenge requires them to seek healthcare services in an effort to maintain a sense of normalcy amid uncertainty. Crucially, the study emphasises that a sense of control is not merely a static attribute but a dynamic experience for older people living with frailty, shaped by their interactions with healthcare providers. Recognising their insiderness can enhance their engagement with healthcare services, promote agency, and foster a greater sense of control. The findings also highlight the emotional aspects of healthcare services, underscoring the importance of often-overlooked existential elements of service provision. Ultimately, this research articulates a language and path toward improving healthcare services and the well-being of older people living with frailty.

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I cannot overlook the incredible contributions of my study participants, who gave of their time and allowed me to share in their experiences, enriching my research in profound ways. Your insights were invaluable, and I am truly grateful.

Most importantly, I want to dedicate this achievement to my beloved mum, Mrs Khamiyat Namusisi Hawa, who is no longer here to celebrate with me. Her love and wisdom have always guided me, and I feel her presence as I reflect on this journey. I also want to take a moment to honour my dear brother, Siraj Nyende, who sadly passed away while I was pursuing my PhD. Siro inspired, supported and motivated me in countless ways, and I carry his memory with me always.

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It has been a profound privilege to walk the PhD journey alongside such remarkable individuals, and I hope I have made them all proud.

Declaration

I declare that the material contained in this thesis has never been presented before for any award.

Adam Nyende:

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Date:

4th April 2024
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Glossary

BGS	British Geriatrics Society
BU	Bournemouth University
CQC	Care Quality Commission
eFI	Electronic Frailty Index
ESAB	Ethics Scrutiny Advisory Board
GDPR	General Data Protection Regulation
GP	General Practitioner
HRA	Health Research Authority
Ln	Line number (In the transcript)
NHS	National Health Service
NIHR	National Institute for Health Research
ONC	Office for National Statistics
OT	Occupational Therapist
PCC	Population, Concept and Context
Physio	Physiotherapist
PPI	Patient Public Involvement
PRISMA-ScR	Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews
REC	Research Ethics Committee
SCIE	Social Care Institute for Excellence
UK	United Kingdom
WHO	World Health Organisation

Chapter 1 Setting the Scene: A sense of control in older people living with frailty

1.1 Introduction

In this section, I will provide the context of my research project, highlighting my motivation to pursue PhD studies and the thought process that led me to choose my particular study area.

Looking back to my early school days in Uganda, I never imagined pursuing a PhD. I was not one of the top students in my high school, and I did not consider myself academically gifted. However, my perspective on my abilities changed after obtaining a first-class degree in my undergraduate studies. I realised that hard work and commitment could turn an average student into a high achiever. I became passionate about research and started working with former lecturers on various research projects while balancing a full-time job at the Ministry of Gender, Labour and Social Development. My desire to advance my research career led me to enrol in a Master's Degree programme. After completing my Master's Degree, I was fortunate to be offered a place in a prestigious PhD programme under the EU Horizon 2020 Marie Skłodowska-Curie Actions programme at Bournemouth University. However, I was conflicted about whether to continue my career as a civil servant in the social development sector or pursue a research career. I consulted with many people from industry and academia, but the more advice I received, the more confused I became. Making the decision was difficult as either choice meant sacrificing something important. For example, if I chose to pursue a research career, I would have to forego the progress I had made in civil service. On the other hand, if I decided to let go of the research opportunity, I would give up a chance to develop my most significant interest. I was convinced only after a conversation with a friend who mentioned that ‘a PhD makes you’. He added that my interest in research would not be enough to contribute or make a significant impact unless I developed a deep understanding of issues in my chosen field. This discussion led me to resign as a social worker and pursue a PhD programme.

This thesis is a part of the InnovateDignity project, a wider EU-funded project, providing a shared research and training agenda to educate the next generation of interdisciplinary care researchers and leaders across Europe. The project was a response to the global need to provide sustainable and dignified care for older people at home and in residential, municipal and hospital settings. The project comprised fifteen (15) research themes that were investigated by fifteen (15) Early-Stage Researchers (ESRs) under a consortium of nine (9) institutions of higher education and supported by non-academic partner organisations in Denmark, England, Greece, Norway and Sweden. The wider network focused on how older people experience care, how to support them in living well in care systems, and how technology, gender, and institutional factors can impact experiences of dignity and well-being. Additionally, the project studied new ways of engaging with older people to examine new kinds of care delivery in response to the growing lack of sustainability in older person care and evidence of current care failings.

Before joining the InnovateDignity project, I served as a social worker in Uganda, working with marginalised groups, including older people. Through my education and experience in social work, I became familiar with key aspects of older person care in the global south, such as human rights, power relations, and quality of care services. I encountered older people who faced challenges in accessing social and health services due to ageist attitudes within society and a care system that was not well-equipped to respond to the unique needs of older people. My professional experience piqued my curiosity about the challenges and opportunities for older person care in other contexts.

Joining the InnovateDignity project has been a significant milestone in my career. It has provided me with an opportunity to work alongside a multidisciplinary team of experts from various parts of the world who share the same passion as I do. My passion lies in understanding service users' experiences, and this project has allowed me to delve deeper into this area of interest. As a social worker, I have always prioritised the needs and preferences of my clients. Therefore, I was looking for a mutually beneficial PhD programme that would be enriched by my previous experiences and also benefit my practice.

I find the social vulnerabilities and the positive challenges of ageing fascinating and relevant research areas. My experience caring for my grandparents has shown me that many older people struggle with multiple health challenges that can include clinical syndromes such as frailty. In Uganda, frailty is not a widely used term among older people, as cultural interpretations of illness prioritise social and cultural meanings over biomedical ones. For example, health challenges which can be related to frailty, such as Parkinson’s disease, are often attributed to mental health challenges by the local population and are seen as requiring traditional or cultural interventions rather than medical ones (Kaddumukasa et al. 2015). Such perspectives make it difficult for professionals to communicate effectively with older people and society at large, as medical information is often perceived as conflicting with the dominant cultural norms and values surrounding ageing. Understandings from different worldviews can become unintended barriers. In the global north, frailty is a well-studied clinical syndrome affecting many older people; however, differences in worldviews may still be causing unintended barriers. I decided to focus my research on this topic because it provided an excellent opportunity to learn more and develop my thinking around the experience of living with frailty. My overall aim was to deepen my understanding of worldviews of frailty and to be able to contribute to service development in Europe and around the world.

At the start of my PhD programme, I had some initial ideas about the areas I wanted to study concerning older people living with frailty. However, selecting an appropriate research question proved to be quite a challenging task. I spent considerable time reviewing existing literature and working on several drafts to find my focus. With the help of my supervisors and colleagues from the InnovateDignity project, I went back and forth until I could choose a research question aligned with the project’s theme and feasible enough to fulfil the requirements for a doctoral degree. This was a difficult stage because I was new to almost all aspects of post-graduate research. It required patience, careful consideration, and consultation to ensure I established a strong foundation for the rest of the project, such as selecting the research methodology. I wanted to ensure my research question was relevant and reflected my personal and professional interests. I started by brainstorming a list of initial thoughts, taking into account the feasibility of the topic, the requirements of a PhD, and the research methodology.

One area that fascinates me is the sense of control, especially in the context of empowering individuals to manage their own lives and affairs. Claassens et al. (2014) proposed a model for supporting older people living with frailty to maintain control over their healthcare, which resonated with me. The model highlights internal and external factors that can support older people in taking responsibility for their healthcare and becoming more proactive. This model enables individuals to focus on their perceived efforts and the influence of external factors to take control of their healthcare and make a meaningful impact.

Through my experience working with older people, I knew that many of them have led active, independent lives. They have worked in various fields and managed families where they were the primary decision-makers. Furthermore, my reading suggested that supporting older people in remaining independent for as long as possible is a crucial component of successful ageing (Teater and Chonody 2020; Motamed-Jahromi and Kaveh 2021). However, as they age and suffer health-related challenges, older people may encounter obstacles that hinder their ability to achieve their desired outcomes or create a sense that their life is now controlled by fate or external factors. The public and policy discourse often implies that older people living with frailty have lost control and independence over different aspects of their everyday lives (Warmoth et al. 2016; Escourrou et al. 2019; Su et al. 2023). I wanted to challenge this negative stereotype and explore positive possibilities with older people living with frailty. This interest prompted me to investigate the sense of control older individuals living with frailty feel that they have over their healthcare to understand the possible factors which may make a positive or negative difference in this experience.

In the following section, I will elaborate on the concept of frailty in older people, the significance of adopting a humanising care approach, and the meaning of a sense of control for older people. Finally, I will end the chapter by providing an overview of the thesis. In qualitative research, the researcher is an integral part of the process. From my hermeneutic learning perspective (discussed further in the section on reflexivity, 6.7), I acknowledge that I conducted the research and that my understanding has evolved throughout my journey from the beginning of my PhD to the end. Therefore, I want to emphasise that my stance and position are central to this thesis. As a result, I have chosen to write this thesis from a first-person perspective (Wertz et al. 2011).

1.2 Understanding the meaning of frailty in older people

Frailty may not always be obvious and can sometimes be overlooked, especially in clinical evaluations focusing on specific medical sub-specialties or single-organ diseases (Turner and Clegg 2014). Nonetheless, there is some consensus in the literature regarding the models that can aid in grasping the notion of frailty. Research indicates two main models of frailty: the Phenotype model and the

Cumulative Deficit Model (Clegg et al. 2013; Turner and Clegg 2014; Woolford et al. 2020).

The phenotype model identifies five patient characteristics that can predict frailty and poor outcomes if present. These characteristics include ‘unintentional weight loss’, ‘reduced muscle and weak grip strength’, ‘self-reported exhaustion’, ‘reduced or slow gait speed’, and ‘low energy expenditure’ (Clegg et al. 2013; Turner and Clegg 2014; Alves et al. 2020; Sukkriang and Punsawad 2020). The model classifies individuals into different levels of frailty depending on the number of characteristics displayed. Those with three or more characteristics are considered frail, those with one or two are pre-frail, and those with none are considered robust or not frail (Fried et al. 2001; Liu et al. 2022; Macêdo et al. 2022; Chen et al. 2022a).

The Cumulative Deficit Model, on the other hand, defines frailty using a combination of ‘symptoms’ (such as low mood and loss of hearing), ‘signs’ (such as tremors), ‘diseases’, and ‘disabilities’ that are collectively referred to as deficits (Flaatten and Clegg 2018; Rogers et al. 2020). According to this model, as people age, the number of deficits accumulates, and the cumulative effect of these deficits determines an individual’s frailty. These deficits are combined to create an individual’s ‘frailty index’ (Rockwood 2005). As a result, the frailty index represents the proportion of potential deficits present in an individual and reflects the likelihood of frailty (Rockwood and Mitnitski 2007; Woolford et al. 2020).

Several tools have been developed and validated for screening frailty based on the abovementioned models. Some of these tools include the ‘Gait Speed Test’, ‘the PRISMA-7 questionnaire’, ‘the Timed Up and Go Test’ (TUGT) and the ‘Edmonton Frail Scale’ (Turner and Clegg 2014). In the UK, frailty has been considered a formal diagnosis since 2017 (Travers et al. 2019; Won 2020), and a new assessment tool called the Electronic Frailty Index (eFI) has been adopted within the NHS to identify the degree of frailty among people aged 65 and over (Clegg et al. 2016; Flaatten and Clegg 2018). The eFI is used by General Practices to identify older people living with varying levels of frailty based on the individual’s ‘cumulative deficits’ and their primary electronic health care data (Luo et al. 2022). It is based on an overall score of 36 points, indicating the sum of deficits present in a person, with a higher score indicating a higher degree of severity in frailty and increasing vulnerability to adverse outcomes (NHS England 2017). The eFI has demonstrated robust predictive validity for frailty-related adverse health outcomes, including hospitalisation, nursing home admission, and mortality, making it a critical tool for delivering evidence-based care interventions for older individuals (Clegg et al. 2016; Flaatten and Clegg 2018; Lin et al. 2023). Therefore, older people living with frailty often present multiple limitations that necessitate a range of integrated, compassionate, and personalised informal and formal care services (NHS England 2014; Souza et al. 2020).

The British Geriatrics Society (BGS) defines frailty as;

> *“a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves”* (BGS 2014, p.6).

Individuals may experience changes in multiple bodily systems; however, it is often the small physical, mental, social, and environmental changes that can suddenly and significantly impact health, contributing to the frailty syndrome (Clegg and Young 2011; Yeolekar and Sukumaran 2014). Minor events such as new medication and minor infections can trigger erratic health changes, placing older people living with frailty at long-term risk for disability, hospital/care or nursing home admission, increased care dependency, and even mortality (Fried et al. 2001; Clegg et al. 2013; Kojima 2015). Consequently, to better manage frailty in clinical settings, it is vital to identify and recognise frailty and its related care needs whenever a consultation occurs between healthcare providers and an older person (BGS 2014). It also requires a multidimensional approach rather than just focusing on a single disease (Abbasi et al. 2018; Sloane and Cesari 2018).

Studies have shown that frailty affects an average of 10.7 per cent of the global population, with a higher prevalence in low and middle-income countries (Majid et al. 2020; Qin et al. 2023). In the UK, 10 per cent of individuals aged 65 and above live with frailty, rising to 65 per cent for those over 85 years (Clegg et al. 2013; BGS 2014). However, it is essential to note that the prevalence of frailty varies due to the highly heterogeneous nature of the older population and a lack of consensus on the operational definition and diagnostic criteria for frailty (Clegg et al. 2013; Sloane and Cesari 2018; Kojima et al. 2019). Although not all older people are frail, evidence suggests that the onset of frailty is linked to old age, which is usually associated with reduced functional capacity and increased risks of diseases and disabilities due to cumulative deficits in multiple organ systems (Song et al. 2010; Nicholson et al. 2013; Turner and Clegg 2014; Kojima 2015). As a result, there will be a significant number of older health and social care service users in the UK (Reeves et al. 2018; Han et al. 2019; Sinclair et al. 2022; Walsh et al. 2023).

Frailty in old age is now described as a long-term health-related status whose onset is often marked by falls, decreased mobility, confusion, incontinence, and sensitivity to medication, which lead to increased exposure to adverse health outcomes (BGS 2014; Turner and Clegg 2014). Likewise, most older people living with frailty have some form of physical and/or mental health limitation, including visual, hearing, and cognitive impairments, are often prescribed multiple medications, and may face delayed hospital discharge (Turner and Clegg 2014). As a result, older people living with frailty may experience personal and social limitations that impact their overall quality of life (Portegijs et al. 2016; Saraiva et al. 2021; Rand et al. 2022; Ellmers et al. 2023).

Research has shown that many older people may not identify with the term ‘frailty’ and may be hesitant to engage with beneficial services (Britainthinks 2015; Warmoth et al. 2016; Nicholson et al. 2017; Schoenborn et al. 2018; Pan et al. 2019; Souza et al. 2020). This attitude is likely due to the negative connotations associated with frailty, such as loss of independence, dignity, and control over one’s life (Britainthinks 2015). However, it is crucial to understand that older people living with frailty still strive to maintain a sense of control in their lives (Underwood et al. 2020). Understanding how healthcare services can either promote or impede a sense of control is essential if services are to be most effective. This perspective also highlights the need for healthcare services to consider the broader human aspects of life and service user perspectives beyond the direct diagnosis, as well as how these affect a sense of control.

1.3 Need for a more humanising care approach

As the population of older people in the UK continues to grow, there is a growing emphasis on meeting their care needs in order to support their dignity and well-being (Ward et al. 2012; Abdi et al. 2019; Aujla et al. 2023). The focus on dignity and well-being is particularly important due to the significant shortcomings within the current health and social care context, which can be seen to be more ‘systems’ driven and less able to address the human needs of service users (Galvin et al. 2020; Amnesty International 2020; Lewis 2022). These limitations also affect older people dealing with frailty and related challenges, including long-term care needs. It is, therefore, crucial to recognise people’s care priorities to enhance their care service outcomes (NHS England 2014; van Oppen et al. 2022; Barker et al. 2023). One way to achieve this is to understand the lives of older people living with frailty as experientially lived. This approach will help in gaining a deeper understanding of their lives and enhance a more humanising care approach in a healthcare system mainly dominated by objectivity and *“the rules of modern science”* (Dahlberg 2011, p.19; Galvin et al. 2020; Ellis-Hill et al. 2021).

Despite the remarkable advancements in healthcare systems due to medical innovations, the healthcare approach is still dominated by the medical model

(Dahlberg 2011; Bunbury 2019; Huda 2021). This model emphasises individuals' measurable and biomedical aspects, which may obscure other dimensions of humanising lifeworld care, which consider the subjective lived experience of healthcare (Dahlberg 2011). To provide healthcare services that are more meaningful for those using them, it is essential to take into account aspects such as insiderness (recognising and valuing the subjective experiences and perspectives of individuals), embodiment (holistic understanding of an individual as an embodied being), agency (empowering individuals to make decisions about their care and take responsibility for their actions), uniqueness (recognising and respecting the individuality of each person), and togetherness (the importance of social connectedness and support in healthcare) (Todres et al. 2009; Borbasi et al. 2013).

However, healthcare professionals sometimes prioritise the medical condition over the whole person, leading to depersonalised and dehumanised care experiences (Dahlberg 2011). This reductionist view may make patients feel that the care they receive obscures their personhood because their thoughts, feelings, wishes, intentions, and other aspects of their existence that are not easily measurable or understandable may be ignored (Galvin and Todres 2013; Galvin et al. 2020). Therefore, there is a need to shift towards a holistic care approach that considers the whole person rather than solely focusing on their medical condition, as is often perceived in highly technical care settings.

In highly technical care contexts, a task-oriented approach often limits the communication between professionals and patients, leading to a depersonalised care experience (Almerud et al. 2007; Ruben 2016; Yoo et al. 2020). This approach involves healthcare professionals prioritising completing tasks and observing institutional routines over fostering meaningful interactions (Ruben 2016; Yoo et al. 2020; Kwame and Petrucka 2021). A task-oriented approach towards healthcare also means healthcare professionals may treat patients as mere bodies and objects whose health needs to be restored through medical and other care practices (Kwame and Petrucka 2021). This care approach can disempower the person as it generates *"the dilemma of others knowing how I am but not who I am,"* depriving individuals requiring care of their right to collaborate in the care process (Todres et al. 2000, p.279). The resultant limited human interaction and communication can lead to feelings of isolation and mistrust among patients as healthcare professionals find it challenging to attend to individual care needs or provide holistic care (Todres et al. 2000; Loghmani et al. 2014; Ellis-Hill et al. 2021).

In addition, the use of machinery in technologically intense care settings can limit human interaction, leading to dehumanising care practices (Ruben 2016; Lekka et al. 2022; Vasquez et al. 2023). For instance, using computer systems in healthcare services can sometimes distract healthcare professionals, reducing patient interaction and making care activities less personal (Haque and Waytz 2012; Price 2013; Kvande et al. 2022). Healthcare professionals may focus more on ensuring that instruments function correctly, which can cause them to lose sight of the person and their basic human and emotional needs (Stayt et al. 2015; Heras La Calle et al. 2017; Rodriguez-Almagro et al. 2019). This focus on technology rather than the person can leave patients feeling objectified, as their bodies are treated as objects for routine treatment activities (Slettmyr et al. 2022). Likewise, patients and their relatives may feel even more vulnerable and less able to influence their care as they tend to accept the authority and judgement of healthcare professionals (Lindberg et al. 2015; Stayt et al. 2015; Slettmyr et al. 2022). Moreover, caregivers in such care contexts often feel obligated to learn and use medical technology while also caring for the patient, striving to balance monitoring machinery and providing adequate attention to the patient (Almerud et al. 2008). Therefore, while technology is an essential component of healthcare, particularly in critical care settings, it should be balanced with humanising care practices to ensure dignified care and more control for the patient (Kvande et al. 2022).

Dehumanising care practices can negatively impact the quality of care provided to patients as they may have limited control during healthcare encounters. According to Jenkins et al. (2023), healthcare settings, particularly psychiatric hospitals, that use depersonalising practices such as restraint and seclusion can restrict patients’ control and autonomy. Such care practices often curtail freedoms and choices, risking patients’ psychological well-being (Demoulin et al. 2021). As a result, such care systems tend not to meet patients in ways that recognise their vulnerabilities and possibilities (Galvin et al. 2018).

In order to make care systems more humanising, it is necessary to reconsider the healthcare approach by focusing more on care aspects that are often taken for granted but can make people feel more human (Galvin and Todres 2013).

Todres et al. (2009) provide a value framework for humanising care stemming from the philosophical ideals of phenomenology and focusing on the lifeworld. This framework is based on eight dimensions (outlined in Table 1), which establish a value base for identifying potentially humanising and dehumanising healthcare possibilities (Todres et al. 2009; Galvin and Todres 2013). According to Todres et al. (2007, p.60), understanding the human experience in *"relation to time, space, body, others and mood is fundamental to describing the holistic context in which being human makes sense",* which in turn can be very useful in gaining a comprehensive understanding of the person at the receiving end of healthcare. The humanising framework is, therefore, centred on the core value of humanising care. It paves the way for 'lifeworld-led care', which is based on the perspectives and qualitative experiences of people as well as the lifeworld dimensions, which can all be applied through qualitative research methodologies such as phenomenology and narrative inquiry (Todres et al. 2007; Todres et al. 2009).

Table 1: ***Dimensions of the Humanising Care Framework***

Humanising dimensions	**Dehumanising dimensions**
Insiderness	Objectification
Uniqueness	Homogenisation
Togetherness	Isolation
Agency	Passivity
Sense-making	Loss of meaning
Personal journey	Loss of personal journey
Sense of place	Dislocation
Embodiment	Reductionist body

Insiderness is a humanising dimension highlighting the significance of acknowledging and valuing individuals' subjective experiences and viewpoints. Ignoring this dimension can lead to a lack of understanding of an individual's inward sense and subjective experience, often resulting in ***objectification*** by treating people as objects (Todres et al. 2009; Borbasi et al. 2013; Todres et al. 2014).

Uniqueness as a humanising dimension highlights the need to recognise and respect each individual's individuality. Dehumanisation occurs when individuals are treated as part of a homogenous group rather than as unique individuals, leading to ***homogenisation*** (Todres et al. 2009; Borbasi et al. 2013; Galvin and Todres 2013).

Togetherness highlights the significance of social connections and support within a community, which lays the foundation for empathy and mutual understanding of each other's struggles in a shared world. ***Isolation,*** conversely, involves separating people from social interactions, disrupting their sense of belonging and leading to dehumanisation (Todres et al. 2009; Borbasi et al. 2013; Galvin and Todres 2013).

Agency focuses on empowering individuals to take control of their care by making and being responsible for those decisions, reflecting the freedom to act within certain boundaries. In contrast, ***passivity*** involves practices that impose decisions on individuals, rendering them passive. Passivity typically happens when there is too much emphasis on technical problem-solving strategies, which can overshadow the human aspect of agency and lead to dehumanisation (Todres et al. 2009; Borbasi et al. 2013; Galvin and Todres 2013).

Sense-making focuses on people's capacity to derive significance and meaning from their seamless experiences. Dehumanisation, on the other hand, happens when this sense-making process is ignored. It reduces individuals to mere numbers and statistics that fail to reflect their human experiences, resulting in a *loss of* ***(personal) meaning*** (Todres et al. 2009; Borbasi et al. 2013; Galvin and Todres 2013).

Personal journey underscores the significance of acknowledging and supporting the individual's engagement with their past and future, not just their present. Neglecting an individual's history and future possibilities can lead to dehumanisation, disregarding their unique experiences and narrative, affecting a person's sense of continuity and leading to ***loss of personal journey*** (Todres et al. 2009; Borbasi et al. 2013; Galvin and Todres 2013).

Sense of place emphasises the significance of establishing a sense of place and a feeling of homeness that offers individuals security, familiarity, and continuity. On the other hand, dehumanisation occurs when people experience a sense of ***dislocation*** and detachment from their surroundings, causing them to lose a sense of place and ultimately feel like strangers in their environment (Todres et al. 2009; Borbasi et al. 2013; Galvin and Todres 2013).

Embodiment refers to the comprehensive understanding of an individual as an embodied being who lives life through their body, carrying felt meanings from their past and present into the future, affecting feelings and experiences moment by moment. These experiences are closely linked to the body's everyday limitations and potentials. Dehumanisation occurs when an individual is reduced to a mere set of physical symptoms or medical conditions, ignoring the more interpersonal aspects of the body, instead promoting a ***reductionist body*** (Todres et al. 2009; Borbasi et al. 2013; Galvin and Todres 2013).

It is important to note that these dimensions are not absolute or dualistic but instead represent possibilities along a continuum ranging from the positive (humanising) to the negative (dehumanising) and should be considered in the context and complexity of the caring situation (Borbasi et al. 2013; Nielsen et al. 2023). Additionally, the negative aspects (dehumanisation possibilities) should not be over-emphasised as there are caring situations when they may become vital to the well-being of the person receiving care (Todres et al. 2009). For example, within the context of intensive care, objectification by professionals through exclusive focus on technological definitions may be accepted by patients as necessary in defining their condition during treatment (Galvin and Todres 2013).

Accordingly, the humanising care framework helps us understand caring practices that can either humanise or dehumanise caring processes. As highlighted above, one key aspect of humanising care is agency, which involves supporting individuals in taking control of their care, including making care decisions and being accountable for those decisions. When these caregiving practices are absent, agency is diminished, leading to a sense of passivity. This aspect influenced the focus of this study, which is to explore the sense of control in older people living with frailty to improve their well-being.

1.4 Sense of control in older people

In this section, I will provide an overview of the concept of a sense of control in older people, including those living with frailty. This overview is important because it provides context for understanding policy priorities on a sense of control in old age, particularly in the UK. I have presented a detailed discussion on the sense of control, specifically among older people living with frailty, in Chapter Two.

A sense of control is an essential aspect of health and social care practice, particularly in the context of old age (Board and McCormack 2018; Lewis et al. 2019; Shippee et al. 2020; Hong et al. 2021; Kam 2023). Control generally describes people's beliefs in their ability to influence their environment, events and desired outcomes in life (Jónsdóttir and Ruthig 2021; Kondo et al. 2021; Chen et al. 2022b). Control has been theorised in various ways, but a key theory is the locus of control (Nowicki et al. 2021). The locus of control theory suggests that perceived control beliefs can be internal or external (Stolz et al. 2020; Murthy and Tapas 2021; Spyridaki and Galanakis 2022). Internal perceived control relates to the belief that life events and outcomes are contingent upon one's efforts and actions, while external perceived control is the belief that events, circumstances and outcomes are based on chance, fate and powerful others (Arakeri and Sunagar 2017; Nießen et al. 2022). Therefore, higher internal locus of control levels correspond to greater perceived control, while external locus of control levels indicate lower perceived control (Chukwuorji et al. 2017; Halse et al. 2022).

Claassens et al. (2014) build on the idea of locus of control to propose a model that helps us understand the concept of control, especially in healthcare for older people living with frailty. The model suggests that perceived control is the belief that healthcare is under control, which arises from multiple internal and external factors. The internal factors include self-confidence in organising professional and/or informal care, as well as self-confidence in health management in the home. On the other hand, the external factors include perceived support from people in the social network, perceived support from healthcare professionals and organisations, and perceived support from healthcare infrastructure and services. These factors collectively reinforce each other and contribute to the belief that healthcare is under control, reflecting the complex interplay between internal and external factors that influence perceived control among older people living with frailty (Claassens et al. 2014). This model has been applied in several studies focusing on control-enhancing strategies (Claassens et al. 2014; Claassens et al. 2016; Jacobs 2019; Souza et al. 2020).

Older people face multiple health problems that decrease their health and vitality resources, undermining their control efforts (Infurna et al. 2011; Halse et al. 2021). Such health challenges can also limit older people’s ability to function cognitively, socially and independently, affecting their beliefs regarding achieving desired health outcomes (Halse et al. 2021). However, the level of perceived control in old age varies among individuals and is considered to be influenced by several factors such as gender, socio-economic status, and ethnicity (Skaff 2007).

Although the available evidence is not definitive, recent studies suggest that older men tend to have a higher internal locus of control than older women in various aspects of life (Eng et al. 2020; Shao and Chen 2021). This difference can be attributed to the influence of gender socialisation, gender roles, and socio-cultural power imbalances on personality development (Schmitt et al. 2017). Similarly, older people with higher socio-economic status are likely to have a more heightened sense of internal control over their health than those with low socio-economic status (Infurna et al. 2011). This difference is because greater socioeconomic status, such as higher education, can lead to a more positive attitude towards health, motivating individuals to adopt healthier behaviours, such as better nutrition (Shao and Chen 2021). Additionally, studies show that older black and Asian individuals have a lower sense of control and may see less overall health gains from perceived control than their white counterparts (Shaw and Krause 2001; Assari 2017; Shippee et al. 2020). Therefore, it appears that older people are impacted in various ways by societal gender, financial, and racial inequalities and differentials. It will be interesting to see how these findings intersect with the personal, unique experiences and perspectives on control for older people living with frailty.

In the UK, the concept of control in health and social care is closely linked to personalised care (NHS England 2019a). Personalised care is an approach that supports the whole population in managing their physical, mental and social well-being while making informed choices and decisions, particularly when their health changes (Johnson et al. 2023). This approach empowers individuals by affording them more control and choice over how their care is planned and delivered by focusing on their unique needs, strengths, and preferences (NHS England 2019a). Personalised care interventions, such as personal budgets and direct payments, have given older people in the UK greater autonomy and control over their care, resulting in improved health and well-being outcomes (Gadsby et al. 2013; Rabiee et al. 2016; Baxter et al. 2020). As a result, personalised care has been identified as a critical priority under the NHS long-term plan (NHS England 2019b).

In addition, a sense of control has been found to enhance dignity in care**.** Dignity is a core value rooted in respect, autonomy and identity and is closely linked to fundamental human rights, such as personal freedom and responsibility, which are inherent to being a person (Clancy et al. 2021). The SCIE (2020) suggests that working with people in ways that recognise their involvement and inclusion, freedom and autonomy to choose, and skills and strengths can promote their dignity. In the UK, dignity in care has been promoted as a central theme in several policy documents. For instance, Care Act 2014 provides that local authorities should promote the well-being of individuals through personal dignity, which includes treating the individual with respect. Similarly, the Care Quality Commission recommends that to meet Regulation 10 of the Health and Social Care Act 2008, providers should ensure that care and treatment are delivered in ways that enhance people's dignity and respect at all times to guarantee their autonomy, independence, and involvement (CQC 2023). Thus, enabling older individuals to control various aspects of their lives, such as care and treatment, can promote dignified care (Rasmussen and Delmar 2014).

Therefore, the goal of healthcare practice should be to reinforce older people's perceived internal health locus of control, which is vital for improved physical and mental health outcomes (Zhang and Jang 2017; Musich et al. 2020; Dogonchi et al. 2022). It has been observed that empowering health and social care service users, particularly older people, to have more control over their health can enhance their participation in care and improve healthcare outcomes (Age Cymru 2019). For instance, providing service users with appropriate information about their health and considering their concerns in care decisions can increase their participation and control over healthcare decisions (Bastiaens et al. 2007; Krist et al. 2017; Ringdal et al. 2017). Building a trusting and caring relationship and supporting individuals to make choices and take actions in their lives, including their care, environment, and personal relationships, can also help facilitate control in health and social care practices (Claassens et al. 2014; Samulowitz et al. 2019; Segers et al. 2022).

The discussion above emphasises the importance of control in healthcare, which requires a better understanding of this concept from the perspective of individuals receiving healthcare. However, there is limited research on the experiences of older people living with frailty in healthcare, even though they represent a significant proportion of healthcare service users (Souza et al. 2020; Ambagtsheer and Moussa 2021; Ikonen et al. 2022). It is crucial to conduct empirical research to gain a deeper understanding of the experience of control in healthcare among older people living with frailty. This is important because they are often seen as weak and in *“need of substantial level of care and support”,* even though they resist the label of frailty, which may signify their desire to have more control over their lives (WHO 2004, p.26; Nicholson et al. 2013). The essence of understanding this experience lies in shedding light on what both older people and healthcare professionals consider necessary for enhancing a sense of control in healthcare services. These insights can shape future research, practice, and policy related to service provision and promote a sense of control and well-being in older individuals with frailty.

1.5 Understanding well-being

Well-being is a complex and multifaceted construct representing a significant outcome of high-quality life experiences (Addo et al. 2021; Ryff et al. 2021). It can be characterised by a preference for positive effects over negative effects and pleasant emotions over unpleasant ones (Bourne 2010). Furthermore, well-being encompasses a value judgment regarding one’s life, framing existence in positive terms, often referred to as a ‘good life’ (Moreno-Leguizamon 2014; Majumdar et al. 2020). The conceptual origins of well-being can be traced back to the philosophical works of Greek philosophers, such as Aristotle and Plato, who characterised happiness as the ultimate state of virtue and as a subjective evaluation of one’s existence (Tenaglia 2007; Reich et al. 2007; Moreno-Leguizamon 2014). This philosophical foundation can be seen as giving rise to two principal dimensions of well-being: hedonic and eudemonic well-being (Deci and Ryan 2008; Oades and Mossman 2017; Ryff et al. 2021). Hedonic well-being centres on pursuing happiness, defining well-being as pleasure attainment and pain avoidance (Deci and Ryan 2008; Gallagher et al. 2009; Ryff et al. 2021). This dimension is often associated with feelings of happiness, life satisfaction, and a general prevalence of positive affect, coupled with lower levels of negative affect

(Dodge et al. 2012). Conversely, eudemonic well-being emphasises the ongoing pursuit of one's human potential and self-actualisation (Deci and Ryan 2008; Gallagher et al. 2009; Ryff et al. 2021). This dimension is closely linked to concepts of positive psychological functioning and human development (Dodge et al. 2012; Gale et al. 2013). Through self-determination theory, Ryan and Deci (2000) articulate that eudemonic well-being is optimally achieved when individuals fulfil their psychological needs for competence, relatedness, and autonomy. While distinctions exist between hedonic and eudemonic well-being, these dimensions often overlap, collectively contributing to the overall well-being of individuals (Gale et al. 2013; Disabato et al. 2016). This intersectionality may explain the rationale behind well-being frameworks in various fields that incorporate both hedonic and eudemonic elements, conceptualising well-being as a state characterised by *"feeling good and functioning well"* (Huppert and So 2013, p. 839).

Fields such as economics, health sciences, and psychology have used positivist epistemology to assess well-being through both hedonic and eudaimonic lenses, frequently employing quantitative indices and concepts such as quality of life, life satisfaction, subjective well-being, and happiness (Stanley and Cheek 2003; Allen 2008; Moreno-Leguizamon 2014). These measurements typically rely on single or multiple-item scales to quantify well-being (Stanley and Cheek 2003; Tenaglia 2007; Age UK 2017). This approach is rooted in the dominant positivist paradigm, which posits that well-being constitutes an objective phenomenon amenable to measurement, prediction, and manipulation through empirical research methodologies, including surveys and scales (Moreno-Leguizamon 2014). However, these measures, often translated into Gross Domestic Product (GDP) or Gross National Product (GNP), have proven inadequate for capturing the complexity of societal functioning (Hamblin 2019). Similarly, in several instances, well-being is inferred from constructs such as life satisfaction and affect, which may not represent the holistic perspective on well-being, particularly in older populations (Stanley and Cheek 2003). Furthermore, the understanding of well-being is frequently constrained by a biomedical lens, wherein it is narrowly defined as the absence of disease and dysfunction, thereby limiting it to a narrow perspective (Bourne 2010; Majumdar et al. 2020). It is imperative that well-being resonates meaningfully with lay individuals and is recognised as pertinent to policy and health outcomes by professionals (Knight et al. 2014). Consequently, it becomes essential to explore and understand the concept of well-being within diverse population groups, including older people.

As the population of older people in the UK continues to grow, concerns regarding their overall well-being have emerged (Age UK 2017; McKinlay et al. 2021). Many older people experience life challenges and high levels of dissatisfaction, which affect their overall well-being (Age UK 2020). The significant life transitions that often occur in this demographic are linked to adverse outcomes for healthy ageing, including increasing morbidity and comorbidity, age discrimination, economic hardship, and social exclusion (Allen 2008; Knight et al. 2014). These factors suggest that older people frequently find coping with life events and related stressors challenging, undermining their well-being (Allen 2008). For example, the COVID-19 pandemic highlighted the disproportionate impact of life stressors on the well-being of older people (Heid et al. 2021; McKinlay et al. 2021). The effect of such life challenges on older people's well-being is particularly evident among those who are impoverished, bereaved, in poor health, have unmet needs, living alone, or residing in care facilities (Allen 2008; Age UK 2020). Furthermore, the rise of neoliberalism as an economic paradigm has shifted the emphasis towards promoting free markets and individual responsibility for financial well-being in later life, leading to reductions in public welfare spending and the privatisation of care services for older people, particularly in the UK (Knight et al. 2014; Ward et al. 2020). This shift has adversely impacted the quality of care and overall well-being of older people, who are often encouraged to engage with their communities but simultaneously perceived as economic burdens by the working population (Powell 2014; Knight et al. 2014). Nevertheless, it is essential to recognise that not all older people experience diminished well-being and that it is possible to experience high levels of well-being in old age despite the challenges associated with ageing (Age UK 2020). Indeed, the level of well-being among this population group is influenced by a myriad of protective and risk factors, including lifestyle choices, preceding life stages, cultural context, current demographic trends, and prevailing policy frameworks (Knight et al. 2014). Similarly, many older people actively strive to confront life stressors, realise their potential, and contribute to society, thereby maintaining their well-being (Allen 2008). These positive efforts underscore the necessity for research and interventions that emphasise wellness over illness and dysfunction in older people (Bar-Tur 2021).

The concept of well-being in old age has emerged as a significant policy priority, particularly within the UK context (Ward et al. 2012; La Placa et al. 2013). The white paper titled *'Caring for Our Future: Reforming Care and Support'* represents a pivotal policy development, underscoring the need for local authorities to prioritise the independence and well-being of older people to mitigate or delay the onset of crises necessitating formal care (Department of Health 2012). Similarly, Care Act 2014 articulates a holistic approach to individual well-being, promoting outcomes such as dignity, physical and mental health, protection against abuse and neglect, autonomy in daily life, societal engagement, social and economic well-being, support for personal and familial relationships, adequate living conditions, and recognition of community contributions. The foundational principles of these policy priorities signal a transition from crisis management to the provision of preventive services that facilitate healthy lifestyles and reablement, aimed at reducing challenges associated with isolation, deterioration and the need for support (Hamblin 2019). Policy recommendations concerning the well-being of older people also emphasise ensuring independence, addressing support needs, and facilitating end-of-life care (Fell and Lukianova 2017). Importantly, these policy frameworks advocate a shift from merely supporting healthy ageing to enhancing overall happiness in later life, highlighting the interconnectedness between well-being and how care is delivered by professionals across diverse care settings (Knight et al. 2014; Bar-Tur 2021).

However, despite the UK's ambitious and forward-thinking policy initiatives concerning well-being, these efforts have not been sufficiently supported by the necessary political will, resources, and quality care, leading to well-being disparities among older people (Allen 2008; Knight et al. 2014; Hamblin 2019). Furthermore, the perspectives of older people regarding their well-being are frequently overlooked in broader discussions on this topic (Stanley and Cheek 2003). Given the current and projected increase in the population of older people, the urgency of prioritising their well-being in the UK context becomes increasingly pronounced (Allen 2008; Ward et al. 2012; Age UK 2020).

The concept of well-being in older people is often framed within the broader frameworks of positive psychology and the notions of positive or successful ageing (Bar-Tur 2021). Positive psychology focuses on studying human flourishing and optimal functioning across individuals, groups, and institutions (Gable and Haidt 2005; Bar-Tur 2021). This discipline draws significantly from the foundational contributions of psychologists Martin Seligman and Mihaly Csikszentmihalyi, who articulated the essential tenets of positive psychology (Seligman and Csikszentmihalyi 2000). Their work encouraged a shift from psychology's predominant emphasis on the medical model or pathological frameworks that typically characterise individuals' responses to life's challenges. Instead, they underscored the importance of exploring factors contributing to a meaningful existence, such as hope, creativity, courage, responsibility, resilience, and perseverance (Peterson and Park 2014). Central to positive psychology is the notion of well-being (Lambert et al. 2015). The principal objective of positive psychology is to cultivate positive attributes--such as positive emotions, creativity, perseverance, and work engagement--within individuals and groups rather than merely addressing deficits and vulnerabilities (Park et al. 2014). These positive attributes serve as protective factors against the adversities encountered in life, thereby making promoting these qualities a priority among older people (Seligman and Csikszentmihalyi 2000). The attributes associated with positive psychology extend to positive ageing, often interchangeably referred to as successful ageing (Marks 2021). Positive ageing encompasses effectively coping with life events related to the ageing process (Bar-Tur 2021). Successful ageing is also associated with the degree of autonomy individuals experience about their care preferences and life choices (Knight et al. 2014). These choices are often related to concepts such as ageing in place, which prioritises the ability to remain in one's home for as long as possible, which significantly contributes to the subjective well-being of older people (Hammarström and Torres 2012; Sun et al. 2023; Wang et al. 2024). Consequently, the principles of positive psychology and successful ageing can provide a solid foundation for enhancing the well-being of older people.

To effectively enhance the well-being of older people, a clear articulation of the meaning of well-being in this population group is imperative. This necessity arises from a notable lack of consensus and clarity regarding the definition of well-being in the older population (Stanley and Cheek 2003). This challenge has been similarly observed in the literature addressing well-being in general terms (Dodge et al. 2012). Well-being is recognised as a multifaceted construct that may be explored from individual and societal perspectives, complicating its conceptualisation (Knight et al. 2014). As Dodge et al. (2012) highlighted, many prevailing definitions of well-being remain broad and ambiguous, predominantly emphasising various dimensions rather than presenting a concrete definition. Furthermore, the existing literature indicates a limited consensus on the essential elements constituting well-being (Gale et al. 2013). For instance, well-being is often understood through and interchangeably used with constructs and dimensions that describe it rather than define it, such as quality of life, life satisfaction, and mental health (Morrow and Mayall 2009; Dodge et al. 2012; Oades and Mossman 2017). Consequently, this inherent complexity renders the definition and measurement of well-being challenging, often resulting in confusion and inconsistencies across various disciplines and research domains (Pollard and Lee 2003; Forgeard et al. 2011; Dodge et al. 2012; Oades and Mossman 2017).

To address the concerns above, there is a proposal to develop a more precise definition of well-being that transcends mere descriptions of the concept, providing a clear and unambiguous articulation of its exact meaning (Dodge et al. 2012). Proponents of this perspective argue that such specificity is essential for formulating a unifying conceptual framework that accommodates the diverse constructs associated with well-being (Dodge et al. 2012; Willroth 2023). For instance, Dodge et al. (2012) suggest that well-being should be understood as a state of equilibrium wherein individuals possess the psychological, social, and physical resources necessary to confront particular psychological, social, and/or physical challenges. However, other researchers advocate for a holistic definition of well-being, proposing that a singular definition may be insufficient (Forgeard et al. 2011). Allen (2008), for example, defines well-being broadly in terms of emotional well-being, encompassing the prevalence of low-level mental health issues such as depression, anxiety, stress, panic disorders, phobias, and obsessive-compulsive disorders, along with life satisfaction and levels of happiness. Regardless of the particular stance taken, it is imperative to understand how well-being is conceptualised, as this clarity is essential for adequate definition, measurement, and enhancement of well-being (Oades and Mossman 2017). This understanding is also vital for guiding researchers to take a position on conceptualising this crucial aspect of daily life, which has significant outcomes.

I align with the argument proposed by Forgeard et al. (2011) that a single definition of well-being may be inadequate for grasping its multifaceted nature, as such an approach risks overlooking other essential dimensions of well-being. This concern is particularly salient when considering the well-being of older people--a heterogeneous demographic with diverse experiences regarding the physiological processes of ageing and the structural conditions that either facilitate or obstruct well-being (Knight et al. 2014). Therefore, it is vital to appreciate the holistic nature of well-being by employing definitions and measures encompassing both hedonic and eudaimonic components (Ruggeri et al. 2020).

In this context, this thesis adopts the definition of well-being in older people as articulated by Ward et al. (2012). This definition states that older people experience well-being by faring in five domains: people, health, care and support, resources and places and environment (Ward et al. 2012). The ‘people’ domain relates to maintaining relationships with family members, friends, neighbours, pets, animals and even strangers. The ‘health’ domain relates to preserving the fluctuating health of the individual and their family members and managing illnesses and disabilities. The ‘care and support’ domain relates to giving and receiving care and support services when required from formal and informal carers. The ‘resources’ domain relates to managing personal resources, such as resilience and adaptability, and practical resources, such as finances, technology and keeping active, which are considered enablers of well-being. The ‘places and environment’ domain relates to the feeling of safety and ‘homeness’ that comes with the place of residence and its environment (Ward et al. 2012).

The above definition is particularly relevant as it accounts for personal and structural factors that influence well-being and centres the definition around the individual’s circumstances (Knight et al. 2014; Hamblin 2019). Rather than understanding well-being as simply an individual quality, the definition looks at well-being as a dynamic state that can be created and seen through people and their relationship with the world in which they live (Ward et al. 2012). Additionally, it resonates with Marks and Shah’s (2004, p. 2) assertion that *“well-being is more than just happiness. Along with feeling satisfied and happy, well-being means developing as a person, being fulfilled, and making a contribution to the community”.* Consequently, to cultivate a more nuanced understanding of well-being in older people, it is essential to grasp its holistic meaning, considering the bio-psychosocial and environmental dimensions and the perspectives of older individuals and their significant others (Bourne 2010). Qualitative research methodologies such as phenomenology and grounded theory may serve as effective approaches to achieve this understanding (Stanley and Cheek 2003). However, in this thesis, I primarily focus on understanding the sense of control in older people living with frailty and how this affects their well-being while considering well-being as a secondary focus.

1.6 Overview of thesis

This thesis is divided into seven major chapters.

1.6.1 Chapter One

In this opening chapter, I presented an introduction and background to my study and thesis, including an overview of my motivation for pursuing a PhD under the InnovateDignity project. In addition, I delved into the meaning of frailty in older people and its clinical diagnosis. I also provided a case for adopting a humanising approach to healthcare practice. I then shed light on the significance of control in older people as well as the meaning of well-being in the context of this thesis. I conclude this chapter by providing an overall outline of my thesis.

1.6.2 Chapter Two

Chapter two examines the available literature on the sense of control in older people living with frailty, highlighting the gaps in the current knowledge base. In this chapter, I provide an overview of the topic and describe the methods and materials used for the literature review. I then comprehensively evaluate the existing literature, categorising it into three distinct themes. These themes include Control as conveyed in bodily expressions and daily activities, Sense of control and influence of place of residence, and Control within health and social care relationships. I also discuss the gaps in the current literature that have informed the present study. To conclude the chapter, I outline the aims of the present study.

1.6.3 Chapter Three

In this chapter, I will introduce the theoretical framework that I used in my study, which is the lifeworld framework. This chapter will cover the meaning of the lifeworld concept and its different dimensions, including embodiment, temporality, spatiality, intersubjectivity, and mood. I will explain what each of these dimensions means and how they are interconnected. Finally, I will highlight the link between the lifeworld framework and qualitative research.

1.6.4 Chapter Four

In this chapter, I will delineate the methodology used in this study and the reasons behind the methodological decisions. Firstly, I will provide an overview of the ontological and epistemological positions that guided the study and the research methodology, including the different qualitative research approaches. Secondly, I will discuss phenomenology as the preferred approach. I will then explain why I selected the hermeneutic phenomenological method to guide the data collection and analysis. Additionally, I will provide details about other key research processes that I undertook, including the PPI, ethical approval, and study sample selection. Lastly, I will conclude this chapter with a section on rigour.

1.6.5 Chapter Five

In this chapter, I will present the results of the study. First, I will give an overview of the study participants and their socio-demographic characteristics. I will then analyse the themes that emerged from the data analysis. These themes include the diminished sense of control as manifested through a shrinking sphere of influence in everyday life, the perceived sphere of influence affected by the healthcare experience, and the home serving as a secure base for navigating an insecure future. Finally, I will conclude the chapter with a model of a sense of control over healthcare services for older people living with frailty.

1.6.6 Chapter Six

In this chapter, I will use the lifeworld framework to discuss the main findings and how they relate to the available literature. Additionally, I will highlight the study's strengths and limitations. This chapter will also emphasise the study's implications and recommendations and provide a section on reflexivity. I will conclude this chapter with a brief discussion of how the findings from this thesis apply in the current healthcare services context and what I would do differently if I undertake this study again.

1.6.7 Chapter Seven

In this final chapter, I will summarise the thesis and the new knowledge derived from the study. I will also discuss the impact of the study findings on my current and future professional practice.

Chapter 2 Literature Review

2.1 Introduction to the chapter

In this chapter, I review the existing literature on the sense of control in older people living with frailty, using a scoping review framework to identify gaps in current knowledge. I follow the PRISMA-ScR checklist to present the chapter, beginning with the title of the scoping review and an overview of the topic, including the rationale and objectives for conducting the review. I then describe the method used for the scoping review and present results in three distinct themes. Additionally, I discuss the results, highlighting gaps in the current literature that have informed the present study. Finally, I outline the aims of the present study to conclude the chapter.

2.2 Title

A Sense of Control and Wellbeing in Older People Living with Frailty: A Scoping Review.

2.3 Structured summary

A sense of control is vital for supporting older people living with frailty in developing adaptive functioning to optimise well-being. This scoping review examined the literature on the sense of control and well-being of older people living with frailty in their everyday lives and care service use. Using the Arksey and O'Malley (2005) scoping review framework, I searched nine databases, including PubMed, PsycINFO, Medline Complete, Web of Science, Social Care

Online, Science Direct, Scopus, CINAHL Complete, SocINDEX, to identify key ideas regarding control and well-being in older people with frailty. The inclusion criteria for the review included papers focusing on experiences of control and well-being, papers focusing on the perspectives of older people living with frailty aged 60 years and above, papers focusing on the perspectives of formal and informal carers for older people living with frailty, papers focusing on empirical/primary research, studies undertaken in different health and social care settings, including, hospitals, nursing homes and the community, both quantitative and qualitative papers, studies published between 2000-2021, studies published in English, studies that were undertaken worldwide and papers from reference lists of included papers. The key search components included Population (older people living with frailty), Concepts (sense of control, well-being) and Context (hospital, home, community, nursing/care home, and municipal). The review highlighted three major themes: a) Control as conveyed in bodily expressions and daily activities, b) Sense of control and influence of place of residence, and c) Control within health and social care relationships. Maintaining a sense of control is not only an internal feeling but is impacted by physical and social environments. Greater focus is needed on the nature of relationships between older people living with frailty and those who work alongside them, which support control and well-being.

2.4 Introduction to the review

As discussed in Chapter 1, the ageing process is often accompanied by the development of complex co-morbidities associated with chronic diseases, illnesses, and injuries (Oliver et al. 2014; Buckinx et al. 2015; De Donder et al. 2019). These conditions can lead to a decline in bodily reserve and functional ability, increasing the susceptibility of older individuals to stressors (Mohile et al. 2009; Pivetta et al. 2020; Jędrzejczyk et al. 2022). This vulnerability can culminate in frailty syndrome, where even minor changes can have a significant impact on the physical and mental health of the individual (Nicholson et al. 2013; Turner and Clegg 2014; Kojima 2015; Villacampa-Fernandez et al. 2017). Frailty primarily manifests as physical decline on two levels: the individual and contextual bodies. The individual body refers to the person's body and its problems, such as ailments and injuries. In contrast, the contextual body refers to the body's limitations concerning the physical and social surroundings, such as the inability to perform daily living activities independently (Ekwall et al. 2012). These deficits and constraints increase the risk of adverse health outcomes, such as admission to higher care levels, emergency hospitalisation, prolonged hospital stay, and increased mortality (Andrew et al. 2012; Dent and Hoogendijk 2014; King et al. 2017; González-Bautista et al. 2020). Consequently, older people living with frailty often report poor self-rated health and low levels of life satisfaction (Abu-Bader et al. 2003; Johannesen et al. 2004; King et al. 2017).

The perception of health in older people living with frailty is significantly influenced by psychosocial factors, particularly the sense of control (Dent and Hoogendijk 2014; Gale et al. 2014; Elliot et al. 2018). Understanding the role of psychosocial factors in health perception is therefore vital as it highlights the complex interplay between physical and psychosocial health among older people living with frailty

(Lloyd et al. 2016; Ye et al. 2021). Although there is no definitive or all-encompassing definition of the concept of control, the literature indicates that it has been examined from various dimensions. These include perceived control, self-efficacy, personal mastery, locus of control, control beliefs, learned helplessness, and primary and secondary control (Skinner 1996). Fundamentally, these dimensions are interconnected to influence individuals' ability to achieve desired outcomes or to feel that life changes are within their control rather than being dictated by fate or external factors (Kempen et al. 2005; Lachman et al. 2011; Robinson and Lachman 2017). Consequently, a perceived sense of control often translates into personal and social resources that individuals can use to effectively manage their daily life and environment and adapt to challenges associated with ageing, including frailty (Kempen et al. 2003).

Maintaining a sense of control is vital for individuals living with frailty. They must manage changes and limitations in their bodies to prevent deterioration and maintain their well-being (Kempen et al. 2003; Underwood et al. 2020; van Oppen et al. 2022). Research has shown that frailty is associated with reduced mobility and independence, leading to a loss of control, often linked to adverse outcomes such as falls in older individuals (Billot et al. 2020; Ellmers et al. 2023). This loss of control can impact one's sense of identity and self-worth as one struggles to maintain authority over the body and environment (Archibald et al. 2020).

Additionally, a perceived lack of control negatively influences the risk and incidence of frailty in older people. Studies indicate that diminishing levels of control increase the likelihood of frailty in old age (Dent and Hoogendijk 2014;

Gale et al. 2014; Infurna and Gerstorf 2014; Elliot et al. 2018). For example, a decline in components of psychological well-being, such as control, is associated with pre-frailty and frailty as people's emotional state can influence frailty-inducing health behaviours such as poor diet, smoking, and limited exercise (Gale et al. 2014; Eze et al. 2023). In addition, older people living with frailty with a low sense of control are more vulnerable and often possess low levels of resilience to cope with or recover from an acute episode of illness (Milte et al. 2015). The demonstrated link between frailty and lower psychological well-being supports the argument that frailty is more than just a physical condition and encompasses psychological aspects (Andrew et al. 2012; Zhao et al. 2023).

On the other hand, perceived control is crucial in preventing frailty in old age, acting as a buffer against challenges that contribute to frailty (Milte et al. 2015; González-Bautista et al. 2020). Studies show that perceived control moderates the impact of low socioeconomic status and chronic stress on the development and progression of frailty in older individuals (Pudrovska et al. 2005; Barbareschi et al. 2008; Dent and Hoogendijk 2014; Mooney et al. 2018). For instance, González-Bautista et al. (2020) found that older individuals with low socioeconomic status but with higher levels of perceived control can have similar health levels to those with a better socioeconomic status. This underscores the importance of a heightened sense of control in protecting against the effects of low socioeconomic status on self-rated health, including frailty.

Despite the bi-directional relationship between perceived control and frailty, the evidence is unclear as to whether the adverse health outcomes in the form of frailty precede the loss of control or the limited sense of control that contributes to frailty. Regardless of the trajectory, however, the above findings make it clear that losing control is one of the primary losses experienced in old age and that such losses are linked to the onset of frailty (Dent and Hoogendijk 2014; King et al. 2017).

Research indicates that as individuals age, regardless of their frailty status, they tend to feel less in control (Ross and Mirowsky 2002; Wolinsky et al. 2003; Barbareschi et al. 2008). However, there is a growing emphasis on fostering a sense of control among older people to mitigate adverse physical and mental health outcomes (Skaff 2007; Kim 2020; Hong et al. 2021). Perceived control is a critical psychological factor that enhances coping and adaptive behaviours, enabling older individuals to leverage available resources to manage life stressors and maintain their psychological well-being (Caplan and Schooler 2007; Firth et al. 2008; Robinson and Lachman 2017). Additionally, perceived cognitive control is linked to greater emotional regulation, which is crucial for enhancing emotional well-being and cognitive performance in older individuals, providing a sense of emotional security (Lachman 2006; Charles and Carstensen 2010; Zahodne et al. 2015; Robinson and Lachman 2018). Furthermore, a sense of control is associated with the adoption of positive health behaviours such as adherence to treatment, maintenance of a healthy diet, and regular physical activity, all of which are vital for improving health outcomes in old age (Barbareschi et al. 2008; Brookes 2023).

From the evidence above, individuals who feel in control of their lives tend to experience better mental and physical health outcomes. These outcomes are linked to lower levels of disability, quicker recovery of bodily functions, and a reduced risk of mortality, particularly among older people facing a gradual decline in functioning (Bailis et al. 2001; Kempen et al. 2003; Kempen et al. 2005; Popova 2012; Ward 2013; Turiano et al. 2014; Assari 2017). Therefore, fostering a sense of control is widely recognised as an essential component of successful ageing and research on older person care highlights the importance of empowering older people to take more control of their health and well-being (Kunzmann et al. 2002; Lachman et al. 2009; Infurna et al. 2013; Oliver et al. 2014; Turiano et al. 2014).

Although it is well-known that a sense of control is crucial in old age, there is limited research that explicitly examines control in specific categories of older people. Previous reviews on the topic have mainly focused on older people in general (Robinson and Lachman 2017; Lorente et al. 2018; Abdi et al. 2019), and no scoping review has explicitly targeted the sense of control in older people living with frailty. This gap in research hinders the development and maintenance of psychosocial resources, as well as the identification of factors that limit control and increase frailty in older people, ultimately compromising their resilience and well-being, making them more susceptible to adverse health outcomes (Nicholson et al. 2012; Claassens et al. 2014; Dent and Hoogendijk 2014; Milte et al. 2015). Consequently, I conducted a scoping review following the five key stages of the Arksey and O'Malley (2005) framework and incorporated recommendations from Levac et al. (2010) to enhance clarity and methodological rigour. I also used the PRISMA-ScR checklist to report the review.

2.4.1 Rationale

In the introduction above, I have established the rationale for conducting the review in the context of the existing knowledge of the topic (Maggio et al. 2021). It was important to clarify this by linking the purpose of the review to the review question and envisioning the desired outcomes (Levac et al. 2010). These outcomes included examining the extent, range, and nature of research activity related to a sense of control and well-being in older people living with frailty in their daily lives and their use of health and social care services, as well as identifying research gaps in the existing literature to inform future primary research on the topic (Arksey and O'Malley 2005; Peters et al. 2020). As such, I ensured my review question was as broad as possible to understand the research activity on the topic, which lends more to a scoping review than other reviews, such as systematic reviews (Arksey and O'Malley 2005). By considering the purpose and the review question together, I was able to justify conducting the scoping review and guide decision-making processes in subsequent stages, particularly in study selection and data extraction (Levac et al. 2010).

2.4.2 Review question

The first step in the scoping review process is identifying an appropriate review question, which forms the basis for the subsequent search steps (Arksey and O'Malley 2005). This step took into account various aspects, including ongoing debates, discussions, and the findings from previous reviews and primary research on the aspects related to the care for older people living with frailty. I intended to explore the literature on how older people with declining health and functional abilities can maintain control over their health, social care, and everyday lives and how this impacts their well-being. I, therefore, aimed to develop a review question that would guide me in gaining a better understanding of the available literature on the sense of control and well-being in older people living with frailty to identify gaps to inform primary research.

Additionally, I sought a review question that would be broad enough to cover a wide range of literature (Arksey and O'Malley 2005) but specific enough to give my review a clear focus (Levac et al. 2010). To accomplish this, I utilised the PCC (Population, Concept, and Context) components of the topic area to define the review question (Arksey and O'Malley 2005; Levac et al. 2010). Although the methodologies of Arksey and O'Malley (2005) and Levac et al. (2010) do not explicitly refer to the PCC framework, the Joanna Briggs Institute (JBI) strongly recommends using this framework to clearly define and ensure consistency between the scoping review title, questions, and eligibility criteria (Peters et al. 2020). The PCC mnemonic has been applied in other scoping reviews to define review questions and eligibility criteria (Iannantuono et al. 2021; Rajwar et al. 2021). I have summarised the PCC components of this review in the table below.

Table 2: ***The components of the scoping review topic area***

Population	**Concepts**	**Context**
Older People living with frailty	Control Well-being	Health and social care settings such as Hospitals, Community or Home, Intensive Care Units, Nursing or Care homes

Consequently, the chosen question for this scoping review was: "*What is known about control and its relation to well-being in older people living with frailty within their everyday life and their use of health and social care services?".*

After defining and clarifying the review question and purpose, I used them to establish the inclusion and exclusion criteria and the search strategy. This strategy helped me define the review scope and identify the relevant studies, all of which form part of the scoping review methodology (Arksey and O'Malley 2005; Levac et al. 2010). In the next section, I discuss how I applied my chosen methodology.

2.5 Methods

I conducted this review using the scoping review methodology. The scoping review methodology is defined as an approach that aims to:

> *"map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as a standalone project in their own right, especially when an area is complex or has not been reviewed comprehensively before"* (Mays et al. 2001, p.194).

Scoping studies have specific purposes, expectations, methodologies, and interpretations (Davis et al. 2009). In contrast to other review methodologies, such as systematic reviews that focus on particular study designs guided by highly focused research questions, scoping reviews aim to comprehensively identify all relevant literature on a given topic, regardless of the study design employed

(Arksey and O’Malley 2005). My goal was to explore the breadth of literature within the topic area to uncover research gaps, rather than to provide clinical recommendations, which is typically the focus of systematic reviews (Arksey and O’Malley 2005). Consequently, given the time constraints and the aim of this review, conducting a scoping study was the most appropriate choice (Munn et al. 2018).

The conduct of scoping reviews can be guided by various methodological frameworks, such as the Arksey and O’Malley (2005) framework, Levac et al. (2010) framework, Daudt et al. (2013) framework, and the Joanna Briggs Institute (JBI) framework by Peters et al. (2020). I conducted this scoping review following the methodological framework proposed by Arksey and O’Malley (2005).

Arksey and O’Malley (2005) point out that scoping reviews can serve four primary purposes: 1) To examine the extent, range, and nature of research activity, 2) To determine the value of conducting a full systematic review, 3) To summarise and disseminate research findings, and 4) To identify research gaps in the existing literature. Therefore, this review was carried out to achieve purposes 1 and 4.

The Arksey and O’Malley (2005) methodology proposes six stages for undertaking a scoping review: identifying the review question; identifying relevant studies; study selection; charting the data; collating, summarising, and reporting the results; and consultation exercise (optional stage). Arksey and O’Malley’s (2005) framework is often cited as one of the earliest scholarly works that clarify the value and methods of conducting scoping reviews (Levac et al. 2010; Daudt et al. 2013; Westphaln et al. 2021). However, in their critique of this framework, Levac et al. (2010) pointed out that the methodology lacked detailed guidance on thoroughly describing the methodological or data analysis process. In response, they modified the framework by providing recommendations for each stage to enhance clarity and methodological rigour for conducting and reporting scoping reviews. I integrated some recommendations from Levac et al. (2010) relevant to this review to enhance clarity and methodological rigour. Please see Table 3 for details.

I applied the five key stages of the Arksey and O'Malley (2005) framework and omitted the optional sixth stage of consultation due to time and cost constraints (Dyar 2019; Kalogiannidis 2021; Andtfolk et al. 2022). The scoping review was conducted as part of a doctoral thesis, and conducting consultation did not fit within the set timelines of the doctoral project. In addition, I have presented 19 of the essential items outlined in the PRISMA-ScR guidance to ensure transparent reporting of this scoping review (Tricco et al. 2018; Dowling et al. 2020). I have also included the scoping review's published paper in the appendices (Appendix 17).

Table 3: ***Arksey and O'Malley's key framework stages and the key Levac et al. recommendations relevant to this review***

	Framework Stage Arksey and O'Malley (2005)	**Recommendations Levac et al. (2010)**
1.	Identifying the research question	▪ Clearly articulate the research question that will guide the scope of inquiry. Consider the concept, target population, and health outcomes of interest to clarify the focus of the scoping study and establish an effective search strategy. ▪ Mutually consider the purpose of the scoping study with the research question. Envision the intended outcome (e.g., framework, list of recommendations) to help determine the purpose of the study. ▪ Consider the rationale for conducting the scoping study to help clarify the purpose.
2.	Identifying relevant studies	▪ Research question and purpose should guide decision-making around the scope of the study. ▪ When limiting scope is unavoidable, justify decisions and acknowledge the potential limitations to the study.
3.	Study selection	▪ This stage should be considered an iterative process involving searching the literature, refining the search strategy, and reviewing articles for study inclusion.
4.	Charting the data	▪ Charting should be considered an iterative process in which researchers continually extract data and update the data charting form. ▪ Process-oriented data may require extra planning for analysis. ▪ A qualitative content analysis approach is suggested.
5.	Collating, summarising, and reporting the results	▪ Researchers should break this stage into three distinct steps: ▪ Analysis (including descriptive numerical summary analysis and qualitative thematic analysis); ▪ Reporting the results and producing the outcome that refers to the overall purpose or research question; ▪ Consider the meaning of the findings as they relate to the overall study purpose; discuss implications for future research, practice and policy.

In the previous section, I discussed how I developed the review question. The following four sections discuss how I approached the stages of identifying relevant studies and study selection.

2.5.1 Protocol and registration

I did not register the scoping review protocol. However, I now appreciate that this is important so that others know a review is being carried out, and I will register/publish protocols for future scoping reviews.

2.5.2 Eligibility criteria

I carefully developed the inclusion and exclusion criteria using the Population, Concepts and Context (PCC) components to align with the purpose of the review and intended outcomes while considering feasibility (Levac et al. 2010; Rajwar et al. 2021). These parameters were vital in determining the scope of the review and guiding the process of identifying the relevant studies (Levac et al. 2010). I discussed these criteria with my academic supervisors throughout the review, ultimately arriving at the most appropriate and feasible criteria to address the aims and objectives of the review (Levac et al. 2010). The following section highlights how I used the PCC components to define and refine my inclusion criteria.

a) Population

I focused on studies that examined older people living with frailty as the main population group. The term ‘older people’ is broad and complex, with no universally agreed-upon definition of old age (Orimo et al. 2006). The onset of old age varies across different contexts based on individual, cultural, and national factors (Kowal and Dowd 2001). For instance, in many contexts, old age is determined chronologically based on statutory retirement age, while in others, it may be related to the onset of physical and physiological declines (Skirbekk et al.

2019; Preston and Biddell 2021). Additionally, in some non-Western societies, the onset of old age is socially or culturally constructed and associated with changes in social roles (Sagner et al. 2002; Majumdar et al. 2020). To ensure inclusivity, I considered the World Health Organisation's definition of 60 years as the onset of old age, aligning the age bracket for old age with their recommendations (WHO 2018). Therefore, I only included papers focusing on older people living with frailty aged 60 years and above. This age bracket allowed for a broader scope of inclusion. I have discussed the definitions, assessments, and manifestations of frailty in Chapter One, but due to variations in the literature, I chose to include papers where frailty was explicitly determined using specific assessment models or assumed due to the presence of multiple diseases or hospitalisations. I also considered studies that captured the perspectives of stakeholders involved in caring for older people with frailty, such as formal and informal caregivers. Their viewpoints provided valuable insight into the sense of control and well-being of older people living with frailty from the perspective of people who provide care.

b) Concept(s)

The main concepts under review include control and well-being in older people living with frailty. As already highlighted, the concept of control relates to the perception that one can influence what happens in life and includes beliefs or expectations about the extent to which one's actions can bring about desired outcomes (Lachman and Firth 2004). Control is a multifaceted concept, encompassing terms such as perceived control, experienced control, locus of control, primary control, secondary control, self-efficacy, and sense of agency.

Although the terminology varies, all these concepts assess individuals' expectations about their ability to achieve desired outcomes (Skinner 1996).

Chapter One highlights that well-being is complex and challenging to define and measure (Dodge et al. 2012). Initially, I looked into various constructs of well-being highlighted in the literature, including positive functioning, life satisfaction, happiness, quality of life, social well-being, psychological well-being, emotional well-being, optimal well-being, positive well-being, and flourishing (Dodge et al. 2012; Huppert and So 2013; Oades and Mossman 2017). However, this yielded an unmanageable number of results. As the main focus of the review was on the sense of control and its influence on well-being, to narrow down the search results, I decided to focus only on papers where the term well-being was explicitly mentioned.

Therefore, I included papers that addressed control and related concepts in older people living with frailty and those that discussed the impact of control on their well-being.

c) Context

I focused on papers that explored the delivery of care for older people living with frailty in various settings such as hospitals, care homes, nursing homes, and domestic homes/communities. This was important for understanding the differences in control and well-being of older people with frailty in different care settings. I also considered studies from around the world to ensure comprehensive coverage of this topic. This is because I expected that there would be valuable information on this topic from different geographical contexts. So, I did not want to miss any vital academic work published in various regions.

In addition to the PCC components, I considered other factors to define my inclusion criteria. These factors included the types of studies, where I considered both quantitative and qualitative empirical studies conducted worldwide, to better understand how researchers employ various ontological and epistemological positions to study the relationship between a sense of control and well-being in older people living with frailty in different contexts.

I applied specific limiters to refine my inclusion and exclusion criteria. For instance, I only considered journal articles with primary data because I was more interested in original data rather than re-analysed data. Other limiters included language and timespan. Therefore, I only considered research papers written in English. The decision to exclude papers written in other languages was due to feasibility reasons to save time and cost with translations (Arksey and O’Malley 2005). Similarly, I only included papers published between 2000 and 2021 because I wanted to balance the feasibility of the review and gain a comprehensive understanding of the current evidence and how the debates on a sense of control and well-being in older people living with frailty have evolved over the past two decades, particularly in light of new pathways for understanding frailty including the emergence of frailty diagnosis in some parts of the world, such as the UK (Arksey and O’Malley 2005). Although these limiters enabled me to manage search results, I acknowledge that some potentially relevant papers might have been left out, which has been further explained under the review limitations (Arksey and O'Malley 2005; Levac et al. 2010).

In terms of the exclusion criteria, I excluded papers which compared older people living with frailty to other population groups, such as adults or adolescents, as the focus on differences across the lifespan was outside the scope of my review. I also excluded review articles and grey literature, such as websites, blogs, reports, conference proceedings, editorials, commentaries, and papers written purely from a theoretical perspective, as I wanted to focus on empirical data. These decisions were made to ensure the feasibility of the review within the time available.

Significantly, I revised the eligibility criteria above through an iterative and post hoc process (Bui et al. 2021). I adjusted the criteria as I became more familiar with the literature, refining them throughout the different stages of the search process (Victoor et al. 2012). For example, initially, I focused on papers about older people living with frailty and their care providers, as well as those concerning control and well-being. As I gathered more papers, I added further limiters such as study type, age of the participants, language, and timespan (Dowling et al. 2020). Table 4 summarises the inclusion and exclusion criteria for the review.

Table 4: ***Eligibility criteria for the scoping review***

Inclusion criteria	**Exclusion criteria**
Papers focusing on experiences of control and well-being	Grey literature, such as working papers
Papers focusing on the perspectives of older people living with frailty aged 60 years and above	Websites, blogs
Papers focusing on the perspectives of formal and informal carers of older people living with frailty	Reports, conference proceedings, editorials, commentaries,
Papers focusing on empirical/primary research	Dissertations/theses
Studies undertaken in different health and social care settings, including hospitals, nursing homes and the community	Papers written from a purely theoretical perspective
Both quantitative and qualitative papers	
Studies published between 2000-2020	
Studies published in English	
Studies that were undertaken worldwide	
Papers from the reference lists of included papers	

In the following sections, I explain how I applied these eligibility criteria to conduct the literature search across various sources of evidence.

2.5.3 Information sources

In this review, I focused on two information sources: databases and reference lists. I searched nine (9) databases, including PubMed, PsycINFO, Medline Complete, Web of Science, Social Care Online, Science Direct, Scopus, CINAHL Complete, and SocINDEX, between February 2020 and December 2020. I also searched the reference lists for all included papers to find any eligible papers. I based the selection of the sources of evidence on the eligibility criteria described in the section above.

2.5.4 Search

I began the process of identifying relevant studies by developing a search strategy guided by the review question and purpose, which I continually refined (Levac et al. 2010). I needed to be as comprehensive as possible in identifying evidence from various sources to address the review question (Arksey and O'Malley 2005). One of the significant strengths of scoping reviews is their emphasis on breadth in identifying studies about a particular topic area (Davis et al. 2009). To establish an effective strategy, I followed the steps outlined by Bettany-Saltikov and Mcsherry (2016) to convert the review question into a comprehensive search strategy.

Table 5: ***Stages of developing a search strategy (Bettany-Saltikov and McSherry 2016)***

a)	Write out the review question and identify the component parts
b)	Identify any synonyms
c)	Identify truncations and abbreviations
d)	Develop a search strategy string
e)	Undertake a comprehensive search using all possible sources of information
f)	Save your searches

a) In the first step, I wrote down the review question and identified its components: the Population, Concept, and Context (PCC). In this case, the PCC components were older people living with frailty (P), control and wellbeing (C), and care context, including settings such as hospitals, homes/communities, and nursing/care homes (C). This step was necessary to clarify the scope of the review (Levac 2010).

b) Next, I identified the synonyms for all the component parts of the review question. These can be seen in Table 6 below.

Table 6: ***Summary of the key search terms and synonyms***

Component	**Synonym**
Population (P): ▪ Older people living with frailty	*frailty OR "frail elderly" OR "frail older people" OR "frail older persons"*
Concept (C) ▪ Sense of control ▪ Well-being	***AND***
	"Sense of control" OR "Perceived control" OR "Primary control" OR "Secondary control" OR "Experience of control" OR "Sense of efficacy" OR "Control" OR "Locus of control" OR "Personal control" OR "Control" OR "Personal efficacy" OR "Self-determination" OR Independence OR autonomy OR Choice OR "self-management" *wellbeing or "well-being" or "well being"*
Context (C) ▪ Health or Social Care setting	***AND***
	(Hospital OR Home OR Community OR "Care home" OR "Nursing home" OR Municipal)

c) I then combined the synonyms using the Boolean operators. Boolean Operators are used *"to retrieve information from computers by expressing the relationships between words and phrases using language"* (BU 2021). The Boolean operators have three components: AND, OR, and NOT (BU 2021). The 'AND' component links concepts or key terms together by comparing search results from different concepts and displaying only those that contain both concepts (BU 2021). On the other hand, the 'OR' component combines different concepts into a single set by locating all the results that contain the chosen concepts (BU 2021). The 'NOT' component excludes search results containing certain concepts the reviewer does not wish to find (BU 2021). Boolean operators helped ensure the search was sensitive and specific enough to retrieve relevant citations to answer the review question (Bettany-Saltikov and Mcsherry 2016).

d) Next, I developed a 'search strategy string' or a list of keywords/terms that I used to comprehensively search the chosen databases. For example, I used the following list of keywords for one of the searches in one of the databases (PubMed) to conduct the searches (Appendix 1). *((frailty OR "frail elderly" OR "frail older people" OR "frail older persons") AND ("Sense of control" OR "Perceived control" OR "Primary control" OR "Secondary control" OR "Experience of control" OR "Sense of efficacy" OR Control OR "Locus of control" OR "Personal control")) AND (Hospital OR Home OR Community OR "Care home" OR "Nursing home")) AND (wellbeing or "well-being" or "well being"). Filters: from 2000 – 2020.* I typed the words in that particular order and combination in other databases. I used a similar search strategy string for the other databases, including PsycINFO, Medline Complete, Web of Science, Social Care Online, Science Direct, Scopus, CINAHL Complete, and SocINDEX, to undertake a comprehensive search (Bettany-Saltikov and Mcsherry 2016).

e) Finally, I ensured that the records of all searches were recorded and saved electronically. I created an account with database suppliers, such as EBSCO, where I electronically saved my search records (BU 2021). I have included the total search results retrieved from each database in the PRISMA flow diagram (Page 75) before removing duplicates.

2.5.5 Selection of sources of evidence

The process began with eliminating duplicates from the search results retrieved from various databases. Subsequently, I reviewed the titles of the retrieved results, excluding papers that did not align with the review aims. I then proceeded to examine the abstracts of the remaining papers, further excluding those that did not meet the review inclusion criteria. I then remained with a manageable number of records I considered for full-text examination. Additionally, I scrutinised the reference lists of the included papers, which led to the identification of more papers that met the inclusion criteria, and these were also included for full-text examination. I have illustrated this process using a PRISMA flow diagram on page 75.

Once I had identified all the potentially relevant papers, I entered the results into the online citation management software EndNote (2013). This helped me to easily access the papers when charting the data and organising and cross-checking the data (Daudt et al. 2013).

In summary, the processes mentioned above correspond to the second and third stages of the Arksey and O'Malley (2005) framework, which involve identifying relevant studies and study selection. Completing these stages sets the stage for the fourth and fifth framework stages, which are charting the data as well as collating, summarising, and reporting the results. I have discussed these stages in the following sections.

2.5.6 Data charting process

At this stage, I undertook 'charting the data' from the full-text reviewed papers. Charting is a technique used to synthesise and interpret data by *"sifting, charting, and sorting the information according to key issues and themes"* (Arksey and O'Malley 2005, p.26). Since this was a PhD project, I conducted the data charting process independently with the guidance of the academic supervisors instead of having a calibration between charters. I developed a data charting form in a

Microsoft Excel (Microsoft 2022) sheet to organise information from the papers I reviewed to answer the review question (Levac et al. 2010). Similarly, I assigned each paper a unique identifying number in EndNote (2013) at the beginning of the charting process to easily track them as a data management strategy (Daudt et al. 2013).

Importantly, the charting process was iterative, and I continually updated the charting form as more information was charted (Levac et al. 2010). Although most papers were straightforward in presenting the required information at this stage, some lacked clarity, particularly in presenting key data, such as the definition and assessment of frailty. However, this is not uncommon in scoping reviews as information papers can sometimes be presented in a form that is problematic to access (Arksey and O’Malley 2005).

2.5.7 Data items

I abstracted data on the country of origin, the study’s setting, the key control and/or well-being construct(s) measured/investigated, and the key findings/aspects related to the review aims and objectives.

The final charting form included the following details.

- Author(s)
- Year of publication
- Origin/country of origin (where the source was published or conducted)
- Methodology
- Population and sample size within the source of evidence (if applicable)
- Setting
- Methodology/methods/design
- Control and/or well-being construct (s) measured /investigated
- Key findings that relate to the review question/s/aims
- Comments

2.5.8 Synthesis of results

After extracting key data from each paper, I followed the thematic synthesis steps to synthesise the findings of each study (Thomas and Harden 2008). I began by reviewing the data in Microsoft Excel (Microsoft 2022) to identify recurring points, similarities, and differences (codes) in line with the review question (Arksey and O’Malley 2005). Then, I categorised the identified codes based on key issues, prioritising certain aspects of the literature according to the review question and what was most noticeable during the review process (Arksey and O’Malley 2005). Subsequently, I developed three overarching themes from the categories, referred to as the literature review findings (Arksey and O’Malley 2005; Levac et al. 2010). The final themes from the analysis were determined after discussions with my supervisors, who provided feedback and alternative perspectives on my interpretation of the initial themes. I applied the thematic synthesis framework to link the meaning of the results to the purpose of the review and future research implications (Arksey and O’Malley 2005; Levac et al. 2010). However, since the scoping review aims to map out the existing evidence for identifying gaps and informing primary research rather than making clinical or policy recommendations, I did not evaluate the methodological quality of the included studies (Grant and Booth 2009; Tricco et al. 2018; Peters et al. 2020).

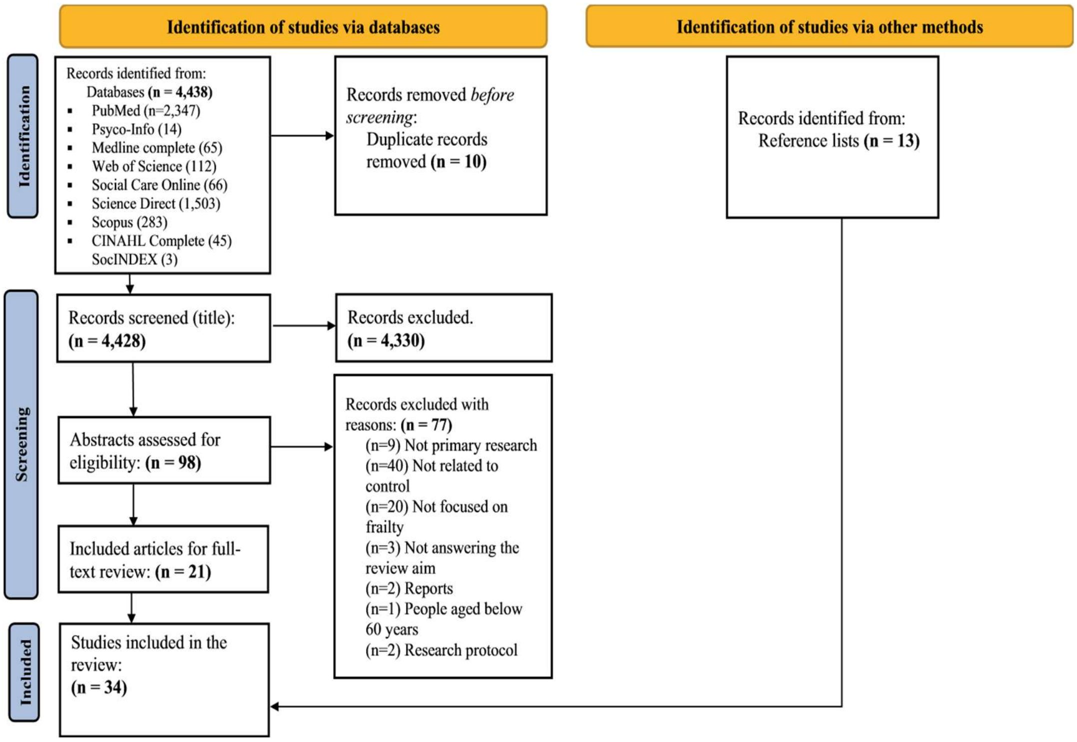
2.6 Results

2.6.1 Selection of sources of evidence

The electronic database search retrieved 4,438 records. After removing 10 duplicate papers, I reviewed the titles of 4428 papers, excluding those that did not focus on the control and well-being of older people living with frailty. Additionally, I applied limiters such as language, timespan, and study type, excluding 4330 papers.

I assessed the abstracts of 98 papers for their eligibility, analysing their aims, study types, and relevance to my review question before excluding 77 papers. I excluded these papers because they were not primary research (n=9), not related to control (n=40), not focused on frailty (n=20), not answering the review aim (n=3), reports (n=2), they included people aged below 60 years (n=1), and were research protocols (n=2). Following discussions and clarifications with the supervisory team, I undertook a full-text examination of the 21 eligible to guide the charting process. I also reviewed the reference lists of these papers and found 13 additional eligible papers, bringing the total number of eligible papers to 34. This process can be seen in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Figure 1), which has been incorporated to enhance the visual accessibility and readability of the literature search (Tricco et al. 2018).

Figure 1: ***PRISMA flow diagram (Matthew et al. 2021)***



2.6.2 Characteristics of sources of evidence

A total of 34 papers were identified, with the majority of them published in Scandinavian countries (n=12), the Netherlands (n=7), and the USA (n=5). A smaller number of papers were published in Australia (n=2), Belgium (n=1), Canada (n=1), England (n=1), Germany (n=1), Hong Kong (n=1), Italy (n=1), Mexico (n=1), and Sri Lanka (n=1). Most of these papers were published between 2010 and 2020 (n=26), while a smaller number were published between 2000 and 2008 (n=8).

In terms of the methodology, most of the papers were quantitative (questionnaires, n=14, other methodologies, n=5), and many of them focused on capturing the outcomes and thoughts of older people living with frailty themselves (n=33) and carers (n=3). Only 13 qualitative papers with limited in-depth approaches were found. Six papers employed content analysis, two utilised grounded theory, only one applied phenomenology, and four did not specify any qualitative research approach.

2.6.3 Results of individual sources of evidence

In Table 7, I present the characteristics for which data were charted for each source of evidence. The table also provides an overview of all the papers in the review and their contributions to the key themes.

Table 7: *Summary of the included papers*

No	Author(s)	Year	Country	Study design and sample	Setting	Control and/or well-being construct (s) measured /investigated	Contribution to the themes		
							1-Body/ADL*(note) 2-Residence 3-H&SC relationships		
							Theme 1	**Theme 2**	**Theme 3**
1.	Abu-Bader et al.	2003	USA	▪ Quantitative (structured interviews) ▪ 99 frail older people aged 60+	Community	▪ Relationship between life satisfaction and physical health, emotional balance, social support, and locus of control. **Key findings/aspects** ▪ All factors above affect life satisfaction. ▪ Subjective perception of health is an important predictor of life satisfaction. ▪ Half of the participants reported high life satisfaction scores.	X		
2.	Andersson et al.	2008	Sweden	▪ Qualitative (narrative approach) ▪ 17 older people having a life-threatening disease and/or receiving palliative care and aged 75+	Community	▪ Aspects of a good life in the last phase of life. **Key findings/aspects** ▪ Health issues can limit daily activities and impact self-image and identity, leading to a more passive lifestyle. ▪ Finding peace with the past and present while facing health challenges and approaching death. ▪ Dependency on caregivers impacts autonomy and care involvement, leading to	X	X	X

						adjustments in behaviour to fit routines. - Involvement of family members enhances care experiences and reduces reliance on staff. - Entrusting oneself to others brings relief, relaxation and security. - A sense of home is characterised by familiarity and control and can be found in personal residences and specialised care facilities. - Feeling valued and contributing to others' lives is essential. - Maintaining dignity, autonomy, and connections with loved ones is crucial in nursing and palliative care.			
3.	Andrew et al.	2012	Canada	- Quantitative (questionnaire) - 5,703 frail older people aged 70+	Community	- Psychological well-being focusing on the relationship between well-being, frailty and mortality. **Key findings/aspects** - Older individuals with greater frailty, poor mental health, and low cognitive ability have worse well-being scores. - Poor psychological well-being increases mortality risk over five years, independent of frailty. - Strong correlation between frailty and poor psychological well-being, particularly in growth, mastery, positive relations, and self-acceptance.	X		

						▪ Autonomy is not clearly linked to frailty, indicating that not all frail older people lack functional independence. ▪ Frailty is influenced by psychological factors, suggesting it is more than just a physical phenomenon. ▪ Psychological well-being is crucial for frail older adults, influencing both their mental health and physical capabilities.			
4.	Bilotta et al.	2010	Italy	▪ Quantitative (questionnaire) ▪ 239 frail older people aged 65+	Community	▪ Relationship between frailty and Quality of Life (QoL). **<u>Key findings/aspects</u>** ▪ Frailty is associated with a lower QoL in many areas, except for social relationships, participation, and finances. ▪ Lower QoL is linked to frailty, dependence on basic and instrumental activities of daily living (ADLs), and depression. ▪ In frail participants, better emotional status and older age linked to better QoL, while in robust individuals, only Body Mass Index (BMI) correlated with QoL. ▪ Frail older people had worse QoL than pre-frail and non-frail people, with impairments in five of seven dimensions: health, independence, home and neighbourhood, psychological and emotional		X	

						well-being, and leisure, activities, and religion. ▪ Interventions should focus on health-related QoL and include the above dimensions.			
5.	Broese van Groenou et al.	2016	Netherlands	▪ Quantitative (interviews) ▪ 74 frail older people aged 65+, 94 informal caregivers, and 102 formal caregivers	Community	▪ Mixed care networks and their impact on activities of daily living level, memory problems, social network, perceived control of care and levels of mastery. **Key findings/aspects** ▪ Only 36% of individuals felt in control of their care, with physical and social impairments requiring high levels of support. ▪ Care networks had more formal caregivers (67%), with a mix of formal and informal caregivers in various dyads. ▪ 4 distinct care network types were identified. ▪ 'Small mixed care network' had an equal mix of informal and formal helpers. ▪ 'Small formal network' had 82% of formal helpers. ▪ 'Large mixed care network' had more informal caregivers and care recipients often felt in control of the care process. ▪ 'Large formal care networks' had the most formal caregiver support but the highest disability levels and lowest perceived control among recipients.	X		

						▪ Effective caregivers' collaboration is vital for enhancing support systems for frail older adults.			
6.	Claassens et al.	2014	Netherlands	▪ Qualitative (Grounded Theory) ▪ 32 frail older people aged 65+	Community	▪ Perceived internal and external factors that constitute perceived control over healthcare. **Key findings/aspects** ▪ Both internal and external factors influence perceived control in healthcare. ▪ Social networks are crucial in helping frail individuals manage their care effectively. ▪ For frail older adults, external support becomes increasingly important as they age. ▪ Significant others often take on a more central role in organising care than professionals. ▪ A balance between informal caregiver responsiveness and the older person's autonomy fosters a sense of control. ▪ Sharing or relinquishing control can enhance the feeling of safety. ▪ Perceived control is influenced by cultural and personal factors and it may decrease with declining health. ▪ Control in healthcare sometimes requires mental adaptation (secondary control). ▪ Both informal and professional support are vital	X	X	X

						for maintaining perceived control and independence.			
7.	Cramm et al.	2014	Netherlands	▪ Quantitative (questionnaire) ▪ 869 frail older adults aged 70+	Community	▪ Relationship of Self-Management Abilities (SMA) and frailty to perceived poor health. **Key findings/aspects** ▪ SMA are linked to frailty and self-perceived health in older adults, improving with higher income and education. ▪ Frail older adults with lower education report worse health, highlighting the need for targeted interventions. ▪ Initiating SMA interventions at a younger age may prevent poor health in older individuals. ▪ Interventions must address physical, social, and psychological aspects to delay frailty and promote healthy ageing.	X		
8.	Dent et al.	2014	Australia	▪ Quantitative (prospective, observational study) 172 frail older people aged 70+	Hospital	▪ Association between psychosocial factors and frailty and the impact of psychosocial factors on the association between frailty and adverse outcomes. **Key findings/aspects** ▪ More than half of the patients were classified as frail. ▪ Frail older patients face high anxiety, depression, and a low sense of control, requiring caregiver assistance.	X		

						▪ Frailty is linked to increased 12-month mortality, higher levels of post-discharge care, longer hospital stays, and higher rates of emergency readmission. ▪ Limited psychosocial resources are linked to negative outcomes. ▪ Involving informal caregivers in care decisions is crucial. ▪ Geriatric assessments should include frailty and psychosocial evaluations. ▪ Psychosocial factors like a sense of control influence frailty outcomes and should be the focus of future research. ▪ Vital to assess the relationship between frailty and psychosocial decline over time.			
9.	Ebrahimi et al.	2013	Sweden	▪ Qualitative (content analysis) 22 frail older adults aged 65+	Community	▪ Influences on subjective experiences of good health. **Key findings/aspects** ▪ A key theme is feeling assured and capable, supported by 5 subthemes: managing the unpredictable body, reinforcing a positive outlook, remaining in familiar surroundings, managing everyday life, and having a sense of belonging. ▪ A familiar routine boosts daily life and enhances health through a sense of assurance and control.	X	X	X

						▪ Unpredictable symptoms create anxiety and a diminishing sense of well-being, while manageable conditions lead to feelings of safety and good health. ▪ A positive outlook helps older adults face challenges with resilience, seeking knowledge to compensate for loss of function. ▪ Staying at home provides safety and a sense of control, enabling older adults to remain connected to their history and values. ▪ Managing daily activities fosters independence and reinforces feelings of security and good health. ▪ Social connections and meaningful interactions contribute to well-being and a sense of belonging.			
10.	Ekdahl et al.	2010	Sweden	▪ Qualitative (content analysis) 15 frail elderly patients aged 75+	Hospital	▪ Preferences for participation in medical decision-making during hospitalisation. **Key findings/aspects** ▪ 3 main Categories: Participation through information and communication, Barriers to communication and Preferred degree of participation. ▪ Frail elderly patients want to be informed and involved in medical decisions. ▪ Effective participation requires good communication	X	X	X

						and information about conditions and treatments. ▪ Patients desire staff to explain their care and allow them to express their feelings. ▪ Even those who prefer not to participate still need to be informed. ▪ Communication barriers include ageing and illness, frequent doctor changes, stress, and language barriers. ▪ Some patients actively seek information, while others desire more involvement or prefer a passive role. ▪ Perception of the hospital as an authoritative entity, with some feeling overlooked by doctors. ▪ Most patients, despite feeling unheard, maintain confidence in their healthcare.			
11.	Ekwall et al.	2012	Sweden	▪ Qualitative (interviews/content analysis) 14 older people in the acute care process (5 men and 9 women) aged 70+	(Acute) Hospital	▪ Experiences of physical decline and strategies for adapting to physical decline (compensating/controlling and accepting/resignation). **Key findings/aspects** ▪ Physical decline impacts daily life for older individuals, affecting both personal and contextual levels. ▪ Adaptation strategies include controlling, compensating, and accepting changes to maintain a sense of normalcy.	X	X	X

						▪ Awareness of decline helps explain symptoms, with fears about losing independence. ▪ Maintaining control involves preserving identity-linked activities, often supported by home care or informal caregivers. ▪ Interaction with social services influences daily life, and compensation strategies include seeking help and adjusting tasks. ▪ Alternative activities, like ready-made meals and clear communication with care staff, help manage decline. ▪ Hope and a fighting spirit are vital, along with understanding the link between self-image and physical ability to enhance activity and coping strategies.			
12.	Falk et al.	2011	Sweden	▪ Mixed methods 155 frail older persons 74 were inter-institutionally relocated (movers), while 81 served as an equivalent reference group (non-movers)	Residential care	▪ Effects and experiences of inter-institutional relocation on QoL, well-being, and perceived personal centredness. **Key findings/aspects** ▪ No significant baseline differences between movers and non-movers for most variables. ▪ Movers had lower well-being and perceived person-centeredness at baseline compared to non-movers. ▪ Movers scored lower in well-being and perceived person-centeredness than non-movers.	X	X	X

						▪ Cognitive functioning declined in both groups. ▪ Mortality rate was higher among movers (24%) compared to non-movers (11%). ▪ The relocation experience was viewed as uncontrollable and uncertain, with fast-paced preparations excluding residents. ▪ Feeling powerless due to a lack of choice in the relocation process. ▪ Information about the move was inadequate, and changes in daily routines negatively impacted residents' attitudes. ▪ The transit facility's environment felt institutional and cold, with long corridors contributing to feelings of abandonment. ▪ Interventions to inform and prepare residents may reduce adverse effects and enhance control and predictability.			
13.	Frieswijk et al.	2006	Netherlands	▪ Quantitative (questionnaire) 193 slightly to moderately frail older people aged 65+	Community	▪ Impact of increasing SMA (bibliotherapy) on mastery and well-being. **Key findings/aspects** ▪ Bibliotherapy can enhance self-management abilities (SMA) in older adults to maintain well-being. ▪ Bibliotherapy has significant positive effects. ▪ Frail people who participated reported increased SMA compared to the control group.	X		

						▪ The increase in SMA initially helped prevent a decrease in well-being, though the effect diminished after 6 months. ▪ Some participants noted behavioural changes, expressing intentions to use bibliotherapy for personal growth. ▪ Some people did not recognise the issues addressed, found the content unfamiliar, or felt certain important topics were overlooked. ▪ Cognitive and behavioural tools can support well-being, and interventions should target physical and psychosocial challenges. ▪ SMA theory can guide future interventions on mitigating age-related declines in well-being.			
14.	Gale et al.	2014	England	▪ Quantitative (questionnaire) 2557 not frail, pre-frail and frail older men and women aged 60+	Community	▪ Prospective relationship between psychological well-being and incidence of physical frailty. **Key findings/aspects** ▪ At follow-up, 43% of participants were pre-frail and 14% were frail. ▪ Frailty was linked to older age, poor cognitive function, depression, poor psychological well-being, and more frailty. ▪ The relationship between psychological well-being and pre-frailty and frailty risk.	X		

						▪ Higher psychological well-being (control, autonomy, self-realisation and pleasure) scores were associated with lower risk of pre-frailty, suggesting it may be a protective factor. ▪ Both hedonic and eudaimonic aspects of psychological well-being were associated with decreased frailty risk. ▪ Declines in psychological well-being were noted in those developing pre-frailty or frailty, suggesting a bi-directional relationship.			
15.	González-Bautista et al.	2020	Mexico	▪ Quantitative (survey questionnaire) 1,519 frail older adults aged 60+	Community	▪ Longitudinal association between Social Determinants of Health (SDH) and frailty status with all-cause mortality. **<u>Key findings/aspects</u>** ▪ Overall mortality rate over 4 years and 5 months: 16.9% (8.5% robust, 17.1% pre-frail, 39.2% frail). ▪ Factors linked to reduced mortality: frequent social interactions, trust, and a sense of control in decision-making. ▪ More interpersonal contacts correlate with lower mortality risk; ▪ Social interactions benefit health regardless of frailty or comorbidities. ▪ Limited control over one's life increases mortality risk. ▪ A sense of control can lessen the impact of socioeconomic status on health.	X		

						▪ A sense of control over vital life aspects may mitigate the impact of socioeconomic status on health. ▪ Lack of trust raises mortality risk. ▪ Frail and pre-frail individuals have a significantly higher mortality risk than the non-frail group.			
16.	Grain, Madeleine	2001	USA	▪ Quantitative (questionnaire) 37 frail nursing home residents and 37 home-bound frail older people (both aged 60+)	Home-bound and Nursing home	▪ Comparison between a sense of control and life satisfaction between nursing home residents and home-bound older people. **Key findings/aspects** ▪ Homebound frail older adults feel greater internal control than nursing home residents. ▪ Internal control beliefs help adaptation to community living but decrease upon nursing home admission. ▪ Long-term nursing home residents have similar personal control and life satisfaction levels as homebound individuals. ▪ Both groups experience well-being, finding satisfaction in independence or structure. ▪ Frail nursing home residents engage in activities and maintain high personal control beliefs. ▪ Residents find control in choosing daily activities. ▪ Preferences for healthcare involvement vary among frail individuals.		X	

						▪ Daily life assessment tools can predict adaptation and identify those needing interventions to enhance well-being.			
17.	Hedman et al.	2019	Sweden	▪ Qualitative (descriptive phenomenology) 13 registered nurses	Nursing home	▪ Experience of caring for older people in nursing homes to promote autonomy and participation. **Key findings/aspects** ▪ Autonomy and participation among older adults. ▪ Caring involves enhancing health and well-being for a meaningful and independent life. ▪ Trusting relationships with older adults and their families. ▪ Collaborate with GPs for informed decision-making. ▪ Engage older people in daily routines and explain care purposes to enhance participation. ▪ Involve them in routines and clinical assessments, such as completing paperwork. ▪ Acknowledging their choices, like meals and end-of-life preferences, is crucial for autonomy. ▪ Personalise activities and respect privacy to promote participation. ▪ Trusting relationships fosters equality and respect. ▪ Regular personal interactions make older people feel valued. ▪ Including relatives in decision-making.	X	X	X

						▪ Recognising individuality and uniqueness. ▪ Awareness of unspoken rules in nursing homes that impact autonomy. ▪ Awareness is key for involving residents in activities and care planning.			
18.	Janlöv et al.	2006	Sweden	▪ Qualitative (Content analysis) 28 frail home help recipients aged 75+	Community	▪ Experience of participation in and influence on decisions about public home help/care. **<u>Key findings/aspects</u>** ▪ The process involves entering, assessing needs, and receiving home help. ▪ Constant need to balance personal needs with the help available. ▪ Key experiences include balancing comfort and guilt, viewing home help as a necessary evil, and integrating help into daily life. ▪ Older people often feel frail, humiliated, and fear being perceived as burdens. ▪ Receiving help from family involves a mix of gratitude, comfort, and guilt. ▪ Decisions regarding home help can evoke disappointment, yet acceptance is often necessary. ▪ The professional leads the assessment, asking questions and determining the help provided.	X	X	X

						▪ Approach assessments with caution, assessing how to engage. ▪ Family involvement empowers them during the process. ▪ Desire for personal needs to be recognised during assessments. ▪ Incorporating help requires carefully balancing resources, family support, and public assistance. ▪ The relationship with care workers can lead to feelings of affirmation or violation of integrity. ▪ Managing dissatisfaction while maintaining gratitude is essential for balancing daily life. ▪ Not knowing what help will be provided affects planning and control. ▪ Building quality relationships with care workers can influence the help received.			
19.	Johannesen et al.	2004	Denmark	▪ Quantitative (interviews) 187 frail men and women aged 85+	Community	▪ Association between social relation, continuity, self-determination, and use of own resources with everyday life satisfaction. **Key findings/aspects** ▪ Satisfaction levels are almost equally divided (49% satisfied, 51% not). ▪ Factors linked to greater satisfaction: Having friends, managing one's life and daily activities, not using home	X	X	

						care, living independently, and not experiencing significant losses or relocation in the past five years. ▪ No significant correlation was found with gender, functional ability, or regular phone contact. ▪ Stopping usual activities, living in nursing homes, or losing close individuals lead to dissatisfaction. ▪ Positive associations with satisfaction include activities like gardening, independence from home care, and not residing in specialised facilities. ▪ Vital to keep disabled older people active, independent, and in their homes.			
20.	King et al.	2017	USA	▪ Quantitative (structured questionnaire) 4,162 frail older people aged 65 to 105 years	Community	▪ Association between a newly developed cumulative laboratory-based frailty index (FI) and intrinsic and extrinsic characteristics. **Key findings/aspects** ▪ Higher frailty was associated with providing less help but receiving more emotional and instrumental support and facing more stressors. ▪ Family and friends may not recognise early frailty signs or lack resources in disadvantaged neighbourhoods. ▪ Greater frailty correlated with poorer self-rated health and increased difficulties with	X		

						activities of daily living (ADLs). ▪ Higher frailty scores indicated shorter survival; 50% of frail participants were likely to die within 5 years compared to 8 years for robust participants. ▪ Increased frailty was linked to lower life satisfaction and more depressive symptoms, but also greater self-esteem and internal locus of control. ▪ Frail older adults have strengths to build upon. ▪ Vital to determine if frailty precedes or follows stressful events. ▪ Neighborhood disadvantage predicted higher frailty levels. ▪ Higher frailty scores increased the likelihood of moving within 4 years.			
21.	Kristensson et al.	2010	Sweden	▪ Qualitative design (open-ended interviews) 14 frail older adults aged 70+	Hospital	▪ Experience of receiving health care and/or social services. **Key findings/aspects** ▪ Experiences of frail older adults in healthcare and social services focus on themes of power and powerlessness. ▪ Key categories: Feeling autonomous versus lacking control in the system; Being affirmed or violated by caregivers; Facing paradoxes in care. ▪ Patients view organisations as both resources and complex bureaucracies.	X		X

						- Feelings of security are linked to awareness of rights, yet many perceive these rights as at risk and needing to be defended. - Interactions with healthcare can be straightforward or struggle with inaccessible systems and uncertainty. - Continuity of care at home impacts relationships with caregivers and the emotional complexity of these relationships. - Trust and care quality is influenced by being known by caregivers or feelings of powerlessness stemming from lack of information and recognition. - Paradoxes can arise from well-intentioned decisions, leading to negative outcomes and dissatisfaction with care. - Insecurity is often rooted in dependency and lack of influence over personal situations.			
22.	Kwong et al.	2014	Hong Kong	- Qualitative (content analysis) (FGDs) 24 frail elderly aged 65+	Nursing home	- Perception of quality of life in nursing homes. **Key findings/aspects** - 5 key themes: physical well-being, peace of mind and fulfilment of basic needs, connection to society, and relationship harmony. - Physical Well-being was linked to pain affecting sleep quality and impaired mobility, leading to dependency on	X	X	

						self-care and poor quality of life. ▪ Experience of severe pain and need for assistance in daily care, causing distress and limited control over activities. ▪ Wish to cope with impairments while maintaining peace of mind and seek opportunities for outdoor activities, which are often limited. ▪ Some find contentment in nursing homes due to the care they receive, while positive relationships enhance psychosocial health.			
23.	Lambotte et al.	2019	Belgium	▪ Qualitative (in-depth interviews) 65 frail older adults aged 60+	Community	▪ Experience of relational aspects of mastery and caregivers' role in maintaining mastery over the care process. **Key findings/aspects** ▪ Frail older adults received care from informal caregivers like family and friends, who provided practical help and social and emotional support. ▪ The involvement of informal caregivers allowed older adults to feel a sense of mastery and maintain their autonomy. ▪ Positive relationships with caregivers made older adults feel more in control, although some felt misunderstood or not involved in decision-making about their care.	X	X	X

						▪ Informal caregivers were essential in building trust with formal care providers, helping frail older adults access services. ▪ When formal caregivers discuss care with informal caregivers without involving the older adults, it leads to feelings of a lack of mastery. ▪ Responsiveness in care was important, with informal caregivers checking if the support met older adults' needs, while reciprocity was present as older adults sought to give back. ▪ Some felt informal care did not fully meet their needs due to time constraints and other responsibilities.			
24.	Milte et al.	2015	Australia	▪ Randomised Controlled Trial (RCT) 136 frail older adults (70 usual care/control group and 66 specialised care).	Hospital	▪ Relationship between health locus of control and changes in health and well-being in older individuals admitted to a hospital and then to a transition care facility 12 months later. **Key findings/aspects** ▪ Participants showed signs of frailty: advanced age (mean age of 84-90), low MMSE scores (below 24), cognitive impairment, and multiple hospital admissions, mainly for musculoskeletal injuries such as falls. ▪ Higher internal MHLC scores are linked to improvements in EQ-5D scores.	X		

						▪ MHLC did not significantly impact EQ-5D scores in the specialised care group. ▪ MHLC contributed to variance in MBI scores, with greater improvement in MBI scores associated with greater perceived control of health outcomes. ▪ Higher baseline cognitive function (MMSE) is associated with better physical function at 12 months. ▪ Suggests that greater internal control may help older adults adopt adaptive strategies after health crises ▪ Influence of control beliefs on older populations transitioning through care sites after an acute event.			
25.	Mooney et al.	2018	USA	▪ Quantitative (questionnaire) Cross-sectional sample included 5,250 respondents, and in the longitudinal sample, 2,013 respondents who were all frail and aged 65+	Community	▪ Effect of chronic stress and socioeconomic status (SES) on baseline frailty and change in frailty status over 4 years. Extent to which perceived control mediates or moderates the effects of chronic stress. **Key findings/aspects** ▪ Chronic psychosocial stress is associated with increased frailty at both baseline and over 4 years. ▪ The relationship between stress and frailty is mediated by perceived control. ▪ Higher stress levels lead to lower perceived control, contributing to greater frailty.	X		

						▪ Stress impacts health indirectly by affecting psychological processes, which may heighten stress reactivity and physiological burden, leading to increased frailty over time. ▪ Perceived control is linked to better psychological and physical health and mediates the effects of chronic stress and socioeconomic status on frailty. ▪ Research and interventions should consider age, gender, and racial/ethnic differences. ▪ Perceived control may provide a stress-buffering effect in various older populations. ▪ Importance of psychological resources in combating frailty.			
26.	Niesten et al.	2012	Netherlands	▪ Qualitative (open-ended interviews) 38 frail older dentulous people aged 65+	Day-care centres and Assisted-living homes	▪ The impact of natural teeth on the QoL. **Key findings/aspects** ▪ Frail older people define QoL by physical health, psychological well-being, social participation, autonomy, and activity. ▪ Natural teeth enhance QoL through themes such as achievement, control, functionality, appearance, and comfort. ▪ Some individuals prefer dentures to maintain independence, while others prioritise control over their teeth.	X		

						▪ Many accept dental deterioration as a natural ageing process and adapt to it. ▪ Some anticipate handling tooth loss easily with increasing frailty. ▪ Preserving teeth positively impacts body image and self-worth, enhancing overall QoL.			
27.	Portegijs et al.	2016	Finland	▪ Quantitative (longitudinal analyses) 753 frail older people aged 75 to 90 years	Community	▪ Relationship between frailty, life-space mobility and perceived autonomy in participation outdoors. **Key findings/aspects** ▪ 53% of participants were not frail, 43% had pre-frailty, and 4% were frail. ▪ Life-space mobility is limited in pre-frail and frail individuals. ▪ Pre-frailty and frailty are associated with greater declines in life-space mobility over time. ▪ Those with pre-frailty and frailty reported more restrictions in outdoor autonomy. ▪ Higher physical frailty correlates with increased mobility and outdoor autonomy restrictions. ▪ Frailty negatively impacts community mobility and outdoor decision-making. ▪ A notable decline in life-space mobility is linked to frailty status over 2 years.	X		

28.	Sandgren et al.	2020	Sweden	▪ Quantitative (questionnaire) 78 frail older persons aged 65+	Nursing home	▪ QoL among different gender and age groups in nursing homes. **Key findings/aspects** ▪ 40% rated their QoL as good or very good; 22% rated it as bad or very bad. ▪ 47.5% were satisfied with their health, while 30.6% were not. ▪ Highest QoL scores were in social relationships, followed by the environmental domain; physical health scored the lowest. ▪ Perceived lack of autonomy and opportunities for activities. ▪ Only 20% felt they could pursue their interests and control their future. ▪ Autonomy should be supported in nursing homes through staff interactions and involvement in care planning. ▪ Residents rated nursing home environments positively for home-like conditions and access to care. ▪ Nearly half did not engage in daily activities but were satisfied with their time usage and activity levels. ▪ Nursing homes foster a positive social environment that enhances QoL.		X	
29.	Schuurmans et al.	2005	Netherlands	▪ Quantitative (questionnaire)	Community	▪ Relationship between SMA, perceived health, subjective well-being, general self-efficacy and mastery.	X		

				Frail older individuals (Study 1 sample n=275 aged 64+), study 2 sample n=1338 aged 65+)		**Key findings/aspects** ▪ SMA decreases with age. ▪ Higher SMA levels are linked to less frailty, better health perception, higher life satisfaction, lower psychological distress, and greater overall well-being. ▪ SMA is distinct from self-efficacy and mastery, contributing uniquely to life satisfaction and well-being. ▪ SMA does not predict psychological distress. It influences life satisfaction and overall well-being. ▪ The SMAS-30 questionnaire can effectively measure SMA and self-regulation of well-being in frail older adults.			
30.	Siriwardhana et al.	2019	Sri Lanka	▪ Quantitative (questionnaire) 746 frail older adults aged 60+	Community	▪ Association of frailty with overall and domain-specific QoL. **Key findings/aspects** ▪ 15.2% were frail, 48.5% pre-frail, and 36.2% robust. ▪ 82.4% with poor social support were in the lowest QoL tertile. ▪ The robust group had a higher proportion in the highest QoL tertile than the frail group. ▪ Median QoL scores decreased across the frailty spectrum. ▪ Frail participants had lower QoL scores than pre-frail and robust individuals. ▪ All QoL domains except ‘social relationships and	X		

						participation' and 'home and neighbourhood' are linked to frailty. ▪ Significant but smaller reduction in QoL due to frailty. ▪ Frailty-QoL association is mainly explained by 'health' and 'independence' domains. ▪ Interventions should target these areas.			
31.	Strohbuecker et al.	2011	Germany	▪ Qualitative (grounded theory) 9 residents suffering from chronic disease or frailty and aged 70+	Nursing home	▪ Palliative care needs of nursing home residents **Key findings/aspects** ▪ Participants expressed their needs in personal terms, not medical jargon. ▪ Multidimensional needs, often basic and beyond just health. ▪ Identified themselves as individuals rather than patients. ▪ Sought recognition and respect from doctors and nursing staff. ▪ Nursing home routines hindered person-centred care, limiting understanding of preferences and reducing personal stories to technical data. ▪ Choice in daily matters was crucial, but institutional routines often limited decision-making. ▪ Felt a lack of influence in everyday situations, such as meal selections. ▪ Significant fear of losing independence and becoming bedridden.	X	X	X

						▪ Dignity was defined in their terms. Need for qualitative studies to capture these perspectives. ▪ Social connections were vital for life engagement and participation. ▪ Family members provided support and identity. Volunteers helped those without family. ▪ Technical devices, like phones for the visually impaired, facilitated outside connections.			
32.	Thorson, James A. and Davis, Ruth Ellen	2000	USA	▪ Quantitative (longitudinal) 269 older individuals with an average age of 79.8 years	Nursing home	▪ Impact of institutional relocation on mortality and morbidity. **Key findings/aspects** ▪ Smooth relocation as residents retained roommates, room locations, and staff. ▪ Preparation minimised disruptions to residents' lives and schedules. ▪ Better pre-move functional capacity was linked to improved survival post-relocation. ▪ Residents with lower functional status had decreased survival and showed declining functional scores around the move. ▪ High disability levels are linked with difficulty adapting to the move. ▪ Preparation for relocation may have contributed to increased mortality before the	X	X	

						move, indicating anticipation can be more challenging than the move itself. ▪ Patients may have different needs for interpersonal control, with those needing more control feeling threatened by changes. ▪ No significant increase in mortality was linked to the relocation, likely due to preparation by care staff. ▪ Change for those nearing the end of life can be disruptive.			
33.	Vestjens et al.	2020	Netherlands	▪ Quantitative (questionnaire) 588 frail older people aged 75+	Community	▪ Relationship between SMA, productive patient-professional interactions and well-being. **Key findings/aspects** ▪ SMA is linked to physical and social well-being. ▪ Interactions with GPs show a weak correlation with overall and social well-being, but not physical well-being. ▪ Link between SMA and both overall and social well-being. ▪ Those with multiple deficits may benefit from SMA-focused interventions to enhance overall well-being. ▪ GPs can improve social and overall well-being by engaging effectively with frail patients. ▪ Healthcare professionals should prioritise quality communication. ▪ Frail older adults need to be informed, active in their care	X		x

						and have clear goals for their health. ▪ Participation requires high-quality information and the skills to manage their well-being. ▪ Information sharing is essential in managing health. ▪ Healthcare professionals must be trained and organised to ensure productive interactions.			
34.	Wallerstedt et al.	2018	Sweden	▪ Qualitative (Content Analysis) ▪ 40 next of kin for frail older people	Nursing home	▪ Next of kin experiences of participating in the care of older people in nursing homes **Key findings/aspects** ▪ Participation in nursing home care involves balancing responsibility for the older person's well-being with staff duties. ▪ Engagement falls into 3 categories: visiting, relationship building, and information sharing. ▪ Participation varies: some feel compelled to help, while others may not engage at all. ▪ Visits vary frequently, influenced by work commitments, distance, and personal limitations. ▪ visits yield mixed feelings, allowing social engagement but raising concerns about the individual's condition. ▪ They assist with transportation, hygiene, laundry, paperwork, and finances.		X	X

						▪ Cleaning the older person's room fosters a home-like environment while organising social activities supports well-being. ▪ They monitor care quality and may increase involvement if trust in nursing staff declines.			

Note: *1-Body/ADL = Control as conveyed in bodily expressions and daily activities; 2- Residence = Sense of control and influence of place of residence; 3- H&SC relationships = Control within health and social care relationships*.

2.6.4 Synthesis of results

The results highlighted three main themes: a) Control as conveyed in bodily expressions and daily activities, b) Sense of control and influence of place of residence, and c) Control within health and social care relationships.

I will delve into each theme in greater detail in the following sections.

2.6.4.1 Theme 1: Control as conveyed in bodily expressions and daily activities

Control in older people living with frailty is mainly expressed within the increasing limitations in their bodies and activities of daily living.

2.6.4.1.1 Control over the body

Older people living with frailty often experience bodily changes and pain, limiting their control over their bodies and independence (Siriwardhana et al. 2019). As a result, many of them usually require assistance from others to perform even the simplest daily tasks, such as getting out of bed, which may cause them to spend extended periods waiting for help (Kwong et al. 2014). These incidents can lead to physical and psychological stress, resulting in a lower sense of control and exposing older people to the potential for increased levels of frailty (Mooney et al. 2018). Therefore, a sense of control is associated with an individual's perception of their ability to manage their bodies and maintain their self-care capacity.

The literature indicates that by engaging in various self-care activities like exercise, medication management, and maintaining a healthy diet, older people living with frailty can better manage the limitations imposed by their bodies and associated symptoms (Niesten et al. 2012; Claassens et al. 2014). Even if their engagement in self-care activities is unrelated to their frailty diagnosis, it can still provide a sense of control and improve their overall quality of life (Kwong et al. 2014; Milte et al. 2015). For instance, maintaining a good oral hygiene schedule can help older people with living frailty feel control over their physical body and promote a greater sense of well-being (Niesten et al. 2012).

Consequently, the review led me to conclude that older people living with frailty tend to display external manifestations and bodily expressions due to their level of control over their bodies. It has been observed that if these individuals believe that they can control certain aspects of their body, it can compensate for the parts they cannot control due to their frailty diagnosis. This perceived sense of control can foster a feeling of well-being, even in light of their frailty diagnosis.

2.6.4.1.2 Control over activities of daily life

In the review, I found that a sense of control in older people living with frailty impacted activities of daily living (Abu-Bader et al. 2003; Janlöv et al. 2006; Ekdahl et al. 2010; Strohbuecker et al. 2011; Hedman et al. 2019; Lambotte et al. 2019). Johannesen et al. (2004) examined the association between measures such as continuity and self-determination with everyday life satisfaction among older people living with frailty, and results indicated that continuation of daily activities is positively associated with life satisfaction. Such individuals feel in control whenever they have choices over everyday life aspects, such as whether to do certain things on their own and maintain regular routines in everyday life such as gardening, cleaning, preparing meals and engaging in community activities (Thorson and Davis 2000; Janlöv et al. 2006; Andersson et al. 2008;

Kristensson et al. 2010; Falk et al. 2011; Ekwall et al. 2012; Ebrahimi et al. 2013; Claassens et al. 2014; Portegijs et al. 2016).

Engaging in meaningful daily activities has been shown to improve control and well-being outcomes for older people living with frailty. These activities provide a sense of identity, independence, and environmental mastery and reduce the risk of adverse health outcomes such as hospitalisation (Andrew et al. 2012; Ekwall et al. 2012; Ebrahimi et al. 2013; Dent and Hoogendijk 2014; Gale et al. 2014; Hedman et al. 2019; Siriwardhana et al. 2019; González-Bautista et al. 2020). Older people living with frailty need at least three preconditions to maintain greater control over their daily activities. Firstly, easy access to practical aids, including vision and mobility aids and supportive architecture such as furniture raisers, can make a significant difference in their sense of control (Claassens et al. 2014). Secondly, utilising a range of self-management techniques can strengthen older people’s cognitive and behavioural capabilities to manage their lives, improve well-being, and prepare for future age and health-related challenges. Studies have shown that self-management abilities such as taking the initiative, investing in resources for long-term benefits, and effectively managing resources are vital in supporting older people living with frailty to take charge of managing aspects of their daily lives and maintaining various multi-functional resources significant in dealing with different age-related declines (Schuurmans et al. 2005; Frieswijk et al. 2006; Cramm et al. 2014; Vestjens et al. 2020). Lastly, remaining at home or in a familiar environment where they feel safe and supported by familiar care providers and connected with family, friends, and societal members is essential in avoiding social isolation and loneliness (Andersson et al. 2008; Ebrahimi et al. 2013; Broese van Groenou et al. 2016).

In summary, theme 1 discusses the challenges faced by older people living with frailty, particularly regarding their control over their bodies and daily activities. It highlights that bodily changes and pain can limit their independence, necessitating assistance for basic tasks, which can lead to stress and a diminished sense of control. Engaging in self-care activities, such as exercise, medication management, and maintaining a healthy diet, can enhance their perceived control and improve their quality of life. In addition, it is important to maintain a routine and engage in meaningful daily activities, which contribute to feelings of identity, independence, and well-being. To enhance control over daily activities, older people living with frailty need access to practical aids, effective self-management techniques, and a supportive environment, which helps mitigate social isolation and loneliness.

2.6.4.2 Theme 2: Sense of control and influence of place of residence

This theme examines the differences in levels and experiences of control and well-being between older people living with frailty living in the community and those transitioning to nursing homes.

2.6.4.2.1 Living at home

Living at home has been associated with independence and a higher sense of control for older people living with frailty. A study by Grain (2001) compared the sense of control and life satisfaction between homebound older people and nursing home residents. The study found that individuals who lived at home had a greater perceived control than those in nursing homes. This difference was attributed to their ability to engage in everyday activities and care for themselves without burdening others. As a result, their sense of continuity, self-determination, and good health increased (Grain 2001; Johannesen et al. 2004; Ebrahimi et al. 2013). Furthermore, living at home allowed for older people's caring needs to be seamlessly integrated and provided a familiar environment, creating a sense of *'homeness'* and continuity that is crucial in enhancing the sense of well-being for older individuals (Andersson et al. 2008). Consequently, older people living with frailty at home feel more secure and engaged and have a greater sense of continuity, which increases their sense of control and overall well-being.

Although many older people living with frailty prefer to stay at home, sometimes trying too hard to maintain independence can become burdensome and harmful to their health and overall well-being (Claassens et al. 2014). Physical and cognitive limitations arising from illness or frailty can make it challenging to participate in decision-making processes. In such situations, the need for control can become a burden rather than beneficial to well-being, compelling older people to entrust some or all of their decision-making power and control to significant others such as professional caregivers and/or family members (Andersson et al. 2008; Bilotta et al. 2010; Ekdahl et al. 2010; Claassens et al. 2014; Lambotte et al. 2019).

However, in cases where older people living with frailty prefer to have their care decisions made by others, they wish to be informed and listened to by their care providers. This transparent communication helps prevent the older person from feeling like the care provider is taking the care responsibility away from them and instead feel like they are willingly handing it over (Ekwall et al. 2012). Likewise, if an older person living with frailty chooses to relinquish control to a family member, it is vital that they do not view this as a burden for the family member, as this can negatively impact their well-being (Janlöv et al. 2006).

In conclusion, living at home can provide older people with frailty a sense of safety, independence, and continuity. Although ageing and illness may require relinquishing some degree of control, willingly surrendering control is paradoxically seen as a way of exercising control, provided care providers keep older people living with frailty informed and listen to their needs.

2.6.4.2.2 Control and relocation away from own home

In instances where older people living with frailty have to relocate from their homes to a nursing home or even from one nursing home facility to another, the experience is often stressful (Falk et al. 2011). This stress is due to the changes in routine, which can create uncertainty, confusion, and a sense of abandonment (Falk et al. 2011). These changes can further limit the control of older people and even lead to adverse health effects, including mortality (Thorson and Davis 2000; Falk et al. 2011). In nursing homes, the loss of regular activities and dependency on others can make older people feel passive and lose control (Grain 2001; Johannesen et al. 2004; Strohbuecker et al. 2011; Kwong et al. 2014; Sandgren et al. 2020). However, through involvement in the planning of the relocation process, undergoing pre-relocation preparation, and maintaining some of their habits, such as moving to the same side of the new building as their previous residence, older people living with frailty can regain some sense of control (Thorson and Davis 2000; Falk et al. 2011).

Formal and informal caregivers are instrumental in supporting older people living with frailty to maintain a sense of control during and after their relocation. On the one hand, formal caregivers such as nurses encourage participation in clinical assessments and care planning while respecting the privacy and dignity of the person, which can enhance a sense of control (Hedman et al. 2019). On the other hand, informal caregivers support these individuals to attend social events, engage in exercise, and supervise their care, allowing them to maintain some of their everyday routines (Kwong et al. 2014; Wallerstedt et al. 2018). However, the shortage of nursing home staff and their lack of expertise in dealing with older people living with frailty may affect the above approaches (Kwong et al. 2014). This is particularly the case when nurses make decisions for older people without consulting them about their wishes or complaints, intensifying their loss of control (Strohbuecker et al. 2011).

In conclusion, relocating older people living with frailty to institutional care can create a sense of diminished control, particularly if the transition leads to abrupt changes in their daily routines. Staff shortages or a lack of expertise in caring for older people living with frailty may also result in formal caregivers making decisions on their behalf, further reducing their sense of autonomy in nursing homes. Conversely, when older people living with frailty are actively involved in decisions regarding their relocation and care planning, and feel supported by their loved ones, they are more likely to retain a sense of control in institutional settings.

Theme 2 emphasises that residing at home enhances independence and control for older people living with frailty, contributing to greater life satisfaction through their ability to engage in daily activities. This familiar environment nurtures a sense of well-being. However, physical and cognitive challenges can render independence burdensome, often leading to an increased reliance on caregivers. In these circumstances, effective communication becomes essential, as older people living with frailty desire to feel informed and involved in their care. Additionally, transitioning to a nursing home frequently induces stress and a sense of lost autonomy. Therefore, involving older people living with frailty in the relocation process and maintaining established routines can help them regain a degree of control. It is also crucial for caregivers to encourage participation in planning for such transitions to institutional care, though challenges like staff shortages and limited expertise in caring for older people living with frailty can sometimes impede these efforts, further affecting their sense of control.

Having explored the potential transition from independent living to residential care, I will now delve into the literature regarding the nature of relationships.

2.6.4.3 Theme 3: Control within health and social care relationships

The literature suggests that the quality-of-care relationships and power dynamics in health and social care systems affect the sense of control in older people living with frailty.

2.6.4.3.1 Role of trusting relationships

Developing a trusting relationship between older people living with frailty and their carers, whether formal or informal, is crucial to enhancing their sense of control

(Kristensson et al. 2010; Claassens et al. 2014; Vestjens et al. 2020). The first step towards building such a relationship is to exhibit empathy and a sense of humour during care interactions through simple gestures like chatting, hugging, and holding hands (Claassens et al. 2014; Hedman et al. 2019). These actions can create a feeling of support and joy for older people living with frailty, helping to develop their communication, cooperation, and a sense of togetherness with their carers (Wallerstedt et al. 2018). This approach, in turn, can lead to more caring and individualised relationships and the perception of the older person being an integral member of the caring team (Claassens et al. 2014; Wallerstedt et al. 2018; Hedman et al. 2019).

In addition, building a trusting and caring relationship is crucial for creating an environment where sharing information and joint decision-making can thrive (Ekdahl et al. 2010; Claassens et al. 2014; Hedman et al. 2019). Such care practices facilitate vital aspects of control, such as choice, autonomy, and participation, which are essential for older people living with frailty (Ekdahl et al. 2010; Hedman et al. 2019). In addition, through such a relationship, mutual respect and recognition of individuality can be developed, which is essential in recognising each individual’s unique experiences and care needs (Claassens et al. 2014; Vestjens et al. 2020). This recognition helps to create a sense of balance and normality, providing a greater sense of control for older people living with frailty (Strohbuecker et al. 2011; Claassens et al. 2014; Lambotte et al. 2019; Vestjens et al. 2020).

Care providers must strive to communicate and cooperate effectively to promote control, autonomy, and participation of older people living with frailty (Claassens et al. 2014; Broese van Groenou et al. 2016; Hedman et al. 2019). Research has shown that interprofessional collaborations between formal care providers, such as nurses and GPs, can fulfil the needs of older people, including treatment, while also making them feel secure (Claassens et al. 2014; Hedman et al. 2019). Furthermore, informal caregivers play a crucial role in promoting the autonomy and participation of older people in their care (Claassens et al. 2014; Lambotte et al. 2019). As such, formal caregivers should establish a trustworthy relationship with the relatives of older people (Broese van Groenou et al. 2016). For example, by engaging informal caregivers in care decisions and processes, older individuals with frailty can feel more in control of their healthcare (Broese van Groenou et al. 2016; Hedman et al. 2019).

Finally, in the context of informal caregiving, trustful relationships are essential for establishing care reciprocity between older people living with frailty and their informal caregivers. Studies have shown that older people who require caregiving support often express gratitude and sometimes want to offer something in return to their caregivers (Janlöv et al. 2006; Ebrahimi et al. 2013; Lambotte et al. 2019). This reciprocation can take various forms, including exchanging physical or psychological goods and passing on everyday skills (Andersson et al. 2008; Lambotte et al. 2019). By engaging in such practices, older adults can feel more in control and valuable, rather than just being perceived as resource takers (Janlöv et al. 2006; Ebrahimi et al. 2013; Lambotte et al. 2019).

In conclusion, the establishment of empathetic and reciprocal relationships between older people living with frailty and their caregivers, coupled with the promotion of interprofessional collaboration among caregivers, has the potential to significantly enhance the independence, togetherness, and perceived control of older people living with frailty in their care processes.

2.6.4.3.2 Sense of control and power relationships

Through the literature review, it has been observed that the depersonalisation of the care process can lead to a perceived power imbalance between older people living with frailty and professional care staff (Janlöv et al. 2006; Ekdahl et al. 2010; Kristensson et al. 2010; Ekwall et al. 2012). This perspective occurs when staff engage more with the system and processes than the person (Andersson et al. 2008; Kristensson et al. 2010; Falk et al. 2011; Sandgren et al. 2020). Some care staff neglect to discuss care options or plans with older people living with frailty, disregarding the need for information sharing or overruling their expressed views (Ekdahl et al. 2010; Falk et al. 2011; Ekwall et al. 2012). For instance, in a study on the older persons' experience of being assessed for and receiving public home help in Sweden, some older people living with frailty reported a lack of information on available care options, such as the type of help they could claim, as home help officers were reluctant to share this information (Janlöv et al. 2006). Such power imbalances can intensify older people's feelings of powerlessness, making them unable to ask questions or query decisions and compelling them to do as they are told (Andersson et al. 2008; Ekwall et al. 2012).

In addition, hospitals and other care organisations often have bureaucratic tendencies that make older people living with frailty feel powerless (Ekdahl et al. 2010; Kristensson et al. 2010). They function in a rigid and unresponsive manner, and older individuals often struggle with the gatekeepers when waiting for key decisions such as relocation or discharge, creating feelings of uncertainty (Janlöv et al. 2006; Kristensson et al. 2010). Additionally, some care organisations focus on specific tasks rather than a comprehensive approach to understanding the person, often disempowering older people living with frailty (Kristensson et al. 2010; Hedman et al. 2019). This task-oriented approach limits older people's sense of control and potential to adjust to their care environment and situation.

In conclusion, the organisational structures within care institutions, coupled with the power dynamics that exist between care professionals and older people living with frailty, can result in a sense of uncertainty, disempowerment, and diminished autonomy among older people living with frailty.

Theme 3 emphasises the importance of trusting relationships between older people living with frailty and their caregivers. Empathy, humor, and simple gestures can significantly promote effective communication and collaboration, enhancing these individuals' sense of control. Moreover, involving informal caregivers in decision-making processes can enhance the autonomy of older people living with frailty. Trusting relationships also encourage a reciprocity of care, allowing these individuals to feel valued rather than merely as recipients of care assistance. On the other hand, the theme highlights that a depersonalised care approach can lead to power imbalances, leaving older people living with frailty feeling powerless and excluded from discussions regarding their care. Ultimately, nurturing supportive relationships fosters independence, togetherness, and a greater sense of control for older people living with frailty.

2.7 Discussion

2.7.1 Summary of evidence and new knowledge from the review

Though the research in this area is limited, there is a small but growing body of literature, with most studies conducted in Scandinavian countries.

There is clear quantitative and qualitative evidence demonstrating a relationship between the body, sense of control and well-being for older people living with frailty. As individuals face increasing bodily limitations, it becomes progressively more difficult to maintain a sense of control and well-being. These findings are consistent with other studies that indicate poor health leads to biological disruptions in the body, further exacerbating physical declines, the loss of functional abilities, and ill-being among older adults (Clarke et al. 2008; Bhullar et al. 2010; Satariano et al. 2010; Clarke and Korotchenko 2011). Moreover, these findings resonate with a broader shift in the sense of identity often observed in older people. Changes in the body, such as unintentional weight loss and slowing down, can significantly impact their sense of self (Alibhai et al. 2005; Thomas 2005; Chapman 2011; Martin and Twigg 2018). Among others, the first theme highlights a disproportionate emphasis on biomedical and psychological aspects of the body, even though internal feelings of control can significantly compensate for the physical decline. Martin and Twigg (2018, p.1) argue that focusing on the biomedical aspects of the body alone is *“reductionist and objectifying”* and that more attention should be placed on the *“embodied experiences of everyday life”* of older people. This perspective can be linked to the concept of subjective ageing, where some older people feel younger than their biological age and physical appearance, which is associated with resilience and better health outcomes in old age (Cleaver and Muller 2002; Kleinspehn-Ammerlahn et al. 2008; Kornadt et al. 2018).

An important finding from the review is that the physical and social environment mediates a sense of control. Theme two suggests that older people living with frailty prefer to stay in their homes for as long as possible, consistent with the wider literature on older people in general (Stones and Gullifer 2016; Bárrios et al. 2020). This finding highlights how the sense of control and well-being is relational and not only based within the individual. Theme two also highlights the detrimental impact of environmental change and the potential lack of control over this change. These findings align with other studies that show how older people feel less autonomous over everyday decisions when they move to nursing homes (Reimer and Keller 2009; Wikström and Emilsson 2014). However, some studies have shown that older people in nursing homes can exercise free will, such as bedtime and privacy, depending on the nurses’ attitude towards them (Tuominen et al. 2016). In both cases, the feeling of control over one’s environment is more about how it makes individuals feel rather than the environment itself. Todres et al. (2009) contend that feeling human is closely related to the physical environment’s comfort, security, and ease, and the lack of these can make a person feel like a stranger. The reviewed literature highlights the challenges that older people living with frailty face when transitioning to nursing homes or relocating from one nursing home to another. However, these aspects have mainly been explored using quantitative approaches, and gerontological research and practice would benefit from understanding the lived experiences of older people during such life changes.

In theme three, it is suggested that trusted relationships at different care levels support a sense of control for older people living with frailty. This finding implies that individuals do not exist in isolation, as seen in the medical model, but rather, they live within networked relationships of meaning throughout their lives. It is this meaning that should be the currency of care (Todres et al. 2007). The review has highlighted the role of formal and informal care providers in facilitating or obstructing a sense of control in older people living with frailty. However, few studies focus on care providers' perspectives on control and well-being in older people with frailty. The review was only able to locate three studies by Hedman et al. (2019), Wallerstedt et al. (2018), and Broese van Groenou et al. (2016), which focused on the perspectives of formal and informal care providers. Given the critical role caregivers play in facilitating a sense of control and well-being in older people, conducting more studies that capture their perspectives is essential.

Furthermore, this review highlights that organisational systems and service user vulnerability sometimes challenge trusting caring relationships. This challenge often manifests in power imbalances at the care provider and organisational levels. For example, care providers are perceived as experts who use their professional knowledge and competence to make care decisions, sometimes without the involvement of the older person, resulting in a diminished sense of control for the older individual (D'Avanzo et al. 2017). Similarly, care organisations can perpetuate power imbalances and limit the sense of control of older people living with frailty by using a 'system' discourse that only considers the professional perspective, leaving no room for other interpretations or discourses (Galvin and Todres 2013).

This review has highlighted new knowledge and gaps in our understanding. A sense of control and its effect on well-being in older people living with frailty could be seen mainly in objective terms relating to deterioration in bodily ability, leading to isolation, reduced sense of control, and poorer sense of well-being. What this review has highlighted is that by using a subjective lens, the sense of control is mediated by the subjective meaning of their situation for older people living with frailty rather than a deterioration of bodily ability per se.

Another new aspect that has emerged from this review is that the physical and social environment mediates a sense of control and well-being. A sense of control and well-being is relational and not only based on the individual, so understanding the experience of service providers and older people living with frailty is important. Also, from the review, it can be seen that the sense of control over one's environment is more about how it makes individuals *'feel' r*ather than the environment itself.

All of these aspects highlight the importance of understanding the subjective experience of older people living with frailty in order to gain deeper insights into how these mediations affect their sense of control and well-being. It is also helpful to gain some understanding of how service providers feel they can create the type of relationships that allow the individual discourse to be heard above that of ‘the system’.

It is also interesting to reflect on the definition of frailty. As with other concepts, frailty in older people has been defined through observing the signs and symptoms of the individual and their susceptibility to physical deterioration (see Chapter 1, pages 18-23). The review pointed out that frailty in older people is a multifaceted concept that affects them differently. When reflecting on this review, it is interesting to note that the lived experience and meaning of frailty could also be seen a) in subjective terms by considering the meanings for that particular person and also b) in relationship to others where the experience of frailty is mediated by relationships with others and the environment Using this approach frailty is seen as something that is more fluid depending on the meaning created and the opportunities within the relational and environmental possibilities Therefore, rather than perceiving it solely in terms of physical declines, frailty should also be perceived in terms of its impact on older people’s social and psychological well-being. In addition, frailty is often not considered as an individual attribute but rather attributed to the person by society. The social environment and interaction with others are important in understanding how frailty affects older people. However, we do not have sufficient evidence on how frailty feels for older people. This more fluid understanding of frailty has been important in informing the rest of the study.

The review has highlighted that considering subjective experience based on meanings and relationships offers a new way forward in understanding the sense of control and well-being. This has informed the research question, which focuses on subjective experience, and the research approach of phenomenology, which focuses on subjective lived experience.

2.7.2 Limitations

I conducted this review as part of a PhD study, meaning I performed all of the work instead of two or more researchers conducting and cross-checking all decisions in detail. However, I discussed all decisions with the supervisory team in regular supervisory sessions and resolved any issues by consulting them. To balance feasibility in terms of time and the ability to answer the review question, I limited the search to only peer-reviewed primary research. As a result, I may have omitted some relevant literature from sources such as review articles, websites, blogs, research protocols, reports, conference proceedings, dissertations/theses, editorials, and commentaries. Additionally, since this was a scoping review, the included papers were not assessed for their methodological quality. Therefore, it is possible that some of the included papers may not be of the highest quality or methodological rigour.

2.7.3 Conclusions

A sense of control in older people living with frailty is increasingly acknowledged as an essential care and policy issue. This review provides clear quantitative and qualitative evidence demonstrating the importance of a sense of control in managing the development of frailty and the active maintenance of ability leading to a sense of well-being. Additionally, this scoping review emphasises that the sense of control is not merely an internally regulated feeling, but it is also highly dependent and inextricably linked to the physical and social environments and the meanings attached to those environments. Most studies have been quantitative, and this review highlights the need for more qualitative studies to explore and gain insight from older people living with frailty and those who work alongside them to understand these relationships and the meanings attributed to them.

2.8 Aim of the thesis

Control is essential to understanding how individuals maintain charge of their lives; however, little research exists regarding how older people living with frailty experience control when using healthcare services and how this impacts their overall well-being. Therefore, this thesis explores the lived experience of control and well-being of older people living with frailty in healthcare services in southern England. To achieve this aim, I formulated two closely interlinked research questions: a) *What is the lived experience of control and well-being of older people living with frailty in healthcare service use*?-providing an in-depth understanding of how older people living with frailty perceive and experience control when using healthcare services b) *What are the experiences of service providers when considering control and well-being of older people living with frailty in healthcare service provision?* exploring how healthcare professionals could integrate principles that enhance service users' sense of control and well-being.

This study differs from many others that focus only on the perspectives of older people living with frailty. Instead, it provides insights into the views of those receiving and delivering healthcare services. The findings highlight areas of healthcare that could be improved to support the sense of control of older people living with frailty and contribute to understanding how lifeworld-led humanising care aspects can be applied in healthcare practices to enhance the dignity and well-being of service users.

Chapter 3 Theoretical framework: The lifeworld

3.1 Introduction

In this chapter, I provide an overview of the theoretical framework that I have chosen, ‘the lifeworld’. I start by discussing the meaning of the lifeworld concept and then present its various dimensions, including embodiment, temporality, spatiality, intersubjectivity, and mood. Finally, I conclude the chapter by establishing a connection between the lifeworld framework and qualitative research.

3.2 Meaning of the notion of lifeworld

The concept of lifeworld was first introduced by philosopher Husserl in the 1920s (Galvin 2010; Hemingway 2011; Hörberg et al. 2019). As the founder of the phenomenological movement, he played a significant role in its development (Ashworth 2016). Husserl, a mathematician, was concerned with the limitations of objectivism or quantitative measures when understanding the human experience (Thoresen et al. 2011; Hemingway et al. 2015). He aimed to honour the pre-theoretical attitude of world-to-consciousness and sought ways to articulate what it means for us and our central role in bringing this world to light through the givenness of experience (Todres et al. 2007).

According to Husserl, the lifeworld is the starting point from which humans categorise and name their experiences (Todres et al. 2007). It is the qualitative, flowing nature of the world that appears meaningfully to consciousness, reflecting the continuous stream of experiential happenings and relational meanings and experiences in everyday life (Todres et al. 2007; Galvin 2010). This concept encompasses unique perceptions, interactions with others and the environment, lived experiences, and the meanings people attribute to these experiences in specific situations (Ashworth and Ashworth 2003; Galvin 2010; Ashworth 2016). In addition, the lifeworld is a holistic and embodied world with interconnected horizons where individuals live as their bodies with others within a larger story or place, experiencing time, space, and the lived body in a humanly lived manner (Galvin 2010). This concept emphasises the qualitative character of our experienced world, the interconnectedness of experiences, and the seamless nature of human existence (Galvin 2010; Hörberg et al. 2019; Galvin et al. 2020).

The lifeworld is not an objective world existing outside of humans but rather a subjective and relational world that is an integral part of human experience (Thoresen et al. 2011; Galvin and Todres 2013). It is where we find information and knowledge relevant to us as human beings to make sense of the world around us (Todres et al. 2007). Although it is often taken for granted, the lifeworld plays a crucial role in shaping our experiences and interactions with our environment (Galvin and Todres 2013). It integrates the objective, subjective, and intersubjective aspects of human existence, emphasising the significance of shared meanings, values, beliefs, aspirations, inner transformation, and shared symbols in shaping people’s experiences (Hemingway 2011). In simpler terms, the lifeworld is where our experiences are immersed and from which we derive much of our meaning (Ashworth 2016). Therefore, the lifeworld is the foundation of human existence and understanding and is essential for studying the experiences of individuals in different situations (Ashworth 2003; Todres et al. 2007).

3.3 Dimensions of the lifeworld

Various philosophers such as Merleau-Ponty, Heidegger, Gadamer, and Habermas have further explored the concept of the lifeworld. They belonged to the continental philosophy movement and built upon the idea by introducing different philosophical perspectives (Biley and Galvin 2007; Dahlberg et al. 2009; Hemingway et al. 2015). These philosophers identified existential dimensions of the concept of lifeworld, such as embodiment, temporality, spatiality, inter-subjectivity and mood (Ashworth and Ashworth 2003; Todres et al. 2007; Galvin 2010; Hemingway 2011). These dimensions are fundamental to describing the holistic context in which human existence makes sense (Galvin and Todres 2013; Ashworth 2016). They shape our understanding of the world and our place within it (Hemingway 2011). Moreover, the dimensions are mutually dependent and intertwined constituents fundamental to human experience (Biley and Galvin 2007; Galvin and Todres 2013; Ashworth 2016; Flinterud et al. 2022). In the next section, I describe each lifeworld dimension, including embodiment, temporality, spatiality, inter-subjectivity, and mood.

3.3.1 Embodiment

Embodiment is a way of understanding the body as the container for all our lived experiences, including the physical, mental, emotional, social, and spatial aspects of our existence in the world (van Rhyn et al. 2021a). It encompasses the individual’s physical presence, embodied knowing and felt sense, as well as bodily experiences, sensations, movements, and interactions with the body and the bodies of others within the lifeworld (Ashworth and Ashworth 2003; Ashworth 2016). The idea was developed by a French existential phenomenologist, Merleau-Ponty, and the focus of this dimension of the lifeworld is the importance of the lived body in shaping people’s experiences (Thomas 2005; Grīnfelde 2018). The concept of embodiment suggests that we experience and perceive the world through our bodies (Thomas 2005). Our physical bodies are not just passive receivers of sensory information but active sources of meaning which are rooted and either revealed or concealed through them (Grīnfelde 2018; van Rhyn et al. 2021a). This perspective challenges the traditional idea of separating the body and mind, instead viewing the body as an integral part of its social and spatial environment (Koopman and Koopman 2018; van Rhyn et al. 2021a). However, the body is rarely at the forefront of our consciousness and often recedes from view during our everyday activities (Martin and Twigg 2018). This perspective means that we sometimes take our bodies for granted, only becoming aware of them when we experience pain, illness, or other changes such as ageing (Hay et al. 2016; Martin and Twigg 2018; van Rhyn et al. 2020). Embodiment, therefore, highlights the essential ontological lens of the ‘flesh’, showing that the body is not just something we have but something we are (van Rhyn et al. 2021a).

Biley and Galvin (2007, p.803) suggest that being human involves experiencing both freedoms and vulnerabilities as part of *“the embodied existence in the world”*. For example, illness, disability, or pain can profoundly affect a person’s existence by disrupting the relationship between the body and the world (Thomas 2005; Grīnfelde 2018). In addition, while embodied experiences are highly subjective and can only be comprehended by the individual (van Rhyn et al., 2021b), our interaction with others involves our bodies contributing to shared bodily experiences, which help us understand and empathise with each other's vulnerabilities (Hay et al. 2016). The inter-corporeal space overlaps shared experiences, leading to co-created, individually reflected bodily understanding and experiences (van Rhyn et al. 2021a; Kuuru 2022). Consequently, a comprehensive description of an individual's 'embodied existence' should include the body's relationship with other dimensions of life, including temporality, spatiality, and intersubjectivity/relationality (Todres et al. 2007; van Rhyn et al. 2020).

The body can be perceived from both the subject and object sides (Thomas 2005; Slatman 2014; Grīnfelde 2023). The object (external) side of the body focuses on the experience of the body as a material thing (Körper) and how others perceive it (Grīnfelde 2018). The subject (internal) side of the body expresses the view of the body as a condition of possibility for world-disclosing and as an affective givenness, which is directly accessible only to oneself (Grīnfelde 2018). Consequently, the object body is what we see, touch, and feel, while the subject body is the principle of experience that enables us to touch and feel the body (Gallagher and Zahavi 2008). In addition, the body can be experienced in four dimensions, i.e. functional, affective, material, and social (Grīnfelde 2018). The functional dimension describes the body and the world as fundamentally united

(Slatman 2014; Grīnfelde 2018). The affective dimension highlights the relationship between the feeling body and itself (Grīnfelde 2018). The material dimension is characterised by the experience of the body as a material object (Grīnfelde 2018). The social dimension refers to how the perception of one's physical body is influenced by the broader social world, impacting the individual's experience of their body (Grīnfelde 2018). Although the dimensions of the body can be experienced *"as both a feeling and acting subject and as a felt and observed object",* they are interconnected and not mutually exclusive (Slatman 2014; Grīnfelde 2018, p.114).

The concept of embodiment offers a framework to explore the bodily aspects of experience, leading to a holistic understanding of how individuals sense, feel, think, act, and relate in different situations (Kuuru 2022). This approach promotes a deeper connection to the self and others, enabling a more comprehensive understanding of lived experiences (Küpers 2020). Embodied experiences have played a fundamental role in understanding various phenomena such as ageing, illness, customer experiences, and organisational practices (Hay et al. 2016; Küpers 2020; Kuuru 2022; van Rhyn et al. 2022). In addition, embodiment methodologies have been applied in interdisciplinary research fields such as sociology, anthropology, health, and (critical) psychological studies of gender, race, and ageing, challenging traditional societal norms (van Rhyn et al. 2021b). For example, in gerontological studies, the perspective offers an opportunity to challenge dominant discourses of ageing based on medical approaches that often consider the body in old age as associated with ill health, loss of function, and biological decline (Martin and Twigg 2018). Instead, it recognises bodies as objects of knowledge and as sources of identity and meaning, enabling a more comprehensive understanding of lived experiences (van Rhyn et al. 2021b).

3.3.2 Temporality

Temporality, in the context of lifeworld, refers to the way time and events are understood and experienced by individuals (Ashworth and Ashworth 2003; Ashworth 2016). It includes the continuity and discontinuity of time as it is humanly experienced (Todres et al. 2007). It is a dimension of the lifeworld that pertains to the experience of time as a story where individuals live in the context of what possibilities life may bring and what the future may offer (Galvin 2010). Temporality encompasses our recollections of past events and the possibilities that arise from seasonal rhythms (Hemingway 2011). It also includes the impact of time pressures in a horological sense (Hemingway et al. 2015). Overall, temporality relates to the individual’s experiences of time and events within their lifeworld.

All experiences are part of a story and have a temporal flow (Todres et al. 2007; Ashworth 2016). This perspective means that time is not just a linear progression but is experienced subjectively (Galvin 2010). People can feel time passing slowly or quickly, and their perception of the past, present, and future is part of their engagement with events and routines in their daily lives (Ashworth and Ashworth 2003; Galvin 2010). It is not just about the quantitative, neutral passage of time but also about the qualitative aspects of time, such as the past coming up close, the future receding, and the rhythms of the seasons affecting our experiences

(Todres et al. 2007). In addition, temporality includes feelings of possibility related to personal histories, memories, and aspirations for the future (Hemingway et al. 2015). In other words, people's experience of time can either offer a feeling of possibility or become a negative pressure, depending on whether it is oppressive and overly rigid or allows for options and possibilities (Hemingway 2011).

This dimension of the lifeworld emphasises the connection between past, present, and future experiences and how they shape human existence (Galvin 2010). It also includes the feeling of multiple possible futures, the sense of possibility, and the anxiety or depression that arises when the future seems limited, restricting the opportunities for living forward (Todres et al. 2007). Temporality encompasses the flow of events, the historical context, and the impact of time and duration on an individual's experiences (Todres et al. 2007; Ashworth 2016). Todres et al. (2007) recommend that a lifeworld description in healthcare would need to include these temporal aspects, not just the quantitative measures of time but also the qualitative and storied nature of human experience. For instance, in the context of dementia care, temporality plays a significant role as individuals with dementia may experience time differently, focusing more on the immediate present and struggling to orient themselves to past and future events (Ashworth and Ashworth 2003). Consequently, temporality encompasses the subjective perception of time, including the past, present, and future, and how individuals relate to and make sense of time in their lived experiences (Ashworth 2003).

3.3.3 Spatiality

Spatiality refers to how individuals experience and interact with physical spaces and places within their lifeworld (Ashworth and Ashworth 2003). It is the dimension of an individual's lifeworld that encompasses their perception and interaction with physical spaces and objects in various contexts, including their immediate physical and social environment, as well as the broader geographical context (Ashworth 2003; Biley and Galvin 2007; Galvin 2010; Hemingway 2011; Hemingway et al. 2015). In essence, spatiality refers to the world of places and things that have meaning to living (Todres et al. 2007).

We exist in relation to our spatial surroundings, encompassing the physical environment, the layout of spaces, and how we navigate within them (Todres et al. 2007; Galvin 2010). Our interaction with the environment, objects, and the spatial dimensions of our experiences contributes significantly to our perception of the world around us (Ashworth and Ashworth 2003; Ashworth 2016). The significance of our surroundings may vary, causing us to view space differently. For example, a space may feel open or enclosed, hostile or welcoming, restrictive or accommodating for people in different situations (Todres et al. 2007). Todres et al. (2007) further argue that space is not just confined to physical measurements like meters and centimetres, but it extends to the human experience and the significance of the meaning they attach to that space. For example, spatiality could be viewed as being close to somebody or being in the same room with someone but feeling very distant from them (Hemingway et al. 2015). Moreover, our experiences are also influenced by our space's social and cultural context (Hemingway 2011). Social norms and other social meanings associated with places can affect our perception of space and our experiences within it (Ashworth 2016).

Spatiality concerns how physical spaces impact social interactions and relationships and how individuals perceive and navigate their surroundings, particularly in healthcare (Ashworth 2003; Hemingway 2011). For instance, in individuals living with dementia, spatiality is of utmost significance, as changes to their familiar surroundings can affect their sense of orientation, navigation, and familiarity (Ashworth and Ashworth 2003). Furthermore, spatiality is a qualitative way of describing how things appear in terms of their proximity or distance, and it varies depending on the experience (Todres et al. 2007). The meaning of things is determined by how they fit into our lives at a specific moment, including personal topography and the various meanings that things can hold (Galvin and Todres 2013). Consequently, spatiality can offer opportunities for socialisation, purpose, and leisure activities or limit our potential by not providing opportunities for socialisation or access to the natural environment (Todres et al. 2007; Thoresen et al. 2011).

3.3.4 Intersubjectivity

Intersubjectivity is a concept that explains how individuals coexist with others in a mutually intelligible way within their lifeworld (Todres et al. 2007). It is the interconnectedness of human experiences in relation to one another and encompasses an individual’s interactions and relationships within their lifeworld (Galvin 2010; Ashworth 2016). Ashworth and Ashworth (2003) mention that intersubjectivity is the capacity for individuals to engage in social interactions, comprehend others as minded beings, and participate in shared experiences within their lifeworld. The understanding of intersubjectivity as a continuous process underlines the ongoing interaction and shared understanding between individuals and their environment (Hemingway 2011). Intersubjectivity involves recognising and interacting with others as subjects in the world, sharing perspectives, and engaging in reciprocal relationships (Ashworth and Ashworth 2003). This interaction allows individuals to frame their thinking, identity, and relationships within the context of time and space (Hemingway et al. 2015).

Human beings are part of an embodied world, and intersubjectivity emphasises that others are always considered in some way (Todres et al. 2007). This perspective means that all our experiences are in relation to others, and we engage with the world through shared language, interpersonal connections, and mutual engagement (Galvin 2010; Hemingway et al. 2015). Intersubjectivity, therefore, highlights the impact of social connections on an individual’s selfhood and identity, as well as the role of others in shaping an individual’s experiences and concerns within their world (Ashworth 2016). In addition, this dimension highlights the capacity of humans to communicate through language, enabling them to share and understand social contexts and relate the same to their unique situations (Todres et al. 2007; Hemingway 2011). In essence, intersubjectivity emphasises the importance of human connection and how individuals interact and engage with each other within their lived experiences (Galvin 2010). As a result, our personhood occurs within the context of the lifeworld and is often affirmed or undermined by others (Ashworth 2016).

In the context of healthcare, intersubjectivity is crucial in understanding the experiences of individuals living with conditions such as dementia. Intersubjectivity may be threatened for such individuals, leading to challenges in maintaining social connections and participating in shared social experiences (Ashworth and Ashworth 2003). However, the power of language in enabling individuals to communicate and understand social contexts is a key factor in preserving intersubjectivity (Hemingway 2011). Consequently, through intersubjectivity and language, individuals can locate themselves meaningfully in the ongoing interpersonal world, with their relationships with others often central to their meaningful living (Todres et al. 2007).

3.3.5 Mood

Another critical dimension of the lifeworld is mood. Heidegger largely developed this aspect of the lifeworld, which relates to the emotions that shape lived experiences (Todres et al. 2007). It refers to an individual's emotional state or quality of feeling and plays a central role in shaping our experiences (Hemingway 2011; Ashworth 2016). Different moods, such as happiness, joy, sadness, anger, contentment, or other emotional states, can significantly impact how individuals perceive and engage with the world around them and their life outcomes (Todres et al. 2007; Hemingway 2011; Hemingway et al. 2015). Similarly, mood is considered a primary aspect of our being in the world, saturating our experiences and influencing our perception and engagement with our surroundings (Todres et al. 2007; Ashworth 2016). Consequently, mood interconnects with other dimensions of the lifeworld, and it is impossible to isolate it from the context in which it occurs (Todres et al. 2007; Hemingway 2011; Hemingway et al. 2015; Ashworth 2016).

Furthermore, mood is not just an internal happening but is perceptual and interactive, serving as a powerful messenger of the meaning of our situation and influencing our bodily-felt experiences and responses (Todres et al. 2007; Hemingway 2011). Ashworth (2016) adds that mood can be perceived as an emotional atmosphere or tone characterising a situation within an individual's lifeworld. It is intimately linked to our ability to realise our potential and achieve our goals (Hemingway 2011). Love and fear, for instance, can highlight or obscure different aspects of our reality and shape our engagement with the world in distinct ways (Todres et al. 2007). Therefore, mood can motivate or demotivate directed action in the world and has an organising power that shapes priorities and activities (Todres et al. 2007; Andrews et al. 2022).

In everyday life, we experience a sequence of fluctuating moods, manifesting as different emotions such as anxiety and joy, each with its unique emotional content (Hemingway 2011; Ashworth 2016). For example, if we are in a low mood, the world might come to us like a dark place, yet it might not be dark. However, mood is more than just a passing internal emotional state (Todres et al. 2007). It is an essential dimension of the lifeworld as it influences how individuals perceive and interact with their environment and can shape their experiences and relationships

(Hemingway 2011). Consequently, mood is essential to understanding the complexity of people's lived experiences.

3.4 The Lifeworld and Qualitative Research

I have emphasised the importance of the lifeworld concept in the above description, highlighting the need to focus on the distinct actualisation of the lifeworld structure (Ashworth 2003). Within qualitative research, it is helpful to prioritise the lifeworld perspective, which emphasises understanding and describing individuals' perspectives and experiences in their specific context (Galvin and Todres 2011; Hemingway et al. 2015).

The lifeworld concept enriches the description of experiences in qualitative research by emphasising their embeddedness in the lifeworld and is generally applicable to empirical qualitative studies (Ashworth and Ashworth 2003; Ashworth 2016; Andrews et al. 2022). The lifeworld comprises various dimensions, such as spatiality, intersubjectivity, embodiment, temporality, and mood, and researchers can actively investigate these aspects to enrich the description of experiences (Ashworth 2016). Especially in phenomenological studies, a focus on the lifeworld is vital as it provides context and meaning for an individual's experiences (Galvin and Todres 2013). People's experiences are immersed in the lifeworld and derive much of their significance from it, making it a foundational framework for understanding individuals' lived experiences and perspectives (Ashworth 2016). This approach helps ensure that the research speaks in first-person terms of the individual's involvement in their lived environment, leading to a more nuanced and holistic understanding of the phenomenon being studied (Ashworth 2003; Ashworth 2016; Toft et al. 2021).

In addition, the notion of the lifeworld transcends disciplinary or professional categories and addresses human existence as a seamless whole (Galvin 2010). To investigate any experience, it is necessary to consider the lifeworld and its system of implications, associations, and meanings that constitute it (Ashworth 2016). Many scholars have applied the ‘lifeworld’ concept to describe their research and practice approaches. For instance, Friberg et al. (2007) discuss how the ontology of the lifeworld can be employed in phenomenological research to understand encounters between patients and nurses in a medical ward. Ashworth (2003) highlights ‘lifeworld fractions’ and illustrates how phenomenological bracketing can be used to reveal the lifeworld. Dahlberg (2011) emphasises the importance of considering the lifeworld phenomenology in medically dominated healthcare systems.

Similarly, Galvin et al. (2020) have applied the lifeworld-led research approach to study what is most important for older people to improve human aspects of healthcare services. Likewise, the lifeworld facets have been considered essential to understanding end-of-life care (Thoresen et al. 2011). Furthermore, the lifeworld-led approach has also been vitally important in providing a philosophical and theoretical basis for humanising caring approaches (Dahlberg et al. 2009; Ellis-Hill 2011; Hörberg et al. 2019; Galvin et al. 2020; Ellis-Hill et al. 2021). Basing my research question on the lived experience of control and the effect on well-being and a lifeworld approach allowed me to move beyond the evidence from quantitative studies and more general views on control within qualitative studies to explore the existential aspects of a sense of control within everyday life which affects how people view their lives and what is possible for them. In addition, this framework allowed me to link the lifeworld with the qualitative research methodology, specifically phenomenology. By incorporating this theoretical lens and reviewing existing literature, I was able to craft research questions that would enable me to *"flesh out"* people's lived experiences and their diverse ways of being-in-the-world, grounded in phenomenology as a research approach (Fandino 2019; Toft et al. 2021; Køster and Fernandez 2023, p.156).

3.5 Conclusion

This chapter introduced the lifeworld concept as my study's main theoretical framework. I explained the meaning of the lifeworld as the qualitative, flowing nature of the world that appears meaningfully to consciousness. I also provided an overview of the intertwined dimensions of the lifeworld, such as embodiment, temporality, spatiality, intersubjectivity, and mood. Finally, I explained how the lifeworld framework is linked to qualitative research and how it influenced my research aims, questions, and approach.

Chapter 4 Methodology

4.1 Introduction

I carried out this study following a phenomenological approach that aimed to explore people's (subjective) experiences. The main focus of this chapter is on the methodology, methods, and research tools that I used to conduct this study. In this chapter, I will discuss the key methodological decisions I made during the research and their justifications. I will start by providing an overview of the philosophical background and then describe the study design, data collection, and analysis processes. Finally, I will conclude the chapter with a section on rigour.

4.2 Ontological and Epistemological Positions

Researchers need to understand the nature of reality to be studied and how to study it. This understanding is vital in defining the research process and other methodological decisions (Tubey et al. 2015). This sometimes-implicit thought process forms part of the components of the research paradigms. Research paradigms are beliefs or assumptions about the nature of reality and how this reality can be studied (Guba and Lincoln 1994; Willis 2007; Rehman and Alharthi 2016). They provide philosophical foundations that shape perspectives about reality, provide direction for the research design, and are communicated through distinct ontological, epistemological and methodological positions (Houghton et al. 2012; Abdulkareem et al. 2018). Ontology refers to the nature of the researcher's beliefs about reality, while epistemology considers the nature and forms of knowledge and how this knowledge can be acquired, validated, and communicated (Richards 2003; Rehman and Alharthi 2016; Alharahsheh and Pius 2020). Consequently, ontology considers questions such as ‘what can exist’ or ‘what is real’ while epistemology considers aspects such as desirability, subjectivity, objectivity, validity, causality and generalisability (Patton 2002; Willis 2007).

Two research paradigms are commonly used to guide methods of inquiry, i.e., positivism and interpretivism, both of which have distinct ontological and epistemological assumptions (Rehman and Alharthi 2016). These paradigms have distinct principles and values that guide the design, methodology, and analysis of research studies, reflecting different perspectives on truth, reality, and knowledge (Ryan 2018).

Positivism adopts an ontological position called realist/objectivist and an empiricist epistemology (Sarantakos 2012; Scotland 2012; Karupiah 2022). Realism assumes an objective reality that exists out there, independent of humans or the knower (Scotland 2012; Al-Ababneh 2020). According to positivism, the social world is understood in the same way as the natural world, with cause-effect relationships between the phenomena considered important (Scotland 2012; Ugwu et al. 2021). Positivism is also characterised by valuing objectivity, empirical evidence, and the proving or disproving of hypotheses through controlled experiments or observations (Ryan 2018). The key principles of positivism include deductivism, objectivity, and inductivism, emphasising that knowledge should be confirmed by scientific evidence, that theories should generate testable hypotheses, that science must be free from personal biases, and that knowledge is obtained by gathering factual evidence that supports scientific laws (Ryan 2018).

Consequently, positivism mainly focuses on collecting quantitative data to uncover universal laws and generalisations (Rehman and Alharthi 2016; Ryan 2018). Quantitative research is, therefore, based on the notion that reality is objective, fixed and can only be studied empirically (Goertzen 2017). Likewise, quantitative research is concerned with numeric and statistical accuracy, and it is often used to answer the ‘what’ and ‘how’ questions using percentages, proportions, or frequencies (Collin 2003).

Conversely, interpretivism assumes a constructivist ontology and an interpretivist epistemology (Sarantakos 2012; Moon and Blackman 2014; Gichuru 2017). Interpretivism values subjectivity and considers the truth and knowledge to be subjective, culturally and historically situated, and based on people’s experiences and understanding (Ryan 2018). It also assumes that reality is socially and actively constructed by individuals as they interact with each other (Gichuru 2017; Alharahsheh and Pius 2020). In addition, interpretivism emphasises that researchers cannot be separated from their values and beliefs, which inevitably inform the data collection, analysis and interpretation (Ryan 2018). Consequently, interpretivism is mainly used to guide the collection of qualitative data and explore individual perspectives and meanings (Rehman and Alharthi 2016; Ryan 2018; Ikram and Kenayathulla 2022). Qualitative research is premised on the notion that there is no objective reality; instead, the reality is subjective and can only be studied by understanding and interpreting people’s experiences at a particular point in time and context (Koro-Ljungberg 2008; Merriam and Grenier 2019).

As seen above, each research paradigm has unique assumptions about reality and how it can be approached and studied. These assumptions determine the research approach or lens through which to understand and conduct research, often reflected in the methodology and methods (Ryan 2018; Alharahsheh and Pius 2020). Houghton et al. (2012) argue that it is vital for researchers to be consistent and transparent in selecting and applying a paradigm in research. This consistency and transparency involve ensuring that the ontology, epistemology, and methodology of the chosen paradigm are evident in the research methods and strategies employed (Scotland 2012; Waring 2012). Similarly, the study aims, paradigms, and methods must be ontologically and epistemologically coherent, aligned and integrated throughout the research process (Houghton et al. 2012). Because I was interested in using a humanistic approach to understand people’s lived experiences, my perspective on reality (ontology) right from the outset of this study was that it is multiple and socially constructed rather than singular and fixed (Patton 2002; Gichuru 2017; Ikram and Kenayathulla 2022). These beliefs would then shape how I approached and studied this reality (epistemology).

Consequently, this research study was guided by a constructivist ontology and interpretivist epistemology. The values and principles of interpretivism align with my research aims and have been found to align with many healthcare approaches, including lifeworld-led humanising care and personalised care (Galvin and Todres 2013; Ryan 2018). This ontological and epistemological stance serves as a philosophical foundation for my chosen methodology, which is qualitative. In the next section, I provide further details about the distinctions between the dominant research methodologies and justify my chosen methodology.

4.3 Research Methodology

Methodology is a theoretically informed strategy or plan that guides how the research should be undertaken, including the choice of research approach, methods, type of data to be collected, and the appropriate data collection tools (Lapan et al. 2012; Rehman and Alharthi 2016; Ugwu et al. 2021). Put differently, methodology explains how we gain knowledge and provides guidelines for conducting research based on ontological and epistemological principles (Sarantakos 2012). From the ontological and epistemological foundations discussed above, there are two dominant research methodologies: qualitative and quantitative (Tuli 2010; Hassmén et al. 2016; Christofi et al. 2024). Qualitative research explores relationships and human experiences to obtain in-depth information and understand different dimensions of a phenomenon, often within a natural setting (Murphy and Yielder 2010; Queirós et al. 2017; Lester et al. 2020). It is characterised by inductive reasoning, a focus on participant perspectives and an emphasis on the holistic view (Tuli 2010; Moule et al. 2016). In addition, qualitative research uses interactive data collection methods, and the findings are often presented in descriptions, themes, theories and models or frameworks (Moule et al. 2016; Lester et al. 2020; Tomaszewski et al. 2020). On the other hand, quantitative research focuses on objectivity and is concerned with quantifying data from generally large samples with findings generalised back to the entire population (Murphy and Yielder 2010; Martin 2012). Quantitative research, therefore, uses structured procedures and data collection methods and involves statistical analysis of data (Tuli 2010; Queirós et al. 2017).

Although quantitative research is vital for producing easily replicable findings classified as objective, representative, and generalisable, it does not provide insights into 'why' people feel, think, and act in certain ways (Goertzen 2017). In addition, this methodology detaches the object from its context and treats the personal attributes of research participants, such as emotions and attitudes, as variables, converting them into statistical data. This approach can impact social dynamics, making the world appear like an artificial laboratory (Sarantakos 2012). In contrast, qualitative research does not possess the notions of generalisability, objectivity, and replicability that quantitative studies have. However, it provides an opportunity to gain an in-depth understanding of people's feelings, behaviours, and experiences, including how people make sense of their experiences in the world around them (Moule et al. 2016). Simply put, qualitative research is based on interpreting social reality and describing people's lived experiences (Holloway and Galvin 2016).

My research aimed to explore the healthcare experience of older people living with frailty and how they make sense of their lifeworld. This focus was important to *"contextualise, understand and interpret"* the lived experiences of control and well-being within the healthcare service use (Szyjka 2012, p.2). Therefore, I needed data that could enable me to understand how people felt and the impact the context had on their lives (Gichuru 2017). As a result, I used a qualitative research approach guided by a constructivist ontology and an interpretivist epistemology to gather in-depth perspectives from participants. The qualitative methodology offered me the potential to obtain a deeper understanding and interpretation of the phenomena (sense of control and well-being) from the perspective of the people involved in the healthcare system, including older people living with frailty and Day Hospital staff, as experienced in their everyday life (Glesne 2016).

4.3.1 Qualitative Research Approaches

Qualitative research is an umbrella term whose methods have been applied across different disciplines, including healthcare (Tomaszewski et al. 2020). As already highlighted, qualitative research follows a constructivist ontology and an interpretivist epistemology, focusing on understanding the subjective experiences of individuals (Ryan 2018).

Denzin et al. (2023, p.88) offer a generic definition of qualitative research as:

> *"a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, performances, including memos to the self. At this level, qualitative research involves an interpretive naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, which are socially constructed, attempting to make*

> *sense of or interpret phenomena in terms of the meanings people bring to them".*

In practical terms, qualitative research approaches mainly adopt non-probability sampling techniques, including purposeful, convenience, snowball, and theoretical sampling (Lopez and Whitehead 2013; Shaheen et al. 2018). As a result, qualitative research studies typically involve small sample sizes as the goal is not to select a representative sample or generalise findings back to the study population (Queirós et al. 2017; Mweshi and Sakyi 2020). Furthermore, qualitative research employs various data collection methods, including interviews, focus group discussions, observation and open-ended questionnaires (Lopez and Whitehead 2013; Busetto et al. 2020). Accordingly, data analysis in qualitative studies is typically conducted using content, thematic, or constant comparative analysis frameworks (Braun and Clarke 2012; Mweshi and Sakyi 2020; Lester et al. 2020). As a result, qualitative researchers often use thick descriptions of participants' words to portray their emic perspectives and answer research questions (Todres et al. 2000; Younas et al. 2023).

Broadly, qualitative research can follow five major approaches, all unique and applicable to different types of inquiry. These include *Grounded theory, Ethnography, Narrative inquiry, Case study research, Action research and Phenomenology* (Holloway and Todres 2003; Lewis 2015; Holloway and Galvin 2016; Tomaszewski et al. 2020).

Table 8: ***Summary of the dominant qualitative research approaches***

Grounded theory	Applied to investigate social processes and interactions to generate a theory grounded in the data.
Ethnography	Focuses on the description, analysis and interpretation of cultures and customs. Interested in observation/ behaviour as well as thoughts/ feelings.
Narrative inquiry	Aims to explore the structure and use of personal stories or narratives to access new perspectives, thoughts, and experiences.
Action research	Involves researchers collaborating with participants or practitioners to examine problems or issues and deliver an action-oriented intervention or evaluation of an intervention.
Phenomenology	Focuses on exploring and describing people's lived experiences of phenomena in their lifeworld.

(Mantzoukas 2012; El Hussein et al. 2014; Holloway and Galvin 2016; Neubauer et al. 2019; Tomaszewski et al. 2020)

As seen in the table above, all qualitative approaches focus on understanding how the human experience is shaped. However, different approaches focus on the role of culture and customs, human social interaction, narrative creation, and lived experiences, as elaborated in the following section.

4.4 Selecting the Methodology

Although the qualitative research designs outlined in Table 8 above have some similarities, including the focus on reality as socially constructed and the understanding of how experiences are shaped (Lapan et al. 2012), they also have differences that set each apart. As discussed below, the differences often manifest in the procedures and challenges researchers encounter in applying these approaches.

4.4.1 Grounded theory

Grounded theory is a research approach involving systematically collecting and analysing data to generate or discover a theory grounded in the data (Creswell 2007; Holloway and Galvin 2016; Singh and Estefan 2018). Initially developed by Barney Glaser and Anselm Strauss in the 1960s, the approach goes beyond simply describing an experience, instead aiming to generate a general explanation (theory) of a process, action, or interaction based on the views of many participants (Creswell 2007; Thornberg et al. 2014; Charmaz and Thornberg 2021). The theory generated has explanatory power, and it is developed through the researcher allowing relevant ideas to develop from the data rather than imposing preconceived theories or preconceptions (Holloway and Galvin 2016; Stough and Lee 2021). As a result, grounded theory can be useful in constructing theories, exploring new areas of study, understanding major processes, illuminating marginalised groups' situations, developing policy, and informing professional practice (Charmaz and Thornberg 2021).

Participants involved in grounded theory studies must have first-hand experiences, and their insights can be used to develop a theory that might inform practice or further research and be applied to similar contexts or settings (Creswell 2007; Holloway and Galvin 2016). These participants are selected through a technique known as theoretical sampling, where the amount of data collected depends on whether the categories of information can become saturated and if the theory can be fully elaborated (Creswell 2007; Robinson 2014). This approach implies that data collection and analysis in grounded theory are conducted simultaneously, each informing the other in an iterative process (Lapan et al. 2012). In other words, researchers can collect relevant data to refine and elaborate categories in the emerging theory (Lapan et al. 2012; Robinson 2014). This inductive approach enables the researcher to begin by studying individual cases or instances from which they eventually develop abstract concepts (Lapan et al. 2012; Thornberg et al. 2014). Similarly, the researcher decides what data to collect next and from whom to advance the theory based on emerging concepts (Holloway and Galvin 2016).

Furthermore, grounded theory allows for various data collection methods, including but not limited to observations, interviews and focus groups, as long as they address the research problem and facilitate the ongoing analysis of the data, and these methods can be integrated during the study (Lapan et al. 2012; Thornberg et al. 2014; Holloway and Galvin 2016).

Though attractive to qualitative researchers, grounded theory is best used when no theory can explain a process (Creswell 2007). In my study, I am interested in understanding lived experiences rather than building a theory around a process based on experiential data, so I did not find it suitable.

4.4.2 Ethnography

Ethnography is a science of cultural description that focuses on studying the processes, structures, actions, and interactions of people located in the same place or interacting frequently and developing shared patterns of behaviours, beliefs, and language (Creswell 2007; Sarantakos 2012). It aims to provide deep insights into social structures, cultural values, meanings, and expressions within a specific context (Mantzoukas 2012; Madison 2020). This process involves documenting such insights through detailed and descriptive accounts, known as ‘thick descriptions’ (Palmer and Caldas 2016; Madison 2020). Ethnographers mainly focus on studying and understanding various phenomena and problems within the context of a particular culture (Holloway and Galvin 2016). This approach involves examining shared patterns within a typically large cultural group that interacts over time, such as clinicians in a hospital (Creswell 2007). By doing so, ethnographers are able to comprehensively understand the culture and its practices (Powell 2022; Nepali et al. 2023).

The ethnographic approach involves extended fieldwork, including observation (overtly or covertly) of actions and interactions, participation in the daily lives of the culture-sharing group being studied, and interviewing them about their perceptions and experiences (Hammersley and Atkinson 2019; Madison 2020; Nepali et al. 2023). By immersing themselves in the daily lives of the people they study, ethnographers often use the participant observation method to contextualise the behaviour, language, and interactions of members within a culture (Creswell 2007; Holloway and Galvin 2016; Hammersley and Atkinson 2019). Ethnography is considered both a process and a product where the researcher explores and interprets shared patterns of a cultural group’s values, behaviours, beliefs, and language and then describes these aspects in the form of a report (Creswell 2007; Holloway and Galvin 2016; Nepali et al. 2023).

Ethnography is appropriate for researchers interested in describing a cultural group’s beliefs, behaviour patterns, language, and other structural aspects, such as power and resistance (Creswell 2007). This approach was unsuitable for my study because I was interested in studying individuals' lived experiences.

4.4.3 Narrative inquiry

Narrative inquiry is a research approach that focuses on people's experiences as expressed in their stories and the structure of those stories (Creswell 2007). This method allows researchers to listen, observe, and interact with participants and interpret their stories to uncover the meanings created within the structure of their stories (Clandinin et al. 2017). Narrative inquiry enables an in-depth exploration of participants' experiences and access to rich layers of information, giving voice to those who may have been overlooked (Wang and Geale 2015). It is a way of investigating experience while being attentive to the larger contexts and relationships in which lives and stories are situated (Clandinin et al. 2017).

This approach highlights the significance and structure of storytelling in uncovering the nuance and detail of experiences, facilitating a better understanding of the participants' realities (Wang and Geale 2015). Narrative inquiry also involves searching for stories that accurately reflect people's experiences and the meaning they hold for them (Holloway and Galvin 2016). The approach acknowledges that stories are lived and told and cannot be separated from those who tell them (Clandinin et al. 2017). It therefore involves researchers engaging in dialogue and reflection, acknowledging the therapeutic and calming power of stories (Wang and Geale 2015).

The terms 'storytelling' and 'narrative' are often used interchangeably, but there is a subtle difference between them. According to Holloway and Galvin (2016), stories refer to individual tales that people tell, whereas narratives encompass a broader structure which includes multiple stories. A narrative is a written or spoken text that chronologically connects an account of an event or action (Czarniawska 2004). It is a valuable way to access new perspectives, thoughts, and experiences and analyse them in the context of personal stories and sense-making (Holloway and Galvin 2016). As a result, first-person narratives are important for researchers because they offer valuable insights when people interpret them with insight into their meaning and significance (Holloway and Galvin 2016; Breton 2020).

Narrative research involves collecting stories from one or two individuals, reporting their experiences, and ordering the meaning of those experiences chronologically (Creswell 2007). It is essential to focus on the relationship between the researcher and the researched, as both negotiate the meaning of the stories (Creswell and Miller 2000; Pinnegar and Daynes 2007). Narrative studies may also have a specific contextual focus and be guided by a theoretical lens or perspective (Ollerenshaw and Creswell 2002; Creswell 2007). Therefore, narrative inquiry is helpful in healthcare research to study professional-patient relationships, identity formation, and the dynamic processes of healthcare practices (Wang and Geale 2015; Holloway and Galvin 2016; Clandinin et al. 2017). For instance, the approach has been applied to study people’s experiences, such as those living with chronic health challenges, including acquired brain injury (Karpa 2021).

Narrative inquiry allows the researcher to gain insight into an experience's meaning by studying the narrative's structure and how the person positions themselves within it. Rather than focusing on how individuals construct and communicate their perspectives or experiences through structured storytelling, I was more interested in understanding the fundamental nature of the lived experience and how it felt. Therefore, this methodology was equally unsuitable for me.

4.4.4 Action research

Action research is an approach to inquiry that involves practitioners conducting research within their professional settings (Coghlan 2011; Toledano and Anderson 2020). It is a participatory, collaborative, and reflective method that empowers participants to take action to address practical problems and improve practices (Coghlan 2011; Holloway and Galvin 2016; Clark et al. 2020). In this approach, researchers and participants work together as co-researchers towards a common purpose, evaluating the process of gathering evidence to implement changes in practice (Coghlan 2011; Holloway and Galvin 2016; Clark et al. 2020). Such collaborations are vital in fostering reflection based on participant interpretations (Clark et al. 2020). This approach is commonly undertaken by practitioners who either become researchers themselves or collaborate with university researchers (Holloway and Galvin 2016).

Action research is also important in bridging the gap between theory and practice, which is often a challenge in professional work (Holloway and Galvin 2016). Its main objective is to improve professional practice by studying the actions taken and creating practical knowledge that can be applied in everyday life (Casey et al. 2018; Guertler et al. 2020). Similarly, action research involves using interventions to improve practices where change is necessary, rather than just producing knowledge about a problem or a topic (Holloway and Galvin 2016). This approach involves studying real social or organisational issues directly with those who experience them (Coghlan 2011). Unlike traditional research, action research is done with people as co-researchers rather than subjects (Casey et al. 2018). Consequently, the focus of this approach is to bring about transformative change by simultaneously conducting research and taking action to understand, develop, and improve social practices (Rowell et al. 2015; Guertler et al. 2020).

In addition, action research generates practical and emancipatory knowledge that empowers people by fostering social justice, autonomy and change of power dynamics in practice settings (Titchen 2015; Holloway and Galvin 2016; Biggeri and Ciani 2019). Collaborative learning is a vital aspect of this process, empowering individuals to critically reflect and challenge existing power imbalances inherent in other forms of research (Casey et al. 2018). For instance, healthcare professionals such as nurses have used action research to overcome barriers to becoming practitioner-researchers in their settings (Titchen 2015).

Action research is a cyclical process involving multiple stages, each building on the previous one (Holloway and Galvin 2016). The process includes planning the research, collecting and analysing data, evaluating findings, and disseminating the results (Ollila and Yström 2020). This iteration leads to ongoing reflection and revision of the research process (Clark et al. 2020). During action research, the findings that emerge from the action are provisional, not absolute (Clark et al. 2020). Action research is, therefore, distinct from other qualitative approaches in that it incorporates action as a crucial component (Holloway and Galvin 2016). The knowledge produced by this approach is practical, immediately applied, and evaluated in specific situations and contexts (Coghlan 2011; Holloway and Galvin 2016; Clark et al. 2020). Although action research interventions may not be replicable due to unique settings, the learning and process can be transferable to other contexts (Coghlan 2011).

Furthermore, action research focuses on research style and development rather than a specific method (Holloway and Galvin 2016). It is a flexible approach that allows researchers to use various methods and techniques to collect data and create actionable knowledge relevant to all participants (Rowell et al. 2015; Holloway and Galvin 2016). These methods can include qualitative and quantitative approaches, such as interviews, surveys, informal discussions, reflection sections and notes taken during workshops (Eden and Ackermann 2018; Sendall et al. 2018; Clark et al. 2020). However, the choice of methods should align with the action researcher’s personal and professional beliefs while also engaging in dialogue with the larger organisation and society’s discourses (Rowell et al. 2015). Consequently, the effectiveness of action research can be determined by evaluating the thoroughness of the research process and the impact it has on individuals and the overall system (Coghlan 2011).

Action research is a popular method practitioners use to investigate problems in their practice settings, such as education, healthcare, and community development. They act as both informants and researchers to create change or improvements in professional and organisational settings (Holloway and Galvin 2016). The research is conducted where the changes occur, which means it is carried out in the actual setting where the problem exists (Holloway and Galvin 2016). For instance, in healthcare, action research has been found to enhance patient-centred care and evidence-based decisions by engaging patients and other stakeholders as co-researchers (Holloway and Galvin 2016; Ivankova 2017). Similarly, action research supports educators in making effective pedagogical decisions to enhance student engagement and learning (Elliott 2015; Clark et al. 2020). This is an interesting approach with power at its core, but my aim was not to directly change practice, so I did not use this methodological approach.

At the outset, all the approaches outlined above seemed attractive. However, reviewing the available literature and the limitations of each approach, I realised that most approaches did not allow me to explore my research interests-- people's everyday lives as experientially lived in their lifeworld. In other words, I wanted to elucidate the first-person experiences of phenomena based on the appreciation that reality is better understood when *"seen through the eyes"* of the people experiencing it (Matua 2015, p.31).

My attention turned to phenomenology, which I found relevant to my research interests and beneficial in guiding me to answer the research question (Dowling and Cooney 2012). Because of its inherent connection to the lifeworld and emphasis on understanding the fundamental nature of lived experiences, phenomenology enabled me to investigate how phenomena appear in people's experiences and the meanings they attach to them, which other approaches cannot adequately provide (Holloway and Galvin 2016; Neubauer et al. 2019; Polit and Beck 2021).

4.4.5 Phenomenology

Phenomenology is a qualitative research approach that aims to explore and understand the subjective experiences of individuals in the world (Converse 2012; Abalos et al. 2016; Neubauer et al. 2019). It is commonly known as the study of the lifeworld or the lived experiences, which involves studying phenomena as they appear in everyday situations and conditions as described by people (van Manen 1990; Dowling and Cooney 2012; Tuohy et al. 2013; Holloway and Galvin 2016). Phenomenologists aim to uncover the essence of lived experiences and the meanings that individuals attribute to them (Reiners 2012; Abalos et al. 2016). They explore what an experience is like pre-reflectively and aim to identify the underlying structures of human experience and consciousness, providing insights into the essence of phenomena as they are perceived by individuals who have experienced them (Cashin et al. 2008; Converse 2012; Tuohy et al. 2013).

Phenomenology addresses two fundamental questions: the ontological question of 'what is being', which is linked to the nature of reality, our beliefs and knowledge about it, and the epistemological question of 'how we know', which is connected to the relationship between the person who knows and what can be known (McLeod 2001; Holloway and Galvin 2016; Adams and van Manen 2017). These questions link to the main aim of phenomenology, which is to describe *"the* *essence of a phenomenon by exploring it from the perspective of those who experienced it to understand the meaning participants ascribe to that phenomenon"* (Teherani et al. 2015, p.670). This aim emphasises the interactions between the researcher and the participants in achieving knowledge (Reiners 2012). As previously established, such interactions often occur within the subjects' world, and phenomenology considers the lifeworld as the starting point for understanding people's lived experiences (van Manen 1997a). Accordingly, the key characteristics of phenomenological research include its focus on the study of lived experience or the lifeworld, illumination of phenomena, study and description of meaning or essences, and the search for what is meant to be human (Holloway and Galvin 2016).

Phenomenologists describe and sometimes interpret the subjective perspectives of participants, providing insight into their unique perceptions or experiences and interpretations of the world around them (Converse 2012). This approach has been widely applied in healthcare research and practice. For example, phenomenology has been applied to understand the meaning of experiential aspects such as well-being, suffering, and dependency, and improving the quality of care practices (Norlyk and Harder 2010; Galvin and Todres 2013; Dahlberg 2019; Patton 2020; Martinsen et al. 2022; Norlyk et al. 2023).

However, phenomenology is both a philosophy and a research methodology, and to develop a better understanding of this approach, one has to appreciate its philosophical background (Abalos et al. 2016; Holloway and Galvin 2016; Gill 2020). In the following section, I will explore the philosophical background of phenomenology and explain how this guided me in choosing the method used in this study.

4.5 The philosophy underpinning the phenomenological approach

Phenomenology as a qualitative research approach is rooted in philosophy. Thus, it is essential to trace its philosophical origin (Holloway and Galvin 2016). Phenomenology as a philosophy emerged in the 20th century through three phases: the Preparatory phase, the German phase, and the French Phase (Abalos et al. 2016). The Preparatory phase focused on the idea of intentionality, with Franz Brentano as the prominent figure. The German phase concentrated on ideas, such as essences and bracketing (phenomenological reduction), with Edmund Husserl and Martin Heidegger as the key figures. The French Phase was dominated by philosophers Merleau-Ponty and Jean-Paul Sartre, who developed the phenomenological concepts of embodiment and ‘being in the world’ (Giorgi 2005; Abalos et al. 2016; Holloway and Galvin 2016).

The phenomenological movement gave rise to two major philosophical streams: descriptive phenomenology and interpretive or hermeneutic phenomenology, with overlaps and linkages (Finlay 2009; Holloway and Galvin 2016). These philosophical streams give rise to different methods within phenomenology.

4.5.1 Descriptive phenomenology

Descriptive phenomenology can be traced back to the philosophical works of Edmund Husserl (1859-1938) (Reiners 2012; Tuohy et al. 2013). Husserl is considered the founder of the phenomenological movement, although his work was influenced by earlier philosophers, particularly Franz Brentano (Giorgi 2005; Reiners 2012; Holloway and Galvin 2016; Christensen et al. 2017). Husserl focused on aspects such as consciousness, phenomenological reduction, and the essence of individual experiences (Giorgi 2005; Reiners 2012). His ideas about phenomenology revolve around understanding and describing the lived experience, using the lifeworld as a foundation to capture the essence of phenomena as they appear to consciousness (Giorgi 2005; Converse 2012; Christensen et al. 2017).

4.5.1.1 Describing the lived experience

Husserl's descriptive phenomenology focuses on describing lived experiences without any form of interpretation (Finlay 2009). Descriptive phenomenology is a method of studying a person's experience of a particular phenomenon and discovering its essence through experiential epistemology (Converse 2012; Reiners 2012). Put simply, it is a process that aims to describe an everyday experience to understand its general meaning and fundamental structure, such as the experience of care (Finlay 2009). Philosophers following the Husserlian phenomenology emphasise the need for researchers not to go beyond the data and instead describe what is presented to them without their influence (Holloway and Galvin 2016). As a result, this approach involves researchers staying close to what is given to them in all its richness and complexity (Finlay 2009).

Husserl expounds on the above aspect by highlighting that the central premise of phenomenology is a *"return to the things themselves"* using a phenomenological transcendental attitude that focuses on the things that appear to us instead of looking outside to the world to be discovered and analysed by our faculties (Slatman 2014, p.522). This transcendental attitude includes setting aside the question of whether certain things really exist and instead asking what their meaning is to us and how this meaning comes to be (Thomasson 2007; Beatty 2014; Slatman 2014). Consequently, describing the essential features of a phenomenon involves applying linguistic expressions to the object of consciousness precisely as it appears to the researcher (Giorgi 1997).

4.5.1.2 Consciousness

One of the critical features of Husserlian phenomenology (descriptive phenomenology) is the focus on the concept of consciousness. Husserl believed that conscious experiences are experiences of the world and that the world gives meaning to these experiences (Christensen et al. 2017). Consciousness is the medium through which human beings are open to the world, others, and themselves; without it, nothing can be mentioned or accomplished (Giorgi 2005). It is the *"subjective phenomenal awareness"*, comprised of several layers, with the highest form being the fully developed and responsible human mind, capable of complex conceptual thought (Giorgi 2005; Marosan 2022, p.109). Consciousness differs from physical objects because it presents itself exclusively as non-sensory and is permanently attached to biological bodies (Giorgi 2005).

It is essential to find the deepest layers of consciousness and make them phenomenologically accessible (Marosan 2022). Husserl recommends a method known as *"pre-reflective streaming of consciousness,"* which helps us understand the mode of presence of the consciousness as a nonphysical entity with intentional directedness (Giorgi 2005, p.76; Marosan 2022). Consciousness is, therefore, essential for understanding the contents of a lived experience and capturing its essential features (Holloway and Galvin 2016). In addition, consciousness is always conscious of something, emphasising the intentional nature of conscious experiences (Christensen et al. 2017). Every act of consciousness is directed towards an object that transcends the act, whether in the external world or within the stream of consciousness itself, implying that consciousness is characterised by intentionality (Giorgi 2005).

4.5.1.3 Intentionality

Intentionality is a significant aspect of every experience (Ashworth and Ashworth 2003; Ashworth 2016). According to Husserl, it refers to the consciousness directed towards a particular object (Giorgi 1997, 2005; Dowling and Cooney 2012; Holloway and Galvin 2016). Intentionality involves a certain mode and manner of grasping the object that reflects a particular sense of and relationship to it (Applebaum 2014). It means that every act of consciousness is directed towards an object that transcends the act (Giorgi 1997; Churchill and Wertz 2015; Ashworth 2016). Intentionality is an inextricable blend of a mode of consciousness (such as perception, memory, imagination or judgement) and content (such as the perceived thing, what is apparently remembered or the event imagined), which are essential to any experience (Ashworth 2016).

Intentionality highlights the idea that every act of consciousness has an inherent meaning or ‘aboutness’ (Dahlberg and Dahlberg 2004; Christensen et al. 2017). It relates to the intrinsic meaning and essence of our experiences and perceptions, which already exist before we try to understand what we experience (Dahlberg and Dahlberg 2004). In other words, intentionality is not something that is added to an experience but is an integral part of it (Dahlberg and Dahlberg 2004). It can be further distinguished between passive and active intentionality, with passive intentionality constituting pre-reflective, always already-meaningful objects, and active intentionality involving actively seizing upon objects (Applebaum 2014). One of the core features of consciousness is that it is always conscious of something (Giorgi 1997; Churchill and Wertz 2015; Ashworth 2016). Therefore, a phenomenological exploration of an experience is not an interpretation but a description of the intentional meaning of the event (Dahlberg and Dahlberg 2004). This intentional act includes position-taking with respect to the object of consciousness, reflecting a particular way of engaging with the world (Applebaum 2014).

Heidegger further developed the theory of intentionality to emphasise that objects and events of experience cannot be understood without being viewed in terms of a meaningful world or lifeworld (Ashworth 2016). According to him, the meaning of the objects and events of experience depends on their context in the lifeworld (Ashworth 2016; Burns and Peacock 2019; Öhlén and Friberg 2023). In other words, intentionality is about relatedness to the world and the interconnectedness between humans and the lifeworld (Thomas 2005). Intentionality is thus a fundamental aspect of human subjectivity and consciousness, introducing new forms of relationships in the world (Giorgi 2005). Therefore, any investigation of an experience should consider the directedness towards that experience and the meanings that constitute the lifeworld, and this should involve bracketing on the researcher’s part (Giorgi 1997; Ashworth 2016).

4.5.1.4 Phenomenological reduction (bracketing)

According to Husserl, investigating phenomena involves the process of ‘phenomenological reduction’ or ‘bracketing’ (*epoche*) on the part of the phenomenologist (Pringle et al. 2011a; Ashworth 2016; Marosan 2022). Bracketing is the act of the researcher suspending pre-conceived ideas, attitudes, and beliefs about a phenomenon or experience (Cohen et al. 2000; Mabaquiao 2005; Wojnar and Swanson 2007; Converse 2012). The suspension of pre-conceived ideas allows researchers to reduce their focus of concern to examine what is purely given in experience properly and strictly treat this as the basis for their philosophical reflection and description without imposing their own meanings onto the experiences of research participants (Pringle et al. 2011a; Ashworth 2016; Marosan 2022). This attitude enables the observation and objective description of phenomena to identify their phenomenological essence (Christensen et al. 2017; Zahavi and Martiny 2019).

In addition, phenomenological reduction enables one to understand the pure state of consciousness by setting aside preconceived ideas or past knowledge (Giorgi 2005). It involves describing ‘what is there’ by temporarily suspending any presuppositions, allowing experiences to reveal themselves as they are, and remaining open to how the phenomenon appears (Ashworth and Ashworth 2003; Ashworth 2016). Such a technique enables researchers to approach experiences afresh to describe them purely and simply as they are in themselves by holding back any attempt to go beyond the data (Ashworth 2016; Holloway and Galvin 2016). Consequently, phenomenological reduction, sometimes referred to as bridling, is a core component of revealing the essence of phenomena (Christensen et al. 2017).

4.5.1.5 Getting to the essence of the phenomenon/experience

Descriptive phenomenology is a research approach that focuses on describing the pre-reflective experiences of participants (Tuohy et al. 2013). The goal is to provide an objective description of lived experiences, emphasising identifying the essence of the phenomenon being studied (Tuohy et al. 2013; Fuster Guillen 2019; Gill 2020). The concept of essence is central to Husserlian phenomenology and refers to the *''fundamental meaning without which a phenomenon could not present itself as it is''* (Giorgi 1997, p.242; Abalos et al. 2016). According to Dahlberg and Dahlberg (2004), essences are immediately grasped in experiences and integral to them. In other words, when we experience something, we immediately grasp its essence, which is inseparable from the experience itself, implying that essence and meaning are inherent in our experiences and not separate from them (Dahlberg and Dahlberg 2004; Umanailo 2019).

To get to the essence of the experience, descriptive phenomenologists recommend a technique of free imaginative variation, which involves creating multiple possibilities or variations of a phenomenon and identifying the essential features that cannot be changed without making it inconceivable, i.e., essential for the object to be given to consciousness (Giorgi 1997; Umanailo 2019; Gill 2020). One aspect of free imaginative variation is *eidetic* reduction, a further form of reduction to the essence (Gill 2020). Other techniques to get to the phenomenon's essence or experience include intuition and reflection (Fuster Guillen 2019; Umanailo 2019; Gill 2020).

In summary, descriptive phenomenology aims to describe the experiences of study participants in detail while searching for the essential aspects of the phenomenon under investigation. Husserl believes that essences are crucial to experiences and serve as the basis of knowledge. This idea is also shared by other phenomenologists such as Giorgi. Indeed, Giorgi (1997, 2017) further developed Husserl's philosophical approach into a specific research method. Giorgi, following Husserl's philosophy, provides a more specific summary of the core tenets of descriptive phenomenology by highlighting that this approach should focus on three key aspects, i.e., description, an attitude of phenomenological reduction, and the meaning of context through the search for essences or structures (Giorgi 2009). Other proponents of descriptive phenomenology include Wertz (2005, 2010).

However, Martin Heidegger, who was once a student and assistant to Husserl, criticised some of Husserl's ideas. He took phenomenology in a different direction, specifically regarding how reality is approached and the application of phenomenological bracketing (Converse 2012). Heidegger posits that it is necessary to move beyond the description of phenomena and include a layer of interpretation and cautions against the use of phenomenological reduction (Reiners 2012; Sass 2021). His ideas form part of the branch of phenomenology known as interpretive phenomenology.

4.5.2 Interpretive phenomenology

Interpretive phenomenology stands in stark contrast to Husserlian phenomenology. It was introduced by Martin Heidegger (1889-1976), one of Husserl's students, who built on Husserl's central ideas and presented the interpretive phenomenological approach (Wojnar and Swanson 2007; Holloway and Galvin 2016). This approach emphasises the importance of connecting with the individual on numerous levels while objecting to Husserl's ideas of duality and objective intent (Burns and Peacock 2019). Rather than uncovering the essences of phenomena that remain unaffected or unchanged by the researcher, interpretive phenomenology emphasises the significance of understanding and interpreting lived experiences within a situated context of time, place, person, and extraneous influences of prior knowledge, perception, and understanding (Tuohy et al. 2013; Burns and Peacock 2019).

The key ideas in interpretive phenomenology include the lifeworld, being-in-the-world (*Dasein*), interpretation, and hermeneutic circle (Tuohy et al. 2013). Heideggerian phenomenology, also known as hermeneutic or existential phenomenology (Dowling and Cooney 2012), is best understood by focusing on hermeneutic ontology, which focuses on the role of language in being in the world (Abalos et al. 2016). In other words, interpretive phenomenology aims to achieve understanding by interpreting the lived experience, adopting a process that clarifies the phenomenon of interest in its context (Dowling and Cooney 2012; Tuohy et al. 2013).

Heidegger’s deviation from Husserlian phenomenology occurred at two main levels: how he developed the concept of *Dasein* (Being in the world) and his views on phenomenological reduction. I have explored the meaning of the concept of lifeworld in Chapter 3. In the following sections, I will shed light on the meaning of being in the world, as well as the interpretation and hermeneutic circle according to Heideggerian phenomenology.

4.5.2.1 Being in the world

According to Heidegger, phenomenology should be used to investigate the nature of ‘being’ and the meaning of entities rather than uncovering the essence of phenomena (Converse 2012). He intended to react to the epistemological and purely descriptive focus of Husserl’s phenomenology by extending it to be more ontological in nature (Burns and Peacock 2019). He sought to understand the ontological question of the *“meaning of being”* rather than the experiential epistemology emphasised by Husserl (Converse 2012, p.29). Understanding occurs through being in the world, and therefore, the aim is to understand the nature of being rather than searching for what can be known (Burns and Peacock 2019). In other words, the world is an essential part of understanding the meaning of being, and the two are inseparable, unlike in Husserl’s notion of intentionality, where the person is detached from the world of the phenomena (Converse 2012).

Heidegger uses the term *‘Dasein’* to represent human existence within context, or what it is to be human in the world (Burns and Peacock 2019). The concept of ‘*Dasein’*, as defined by Heidegger, refers to ideas of being and existence in the world (Holloway and Galvin 2016). According to Heidegger, a person’s world comprises history and culture, often taken for granted (Holt and Mueller 2011). Similarly, the person's existence has things of value and significance, which can only be understood by studying the context of people's lives (Lopez and Willis 2004). Interpretive phenomenology aims to uncover those fundamental dimensions of phenomena which are rarely accounted for, allowing for a deeper understanding of the lived experience of being in the world (Burns and Peacock 2019). As a result, the concept of being in the world is considered a fundamental and necessary aspect of *'Dasein'* (Burns and Peacock, 2019).

To understand human existence, Heideggerian phenomenology requires one to consider 'being' in relation to philosophical concepts, such as space, time, and embodiment (Horrigan-Kelly et al. 2016; Burns and Peacock 2019). Accordingly, interpretive phenomenology emphasises the importance of the lifeworld and seeks to understand the deep layers of human experience and how the lifeworld shapes this experience (Bynum and Varpio 2018). Heidegger also emphasises the interconnectedness of being and the world, placing 'being' within the world and conceptualising the nature of being as a circular, hermeneutic process (Converse 2012; Burns and Peacock 2019). In this process, the researcher becomes a part of the phenomenon; hence, the preconceived ideas or opinions are not bracketed (Reiners 2012; Burns and Peacock 2019). Similarly, as we explore the context of people's lives, Heidegger assumes that these people are self-interpreting and thus capable of interpreting knowledge (Lafont 2017).

4.5.2.2 Interpretation

Interpretive or hermeneutic phenomenology is a method of inquiry that aims to interpret the meaning of experiences to aid understanding (Holloway and Galvin 2016). Heidegger developed Husserl's work further to be more interpretive than descriptive because he believed that all knowledge is an interpretation (Burns and Peacock 2019). According to Heidegger, the method of phenomenological description finds its significance in the process of interpretation (Shinebourne 2011). Interpretive phenomenology thus differs from descriptive phenomenology by focusing on interpreting participants' experiences to determine the meaning of the experience within a specific context and extraneous influences of prior knowledge, perception, and understanding (Tuohy et al. 2013).

This approach goes beyond description and involves interpretation by focusing on the taken-for-granted practices and meanings of being in the world (Crist and Tanner 2003; Bynum and Varpio 2018). Interpretation is not a separate process but an innate and fundamental structure of our being in the world, where everything is experienced as already interpreted (Finlay 2009). As a result, it plays a central role in interpretive phenomenology and forms an integral part of the research process (Converse 2012; Tuohy et al. 2013).

Unlike Husserl's emphasis on bracketing, interpretive phenomenology recognises that researchers inevitably become enmeshed with the experience, making impartiality impossible (Reiners 2012). Researchers' assumptions and preconceptions are intertwined with the phenomena under investigation and cannot be removed from the research process (Tuohy et al. 2013). The interpretive school of thought further posits that researchers cannot divorce themselves from the meanings derived from the text, and as the interpreter moves through the process, their preconceptions become incorporated and may shift to new understandings (Converse 2012; Reiners 2012). This approach embraces the researcher's prior understanding and engagement with the subject under study, considering bias advantageous to the research process (Reiners 2012). This perspective means that interpretation is acknowledged and integrated into the research process as the researcher's assumptions and preconceptions about the phenomena under investigation are considered inseparable from it (Tuohy et al. 2013).

Additionally, Heidegger's philosophy acknowledges the world's influence on the observer and does not advocate for a reduction of preconceptions but rather an awareness of their influence (Converse 2012). In interpretive phenomenology, researchers come with pre-suppositions and strive to make them explicit by examining them rather than suspending them, as in Husserl's descriptive phenomenology (Holloway and Galvin 2016). Humans cannot be detached from their cultural background, relationships, or past experiences and come into situations with pre-understandings or fore-structures that cannot be bracketed (Burns and Peacock 2019). Interpretation, therefore, includes referring to one's historical background and the fore-conceptions that one might develop about something (Holloway and Galvin 2016).

Epistemologically speaking, the interpretive approach in research considers the researcher to be a part of the research world and, hence, not free from bias

(Neubauer et al. 2019). Researchers' subjectivity is essential as they attempt to differentiate between their own biases and the study subjects' experiences (Finlay 2009). In other words, interpretation involves reflecting on the essential themes of the participants' lived experiences while reflecting on the researcher's own experiences (Neubauer et al. 2019). This reflective process requires the researcher to be open to recognising their pre-conceived biases and pre-suppositions and separating them from the participant's descriptions (Finlay 2009). In this context, the interpretive phenomenological approach includes 'reading between the lines' and going beyond the surface expressions to access the implicit dimensions and intuitions (Finlay 2009). The researcher considers this interpretation while re-reading the text and interprets further after identifying patterns, commonalities or themes from the text (Converse 2012). In addition, interpretation of meaning includes using language such as humour, tone, laughter, repetition, and coherence (Love et al. 2020; Alsaigh and Coyne 2021). Therefore, the interpretive approach is a never-ending, non-cognitive way of knowing that reveals new knowledge (Converse 2012).

Interpretation is crucial in understanding individuals' subjective perceptions and experiences within their unique contexts (Tuohy et al. 2013). However, the extent to which interpretive phenomenology goes beyond what the participant has mentioned and enters the realm of interpretation is unclear (Finlay 2009). Despite this, interpretive phenomenology emphasises the process of data interpretation, which includes reading, reflective writing, and interpretation, also known as the hermeneutic circle (Kafle 2011). Heidegger conceptualised the nature of being as a never-ending, circular process, implying that the meaning of being in the world is also circular or sometimes referred to as a ‘hermeneutic’ circle (Converse 2012; Burns and Peacock 2019).

4.5.2.3 Hermeneutic circle

The hermeneutic circle and *Dasein* are two concepts that contribute to a better understanding of the world around us (Cucen 2017). The hermeneutic circle, in particular, is an essential concept in interpretive phenomenology that highlights the importance of interpretation and understanding (Sebold et al. 2018; Burns and Peacock 2019). It is a cyclical process between pre-understandings and complete understanding (Burns and Peacock 2019). This process involves back-and-forth questioning, leading to an expanding circle of ideas known as the circle of understanding, formed through a continuous process of interpretation and constant re-examination of propositions (Tuohy et al. 2013). Heidegger proposed investigating the meaning of being through such a circle, which involves interpreting the entity with an understanding of the researcher’s historical, social, and political context (Converse 2012). This process allows the researcher to discover the true meaning of the experience and understand the lived experiences of individuals more deeply (Tuohy et al. 2013).

In the hermeneutic circle, shared knowledge and experiences are developed to gain understanding and interpretation of phenomena (Reiners 2012). This circle of understanding involves the researcher moving between the parts and the whole of the data by reading and re-reading the text, and between dwelling within the participant’s world and observing it from afar to understand and interpret the experience (Converse 2012; Burns and Peacock 2019; Montague et al. 2020). This continuous process of movement between the details of the text (in the form of transcribed data) and the interpreter of the text (researcher) is essential for revealing the meaning and significance, including commonalities and contradictions of lived experiences (Suddick et al. 2020; Alsaigh and Coyne 2021). In addition, researchers do not bracket their biases, as they are considered to validate the participants' interpretations (Reiners 2012). Crucially, prior to entering the circle, the researcher needs to have developed a clear understanding of their *"fore-having, fore-sight, and fore-conception"* regarding the entity in question (Converse 2012, p.29). Consequently, the hermeneutic circle emphasises the interconnectedness of individuals with their world and the importance of continuous interpretation and understanding in our lives (Tuohy et al. 2013).

The above ideas shaped Heidegger's interpretive philosophy and served as the foundation for the central philosophical concepts of the interpretive, hermeneutic, or existential-phenomenological approach.

It is important to note that some phenomenologists seek to combine the philosophical assumptions of both descriptive and interpretive phenomenology, and these belong to the Dutch phenomenological school (Holloway and Galvin 2016). Similarly, there are recent phenomenological approaches that have emerged, including the lifeworld approach (Ashworth 2003), dialogical phenomenology (Halling et al. 2006), embodied lifeworld approach (Todres et al. 2007), and reflective lifeworld research (Dahlberg et al. 2008) that have been used to provide philosophical and methodological guidance to researchers (Finlay 2009).

All schools of thought in phenomenology have a similar definition of its objective--to study the meaning of phenomena through our subjective experiences (Sloan and Bowe 2014; Neubauer et al. 2019). However, applying phenomenology in research can be challenging due to its dual nature as a philosophy and methodology and the different genres proposed by various philosophers (Dowling 2007; Pringle et al. 2011a; Errasti-Ibarrondo et al. 2018; Neubauer et al. 2019). Nevertheless, it is essential to understand phenomenology's theoretical or philosophical background to choose the appropriate method (Finlay 2009; Reiners 2012).

4.5.3 Choosing the Phenomenological Method

As highlighted in the section above, descriptive and interpretive phenomenology have different philosophical ideas about conducting research, and researchers should align themselves with either approach (Holloway and Galvin 2016). According to Caelli (2001), any phenomenological approach chosen to guide a study should emerge from the philosophical implications inherent in the research question. Therefore, researchers should be clear about their phenomenological philosophical traditions and link them appropriately to the chosen philosophy or theory (Finlay 2009). For my part, I opted for the interpretive phenomenological approach as the philosophical background for my study to investigate the experiences of control and well-being for older people living with frailty in their healthcare service use.

My interest was in understanding and analysing the experiences of the participants to interpret the meaning of their encounters with the healthcare system by focusing on their interpretations and understandings of lived experiences within a specific context of time, place, person, and external influences such as prior knowledge, perception, and understanding (Tuohy et al. 2013). Moreover, like other hermeneutic researchers, I disagree that it is feasible, or desirable, for a researcher to separate or bracket their experiences and understandings because researchers always interpret through their experiences (Finlay 2009; Converse 2012). Researchers need to bring critical awareness to their pre-existing beliefs, vested interests, and assumptions, scrutinise how these might influence the research process, and question them in light of new evidence (Halling et al. 2006; Finlay 2008). Therefore, the experiences of researchers are perceived as legitimate and necessary for understanding other people (Hov et al. 2007).

Although theoretical analyses provide a philosophical background to phenomenology, they do not provide rules or procedures for conducting interpretive or hermeneutic phenomenological research (Earle 2010). Therefore, researchers need to understand the various methods under interpretive phenomenology to choose the most appropriate one for their research. A research method refers to specific techniques, procedures, and tools researchers use to gather, analyse, and interpret data to answer research questions (Grover 2015). In other words, it is a mode of inquiry used to investigate a research question (van Manen 1990).

Research methods are guided by the researcher’s chosen research paradigm and are selected based on the nature of the research problem and the desired outcomes (van Manen 1990; Makombe 2017). Understanding the methods is vital because each is suitable for a particular type of research problem and requires specific skills and worldviews of the researcher (Burns and Peacock 2019). In addition, each method has a unique way of approaching the collection and analysis of phenomenological data, including key elements to consider, such as the nature of the interview questions, the use of interview schedules or guides, clarity and rigour, the use of computer-assisted programmes, navigating thematic reflection and whether or not the participants should validate findings (Laverty 2003; Ray and Locsin 2023; Shirdelzade et al. 2023).

Interpretive phenomenology includes methods such as the Interpretative Phenomenological Analysis (IPA) by Jonathan Smith (2004), Reflective Lifeworld by Dahlberg et al. (2008), and Hermeneutic Phenomenology by van Manen (1990, 1997a) (Zahavi 2019a). These interpretive phenomenologists used the philosophical frameworks discussed above to develop phenomenology as a method with guidelines for conducting human science research in different disciplines (Earle 2010).

4.5.3.1 Interpretative Phenomenological Approach (IPA)

Interpretative Phenomenological Analysis (IPA) is a qualitative research method that helps explore and understand individuals’ lived experiences (Smith et al. 2002; Biggerstaff and Thompson 2008; Smith and Osborn 2015). The primary goal of this method is to explore, interpret, and understand personal experiences and perceptions concealed by the phenomenon’s mode of appearance (Shinebourne 2011; Pringle et al. 2011b). The focus lies on the subjective and personal meanings that individuals attribute to their experiences (Smith 2004; Brocki and Wearden 2006). Originally developed by Jonathan Smith and his colleagues, IPA has its roots within the field of psychology and has become an established and popular method within qualitative psychology (Smith 2004; Pringle et al. 2011b; Love et al. 2020; Smith et al. 2022).

Regarding the philosophical background, IPA is a qualitative approach rooted in philosophies of phenomenology, hermeneutics, idiography and symbolic interactionism (Smith 1996; Biggerstaff and Thompson 2008; Pringle et al. 2011a; Shinebourne 2011; Tuffour 2017; Love et al. 2020). It emphasises a deep understanding of participants’ lived experiences and the meanings they ascribe to them within their social and personal world (Smith et al. 2002; Biggerstaff and Thompson 2008; Shinebourne 2011). In common with other interpretative phenomenological methods, such as the one advanced by van Manen (1990), IPA is a method that aims to understand how individuals make sense of their experiences by focusing on the participants’ accounts within the context of their lifeworld (Shinebourne 2011; Tuffour 2017). Drawing on Heidegger’s views, IPA sees phenomenological inquiry as an interpretative process, using hermeneutics as a prerequisite to phenomenology (Shinebourne 2011; Tuffour 2017). In addition, IPA is concerned with the inductive analysis of each individual’s account before moving on to the wider group analysis (Smith 2004; Love et al. 2020). These philosophical underpinnings allow the rigorous exploration of idiographic subjective experiences and social cognition (Smith 1999; Biggerstaff and Thompson 2008; Smith and Osborn 2015).

The process of IPA involves examining personal accounts to uncover the underlying meanings and interpretations (Biggerstaff and Thompson 2008). This process focuses on the individual’s wholeness and uniqueness and provides a complete and in-depth picture of their cognitive, linguistic, and physical being (Smith 1999; Smith et al. 2002; Pringle et al. 2011b). Additionally, IPA’s approach to interpretation involves multiple levels of analysis, ranging from empathic sharing of the participant’s feelings to more abstract and conceptual readings, all grounded in the participant’s own words (Shinebourne 2011). Therefore, it is crucial to interpret and contextualise IPA accounts beyond the text, possibly on a psychological level (Brocki and Wearden 2006).

IPA is relevant to health psychology research, as it provides a flexible and in-depth analysis of individual experiences, allowing for the examination of divergence and convergence in smaller samples (Smith 1996; Brocki and Wearden 2006). It has been used in psychology and other healthcare fields, such as nursing and medicine, to gain insight into individuals’ subjective experiences (Biggerstaff and Thompson 2008; Cases et al. 2011). In addition, IPA is suitable for application to novel research questions and can be adapted to different research questions and data sources, such as interviews, focus groups, diaries, and email communication (Brocki and Wearden 2006; Love et al. 2020).

It is important to note that IPA, while suitable for exploring novel research questions, may not always be appropriate for work within pre-existing theoretical frameworks (Brocki and Wearden 2006). In addition, IPA recommends suspending presuppositions and critical judgment, particularly when encountering text for the first time, which contradicts the principle of interpretation as advanced by hermeneutic phenomenology (Biggerstaff and Thompson 2008). Moreover, IPA is grounded in psychology, and its advocate, Jonathan Smith, suggests that the analysis should be guided by a broad psychological curiosity and sense-making instead of a preconceived formal theoretical perspective, which might lessen its applicability to other disciplines (Pringle et al. 2011b; Adams and van Manen 2017). Due to these limitations and my interest in exploring the lifeworld experiences of the participants through explicit interpretation, I chose the hermeneutic phenomenological approach proposed by van Manen as my preferred phenomenological method (Toft et al. 2020).

4.5.3.2 The hermeneutic-phenomenological method by van Manen

The hermeneutic-phenomenological method was advanced by van Manen, an educationist from the Utrecht (Dutch) school of phenomenology (van Manen 1990, 1997a, 1997b; Dowling and Cooney 2012). This school combined descriptive and interpretive phenomenology elements with a practical and professional focus (Dowling and Cooney 2012; Finlay 2014; Aagaard 2017; Neubauer et al. 2019). The scholars of the School of Utrecht were inspired by the phenomenology of philosophers such as Husserl, Heidegger, and Merleau-Ponty (Errasti-Ibarrondo et al. 2018; van Manen and van Manen 2021). They used literature, poetry, cinema, and fine arts to enhance the vividness of their phenomenological texts (Errasti-Ibarrondo et al. 2018). Unlike purely philosophical phenomenology, the Utrecht School emphasised practical application, as scholars were interested in applying phenomenology to understand the practices of everyday life and their own professional disciplines (Errasti-Ibarrondo et al. 2018; van Manen and van Manen 2021). van Manen, who derived much of his methodological ideas from the Heideggerian phenomenological school of thought, embraced an interpretive branch of phenomenology focused on meaning and interpretation (van Manen 2017; Ray and Locsin 2023; Shirdelzade et al. 2023). Heidegger’s ideas are premised on the notion that lived experiences are inherently interpretive and that hermeneutics is a core feature of human existence (Polit and Beck 2021).

Hermeneutic phenomenology is a research method that aims to understand and interpret people’s experiences and the meanings they attach to them (Hein and Austin 2001; Aagaard 2017). This method emphasises that human understanding is always interpretive and that interpretation is indispensable to being in the world (Aagaard 2017). Interpretation is aided by focusing on the power of phenomenological texts that disclose our world and offer meaning (Van der Zalm and Bergum 2000). The practical purpose of van Manen’s hermeneutic phenomenology is to develop phenomenological texts that provide a thorough understanding of lived experiences (Errasti-Ibarrondo et al. 2018). This method perceives human experience as a semantic and textual structure (Hein and Austin 2001). In this sense, van Manen suggests that hermeneutics should aim at describing how an individual *“interprets the texts of life”*, resulting in phenomenological texts that have a vivid narrative quality, making them more evocative and expressive (van Manen 1990, p.4; Errasti-Ibarrondo et al. 2018).

Such texts engage the reader in reflection, vital to interpretation (van Manen 1990).

One aspect that shapes phenomenological texts and interpretation in hermeneutic phenomenology is the use of language. In hermeneutic phenomenology, language is considered a fundamental mode of operation for human beings in the world and an all-embracing form of the constitution of the world (Aagaard 2017). It is a socially constructed tool that individuals use to communicate the meaning attributed to objects (Lauterbach 2018). Language is regarded as the *"house of being"* as it generates and facilitates all human activities (Sloan and Bowe 2014; Aagaard 2017, p.523; Dibley et al. 2020). It allows us to understand abstract concepts by transposing them into a form we can understand and interpret through written text (Holloway 2005). Language also plays a fundamental role in shaping human experiences and mediating their meanings (Aagaard 2017; Errasti-Ibarrondo et al. 2018). As such, it is essential for interpreting and understanding lived experiences (Laverty 2003; Dibley et al. 2020). Hermeneutic phenomenological research recognises that language permeates experiences, and hermeneutics is a way of understanding how language and text affect the interpretation of experience (Holloway 2005; Aagaard 2017; Ali and Abushaikha 2019; Love et al. 2020). This understanding often arises within the context of history, giving meaning to understanding (Holloway 2005).

Phenomenological texts and language are applied throughout the writing process. Writing involves forming connections and searching for understanding to construct a comprehensive discourse (van Manen 1990). It is considered central to hermeneutic phenomenology, with research and writing viewed as two aspects of the same process (van Manen 1990; Santiago et al. 2020). Hermeneutic phenomenologists emphasise the creative aspects of writing and the expressive qualities of language, presenting their results to readers as meaningful insights (Laverty 2003; Aagaard 2017; Errasti-Ibarrondo et al. 2018). This creative and expressive approach to writing highlights the poetic qualities of language in shaping lived experiences and in the textual presentation of findings (Aagaard 2017). In addition, writing encourages an individual to adopt a reflective attitude vital for interpreting and producing meaning (van Manen 1997a; Laverty 2003). Therefore, textuality can help analyse the meaning of experiences and their social construction, and by treating experiences as texts, we reveal how language and social context shape our perceptions of the world around us (van Manen 1990).

Hermeneutic phenomenology aims to understand the complexities of human life by studying how people naturally engage in their daily lives (van Manen 1990). This method relies on a methodological framework that encourages the expression of complex experiences, leading to a deeper understanding of the nature and meaning of everyday experiences and what it means to live in the world (Errasti-Ibarrondo et al. 2018). As a result, hermeneutic phenomenologists strive to comprehensively describe the lifeworld, acknowledging the complexity of lived human experience beyond the limits of any meaning explication (van Manen 1990). The goal is to create a rich and deep account of a particular phenomenon, focusing on uncovering insights rather than replicable results of structural analyses (Hein and Austin 2001).

Hermeneutic phenomenology encompasses reflection and analysis, allowing for explicating and interpreting participants' experiences (Laverty 2003; Ray and Locsin 2023). This interpretive mode of inquiry involves exploring extensively the words used by participants to describe a phenomenon, including tracing their etymological sources (Hein and Austin 2001). Similarly, the approach involves analysing text thematically to creatively reveal the *"embodied and dramatised"* meanings of the human experience (van Manen 2016, p.406; Aagaard 2017). In other words, hermeneutic phenomenology seeks to interpret life texts in powerful and evocative descriptions that go beyond the words of the participants (van Manen 1990; Holloway 2005; Aagaard 2017). This interpretation involves careful reflection on the fundamental structures of lived experience, using discursive language and sensitive interpretive devices to enable the explication, analysis, and description of phenomena (van Manen 2016). Holloway (2005) suggests that interpretation requires a reciprocal question-answer relationship between the text and the interpreter. Consequently, the researcher should not impose their own meaning on the phenomenon but should consider factors such as the historical and cultural context that precedes the analysis (Ray and Locsin 2023).

While hermeneutic and descriptive phenomenology share some ideas on data analysis, they rely on different epistemologies (Holloway 2005). Hermeneutic phenomenology emphasises *"contextualisation and amplification instead of structural essentialisation,"* which is the case for descriptive phenomenology

(Hein and Austin 2001, p.9). In addition, hermeneutic phenomenology underscores the role of the hermeneutic circle, particularly in aiding the researcher to put the individual parts of the text in the context of understanding and interpreting the whole text (Sloan and Bowe 2014; Alsaigh and Coyne 2021; Ray and Locsin 2023). However, it is important to note that there are always many possible perspectives on a phenomenon; therefore, a complete understanding of it is impossible (van Manen 1997a; Hein and Austin 2001). In that context, the hermeneutic phenomenological inquiry is a circular questioning process that has no final analysis or saturation point, and the readers of the text play a vital role in bringing *"attentiveness and thoughtfulness to what is said in and through the words"* (Hein and Austin 2001, p.9).

Although van Manen's method has been criticised for being *"excessively complicated"* (Zahavi 2019b, p.1), it emphasises the practical orientation of phenomenology, making it relevant in a range of fields, including nursing, education, and pedagogy, where interpersonal connections and deeper understanding of the experiences are paramount (Errasti-Ibarrondo et al. 2018). Similarly, van Manen (1990, 1997a) attempts to clarify a methodological structure as a dynamic interplay of six research activities. These activities are outlined in the table below.

Table 9: ***Stages of conducting human science research***

i.	Turning to the nature of lived experience
ii.	Investigating experience as we live it
iii.	Reflecting on the essential themes which characterise the phenomenon
iv.	Describing the phenomenon in the art of writing and rewriting
v.	Balancing the research context by considering the parts and the whole
vi.	Maintaining a strong, oriented stance toward the research question

This study was, therefore, guided by the hermeneutic phenomenological method as informed by the works of van Manen. This method enabled me to pursue a methodological research journey in describing and interpreting participants' experiences of a sense of control and well-being (Vivilaki and Johnson 2008).

The above methodological steps do not need to be followed in a pre-determined order but should be considered when conducting hermeneutic phenomenological research (Shirazi et al. 2016; Errasti-Ibarrondo et al. 2018). In the following sections, I highlight how I investigated the lived experience of a sense of control and well-being in older people living with frailty and subsequently reflected on the essential themes that characterised the phenomenon. I will also reflect on how I applied other stages of van Manen's hermeneutic phenomenology under the section on reflexivity.

4.6 Investigating experience as we live it

This section entails collecting data by thoroughly questioning the meaning of the experience (Ray and Locsin 2023). This was a hermeneutic phenomenological study involving individual semi-structured interviews with 20 older people living with frailty and 10 Day Hospital Staff for four months. Miller et al. (2018) suggest that semi-structured interviews are one of the most commonly used data collection methods in hermeneutic phenomenology. They are vital in gaining insight into, and understanding lived experiences (Toft et al. 2021). By using semi-structured interviews, I was able to balance structure and flexibility, enabling me to guide the questioning process and obtain detailed perspectives and feelings about the topic, which, in turn, facilitated the analysis and interpretation processes

(Bevan 2014; Ray and Locsin 2023). In terms of structuring the interview process in hermeneutic phenomenology, van Manen recommends a process of ‘conversation’ with participants in a relational manner to encourage linguistic narrative statements to unfold from the researcher’s reflection (Adams and van Manen 2017; Ray and Locsin 2023). Some of the most common alternatives to semi-structured interviews are structured and unstructured or in-depth or narrative interviews (Roulston 2010; Stuckey 2013; Mueller and Segal 2014). However, structured interviews are too rigid to obtain detailed information, while unstructured interviews are often lengthy and time-consuming (Stuckey 2013; Queirós et al. 2017).

Before discussing the interviewing process, I want to describe the steps taken prior to data collection.

4.6.1 Patient and Public Involvement (PPI)

In this section, I provide details regarding the involvement of the public/patients in the design of my study and the changes I made in light of the experts’ feedback (McMurdo et al. 2011). Specifically, I shed light on the input provided by the experts on aspects such as the relevancy of the study, structure and wording of the study documents, and tips on encouraging older people’s participation in my study.

There is a growing recognition of the significance of involving people other than the immediate research team, particularly in health-related research through the Patient and Public Involvement (PPI) process (Boylan et al. 2019; Russell et al.

2020; Scholz and Bevan 2021). The PPI process offers individuals with expertise in specific areas an opportunity to bring their specialist knowledge from their personal experiences, such as health and illness, to the research process (Oliver et al. 2015; Greenhalgh et al. 2019). This initiative is considered empowering because the opportunity for patients to have input in research on their condition or experiences reduces the power imbalances between researchers and patients, especially in marginalised and seldom-represented groups (Greenhalgh et al. 2019). As a result, PPI increases the possibility of enhancing the research process, including developing more relevant research questions, ethical recruitment procedures, acceptable research tools, appropriate study participants, accurate data, and findings that are more likely to be useful to those who use services (Oliver et al. 2015; Hughes and Duffy 2018).

I conducted the PPI with the support of the BU PIER partnership (BU 2023). This partnership involves engaging people who have used a wide range of health and social care services or are carers for family members or friends, and work alongside BU staff members to support research and education. I organised meetings with three experts (aged 65, 70 and 80 years) to provide input on various aspects of the study. The following is a summary of the feedback I obtained from the experts.

Table 10: ***Suggestions obtained from the PPI sessions and the lessons learned***

	Suggestions	**Lessons derived**
1.	The study is significant because, so often, the care of older people is viewed from the point of view of the carer(s) rather than what the older person would like or need.	I used these insights to develop the justification for my study.

2.	A sense of control is a good subject for investigation because there is a degree of loss of control for people within the care system who are alleged to have lost their independence and have to depend on others, particularly in care/nursing homes.	I used these insights to develop my justification for the study and further understand the notion of a sense of control in older people.
3.	The study is beneficial to older people because it gives them the feeling that their voices are being listened to and that they count.	I used these insights to develop my justification for the study.
4.	Taking part in this study would also give older people living with frailty a feeling of usefulness, and from their well-being point of view, it would boost their morale.	This information helped me understand the immediate benefits of involving older people in research.
5.	Regarding the costs associated with the study, older people living with frailty will most likely get tired during the interviews and would, therefore, need to be treated gently. This could involve physical and mental tiredness because of concentrating- something they may not be used to. Furthermore, if they are in a hospital setting, it is assumed that they are there because they are sick and need a lot of care. So, I would require being very sensitive to how they are. It is possible that some older people, particularly in the hospital setting, might well find themselves falling asleep when the researcher is talking to them, and that would signal that they have had enough and need a break.	I was very observant of the participants' body language and paid great attention to how they responded to have a heightened awareness of whether they were tired and paused for a break.
6.	It would also be essential to understand how older people experienced care from different angles, i.e., those living with frailty and needing care at home, in a nursing home environment, and a rest home environment.	Although this suggestion is interesting, it is beyond the scope of the current study.
7.	The font size of the older people's participant information sheet is small, which could be enlarged in the final version, considering that the people who will read this information are old and might not have good eyesight.	I increased the font size of the study documents from 12 to 16.

8.	Some parts of the Participant Information Sheet were wordy, particularly the section on the ‘purpose of the study’, and the experts suggested that it would be better to compress them using everyday language to make them less wordy.	I simplified the wording and removed repetitions in the documents. In particular, I used simpler statements to reduce the words under the section on the ‘purpose of the study’ in the participant information sheet.
9.	Although some sections in the Participant Information Sheet might sound complicated and may not easily make meaning to some people, they need to be said (maintained), particularly the section on how ‘information will be managed’ (data protection).	I maintained the wording under the ‘data protection’ section of the older people’s Participant Information Sheet.
10.	Gentleness is necessary because older people respond to gentleness and kindness. This may include being patient, not hurrying participants, and thinking of different ways of saying something if participants do not understand what the researcher is saying. Older people need adequate time and patience to process the researcher’s words before responding.	I ensured that I was kind and gentle to the participants. This included allowing them to choose the most convenient place and time for the interview and exercising patience when listening to their perspectives.
11.	Older people are more likely to respond to invitations to participate in research studies when study documents are printed out and given/sent out to them in hard copy rather than through email.	I printed all the study documents and then sent them to potential participants to increase the study response rate and support older people in participating in the study.

Table 10 outlines the key suggestions derived from the PPI sessions I held with the experts. These suggestions were vital in improving various aspects of my study, from designing the research to publishing the results. The above outline also highlights the significance of PPI in research studies.

4.6.2 Gaining ethical approval

Obtaining ethics approval is considered one of the critical aspects of any phenomenological research project due to the potential to intrude into the private sphere of people's lives and contribute to emotional vulnerability (Walker 2007; Thomson et al. 2011). The Declaration of Helsinki recommends that researchers submit a research protocol for consideration, guidance, and approval to a Research Ethics Committee (REC) before commencing a study involving human subjects (WMA 2013). Accordingly, prior to the study, I sought a favourable opinion from the HRA's (NHS) REC and Bournemouth University's Science, Technology & Health Research Ethics Panel (REP). These ethics committees provided a favourable opinion and approved the study protocol (Appendix 18) and all the relevant documents, including the Participant Information Sheets and Consent forms.

In addition, the research plans and actions underwent additional independent scrutiny by the INNOVATEDIGNITY Ethical Scrutiny & Advisory Board (ESAB). Although the study protocol had initially gone through the HRA and BU ethical scrutiny committees, the ESAB added a layer of independent scrutiny. The ESAB reviewed all supporting documentation for the study's ethical process, including the Participant Information Sheet, Consent form, and Data Management Plan. The ESAB drew on the guidance from the UK Department of Health Research Governance Framework for Health and Social Care (Department of Health 2005).

I have attached the HRA and the InnovateDignity ESAB ethics approval letters as Appendix 8 and 9, respectively. I also applied for NIHR portfolio support as part of the ethics process. This enabled me to take advantage of the NIHR study delivery support services to ensure study timelines, achieve recruitment targets, and enhance performance.

This section will discuss the key ethical considerations relevant to my study.

4.6.2.1 Assessment and Management of Risk

The vulnerabilities of older people are not always obvious. Therefore, researchers should protect the participants' physical and emotional well-being. The Declaration of Helsinki highlights that research participants' rights, well-being and interests must take precedence over the interests of society and science (WMA 2013). I recognise that any research might cause distress and, in some cases, harm. In this study, the potential causes of harm or distress to the participants could have been the nature of the questions, the setting/timing of the interviews/research and my attitude as a researcher. It was difficult to know how people could react to seemingly simple questions which may be sensitive, emotional or have personal meanings for that person, thus causing anxiety or upset and necessitating support. Additionally, as the overall research aimed to seek a deeper understanding of the lived experiences of older people living with frailty, there was a possibility or even likelihood that sensitive topics could arise as participants described their life experiences, because how much they disclosed during the interviews was entirely up to each participant.

Therefore, to ensure the safety and well-being of the study participants, I adopted several safeguards, including the NHS safeguarding procedures (NHS England 2023). For example, I reminded participants at the beginning of each interview that they could stop the interview at any time or choose not to answer any specific question posed to them. Furthermore, when a participant became distressed during the interview, I paused it and ascertained if they wished to stop or continue after a break or ultimately end it. For instance, during an interview with an older male participant living with cancer, he became distressed while discussing what he considered to be impending death and his fear of leaving his spouse unsupported after he was gone. As an interviewer, it was challenging to deal with such emotional pain. The participant and I agreed to take a break and resumed the interview after ensuring he was ready to continue (Dickson-Swift et al. 2009; Draucker et al. 2009; McGrath et al. 2019). This mutual decision was made to ensure that the break was not abrupt and that the participant did not feel rejected due to his personal feelings (Whitney and Evered 2022).

I drew on my professional social work knowledge and experience working with older people to ensure I was attentive to the subtle indications of distress (Yaffe and Tazkarji 2012). Some of these signs included appearing sad, avoiding discussions or becoming quiet after asking specific questions, especially those relating to an illness or the loss of a loved one. This situation was particularly noticeable when I was interviewing an older female participant, who became emotional while discussing the impact of Parkinson’s disease on her everyday life.

Importantly, I provided participants with brief, appropriate leaflets and information to signpost them to support services below.

Table 11: ***Information on support services available to older people***

i.	The Patient Advisory Liaison Service (PALS)	https://www.nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service/
ii.	The local Age UK "Relieving Loneliness: Community Connections" services	https://www.ageuk.org.uk/bournemouthpooleeastdorset/our-services/visiting-and-befriending/
iii.	The Silver Line	https://www.thesilverline.org.uk/what-we-do/

Furthermore, I informed participants that for safeguarding reasons, I had a duty to disclose any information from the interview that I thought had the potential to cause immediate harm to the participant or other people. This safeguarding responsibility was mentioned in the participant information sheet so that the participant could decide whether to talk about certain aspects during the interview.

I also informed the Hospital staff in their participant information sheet that if they raised any issues of concern about practice or safeguarding, such as potential criminal offence, including professional malpractice or anything that had the potential to cause them immediate harm or harm to other people, then I would have to raise the issues to the relevant authorities. If I had any concerns, I would discuss them with the supervisory team first. I would talk to the Trust research coordinator and follow the Trust's Escalating Concerns Policy when required. The safety and welfare of the participant and the staff member would be protected by remaining anonymous while discussing the case with supervisors and the Trust Research Co-ordinator, and keeping the participant informed as much as they wished about the process. If the case escalated, I would expect the safety and welfare of the participant and staff member to be covered under the Trust's

Escalating Concerns Policy. Fortunately, I was not required to take any of these actions during the data collection.

Similarly, the research posed some risks to my safety and well-being as a researcher. For example, the possibility of lone working carries potential safety risks, including physical and emotional harm. This risk of harm might come from some participants, their family members, and pets, as well as people from their community, particularly for participants living in violent communities and neighbourhoods. Although I did not encounter any of the risks above, I put in place safeguards to ensure my safety and well-being. In addition to the Bournemouth University Lone Working Guidance (BU 2012), I adopted the NHS Employers' Lone Working Guide (NHS Employers 2018). For example, as a safety precaution during lone working, I ensured emergency plans and equipment were in place. This plan included keeping my mobile phone charged and on hand for communication during emergencies. I also scheduled interviews with participants early enough in the day to ensure that I could leave their homes or communities before it got too late. In addition, whenever possible, I took busy routes to and from interview locations to ensure I was visible and around others.

Moreover, before entering the participants' homes, I developed an exit strategy in case of an emergency. This strategy included identifying exit points and planning to excuse myself from a difficult situation. Finally, I informed the lead clinician at the Day Hospital whenever I would undertake interviews in participants' homes.

Furthermore, an agreed strategy was put in place for me to seek support in case I became distressed due to the data collection to ensure my emotional well-being.

The first level of support was for me to talk to one of my colleagues at the University, being careful not to disclose participants' personal details. I would share this with my supervisors to seek support if I remained distressed. If further support was needed, the university counselling service could provide this.

4.6.2.2 Data Protection and Patient Confidentiality

I complied with Data Protection Act 2018 requirements of Great Britain regarding collecting, storing, and processing personal information and upheld the Act's core principles related to my study. I was the custodian of the data generated from the study. Accordingly, I ensured that all the information obtained from the research was used only for the purpose outlined in the participant information sheet. In addition, at the participant identification stage, I ensured that sample participants were identified and initially approached by the clinicians who were part of their routine care team and had access to the participants' medical records and personal identifiable data. Participants' contact details, including telephone numbers/email addresses and other identifiable data, were only passed on to me when the participant had expressed interest in the study and willingness for me to contact them.

Furthermore, I ensured that I did not disclose the identity of the participants to anyone except for safeguarding or lone working safety reasons. The hospital's name, the participants' names, and job roles did not appear anywhere in the transcripts or the written report/publications. Instead, I assigned participants pseudonyms in the form of fictitious names to protect their anonymity. For the hospital staff that could be easily identified due to their job roles, I used general terms such as ‘nursing staff’ or ‘therapy staff’, etc., alongside any quotes when referring to clinicians to make it appear more generic but still enable the reader to understand the participant’s professional background. I also replaced the identity of the recruitment site with a ‘Day Hospital in southern England’ tag to protect its anonymity. Furthermore, I used data reduction by taking out potentially identifying information from participants’ responses (Pascale et al. 2022).

Moreover, I securely stored the data collected to avoid unauthorised access that could compromise the confidentiality of the information obtained. Likewise, the original audio recordings were stored in a secure private, locked drawer (cabinet) at Bournemouth University and transferred (scanned) into electronic format (typed transcriptions) as soon as possible and stored on a Bournemouth University secure H-drive in a separate folder. The original audio recordings were then securely deleted at the end of the study. Only the academic supervisors and I had access to the data generated from the study. Similarly, I analysed the data generated from the study myself with guidance from the academic supervisors, and this was done at Bournemouth University.

Finally, I ensured that I used minimal personal data in the study. The only personal identifiable data used include participants’ names and signatures (on the consent forms), telephone contacts and/or email addresses for contacting participants, and postcodes (personal addresses) for participants who chose to be interviewed from their homes. The signed paper copies of the consent forms were stored in a private locked drawer (cabinet) at my office after the interviews before being transferred (scanned) into electronic format as soon as possible and stored on a

Bournemouth University secure H-drive. For audit purposes, the paper and electronic consent forms will be securely stored for five (5) years after the study. After this period, they will be destroyed, and any electronic files will be deleted and overwritten.

4.6.3 Participants and recruitment

This section details the sampling and recruitment decisions made during the study and their justification. I will provide details on the sampling technique, including the inclusion and exclusion criteria and procedures for gaining access to the recruitment site. This discussion is intended to provide context on the nature of the participants I selected for my study.

4.6.3.1 Gaining Research and Development approval

The recruitment setting was a Day Hospital. I gained initial access to the site by contacting the Day Hospital Research and Development (R&D) office to initiate the local NHS R&D capability and capacity confirmation process. However, due to the uncertainties caused by the COVID-19 pandemic, I made some amendments to my original data collection plan and, through the sponsor, submitted a valid notice of the substantial amendment to the NHS/HRA REC with supporting documents for consideration and approval. These amendments were also communicated to the R&D office at the Day Hospital to assess whether the amendment affected the site's capacity and capability. I have attached the NHS/HRA REC amendment approval letter as Appendix 10.

Once I had obtained all ethical approvals and amendments from all the relevant Research Ethics Committees, I again contacted the Day Hospital R&D office to obtain a ‘Letter of Access’ which would legally allow me to access the recruitment site.

4.6.3.2 Sampling and Participants

I used purposeful sampling to identify and select the study participants (Mohammadi et al. 2015). Purposeful sampling is ideal for the research question and the chosen approach as it allowed me to seek and select participants based on pre-determined criteria who had a unique or important perspective on the phenomenon under study and could provide rich and appropriate information (Patton 2002; Robinson 2014; Campbell et al. 2020). I applied the purposeful sampling technique using a four-stage process, which involved defining the sample universe, deciding upon a sample size, selecting a sampling strategy, and sample sourcing (Robinson 2014).

a) Defining the sample universe

I began by clearly defining the study’s target group and linking it to my aims and objectives by reviewing the literature (Umar and Usman 2015; Willie 2024). One key consideration of my sample universe was ensuring heterogeneity (Bekele and Ago 2022). I was interested in understanding the diverse perspectives of older people with varying frailty levels, gender, and cultural backgrounds. In addition, I was interested in exploring the viewpoints of the different Day Hospital staff who provide care services to this group. From this pool of potential participants, I was able to set a boundary and select the sample for the study using eligibility criteria (Robinson 2014).

I developed separate inclusion and exclusion criteria for older people living with frailty and the Day Hospital staff. The goal was to ensure that participants in the study were not randomly chosen but instead included based on specific eligibility criteria (Campbell et al. 2020).

The inclusion criteria for older people living with frailty included individuals aged 65 and above, considered the marker of old age in the UK (Age UK 2019; ONC 2019). In addition, these individuals were living with frailty as determined by the clinicians based on their clinical notes and general observations. Furthermore, they were receiving part of their care services at the Day Hospital and judged by the clinical staff to have the capacity to provide free and fully informed consent, the ability to use the English language, and to participate in an in-depth interview. Anyone who was acutely medically unwell or part of the high-risk COVID-19 category was not approached to take part in the study. I have summarised the inclusion and exclusion criteria for older people living with frailty in Table 12.

Table 12: ***Eligibility criteria for older people living with frailty***

Eligibility criteria	**Inclusion Criteria**	**Exclusion Criteria**
Older people	a) Older people (aged 65 years and over) b) Individuals living with frailty c) Receiving (part of their) care services at the Day Hospital d) Capacity to give informed consent e) Judgement by the clinical staff and/or nominated manager that the potential participant can take part in an in-depth interview	a) Inability to communicate in English b) Acutely medically unwell individuals c) Those in the COVID-19 high-risk category

In terms of the hospital staff, I included those who routinely worked with older people living with frailty at the Day Hospital, such as nurses, physiotherapists, occupational therapists, and therapy assistants, who could give free and fully informed consent. I considered this professional diversity because I wanted to obtain firsthand experiences of caring for older people living with frailty from a multi-disciplinary care team. Furthermore, I included both part-time and full-time staff with a minimum of six months of work experience with older people living with frailty. I wanted to ensure that all staff with sufficient care experience could participate in the study. I assumed that regardless of the contract type, six months of experience would provide a solid base for participants to draw deep insights to answer the research question. Therefore, I excluded staff who did not have routine direct contact with patients' care, such as senior managers, because I thought they would not have sufficient current direct care experience with service users to draw in-depth perspectives. I have summarised the inclusion and exclusion criteria for the Day Hospital staff in Table 13.

Table 13: ***Eligibility criteria for Day Hospital staff***

Eligibility criteria	**Inclusion Criteria**	**Exclusion Criteria**
Hospital Staff	a) Staff working routinely with older people living with frailty at the Day Hospital b) Full-time and Part-time employment c) Minimum of six (6) months of work experience with older people living with frailty d) Capacity to give free and fully informed consent	a) Staff who do not have routine direct contact with patients' care, such as the senior managers

My target group and inclusion and exclusion criteria were vital in enabling me to define the sample size.

b) Deciding upon a sample size

During the design stage of the study, I chose a preliminary sample size to help with my time and resource allocation planning. This preliminary sample size was not intended to be fixed or final but rather a tentative number to assist me with my study planning (Robinson 2014). Accordingly, I aimed to recruit up to 20 older people living with frailty and 10 hospital staff members for my study. I considered this a sufficient number of participants to better understand the phenomenon under investigation. I based the decision to have this sample size on the need to balance having a small sample size, as recommended in most hermeneutic phenomenological studies (De Gagne and Walters 2010; Santiago et al. 2020), with the need to increase the possibility of gaining rich insights about the phenomenon (Laverty 2003). I also assumed that older people living with frailty might be unable to provide lengthy interviews in one session, hence the inclusion of more older people in the sample (Peel and Wilson 2008; Haak et al. 2021).

To deal with the possibility of having more participants than I needed for the study, I ensured that I started by working/recruiting five participants at a time, then stopped for a bit before starting again. This approach was crucial in allowing me the opportunity to briefly reflect on the data and the data collection process to ensure that I collected adequate data to answer my research questions (Laverty 2003; Robinson 2014; de la Croix et al. 2018).

Since I was interested in exploring the experience of control for older people living with frailty within their healthcare service use, participants needed to have experience with the healthcare service for people living with frailty to provide relevant data (van Manen 1997a; Laverty 2003; Dibley et al. 2020).

c) Selecting a sampling strategy

Once I had developed the eligibility criteria, I discussed this with the lead clinicians (gatekeepers) at the Day Hospital, who went through the patients' records and brought me into contact with those who met the inclusion criteria. For the Day Hospital staff, I asked the lead clinicians to share an invitation email with all staff members who met the inclusion criteria and requested that they contact me to learn more about the study. Although this sampling approach had a convenience element in that I relied on a pool of potential participants, as highlighted in the voluntary nature of the consent process, the sampling process was purposive because it was based on specific inclusion and exclusion criteria designed to select participants that I felt would enable me to answer my research questions (Robinson 2014; Campbell et al. 2020).

d) Sample sourcing

After receiving ethical and R&D office approvals, I obtained details of potential participants through the recruitment setting. I then began sourcing participants according to my sampling strategy. In the following sections, I explain how I carried out this process.

4.6.3.3 Recruitment setting

I recruited study participants from a Day Hospital, part of the NHS community-based healthcare service infrastructure for older people in the UK (Bell et al. 2005; Forster et al. 2008; Irvine et al. 2010). Day Hospitals are outpatient facilities where healthcare professionals provide older patients with time-limited medical and rehabilitative services over full or near full days, with the possibility of follow-up visits (Siu et al. 1994; Forster et al. 1999; BGS 2009). Day Hospitals were established in the UK in the 1950s and have evolved from their initial focus on providing services for older people with mental health challenges to addressing other health issues such as frailty, stroke, falls, and Parkinson’s disease, to support older people to remain independent (Rosenvinge 1994; Siu et al. 1994; Black 2005; Nicholson et al. 2005; Forster et al. 2008; Wilson and Hussain 2008; Irvine et al. 2010).

The essential services of Day Hospitals in the UK include assessment, treatment, and support for older individuals' maintenance in the community (Siu et al. 1994; Nicholson et al. 2005; Wilson and Hussain 2008). In addition to the medical and functional benefits, attending Day Hospitals provides older people invaluable opportunities for social interactions and peer relationships, significantly contributing to their well-being (Bell et al. 2005; Forster and Young 2011). Healthcare professionals from Day Hospitals also conduct home visits to assess the home environment and support coping mechanisms for different categories of service users (Wilson and Hussain 2008). Consequently, Day Hospitals have been considered an effective approach to supporting older people in enhancing their independence and delaying institutionalisation (Forster et al. 2008).

The typical length of involvement in the Day Hospital depends on the patient's condition and needs. Depending on their care needs and goals, the patient may attend the hospital for just one or several visits (Bell et al. 2005; Nicholson et al. 2005; Irvine et al. 2010). However, during the COVID-19 pandemic, the number of sessions, specifically in the chosen Day Hospital, was reduced to four for each patient. Despite this challenge, the Day Hospital demonstrated adaptability and resilience by continuing to provide essential services to older people.

The Day Hospital I selected provides various services for older people living with frailty, including assessment, treatment, and rehabilitation to maximise their health and independence. It assists primary and social care services with treating and managing complex conditions associated with ageing, avoiding hospital admissions, and facilitating early supported discharge. I chose this specific Day

Hospital as a recruitment setting due to its extensive focus on managing older people's health-related challenges, including frailty, in parts of southern England, hoping to gather valuable insights and perspectives from both the patients and their professional care providers.

It should be noted that Day Hospitals have become rare in the UK due to competition from alternative community service delivery models and the high costs associated with running them (Nicholson et al. 2005; Young and Forster 2008; Forster et al. 2008). In this sense, the recruitment setting used is unusual, which can be seen as a limitation of this study. The staff at the Day Hospital are in an unusual setting for the current NHS. However, the service has a good reputation, and it was felt that exploring what is possible within such a service would be interesting.

4.6.3.4 Gaining access to the recruitment setting - older people

Once I obtained the Letter of Access from the Day Hospital R&D office, I worked with the R&D Nominated Manager, who introduced me to the lead clinicians at the Day Hospital, who acted as gatekeepers and brought me into contact with other clinicians. Gatekeepers are crucial in qualitative research as they facilitate access to research sites and potential participants (Thomas et al. 2007; McFadyen and Rankin 2016). At the time of recruitment, I approached and discussed the inclusion and exclusion criteria with the clinicians and requested them to identify and bring me into contact with the potential participants who met the study inclusion criteria. The discussion took place through email and by attending staff meetings at the Day Hospital, where I discussed the study details, including recruitment with clinicians, such as nurses, occupational therapists, occupational therapy assistants, and physiotherapists.

The recruitment setting was, therefore, a vital aspect of the study. I ensured that I maintained a good working relationship with the recruitment site and gatekeepers through open communication (with data protection rules), complying with the research protocol and the local Standard Operating Procedures (SOPs), as well as ensuring the safety and well-being of all the parties involved in the study, particularly the participants (McMurdo et al. 2011; McFadyen and Rankin 2016; Negrin et al. 2022).

4.6.3.5 Gaining access to the participants -older people

In recruiting older people, I was guided by Good Clinical Practice (GCP) principles and the local site's standard operating procedures (SOPs). Accordingly, the identification and recruitment of potential participants were carried out by the clinicians at the Day Hospital, who then informed me. The clinicians reviewed the patients' medical records and other identifiable data to identify all those patients who met the criteria. I also collaborated with the clinicians to identify potential participants who fell into the COVID-19 high-risk category and excluded them based on that assessment.

Once the potential participants had been screened and identified, the clinicians contacted them through face-to-face interaction, email, or telephone. They asked them if they would like to learn more about the study. Also, invitation flyers with my contact details were handed out to the patients by the clinical team as part of their treatment packs. At this stage, I requested the clinicians to take verbal permission from potential participants (once screened) to give their contact details to me so I could contact them to expedite recruitment (Marks et al. 2017). Therefore, if I needed participants' contact details, they were only passed on to me when the participant expressed interest in the study and was willing to be contacted. Additionally, I used study posters with key study details to invite potential participants (Fleming et al. 2015). I displayed the posters at the Day Hospital reception and notice boards where the older people and the staff could easily read them.

Once the potential participants (older people) had expressed interest in the study, I approached/contacted them to discuss the study details, including the participant information sheet (Appendix 2) and consent form (Appendix 4), to seek their informed consent to participate.

Informed consent is not just a formality but a demonstration of our respect for the autonomy of potential participants. Before agreeing to participate, they must understand all aspects of the proposed research to minimise possible risks and inconveniences (Schofield 2014; Manti and Licari 2018). The Declaration of Helsinki, a cornerstone of ethical research, emphasises the importance of obtaining informed consent from potential research subjects to safeguard their rights, safety, and well-being (WMA 2013). Accordingly, I conducted a detailed discussion about the study with the potential participants and obtained a written confirmation before engaging each participant in any research activity.

In preparation for this process, I carefully considered the potential participants' capacity to consent. I also took into account the nature of the information about the study that would be provided to them, allowing sufficient time for absorbing and understanding the information, ensuring voluntary participation, providing the right to withdraw from the study, and recording the consent. This careful consideration was essential to ensure respect for the potential participants and their rights.

The process of obtaining consent began with me providing participants with all the necessary information about the study, including the topic, objectives, research question, methods, and details on how their data and privacy would be handled through the Participant Information Sheet (Ahern 2012). This information also explained the selection and inclusion criteria, why those participants had been selected, and any potential benefits and risks associated with the study (Manti and Licari 2018).

Additionally, all participants were informed about their right to withdraw from the study at any time without the need to provide a reason. I also clarified that their decision to withdraw would not impact their ongoing care. Similarly, participants were not obligated to give a reason for their withdrawal, but if they chose to, I documented the reasons in the reflective field journal. For instance, four participants withdrew their verbal consent to participate in the study before the interview dates. Some reasons they gave for their withdrawal included the study topic not being relevant to them and a lack of adequate time to participate.

All the above study-related information was provided both orally and in writing. The written information was in printed documents (participant information sheet and consent form) approved by the relevant Research Ethics Committees (RECs) and in the correct version. I also wrote all the study documents in simple language and appropriate font sizes (Provencher et al. 2014; Ennis and Wykes 2016). It is recommended that researchers working with older people should use documents with a font size of at least 16 points (HRA 2020).

If, after providing and discussing information about the study, the participants expressed willingness to participate, I requested them to sign the consent form to state that they fully understood the purpose of the research and were willing to participate. The participant and I signed and dated the consent forms on the interview day. The participants were also requested to initial each item of the consent form as a confirmation that they had agreed to each one and to demonstrate that the participant completed each item and not by any other person. I re-checked the consent form at the start of each interview to ensure it was correctly completed.

Significantly, in deciding to go through the clinicians to identify the potential participants, I weighed up the possible risks associated with this decision, particularly the possibility of some patients feeling obliged to participate in the study due to the perceived power that clinicians may have over them (Namageyo-Funa et al. 2014). It is important to note that due to the dependency of older people on professional care providers, they may be in a vulnerable position when deciding whether to take part in research studies. To minimise such a risk, I took extra care to explain the study and obtain consent in a way that reassured participants that their care would not be compromised by their participation in the study (Negrin et al. 2022). This approach included briefing the clinicians that while it is valuable to me for patients to take part in the study, it is a voluntary endeavour. Furthermore, I discussed the potential participants' participation without the presence of the clinicians. Here, I emphasised that participating in the study was entirely voluntary, that the participant could opt out without any consequences, and that the clinical care team would not know their decision (Ritchie et al. 2013). Additionally, the possibility of interviews in participants' homes away from the hospital minimised the likelihood of participants feeling pressured to participate in the study.

Furthermore, it is vital to acknowledge potential biases within the recruitment process, particularly concerning the likelihood of certain individuals being invited to participate over others. The clinicians who were responsible for screening potential participants may have inadvertently exhibited a selection bias, particularly against individuals whom the clinical care team perceived as 'difficult'. To mitigate this concern, I provided the gatekeepers with relevant information regarding the study's recruitment strategy and the rationale for seeking insights from diverse participants (Jessiman 2013). I informed clinicians that my focus was on understanding individuals' lived experiences rather than evaluating the quality of their services, emphasising that the data collected would remain unlinked to the clinical care team (Jessiman 2013). My objective was to gain an in-depth understanding of the challenges and opportunities encountered by individuals interacting with the healthcare system, thereby prioritising exploring their experiences rather than forming judgments on the service itself. Consequently, I found it particularly valuable to engage with individuals whom the care team identified as ‘challenging’, not in an evaluative manner, but to understand their subjective experiences. To further enhance the inclusivity of the recruitment process, I designed flyers that I asked clinicians to disseminate to potential participants, and a poster was displayed in the Day Hospital reception area, inviting individuals to participate in the study. These measures were implemented to diminish the risk of selection bias and promote a more diverse sample of participants.

4.6.3.6 Gaining access to the recruitment setting – Hospital staff

As mentioned in the section above, I recruited the study participants from a Day Hospital with various specialists, including occupational therapists, physiotherapists, nurses specialising in older persons and multi-pathological conditions, and older person consultants. These professionals offered multiple services, including community falls team reviews and treatment planning, memory clinics, Multi-Disciplinary Team (MDT) assessments and rehabilitation programmes, balance groups, cardiovascular services for stroke patients, Parkinson’s groups, Functional Electrical Stimulation (FES), vestibular interventions clinic, and ear irrigation.

4.6.3.7 Gaining access to the participants -Hospital staff

At the time of recruitment, I approached and discussed the inclusion and exclusion criteria with the lead clinicians and requested them to identify and bring me into contact with staff who met the study inclusion criteria. The lead clinicians shared an invitation email and study flyer with all the potential participants. They requested that the staff contact me if they wished to hear more about the study. The invitation email and flyer signposted interested individuals to me. Additionally, I attended staff meetings at the Day Hospital where I discussed the study details with all the clinicians, including occupational therapists, occupational therapy assistants, physiotherapists, nurses, and physiotherapist assistants and requested them to take part in the study. Once the potential participants had expressed interest in the study, I approached/contacted them to discuss the study details, including the Participant Information Sheet (Appendix 3) and the Participant Consent Form (Appendix 5), to seek their informed consent to participate in the study.

As mentioned earlier, I followed the principles of Good Clinical Practice while seeking consent from the study participants. I provided hospital staff with information about all study aspects before they agreed to participate. I also obtained written confirmation from them before they participated in any research activity. The information I provided included the study objectives, the reasons for their selection, how their data and privacy would be handled, and the potential benefits and harm of the study. I presented this information in the participant information sheet and discussed it with the participants at the start of each interview. Importantly, all participants had the right to withdraw from the study at any time without providing any reason. For example, two hospital staff who had agreed to participate in the study withdrew before the interview due to time constraints and loss of interest in the study.

After providing all the necessary information about the research study, I asked the participants if they would participate. If they agreed, I requested them to sign a consent form on the interview day. This consent confirmed that they understood the purpose of the study and were willing to participate. I also asked the participants to initial each item on the consent form to demonstrate their agreement with each point and ensure they completed the form. At the start of the interview, I double-checked the consent form to ensure it had been filled out correctly. As a token of appreciation for participating in the study, I provided biscuits for the recruited staff. I also gave the Day Hospital staff a cash voucher worth £10 to express my gratitude for their participation in the study in their own time.

4.6.4 Data collection process

In this section, I will provide details on the data collection process for my study. I begin by providing context on the interview setting before discussing the interview process with both older people living with frailty and the Day hospital staff, the role of field notes, and the data transcription process.

4.6.4.1 Interview settings and the impact of COVID-19 (older people)

I interviewed older people at their homes (n=17) and at the Day Hospital (n=3), whichever was more convenient for the person. Although I collected the data during the COVID-19 pandemic, it was at a time when it was possible to visit older people in their homes in the UK. I discussed with the lead clinician the availability of a safe, private, and comfortable space to conduct interviews with those participants who decided to meet at the hospital. Conducting interviews in the older participants' homes was considered convenient for most of them because it allowed them to meet me in their 'territory' where they felt more comfortable and sometimes supported by their family members. However, because of the risks posed by the COVID-19 pandemic, some potential participants declined to participate in the study because they found it risky to have people over in their homes, while others took up the option of having the interviews at the Day Hospital because they felt it would be safer for them and myself. Although having the interviews at the Day Hospital provided a more COVID-secure environment for the interviews, it was a bit inconvenient for the participants, as some had to combine both the medical and interview appointments on the same day. To make it easy for such participants, I covered the transport costs for those who opted to have interviews at the Day Hospital and required transport to get there (n=1). This was done to minimise the inconveniences associated with having interviews at the hospital and to enable participants to choose the most appropriate time for the interview, even outside of their medical appointments. Generally, the interviews lasted 38-93 minutes (median = 66 minutes), no longer than 93 minutes.

4.6.4.2 Interviews with older people

The interviews were guided by an interview topic guide (Appendix 11), which I developed before the data collection phase. I used the topic guide to structure the interview process, but there was flexibility as each interview was largely driven by the participants' accounts. In developing the topic guide, I considered the historical data regarding control and well-being in older people, which helped me come up with questions that would aid in gathering data to answer the research question and interpret the overall meaning of the participants' experiences (Sholokhova et al. 2022; Ray and Locsin 2023). In other words, instead of setting aside (bracketing) my own beliefs as a researcher, I made them a part of the historical data used to create the topic guide and to direct the investigation of the topic at hand (Ray and Locsin 2023).

Before the interviews, I negotiated and established relationships (rapport) with the participants (Negrin et al. 2022). I established rapport in a variety of ways, including reminding potential participants that I am independent of any service providers and will not feedback on any individual responses to clinicians; expressing interest in participants' concerns, such as the appropriate time for the interview; accommodating routines; expressing humility and kindness; as well as expressing interest in participants' conversations before and after the interview (Devers and Frankel 2000). I considered these aspects during the entire data collection process.

During the interviews, I strived to gain entrance into the participants' lifeworld to understand their lived experiences better, but without leading the discussion (Polit and Beck 2021). I was aware that phenomenological interviews are open, and I aimed to facilitate (guide) participants to provide detailed descriptions of the phenomenon under study using their own experiences and everyday life examples (Holloway and Galvin 2016). However, the interviews followed a 'conversational flow' which I divided into activities, such as asking a question, negotiating for meaning between the participant and myself, understanding the participant's concrete description, my interpretation of the descriptions, and the participant's validation and evaluation of their descriptions (Brinkman 2013). This free-flowing interviewing process enabled me to understand *"what it is like to* *experience a phenomenon"*, probing meaning and transforming the lived experience into a textual expression of its essence (Ray and Locsin 2023, p.5).

This form of interviewing also enabled me to obtain rich data through probing and expanding participants' responses (Rubin and Rubin 2005). Generally, I began the data collection with a greeting/introductory remark, and I followed this up with questions on the participants' demographic data, such as age, gender, and marital status. I based the interviews on a range of up to six (6) key topics to answer the research question. In addition, I used the topic guide to probe participants' responses (Devers and Frankel 2000). Generally, the interviews commenced with an opening statement such as *'Tell me about your experience of….'* and followed up with probes such as *'Can you tell me more about that?'; 'What was it like for you?'; 'Can you give me an example?; ' What did that feel like*?' based on emerging information to encourage participants to reflect on the meaning of their responses. These probes were vital in enabling me to understand and interpret the lived experience of control and well-being of older people living with frailty as they navigate health services. By using interpretive interviewing, I was also able to direct conversations towards a more hermeneutic focus (Bevan 2014; Adams and van Manen 2017). Throughout the interviews, I remained attentive and open to what was being said, paying attention to silences and interpreting the meaning. In addition, I ensured that I stayed patient and waited for the participant to continue speaking without feeling pressure (Adams and van Manen 2017).

Furthermore, I conducted the interviews in light of specific ideas from the lifeworld and the humanising caring frameworks. The lifeworld dimensions provided valuable clues for focusing my interviews, guiding me to explore specific and in-depth modes of experiences relevant to my research (Køster and Fernandez 2023). This approach helped me ask and probe the relevant questions using notions such as embodiment, spatiality, temporality, intersubjectivity, and mood, allowing new insights to inform healthcare interventions (Zahavi 2019b). So, I was sensitive to how things felt, how close or distant people felt, aspects of perceived time and their impact on mood. However, I was open-minded throughout the interviews, allowing participants to express their experiences without being unduly influenced or constrained by my research agenda (Zahavi 2019b). All the interviews lasted no less than 40 minutes, providing participants with an opportunity for an *"in-depth disclosure"* (Standing 2009, p.24).

Crucially, I observed the verbal and nonverbal behaviours of the participants, their environment, and the manner of response, which I recorded in a reflective field journal after each interview (Alsaigh and Coyne 2021). I ended the interviews with a closing question to allow the participant to provide additional information or comments. With the participants' permission, all the interviews were audio-recorded verbatim to ensure data completeness and that no valuable information was lost during the interview process (Vandermause and Fleming 2011; Martinsen et al. 2022). One of the key challenges I encountered during interviews with older people was that there were moments when I was not audible enough due to the face mask I was wearing. To overcome this obstacle, I repeated my statements to ensure the participant fully understood what I was communicating.

After completing the interview, I thanked the participant for their valuable time and double-checked to ensure they were not distressed. In addition, I also provided the participants with information about the support services available to them in case they felt lonely, concerned or distressed as a result of participating in the study (see Table 11). For the interviews conducted at the Day Hospital, I saw off the participants out of the building to ensure they were safe to leave. Finally, I also made field notes and filed the signed consent forms at my office at Bournemouth University.

4.6.4.3 Interview settings and the impact of COVID-19 (Hospital staff)

I conducted all the interviews with the hospital staff (n=10) at a Day Hospital. I discussed with the lead clinician the availability of a safe, private, and comfortable space for these interviews. Conducting interviews at the Day Hospital was convenient for the staff as they were in a familiar environment and could refer to certain aspects of it. During the interviews, I adhered to the Trust's COVID-19 protocols by wearing a facemask wherever possible, maintaining a safe distance, and regularly washing or cleaning my hands. Generally, the interviews lasted 38-70 minutes (median= 54 minutes), no longer than 70 minutes, and I provided short breaks between interviews.

4.6.4.4 Interviews with Hospital staff

I conducted interviews with both hospital staff and older people simultaneously. This approach meant allowing participants to provide perspectives on each other's views. The implication of conducting interviews simultaneously is that I could access and understand the intersubjective interconnectedness between older people living with frailty and their healthcare professionals early on in the research process, guiding the combined hermeneutic reflection (Finlay 2009). The interviews with hospital staff were guided by an interview topic guide (Appendix 12), which I developed before the data collection phase. The topic guide provided structure, but interviews were flexible based on participants' accounts.

To build a good relationship with the hospital staff, I assured them I would abide by the confidentiality principles outlined in the participant information sheet. I also allowed them the flexibility to pause our interviews if they needed to attend to emergencies.

I began the interviews with the Day Hospital staff with a friendly greeting and asked about the participants' demographic data, including age, gender, role, and experience at the Day Hospital. We discussed six (6) key topics related to the research question, *'What are the experiences of service providers when considering control and well-being of older people living with frailty in healthcare service provision?'* using a topic guide. I also asked about the nature of the patients they worked with and encouraged reflection by asking follow-up questions. In addition, I shared some perspectives from older people's interviews to gain insight into the hospital staff's viewpoints.

During the interviews, I requested the Day Hospital staff to share their experiences of caring for older people living with frailty. In addition, I asked the staff to provide perspectives on some of the issues raised by the older people. I aimed to understand how healthcare professionals design and deliver healthcare services and how this impacts the sense of control and well-being of older people living with frailty. The Day Hospital staff drew on their work experience at the facility and occasionally compared it to their experiences in other healthcare service organisations. This was important in providing a more comprehensive description of the experiences of service providers when considering control and well-being of older people living with frailty in healthcare service provision. The interviews with the Day Hospital staff generally lasted for 60 minutes. Due to their work commitments, I allowed the staff opportunities to pause the interviews and resume them later in case such a need arose. This flexibility was necessary when one of the staff had to stop the interview to attend to an emergency with a client. We continued the interview with the staff on another mutually agreed date.

Furthermore, I closely monitored how the staff expressed themselves through their words and body language, recording my observations in a reflective field journal. In addition, I audio-recorded all the interviews to ensure I did not miss out on any important details. At the end of each interview, I always asked a closing question to allow the participants to share any additional information or comments they may have had. Once the interviews were complete, I thanked the hospital staff for their valuable time and made quick notes in my field journal. Finally, I confirmed their email addresses and arranged to send them gift vouchers as a token of appreciation.

4.6.5 Fieldnotes

The field notes played a crucial role in the research process, and I took them at all stages of the study. The notes consisted of general field notes for the research project as a whole and specific notes for individual interviews (Phillippi and Lauderdale 2018). These notes contained information on various aspects, such as the evolving research ideas and challenges encountered during the research project. They also included details on participant recruitment, such as the number of participants recruited, those who withdrew from the study, and their reasons for withdrawing. In addition, the notes recorded information related to data collection, such as the participants' identification number, interview date and time, data collection setting, presence of non-recruited individuals, and the participants' verbal and nonverbal behaviours and responses (Alsaigh and Coyne 2021).

During interviews, I took small notes unobtrusively to avoid disrupting the flow of the conversation, and detailed field notes were completed shortly after each interview (Phillippi and Lauderdale 2018; Underwood et al. 2020). Once I had completed data collection, I secured and kept the field journal and original audio recordings in a locked cabinet at my office and then transferred them to electronic files as soon as possible (Tsai et al. 2016). The field notes were valuable in helping me reflect on each interview, better understand the participants' experiences, and contextualise their responses to the phenomenon under study (Phillippi and Lauderdale 2018).

4.6.6 Transcription

All the study interviews were transcribed verbatim immediately after each, and I ensured each transcription had the appropriate labelling. In addition, each transcript contained essential features in line with the recommendations of the UK Data Service (2020) to enhance the sharing and reuse potential of the study data. These features include *"a unique identifier (a name or number); a uniform and consistent layout throughout a research project or data collection; a document header or cover sheet with interview or event details such as date, place, interviewer name and interviewee details; speaker tags to indicate the question/answer sequence or turn-taking in a conversation; line breaks between turn-takes; numbered lines and pages; and pseudonyms to anonymise personal identifying information"*. See Appendix 13 for an example page.

4.7 Hermeneutic Phenomenological Reflection

In this section, I will describe how I approached the process of analysing data to generate a meaningful understanding of the phenomenon under study. Data analysis commenced after the collection of data and transcription of interviews (Sahaf et al. 2017). The data analysis aimed to identify essential themes and provide an interpretation of the experience of a sense of control and well-being from the perspective of older people living with frailty and their healthcare providers (van Manen 1997a). In the following sections, I describe the data analysis process, including how I conducted the line-by-line reading of transcripts and how the meaning units, categories and themes emerged. I have also included some photos of the various stages of the data analysis in the appendices.

4.7.1 Reading and re-reading the transcripts

To gain a reflective understanding of the phenomenological structure of the lived meaning of the phenomenon, I began by getting in direct contact with the participants' lived experiences, which involved analysing their accounts (van Manen 1997a). I located the descriptions of the lived experience in the transcribed data and the field notes taken during the data collection phase (van Manen 1997a). I read and re-read the transcripts and field notes in a back-and-forth movement to make sense of the participants' descriptions (Todres et al. 2000; Storli et al. 2008). I began by reading older people's transcripts to understand their experiences. Initially, I read individual transcripts, and then I developed an understanding by contrasting and comparing all the transcripts from older people living with frailty. The intention was not to 'code' the lived experience but instead to use its description as a starting point to ask, *''What might this particular lived experience description, passage, phrase, or even word say about the phenomenon of interest?''* (Adams and van Manen 2017, p.788). I then analysed the Day Hospital staff transcripts in light of this developing understanding, focusing on their perspectives to add further insights and enrich the developing analysis. This process involved spending over six months engaging with my data until I focused on the essential themes (Errasti-Ibarrondo et al. 2018).

4.7.2 Identifying essential themes

The process of reading the transcripts and field notes included identifying themes or the essential structures that emerge or make up the experience (van Manen 1997a). However, van Manen (1997a) suggests that not all the meanings encountered in reflecting on the lived experience or phenomenon are unique to that lived experience or phenomenon. Therefore, researchers must isolate essential themes to give the lived experience an elaborate and full-fledged narrative (van Manen 1990, 1997a). At this stage, I focused on *"discovering aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is"* (van Manen 1997a, p.107). This process involved identifying common threads that characterised the lived experiences and using them to navigate the participant experience as 'meaningful wholes' and guide my overall phenomenological description (van Manen 1997a).

To isolate the thematic aspects of participants' descriptions, I considered van Manen's (1997a) recommended approaches for uncovering or isolating thematic aspects of the phenomenon from the text. These approaches include the wholistic/sententious, selective or highlighting, and detailed or line-by-line approaches. For the present study, I used the detailed reading or line-by-line approach, which involved analysing every sentence or sentence cluster of the transcripts and field notes to understand what they revealed about the sense of control and well-being in older people living with frailty (van Manen 1997a; van Manen 2012; Martinsen et al. 2022). I have included photos showing how I conducted the line-by-line reading of the transcripts in Appendix 14.

Reading each transcript line by line enabled me to highlight the key findings that made up the phenomenon in each line or sentence cluster. Then, I translated these aspects into meaning units, which I added as comments in track changes in a Microsoft Word document (Appendix 14). To accomplish this, I engaged in a back-and-forth process that involved reading and re-reading the transcripts to allow the phenomenon's essence to appear. However, I sometimes found it challenging to choose the aspects of my participants' data to focus on because I felt many of the insights were equally vital and deserved mention. At this stage, I still had many ideas and had to strike a balance by concentrating on the meaning units directly linked to my research question as the phenomenon's essence emerged.

I used my reflective field journal and discussed my interpretations with the supervisory team, which was very helpful in enabling me to choose those quotations that best represent the participants' descriptions and my interpretations (Clancy 2013). I also reflected on the context of the interviews, language use, and my understanding of the data to develop my interpretation. For instance, regarding linguistic reflection, I paid attention to the words used by the participants, the context, the frequency and intensity of the words, the silences, and the participants' conceptual aspects of control and well-being (van Manen 2012). Like other existential phenomenologists, I refrained from using a preconceived coding scheme during data analysis and instead allowed the various constituents of the phenomenon to emerge from the participants' descriptions as much as possible (Hein and Austin 2001; Martinsen et al. 2022).

After identifying the key findings and meaning units using track changes, I separated these elements from the larger transcripts. This approach allowed me to focus on the highlighted aspects and meaning units without being distracted by other details from the participants' descriptions that I felt were not relevant to the phenomenon under investigation. To achieve this, I manually cut various segments of the transcripts into small pieces of paper (see Appendix 15) instead of using analytical software. This approach was taken because I wanted to remain as close as possible to the participants' experiences (van Manen 1997a). Once I had cut the transcripts into numerous pieces of paper, I spread these pieces across the floor and started linking my initial ideas into preliminary categories.

Next, I approached the phenomenon's multi-layered and multi-dimensional meaning in the form of categories by identifying how the individual expressions and meaning units formed into 'wholes' by moving between the parts and the whole, which is known as the hermeneutic circle (van Manen 1997*a*; Todres et al. 2000; Storli et al. 2008; Ray and Locsin 2023). This circle of understanding involved spending some time reorganising the meaning units using sticky notes (Appendix 16) to sort related aspects, redefine and link units, and add another analytical layer of understanding, enabling me to move from meaning units to preliminary categories. This stage also included looking for similarities, differences, and complexities in participants' accounts to find aspects or qualities essential to the phenomenon under study, which became the final categories (van Manen 1997a). Throughout the process, I referred to the research aim to focus on *'What the lived experience of control and well-being of older people living with frailty in healthcare services is in southern England'* (Martinsen et al. 2022).

After identifying the final categories, I translated them into essential or revealing statements by identifying their similarities and differences and linking this analysis to the research questions. I then finalised this process by translating the various statements into emerging themes using suitable phrases or singular statements to capture their central meaning (van Manen, 1997a). This process also included an interpretive interaction of the text while referring to the topic guides to ensure a comprehensive understanding of the parts of the text within the context of the interview questions and that each theme that emerged was integrated into the whole, which is a central aspect of the hermeneutic circle (Errasti-Ibarrondo et al. 2018; Alsaigh and Coyne 2021). These themes include a diminished sense of control as manifested through a shrinking sphere of influence in everyday life, a perceived sphere of influence affected by healthcare experiences, and the home as a secure base for navigating an insecure future. It is important to note that these themes do not provide a complete description of the lived experience of a sense of control and well-being in older people living with frailty but serve as a reference point for certain aspects of the phenomenon (van Manen 1997a).

Throughout my data analysis, I received support from my supervisors and colleagues, particularly on the InnovateDignity project (van Manen 1997a). I also engaged in collaborative discussions and research seminars, such as the British Society of Gerontology's (BSG) 51st Annual Conference (2022), to share interpretive insights and reflect on the chosen themes to ensure they resonated with the phenomenon being studied (van Manen 1997a). As this is a doctoral project, my academic supervisors played a crucial role in reviewing my work and helping me identify any limitations in my analysis (Alsaigh and Coyne 2021). They supported me in transcending those limits to examine, reinterpret, omit, add, and reformulate the themes through a ‘conversational relation’ at different draft stages (van Manen 1997a).

Finally, I used the reflexive method to reflect and categorise the meaning embedded in the lived experience and write about it as described by the participants in a phenomenological text (Errasti-Ibarrondo et al. 2018).

4.7.3 Focus on the Lifeworld

van Manen (1997a) suggests that it is crucial to begin by understanding people’s lived experiences through their lifeworld. The themes that arise from phenomenological descriptions signify a part of the participants’ lifeworld (van Manen 1997a; Van der Zalm and Bergum 2000). The lifeworld, just like phenomenological descriptions, exhibits thematic structures that permeate almost every human being and become the ground upon which they experience the world (van Manen 1997a; Martinsen et al. 2022). These structures are called the lifeworld existentials or dimensions, including embodiment, spatiality, temporality, intersubjectivity, and mood (van Manen 1997a; Galvin and Todres 2013). Although these dimensions can be distinguished, they are interconnected (Biley and Galvin 2007; Galvin and Todres 2013; Ashworth 2016; Flinterud et al. 2022). I applied these dimensions to understand the experiences of older people living with frailty regarding control and well-being in healthcare service use and to guide reflection and writing (van Manen 1997a).

4.7.4 Composing linguistic transformations

After identifying the essential themes, I composed linguistic transformations through a creative and hermeneutic process (van Manen 1997a). Ray and Locsin (2023) suggest that phenomenological writing should begin with thematic analysis and provide a comprehensive understanding of the phenomenon by using examples from the data and general interpretation to reveal the authentic meaning or the meaning of the whole experience being studied. To achieve this, I presented the selected themes in more ‘phenomenologically sensitive paragraphs’ and generated notes and paragraphs from reading or researching the literature (van Manen 1997a). This textual process required constant writing and re-writing (van Manen 2012; Adams and van Manen 2017).

Hermeneutic phenomenological writing is a process where the researcher reflects on and understands the meaning of a phenomenon and then creates a narrative to clarify its themes (van Manen 1997a; Ray and Locsin 2023). I transcended the experience to understand its essence and create ‘phenomenologically sensitive paragraphs’ using a creative and hermeneutic approach (van Manen 1997a). This process involved using anecdotes and reflecting techniques to carefully describe the lived experience and then reflect on the aspect(s) of the phenomenon given in the anecdote (van Manen 2012; Adams and van Manen 2017). The anecdotes constructed from the interviews are vital in providing context and assisting the reader to resonate with the experience and grasp the moment as lived through in the now to access the subjectivity of the experience of control and well-being in older people living with frailty (van Manen 2012).

Furthermore, I attempted to produce a phenomenological text that goes beyond the usual language using artistic expressions (Aagaard 2017; Errasti-Ibarrondo et al. 2018). This endeavour involved finding words that are sensitive to the phenomenon yet allow it to speak for itself, as it were (van Manen 2012). The texts I developed are characterised by rich and deep descriptions of the phenomenon to give readers a reflexive re-living experience and vividly understand them (Errasti-Ibarrondo et al. 2018). This evocative writing was essential to draw the reader into my writing and help them feel and intellectually understand the most meaningful and essential aspects of the experiences of control and well-being in older people living with frailty, which would be impossible to convey differently (van Manen 1997a). Throughout the writing process, I remained focused on the phenomenon's thematic, existential, and linguistic aspects, i.e., *"the phenomenality of the phenomenon"* (Adams and van Manen 2017, p.789).

Finally, I rewrote several drafts to present a narrative of the evolving themes (Martinsen et al. 2022). I presented the final narrative in Chapter Five as study findings. To balance description and interpretation, I used participants' words to describe their experiences wherever possible (van Manen 1997a; Storli et al. 2008; Martinsen et al. 2022). I also included brief interpretation sections after each descriptive phase in the findings chapter (Todres et al. 2000). However, it is essential to note that hermeneutic phenomenological descriptions are subject to varied interpretations and may result in different lived experiences for different individuals, depending on the context (Eilifsen 2011; van Manen 2012).

Therefore, a phenomenological description is only one interpretation, and no single interpretation can fully capture the complexity of human experience (van Manen 1990).

4.8 Rigour

Rigour is a crucial aspect of high-quality research. It is defined as *“the quality or state of being very exact, careful, or with strict precision or the quality of being thorough and accurate”* (Cypress 2017, p.254). In qualitative research, rigour or trustworthiness refers to a set of criteria, including credibility, dependability, conformability, and transferability, that are used to evaluate the quality of a study (Morse et al. 2002; Cypress 2017; Alsaigh and Coyne 2021; Du 2022). Credibility involves having confidence in the ‘truth’ of the findings and their interpretation, while dependability ensures that the research process is clear enough for someone else to follow. Confirmability establishes that the participants, not the researcher, shape the study findings, and transferability refers to the ability to apply research findings in similar contexts (Cypress 2017; Alsaigh and Coyne 2021; Du 2022).

Sundler et al. (2019) highlight that it is essential to incorporate strategies that enhance scientific rigour into the research process and not solely evaluate them after the study ends. This recommendation is especially crucial for qualitative research, which has a high potential for subjectivity (Cypress 2017). When evaluating the rigour of phenomenological research, emphasis should be placed on adhering to the philosophical and methodological assumptions that guide the chosen method and the experiential and methodological concerns of the study

(Pereira 2012). As a result, to ensure rigour in this study, I followed van Manen's principles of the hermeneutic phenomenological approach, which are derived from Heidegger's philosophy of interpretive phenomenology. At different stages, I committed to ensuring the study was rigorous using the steps discussed below.

At the outset, I explored various research methodologies, as highlighted in my study protocol (Pereira 2012). Through this process, I gained a deeper understanding and appreciation of qualitative research and its philosophical and methodological assumptions, including constructivist ontology, interpretivist epistemology, and hermeneutic phenomenology (Patton 1999). In my study, I chose to utilise hermeneutic phenomenology as it allowed me to explore the lived experience of control and well-being in older people living with frailty (van Manen 1997a). I considered this choice suitable for my study because focusing on the participants' experiences enabled older people living with frailty to gain awareness of their being in the world as they adequately reflected on their experiences, enhancing the credibility of my study (Standing 2009). To further improve my research skills, I underwent training in various qualitative and clinical research aspects, including research methodology, good clinical practice, phenomenological interviewing, and data analysis. In qualitative research, the researcher is an instrument, and I therefore wanted to ensure that I was well-equipped to conduct my research in a thorough and credible manner (Patton 1999; Setoodegan et al. 2019).

At the preparatory stage, I carefully determined an appropriate sample size and purposefully recruited participants. I also detailed the process through which I applied the chosen sampling technique to enhance the transferability of my study (Malterud 2001; Baloushah et al. 2019; Setoodegan et al. 2019). During the data collection phase, I utilised semi-structured interviews as the empirical data collection method to ask ‘meaning questions’ and grasp the essential meaning of the sense of control and well-being in healthcare service use for older people living with frailty (van Manen 1990).

To enhance the data quality, I engaged in a prolonged exploration of the lived experience of control and well-being in older people living with frailty for over four months (Standing 2009; Cypress 2017). Similarly, I interviewed older people living with frailty and Day Hospital staff. This approach enabled me to collect data from two distinct sources, which helped me address my research questions and deepen my understanding of the topic. Initially, I analysed the data from older people living with frailty to establish a foundational understanding. I then complemented this with insights from the Day Hospital staff. This process of data triangulation was crucial in providing a more diverse and comprehensive perspective on the findings (Guion et al. 2011; Carter et al. 2014).

Throughout the interviews, I remained open and sensitive while listening to each participant’s story, ensuring their perspective was noted and represented as clearly as possible (Alsaigh and Coyne 2021). In addition, I have used direct quotes to represent the participants’ voices to enable the reader to validate the data, enhancing the credibility of the findings (Malterud 2001; Standing 2009; Alsaigh and Coyne 2021).

A rigorous data analysis process is essential to strengthen the credibility of a study, and it should be linked to the theoretical background of the research (Du 2022). I devoted more than six months to data analysis, which involved multiple stages of analysis, interpretation and data patterns. This prolonged and persistent engagement with the study data resulted in a clear representation of participants' 'being-in-the world', enhancing the study's credibility (Shirazi et al. 2016; Baloushah et al. 2019; Setoodegan et al. 2019). Throughout the analysis, I acknowledged my pre-understandings, reflecting the confirmability of the data (Alsaigh and Coyne 2021). In addition, my commitment to the hermeneutic circle meant that the data analysis process was interpretive, and I have discussed how interpretations arose from the data, enhancing the study's credibility (Laverty 2003; Standing 2009; Ray and Locsin 2023). To ensure the coherence and reliability of the research conclusions, I ensured that the findings answered the original research questions, i.e. *'What is the lived experience of control and well-being of older people living with frailty in healthcare service use?'* and *'What are the experiences of service providers when considering control and well-being of older people living with frailty in healthcare service provision?' a*nd discussed the findings in relation to the relevant literature (Standing 2009). Additionally, I interpreted the findings in the context of the research and also discussed my analysis and interpretation with my supervisors, who provided feedback at different stages, enhancing the reliability and dependability of the study (Pereira 2012; Shirazi et al. 2016; Du 2022).

Furthermore, I ensured to maintain truthfulness in my description of the lived experience by creating phenomenological texts that are credible to the experience and understandable by outsiders to evoke a *“phenomenological nod”* (Laverty 2003; Pereira 2012; Alsaigh and Coyne 2021; Ray and Locsin 2023, p.4). This process involved providing vivid and in-depth descriptions of the complexities of the experiences and interactions in the data, aiming to create harmony between the whole and parts of the text to enhance understanding and the study’s credibility and transferability (Laverty 2003; Alsaigh and Coyne 2021; Du 2022). I followed the principles of phenomenological writing by describing the lived experience, providing contextual details, such as the social demographic characteristics of the study participants, and information on the study setting, allowing the critical appraisal of my research process (Malterud 2001). Similarly, I separated my voice from that of the participants in the text to enable the reader to fully appreciate the participants’ views (Malterud 2001).

In studying the lived experience, I ensured methodological coherence by linking my study aims to the methodology and methods (Laverty 2003; Alsaigh and Coyne 2021). I moved back and forth between the phenomenological framework and its application to guarantee congruence between deciding the research question, investigating the phenomenon, and undertaking hermeneutic reflection (Laverty 2003). This coherence helped to ensure that the inquiry process reflected the purpose of the study (Laverty 2003). Similarly, I maintained consistency in the chosen method and clearly outlined my research process, including the methodological decisions and justifications (Bevan 2014; Du 2022). I clearly explained the research procedure, including data collection and analysis, such as conducting interviews and analysing transcripts (Du 2022). This methodological coherence and transparent description of the methodological steps undertaken during the study provided an audit or decision trail, enhancing the study's credibility, dependability, and conformality (Standing 2009; Baloushah et al. 2019; Setoodegan et al. 2019).

Hermeneutic research does not aim to generalise study findings (Alsaigh and Coyne 2021). However, the use of thick descriptions and the application of lifeworld and humanising care ideas imply that conclusions from this study can be transferable to similar healthcare contexts to a reasonable extent (Robertson 2015; Shirazi et al. 2016). As a result, I ensured transferability by providing detailed descriptions of the research context, going beyond the data to make interpretations, analysing the relationship between data and the theoretical background, and linking data-based findings to lifeworld and humanising care frameworks (Malterud 2001; Standing 2009; Du 2022).

Finally, I engaged in reflexivity throughout the research process. This practice involved questioning my thoughts, attitudes, and actions to understand my role as a researcher in relation to others, which was vital in enhancing the integrity and credibility of the research (Pringle et al. 2011a; Alsaigh and Coyne 2021). Reflexivity enabled me to become aware of my biases and minimise them as much as possible to ensure that the participants' perspectives shaped the study findings rather than my own biases, emphasising the confirmability of the study (Alsaigh and Coyne 2021). I have acknowledged the preconceptions, motivations, and perspectives I brought into the study (Malterud 2001; Standing 2009). I have also discussed how I dealt with the effects of such aspects on the study under the section on reflexivity in Chapter Six.

4.9 Conclusion

In this chapter, I have provided a detailed account of and justifications for my methodological decisions and how they affected my study. Firstly, I have explained how research paradigms, such as ontology, epistemology, and methodology, are related and how they shaped my study. Then, I have described my selected research method in detail, including the procedures and processes I used to collect and analyse my data. By following these steps, I arrived at the findings I will present in the next chapter.

Chapter 5 Findings

5.1 Introduction

In this chapter, I will present the results of my analysis of the data collected from 20 older people living with frailty and 10 healthcare professionals. I will begin by presenting the socio-demographic characteristics of the study participants. After that, I will present the findings of the study, which are divided into three main themes. The first theme is about a diminished sense of control as manifested through a shrinking sphere of influence in everyday life. The second theme relates to how participants' perception of their sphere of influence is affected by their healthcare experience. The third theme is about the importance of the home as a secure base for navigating an uncertain future. Finally, I will conclude the chapter with a model of a sense of control over healthcare services for older people living with frailty.

Table 14, presented below, highlights the key characteristics of the participants. The older people living with frailty in the study reported a variety of health challenges, including Parkinson's disease, falls, balance challenges, cancer, problems with eyesight, and hearing challenges.

Table 14: ***Social-Demographic Characteristics (Older People n=20)***

No.	Characteristics	Variable	Total
1.	Age (Years)	65-70	2
		71-75	2
		76-80	4
		81-85	9
		86-90	3
2.	Gender	Male	10
		Female	10
3.	Marital Status	Single	1
		Married	13
		Divorced	4
		Widowed	2
4.	Ethnicity	White	20
5.	Living arrangement	Living at home alone	12
		Living at home with another	8
6.	Health condition/challenge	Parkinson’s Disease	8
		Hearing challenges	1
		Cancer	1
		Cerebral vascular dyspraxia	1
		Sight challenges	1
		Guillain-Barré syndrome	1
		Vertigo	1
		Falls	2
		Balance challenges	2
		Systemic sclerosis	1
		Bowel polyp	1

Table 14 shows that most older people living with frailty in this study were aged 80 and above. The implicit frailty within this population group explains why many reported physical limitations. The study included an equal number of male and female participants. This decision was deliberate to ensure heterogeneity within the sample (Bekele and Ago 2022). Furthermore, most older people living with frailty in the study were married, which was expected of this cohort. However, there were a few of them who were single or divorced. In addition, there was a high number of participants (8) who lived with Parkinson’s Disease. It is also worth noting that many older people in this study lived alone, highlighting the possibility of loneliness in this cohort. The most notable characteristic of the study is that all participants were of white ethnicity. This characteristic represents the nature of most of the service users at this particular Day Hospital. Consequently, I did not include the experiences of older people living with frailty from other ethnic backgrounds in the study.

Table 15: ***Social-Demographic Characteristics (Day Hospital Staff n=10)***

No.	Characteristics	Variable	Frequency
1.	**Age (Years)**	30-40	4
		60-70	2
		Not known	4
2.	**Gender**	Male	1
		Female	9
3.	**Role**	Nurses	2
		Occupational therapists	2
		Physiotherapists	3
		Therapy/Rehab assistants	3
4.	**Level of experience**	Less than 5 years	2
		10-20 years	3
		30-40 years	2
		40-50 years	1
		Not known	2

Based on the data provided in Table 15 above, it can be inferred that most healthcare professionals who disclosed their age fell within the 30-40-year age range. This age range is typically associated with experienced and settled staff, reflected in the composition of the Day Hospital staff. Almost all the healthcare professionals who participated in the study were female, with only one male. Additionally, most healthcare professionals were rehabilitation therapists or assistants, with only two being nurses. This characteristic reflects the rehabilitative nature of the services that older people living with frailty expect to receive at the Day Hospital. Moreover, most healthcare professionals had over 10 years of experience working with older patients.

Most interviews with older people living with frailty occurred in their homes (17), with only three conducted at the Day Hospital. I interviewed all healthcare professionals at the Day Hospital. It is essential to highlight that the data collection period occurred two years after the COVID-19 outbreak in the UK. I conducted the interviews after a partial lifting of COVID-19 restrictions. Therefore, the reader needs to interpret the study findings within this context.

Although I interviewed both older people living with frailty and the Day Hospital staff simultaneously, this thesis primarily focuses on the experiences of older people living with frailty. I have included the perspectives of healthcare professionals to provide context for what is possible within the healthcare system. Therefore, healthcare professionals’ views are considered secondary and are only woven in as a healthcare response to the perspectives of older people living with frailty. Similarly, I first analysed older people’s transcripts to gain a better understanding of their experiences. Then, I analysed the transcripts of the Day Hospital staff, focusing on their perspectives to enhance the analysis. The research revealed three overall themes, which I summarise in the table below, along with the categories generated from the data analysis.

Table 16: ***Summary of the categories and themes***

Theme	**Category**
Theme 1: Diminished sense of control as manifested through a shrinking sphere of influence in everyday life.	▪ Gradual changes and deteriorations ▪ Loss of control over everyday life ▪ Giving up everyday activities ▪ Relying on others ▪ Existential vulnerabilities ▪ The dual perspective of self ▪ Striving to do something within the boundaries of physical limitations
Theme 2: Perceived sphere of influence affected by healthcare experience	▪ Access to healthcare services ▪ Welcoming atmosphere ▪ Trusting relationships with some healthcare professionals ▪ Information sharing within healthcare systems ▪ Experience of having a choice in healthcare services ▪ Experience in making decisions in healthcare services
Theme 3: The home as a secure base for navigating an insecure future	▪ Uncertainty about future healthcare ▪ Sense of control and future health-determined plans ▪ Negotiating control over healthcare within the home environment

I have used pseudonyms to protect the anonymity of the study participants (Robertson 2015). To make these pseudonyms more humanising, I have assigned each participant a fictitious name, as summarised in Table 17 below. I have also not included the ages of the Day Hospital staff to maintain their anonymity.

Table 17: ***Participants' pseudonyms***

	Pseudonym	**Nature of participant**	**Gender**	**Age**
1	Denis	Older person	Male	81
2	Lynnet	Older person	Female	82
3	Tom	Older person	Male	80
4	Justine	Staff (Therapy staff)	Female	
5	Beth	Staff (Therapy staff)	Female	
6	Arnold	Older person	Male	76
7	Suzan	Staff (Therapy staff)	Female	
8	Barbra	Older person	Female	85
9	Patience	Staff (Nursing staff)	Female	
10	Angel	Staff (Therapy staff)	Female	
11	Brian	Older person	Male	86
12	Lilian	Staff (Therapy staff)	Female	
13	Boris	Staff (Therapy staff)	Male	
14	Bridget	Staff (Therapy staff)	Female	
15	Lyndsey	Older person	Female	73
16	Emily	Older person	Female	79
17	Robert	Older person	Male	85
18	Teresa	Older person	Female	65
19	Priscilla	Older person	Female	80
20	Kate	Older person	Female	76
21	Peter	Older person	Male	70
22	Stella	Staff (Nursing staff)	Female	
23	Sandra	Staff (Therapy staff)	Female	
24	Frank	Older person	Male	82
25	Jessica	Older person	Female	71
26	Nicole	Older person	Female	79
27	Hughes	Older person	Male	82
28	Julian	Older person	Female	86
29	Alex	Older person	Male	87
30	Mark	Older person	Male	81

The first theme elaborated below pertains to a diminishing sphere of influence for older people living with frailty.

5.2 Theme One: Diminished sense of control as manifested through a shrinking sphere of influence in everyday life.

This theme discusses the shrinking sphere of influence in older people living with frailty. Participants often experienced a loss of control in their daily lives, and this section aims to provide context for their relationship with healthcare services.

A portion of the study sample consisting of older people living with frailty reported experiencing gradual changes and bodily deterioration, which resulted in a diminished sense of control over their daily activities. This loss of control often manifested in giving up essential tasks and depending on others, leading to feelings of existential vulnerability. Nonetheless, some older people living with frailty expressed that their cognitive and sensory abilities remained largely intact despite their physical decline, enabling them to preserve a sense of autonomy. This physiological duality inspired those who were physically limited yet mentally engaged to continue leveraging their cognitive abilities to maintain control over their lives, often with the support of healthcare professionals. I will elaborate on these aspects in the sections that follow.

5.2.1 Category 1: Gradual changes and deteriorations

The findings revealed that older people living with frailty undergo gradual age-related and health-related changes that contribute to gradual incapacitation. Most participants reported multiple health conditions, including Parkinson’s disease, cancer, and challenges with balance and hearing, which adversely affected their control over their bodies. Those who had previously led active lives often faced a decline in their physical abilities, evident through physical manifestations such as falls, tremors, and shifts in their pace of activity. In fact, a significant number of older people living with frailty cited falls as one of the primary reasons for their visits to the Day Hospital. These incidents frequently signalled a breakdown in physical capability, symbolising a perceived irreversible decline. This experience was captured in the words of Tom, an 80-year-old male participant, who illustrated the reality of his bodily deterioration.

> *"Well, that is what happens. Urr, I have fallen in the doorway, urm, but urm, well, there were, I have a spell of that, for about a month I will keep on falling two or three times a week, then I do not get any real trouble for about two or three months, do I? Urm, but it is gradually getting slightly worse all the time, the parameters in which I can work gets smaller and smaller all the time"* (Tom, Ln 98).

Some individuals recognised how fortunate they were to possess a reasonably healthy and energetic body until they experienced their first fall. Unfortunately, these falls caused harm to various body parts. In more severe instances, some individuals experienced a complete 'system breakdown,' leaving them unable to get out of bed or stand without risking collapse. Such deteriorations meant that older people living with frailty were sometimes unable to walk, creating a sense of anxiety and resignation, as explained by 76-year-old Arnold.

> *"…the first sign that I had, I was having a bath, and I could not get out of the bath, my legs collapsed. …the next day, I was coming out of the back door, and I collapsed again……. of course, I was rushed into hospital*

> *because all the time my system was breaking down. I got to the point where I could not walk anymore, I could not even get out of bed without collapsing. All my nerves were going, and I could not even eat. I honestly thought that I was going to die; I thought this is it. The strange thing about that is that you would think that you would feel panic and fear, I did not. I… felt… anxious but no panic, it was almost as if I was resigning myself to my fate, which, at that point, I did not know"* (Arnold, Ln 71).

As the bodily control of older people living with frailty diminished, they began to lose trust and confidence in their bodies, especially in unfamiliar situations or environments. This sense of unfamiliarity heightened feelings of pressure and tension, leading to a sense of existential threat. For instance, Peter, a 70-year-old male participant living with Parkinson's, expressed that he no longer felt confident in his ability to engage in his hobbies, such as attending a football game in a stadium, as he doubted whether his body could withstand the demands of such situations.

> *"….my walking was sufficient, and I could go to the hospital on the nearest buses from here. So, just walking those ten minutes, I can get a bus to most places. So going to work was easy because it was a safe space, I knew what I was doing and everything else. Because of the freezing, I cannot get into certain situations because I cannot trust the legs. Like a friend of mine invited me to go and see Bournemouth play football…… but I knew I could not…..there are certain manoeuvres, like if you are sitting in the stands and you need to get up to meet somebody gets by you, or you*

> *need to try and use your balance and get by people, I would not have any confidence in that. I am not saying I would fall; I am not saying anything would happen, but I do not have the confidence that I could do it properly and not create a problem. Because the more pressure that you have in a situation, the worse it becomes….. But at that initial point, if other people are dependent on your moving, if you are dependent on trying to balance between a row of seats, that is a bit too much for me, so I did not have the confidence to do that"* (Peter, Ln 486).

Many older people living with frailty reported that the COVID-19 pandemic significantly worsened their physical decline. They explained that the risks and restrictions associated with the pandemic led to a deterioration in their physical functioning, reversing any progress they had previously made. Public health guidelines permitted older people to engage in physical activities only once daily, disproportionately impacting them as they spent most of their time indoors. This shift was particularly challenging for those living alone, who felt isolated and neglected. These individuals conveyed a sense that life continued for everyone else while they felt forgotten and sidelined, as they were excluded from meaningful activities. The sense of isolation intensified the contrast between their previously perceived normalcy and their deteriorating condition, particularly regarding their physical abilities. Consequently, such individuals felt that their bodies and bodily functions had declined, leaving them feeling overwhelmed, as Peter elaborated further:

> *“But basically, I was still functioning quite normally; then came the lockdown. Now, the lockdown, as I look back, did not do me any favours because nobody could go out, and I could not go out, but my not going out… brought me lower. My… my routine, like many people, was that you just went for a walk once a day, and otherwise, you were indoors, or you went to the shops for goods for about – that was probably about several months. Unfortunately, that lifestyle of being indoors and not exercising as much, and not doing so much exaggerated, exasperated or sort of pro, increased the Parkinson’s. The tremors got worse, and the fact of not exercising, I had back problems, I had to go to a chiropractor for back problems once a week for about ten weeks……. So, the backs have always been a little bit of a problem since then”* (Peter, Ln 98).

The findings in category 1 illustrate the age and health-related changes contributing to gradual incapacitation in older people living with frailty. These changes often manifest as a loss of bodily control, with falls being a common experience. Such experiences can provoke anxiety and erode trust and confidence in their physical abilities. The impact of the COVID-19 pandemic exacerbated these challenges, as many older people living with frailty faced reduced opportunities for physical activity and experienced feelings of neglect and isolation. As a consequence, older people living with frailty often come to view their bodies as ineffective, struggling to perform even simple daily tasks that younger individuals might take for granted. This negative self-perception emphasises the critical importance of bodily autonomy and control in maintaining, especially, the ‘health’ and ‘resources’ domains of well-being in older people living with frailty. When these individuals grapple with physical limitations, their sense of self-worth and well-being can significantly diminish, affecting their overall control over everyday life.

5.2.2 Category 2: Loss of control over everyday life

Older people living with frailty shared their experiences of losing control over various aspects of their daily activities due to the gradual decline in their bodily functions, a consequence of ageing and different health conditions. Most participants reported that their health challenges dictated their everyday lives, primarily limiting their ability to engage in routine tasks. Similarly, many older people living with frailty felt physically restricted by their bodies, which hindered their ability to participate in enjoyable activities such as travelling, gardening, and sports. These pursuits often required additional effort and usually proved frustrating due to reliance on mobility aids and inconsistent support systems, as illustrated by Tom.

> *“And so, there is lots of aggravation in these things. Urm, it is not like here where you can get on and off. We went to Eastbourne on the train, and we had somebody to help me on and help me off at Southampton and to change the train again at Brighton, and then to Eastbourne, and off at Eastbourne and back again, we have had all that done. But I did end up one day with an African and an Indian carrying me off the train because there was no one to help me off the train. So, all three of us sort of like three old pals, well we looked as though we were half p*ssed. Then we*

> *find ways around these things, but you think to yourself, I cannot be bothered to go through all that. And that is half the trouble is the frustration of it"* (Tom, Ln 147).

Moreover, older people living with frailty who attempted various activities often expressed feelings of fatigue and overwhelm due to their diminished physical strength. Consequently, even everyday tasks such as cooking, doing laundry, and preparing to leave the house became considerably more time-consuming, disrupting their routines and leading to declining confidence, enthusiasm, and motivation to engage in these activities. Nicole, a 79-year-old female participant, provided further insight on this issue.

> *"Urm… it urm, physically, urm… we are now down to the stage where I cannot dress myself so easily. It takes me an hour to get ready to go out. Whereas before, I would come home from work and chon-chon-chon-chon-chon, and I would be gone, like that. That is another big difference. There is certainly a vast difference between me and the people at sixty you will be talking to. But equally, I do know eighty-year-olds who are like sixty-year-olds"* (Nicole, Ln 95).

Category 2 reveals a profound struggle experienced by many older people living with frailty in managing their daily lives, stemming from diminished physical health and mobility. As they navigate the ageing process coupled with chronic health challenges, a poignant transformation occurs--the gradual loss of physical independence. This transition compels them to confront the often painful reality that once-accessible activities may no longer be a part of their lives. Such realisations can evoke intense feelings of frustration and overwhelm, as even the most simple everyday tasks morph into time-consuming and daunting challenges. Yet, amidst these struggles, there is a persistent desire among many older people living with frailty to maintain their daily routines and engage in the activities that once brought them joy. This desire underscores a fundamental need for agency and connection to one’s pre-frailty identity. However, the constraints imposed by physical limitations frequently undermine these aspirations, compelling older people living with frailty to reluctantly abandon their cherished pursuits.

5.2.3 Category 3: Giving up everyday activities

As older people living with frailty experienced a decline in confidence and motivation to participate in daily activities, their perspective about what they could achieve also shifted, leading many to abandon various activities. Most participants shared that they had to relinquish engaging in hobbies such as gardening, walking, shopping, driving, travelling, and other outdoor activities that had previously been integral to their lives. Common expressions among these individuals included phrases like ‘I cannot,’ ‘I am unable,’ ‘I no longer,’ or ‘give up,’ which encapsulated their current levels of involvement in these everyday activities. Notably, walking and gardening emerged as delightful activities that many had to forgo, resulting in feelings of frustration. This sentiment was expressed by Frank, an 82-year-old male participant.

> *“Urr… well, I have been retired quite a long time, but for the last twenty years, I have been taking groups out to urm walking in the New Forest,*

> *and I give lectures on the history of the forest as we go around. Urm, unfortunately, I can no longer do that urr… because I cannot go uphill, my lungs will not, are not functioning well. …..when I got the urm… pulmonary hypertension, and the right heart failure, my lungs were not working so well, and I cannot now go up hills….. Well, I mean obviously I miss it because I have been taking walks in the forest urm, for over twenty years. ..Urm having the….coast urr I used to take all day walks and I mean I take up to, well I was taking up to forty people at a time. And urr, I would sort of give lectures on urm… on aspects of the forest like smuggling, witchcraft urm, the World War Two history of the forest. And we would visit various sights, and I would normally give a lecture while I am there….and we go up onto the moors and up onto the ridges urr… basically for the views and also urm… to see the sort of different wild animals that are present in the forest. So obviously I cannot walk in the forest anymore, so I miss that…because I love the forest. I virtually know the whole of the New Forest is like a map in my head''* (Frank, Ln 43).

Such frustrations were further exacerbated by the fact that even the professionals they hired, such as gardeners, fell short of their expectations. Nicole expressed her concerns, stating that her gardener was *'not a good gardener. Very willing and helpful, but not a good gardener'* (Ln 527). This struggle with performing certain tasks fostered a sense of incompleteness and led to feelings of disappointment and guilt. Even simple tasks, like lifting a kettle, could become burdensome, contributing to the overall frustration, as noted by Alex, an 87-year-old participant living with Parkinson’s.

> *“How do I feel? Well, how does everyone else feel when you cannot do something? If it is something dead easy, I mean when you lift the kettle you have got to support your hand to lift the kettle, isn’t it……..frustrated but you keep on”* (Alex, Ln 148).

The findings in category 3 highlight that older people living with frailty often experience a decline in confidence and motivation to participate in daily activities as they face age and health-related limitations. The shift in perspective regarding what they can and cannot do can result in relinquishing hobbies and pursuits previously integral to their lifestyles. This profound existential transformation means that the lived experience of frailty becomes central to their identity, as activities that once provided a sense of agency and purpose are now fraught with challenges. As older people living with frailty navigate this changing reality, they may grapple with a diminished sense of self, where the continuous negotiation between desire and capability fosters a deep sense of loss not only of hobbies but also of their previous selves. Similarly, the waning motivation and perception of unfulfillment may also give rise to feelings of frustration, disappointment, and guilt. This emotional landscape is marked by an internal conflict, where the intrinsic value of their past activities clashes with the stark reality of their current limitations. As a result, older people living with frailty may accept that they cannot accomplish much without relying on external assistance.

5.2.4 Category 4: Relying on others

Older people living with frailty often experienced a significant loss of independence when they were unable to engage in daily activities. This loss often led to an overreliance on family members or professional carers, resulting in feelings of frustration. For instance, older people living with frailty felt frustrated when they had to adjust their routines to fit into their informal caregivers' schedules to complete everyday tasks. Such experiences resulted in a diminished sense of autonomy, as they sometimes felt obligated to participate in activities with others, even when they would prefer to complete these tasks independently. This was the opinion expressed by Julian, an 86-year-old female participant who was widowed and lived alone.

> *"………about half past twelve, someone will be coming to pick me up. Yeah, but I cannot go out on my own, I am not able. I hate having to rely on other people all the time. I mean, if I want to go to the crematorium to take some flowers over for my husband,…. I have to rely on Paul (son) or one of the kids to take me over, you know, to see him and have a chat with him and tell him what is going on……"* (Julian, Ln 400).

Furthermore, the loss of independence and the need to depend on others for certain tasks often led to a resigned loss of both privacy and confidence. One example is when an older person living with frailty struggled to dress appropriately and required caregivers to assist them in their homes. On occasion, they found themselves undressed in front of these caregivers, which they perceived as a breach of their privacy. As Julian elaborated, this loss of control over their lives further undermined their confidence, leaving them feeling incapable of managing tasks independently.

> *"I was trying to describe it in… terms.… you are reliant on somebody else all the time, and I mean, you lose… all confidence as far as urm people just walking in and seeing you undressed and things like that. Urm, you just have to accept it because there is nothing you can do about it. You know you just got to accept that you are not as good as you were"* (Julian, Ln 231).

Category 4 reveals that older people living with frailty often depend on family members or professional caregivers to participate in everyday activities, which can lead to frustration and a reduced sense of autonomy. Although relying on the support of caregivers is not entirely a negative experience, some older people living with frailty may feel frustrated when such dependence affects their autonomy, which can result in a loss of confidence in their ability to perform tasks independently. This experience can be interpreted as a significant shift in how older people living with frailty engage in their lifeworld. The loss of independence over daily routines and reliance on others is not just a temporary inconvenience but a profound existential crisis that makes them rethink who they are, what they can do, and where they fit in the world. The ongoing adjustment to being dependent, coupled with the struggle over their altered identity and sense of autonomy, can lead to feelings of existential vulnerability.

5.2.5 Category 5: Existential vulnerabilities

The loss of control was frequently marked by persistent disruptions to the health and daily lives of older people living with frailty, leading to existential vulnerabilities. These changes often left many older people living with frailty feeling despondent as they grappled with accepting their circumstances, frequently culminating in a sense of resignation. This experience was particularly pronounced following an abrupt diagnosis of life-altering illnesses such as Parkinson’s, which brought significant distress to many older people living with frailty. This sentiment was echoed by Lyndsey, a 73-year-old woman who lived with Parkinson’s.

> *“……..I feel a bit miserable and sorry for myself sometimes because I know I am going somewhere and I am not coming back….”* (Lyndsey, Ln 285).

Many formerly active and independent individuals reported feeling as though a part of their identity had been taken from them, expressing a sense of being *‘cheated, physically’* (Brian, Ln 207). This sentiment stemmed from physical limitations that hindered their ability to engage in activities they once enjoyed, such as gardening or walking long distances. Similarly, some older people living with frailty voiced concerns over minor issues, like the availability of seating when they arrived at the hospital. This anxiety highlights why certain participants felt apprehensive about visiting unfamiliar places, a point elaborated upon by Kate, a 76-year-old female participant.

> *"I think the worst thing is not being very happy going out, I am all right if I can urm… frog in my throat. I am all right if I… know where I am going, and I have been there before. But now I need to know that when I get there, there is somewhere I can sit down. Urm… just silly little things bother me, like going for my next vaccine. I am not going to my surgery anymore because it was a bit of a nightmare there because, of course, my sister cannot take me there. I will not ask a friend to take me, so I have chosen to go to XXXX Hospital because that is the main unit now, and I am thinking, ah, I hope they have got some volunteers there that will walk with me, you know. So, I am worried about that already. I never used to; I have become quite anxious about going to places I don't know. And I don't mind going, I go to a knitting, knitting class, I do not mind going to that, I do not mind going out for coffee with my friends, go out for a meal. Well, it (maintaining familiarity) seems to have become very important, but I had not realised it was until you said it was. Yeah, I think it has become quite important, yeah"* (Kate, Ln 556).

Additionally, many older people living with frailty encountered physical limitations that impeded their ability to walk independently. As a result, they often relied on mobility aids such as walking sticks to navigate their physical challenges. Furthermore, those with Parkinson's experienced concentration difficulties, which exacerbated their tremors. These age-related physical changes led to feelings of discomfort and social embarrassment as individuals grappled with their physical losses and a reluctance to be perceived or identified as old. Despite the visible signs of ageing, some older people living with frailty still felt young on the inside, leading them to decline certain services aimed at older populations. This created an identity challenge for them, as they resisted being regarded or treated as old, as highlighted by Lyndsey.

> *"No, I do not want to do that at the moment (joining the Parkinson's Society at the Day Hospital). Well, I do not want to be, not at the moment. I do not think I am an old lady enough to go, sort of thing. So, I might like it if I feel I am ready for it, but I am not really ready for it at the moment"* (Lyndsey, Ln 904).

Many older people living with frailty expressed that their lives had become increasingly unpredictable, particularly concerning their health trajectories. As Emily noted, *'nobody could predict how bad the disease would get and how quickly'* (Ln 404), leading to additional uncertainties in their lives. This lack of predictability fostered feelings of anxiety, especially among those living with conditions like Parkinson's disease. These individuals often struggled with concerns about their health, future medications, and overall well-being. Life felt *'a bit of a lottery'* (Emily, Ln 405), which contributed to a general sense of anxiety and uncertainty regarding the future. This apprehension may clarify why many participants struggled to formulate future plans. Consequently, the absence of predictability and continuity caused older people living with frailty to focus more intently on the present, resulting in a disconnection from their future. This perspective was particularly articulated by Emily, a 79-year-old woman who lived with Parkinson's disease.

> *"..nobody can say, well, this is how you feel today, tomorrow you will feel like that, and the next day, you will feel like something else. Yes, nobody can predict how bad the disease is going to get and how quickly. Urm… it is a bit of a lottery in that respect, and I expect that that applies to a lot of other diseases as well. So, I do not think there is any answer to… urm… how soon will I reach the ceiling of the medication that I can take"* (Emily, Ln 398).

Similarly, some older people living with frailty reported a sense of losing control over their daily routines, which led to heightened anxiety. For example, Nicole, who lived with Parkinson's disease, described how the condition impacted her sleeping patterns. She found it increasingly difficult to sleep at night and had to rely on sleeping pills. Additionally, she faced challenges with fluctuating sleep patterns due to fatigue. This loss of control over her usual sleep schedule was a source of concern for her and others in similar situations, as they worried that life was no longer what it used to be. It is, therefore, evident that the erosion of regular routines can adversely affect the well-being of older people, particularly those in poor health.

> *"But gradually, it (Parkinson's) has been digging away, and I am gradually going down and down and down. And I am hoping at this level now, urm, because it does seem to be a recognisable level, I am going to have another ten years of five years like this. But it affects me because I cannot sleep very well. I woke up at five o'clock this morning, and I shall go to bed tonight and hopefully go to sleep. I do take a tablet for going to sleep; that*

> *is a pain because I get tired, and… you cannot do things well when you are tired. And I always used to be able to manage six hours of sleep, you know. I did not need a lot of sleep, but now I think I do not know, now everything is all haywire. It is not like it used to be. Which I suppose is worrying because things are not as they used to be”* (Nicole, Ln 232).

As older people living with frailty faced personal struggles, they also had to navigate a world that often failed to understand the constant disruptions in their lives. Many found it challenging to communicate their feelings and the difficulties they encountered to others. This challenge was partly due to the perception that the people they interacted with sometimes lacked empathy for their concerns. Consequently, some older people living with frailty often hesitated to voice their worries, opting instead to feign normalcy, even when they were not feeling their best.

> *“I want to do these things [everyday activities], but I cannot.… At Christmas, I do not know what daughter I am going to, I have got one in Dubai and one in Germany. And I have just read that the German health situation is not so good there is a lot of COVID around. So, I do not know what I am going to do, and I may yet be forced to stay here, and I shall say, oh, that is all right, I do not mind, but it will upset me…..Whereas if I was even seventy-five, I would have said a rude word and gone. Now, if I go on a plane, I have to think when I get to Dubai, I have to have someone pushing me in a wheelchair because I cannot walk that far, and I do not like it because people look at me and think, oh what is wrong with her, she*

> *does not look as if there is anything wrong with her, and it is very frustrating, and you know I scream. But you know you are asking me normally, I would put on a good show, and if I was going anywhere like that, oh, I am fine, you know, do not worry, I will be all right, but of course, you are not, and that is where the lack of control over the situation comes in. Because you cannot suddenly leap out of your wheelchair and say, do not you look at me like that, you know (laughs)"* (Nicole, Ln 106).

The findings under category 5 describe the significant challenges older people living with frailty face as they lose control over their health and daily lives, impacting their self-perception and social interactions. Participants expressed anxiety about familiar environments now filled with uncertainty, highlighting a loss of agency where even simple tasks can cause distress. For individuals like Lyndsey and Kate, illnesses such as Parkinson's not only lead to physical decline but also disrupt their sense of identity, transforming their once-independent bodies into sources of existential anxiety. Mobility aids, while intended to empower, can also evoke embarrassment and deepen feelings of vulnerability, perpetuating negative emotions and affecting overall well-being. Similarly, the shared sentiment of feeling 'cheated, physically,' suggests a dissonance between the expectations of ageing and the reality older people living with frailty face, compelling them to negotiate their identities in a society that often equates ageing with decline. Furthermore, Emily's view of health uncertainty reflects existential fears of mortality and fragility prevalent in older people living with frailty, which often lead to a shift in priorities towards the present rather than future goals.

Ultimately, their journey involves continuous negotiation with their changing realities, fostering a complex perception of self in relation to their body, environment, time and others. These challenges illustrate the intricate connections between lifeworld dimensions of embodiment, spatiality, temporality, intersubjectivity, and mood, shaping the being in the world of older people living with frailty. Consequently, the experience of losing control over health and everyday lives in older people living with frailty is marked by continuous negotiation with their shifting physiological reality, which can sometimes create a dual lens through which they perceive themselves.

5.2.6 Category 6: The dual perspective of self

Many older people living with frailty perceived themselves in two distinct aspects: the body and the mind. While most had experienced a decline in their physical abilities due to bodily deterioration, they felt that their cognitive functions remained intact. Some individuals expressed a sense of detachment between their mind and body, highlighting the challenges their bodies faced in executing the commands from their brains. This perspective was illustrated by Hughes, an 82-year-old male participant who lived with Parkinson’s disease.

> *“I have still got the old brain, I can still do… from a mental point of view, I am pretty sound. It is only from a physical point of view that I… I have a problem, I cannot walk around, I have just come to accept it. It does not worry me”* (Hughes, Ln 240).

In discussing the changes he had encountered throughout his life, Hughes elaborated that while his body was weak, his spirit was strong, highlighting a sense of dualism among older people living with frailty. Despite their physical limitations, many older people living with frailty found fulfilment in utilising their mental abilities to engage in activities such as reading, which enabled them to compensate for their physical challenges.

> *"I have quite a lot of control, the only thing that, from a physical point, I do not have, physically very little control, but mentally, total control. I still remember, you know, we are still doing things, provided someone actually does the physical bit for me, from the mental point of view, yeah, we are, I think we are in control"* (Hughes, Ln 412).

Some older people living with frailty found that technology, such as computers, iPads, and smartphones, enhanced their cognitive abilities. This technological engagement enabled them to manage various daily tasks despite their physical limitations. As a result of this duality, they often cultivated a positive outlook on life, recognising that their circumstances could be worse. By acknowledging their functioning faculties, they could balance the positives and negatives of their situation.

Category 6 highlights the complex relationship between the physical and cognitive aspects of older people living with frailty. Many experience dualism, feeling a separation between their declining bodies and intact minds. For example, Hughes acknowledges his mental strength while accepting his physical limitations, showcasing resilience in adapting to his situation. This category not only addresses the challenges faced by this population group but also emphasises their enduring spirit despite physical decline. Hughes’ experiences reflect a conflict where a ‘willing spirit’ is often at odds with bodily capabilities, yet this acceptance leads to a sense of peace. Activities like reading allow older people living with frailty to reclaim agency and well-being, enabling them to engage mentally. Additionally, technology is crucial in bridging the gap between mind and body, empowering older people living with frailty to maintain autonomy and manage daily tasks. This positive adaptation illustrates a balance where older people living with frailty can appreciate their cognitive strengths while recognising physical limitations, enabling them to engage in meaningful activities despite their challenges.

5.2.7 Category 7: Striving to do something within the boundaries of physical limitations

The findings highlight that, despite experiencing physical and age-related limitations, most older people living with frailty made concerted efforts to remain active and maintain control over their lives. They successfully carried out daily routines at home, engaged in sports, travelled, and participated in voluntary and community activities, though often at a slower pace and reduced frequency. These individuals assessed their current activities in light of their age and declining health, and they expressed satisfaction with their ability to navigate the challenges of ageing and frailty, particularly in relation to bodily limitations. The capacity to perform everyday tasks contributed to their sense of independence and purpose, which positively impacted their overall well-being. Mark, an 81-year-old male participant who lived with his wife, illustrated this perspective.

> *"Well, I suppose that urr as you get older, you expect to do less and perhaps not able to do some things. Okay, I cannot lift heavy things, urm, but urm… urr, we do not have too many heavy things around the apartment. So, urm, so yeah, I can, I can do most things. And urm, it makes me feel satisfied that I have still got the function in life, you know that I am not just sitting waiting to die, something like that, as some people when they get they just almost collapse and do not do anything. And that makes me urm… I am happy and pleased that I can still do what I want to do. Urm, but I know, I know my limitations"* (Mark, Ln 193).

The findings under category 7 indicate that many older people living with frailty actively strive to maintain a fulfilling lifestyle despite facing physical and age-related challenges. They manage daily tasks and participate in community activities at a more measured pace. In the context of ageing and declining health, this approach to handling tasks is often associated with a sense of resilience and satisfaction. A significant aspect of their experience is the independence and sense of purpose derived from accomplishing everyday activities, ultimately enhancing their well-being. Mark exemplifies this resilience and independence by recognising his physical limitations while expressing contentment in managing most tasks at home. His perspective reflects a broader desire among older people living with frailty to maintain their functionality and adopt a proactive approach to life rather than passively accepting the impact of frailty on their sense of control and well-being.

Theme One discussed the challenges faced by older people living with frailty, emphasising the complex relationship between age-related changes and their effects on health and daily life. As physical health and mobility decline, many experience a loss of confidence and a heightened risk of falls, which can lead to anxiety and isolation--issues exacerbated by the COVID-19 pandemic. This decline often results in a negative self-image, affecting their ability to perform everyday tasks and diminishing their bodily autonomy. Furthermore, older people living with frailty may experience a decline in motivation and confidence, leading to the abandonment of hobbies and a transformation in their sense of self. Dependence on caregivers can complicate their experience, triggering a crisis of identity and existential vulnerability. The loss of control over health and daily activities also creates anxiety and impacts their self-perception and social interactions. Such challenges highlight a multifaceted struggle faced by older people living with frailty as they navigate ageing, identity, and dependence. Despite facing significant challenges, many older people living with frailty strive to stay active and maintain a sense of purpose. They engage in daily routines and seek healthcare services to help manage their abilities. Accessing services like rehabilitation is essential for them to preserve their capacity to manage their lives.

5.3 Theme Two: Perceived sphere of influence affected by healthcare experience

The current theme introduces the experience of healthcare services among older people living with frailty and how this affects their sense of control and well-being over healthcare services.

In this study, all older people living with frailty had interacted with the healthcare system at some point for various reasons. Most of them expressed that healthcare professionals were instrumental in supporting them to maintain control over their health and daily lives. They highlighted six factors that contributed to control over their healthcare services, which are a) easy access to healthcare services, b) a welcoming atmosphere in healthcare service organisations, c) trusting professional relationships, d) information sharing, e) healthcare choices, and f) decision making. In the following section, I will detail each of these factors.

5.3.1 Category 1: Access to healthcare services

Accessing the healthcare system can have both positive and negative effects on the sense of control and well-being among older people living with frailty. While these experiences may seem opposite, they are not mutually exclusive and can coexist. The degree of ease in accessing healthcare service organisations and professionals plays a crucial role in determining whether the experience is perceived as positive or negative.

5.3.1.1 Positive experiences

Access to healthcare services is a critical component of control over healthcare, especially for older people living with frailty. These individuals often grapple with comorbidities that require them to take multiple medicines and interface with several healthcare professionals, making easy access to healthcare providers and organisations--such as hospitals and general practitioners (GPs)--essential. GPs are the primary contact points within the healthcare system, addressing various health concerns and facilitating medical referrals. They are instrumental in referring older people living with frailty to specialised care services, such as physiotherapy offered at Day Hospitals. In an optimally functioning system, these referrals are typically accompanied by comprehensive information sharing, often in the form of patient notes. Such documentation was crucial for enhancing care coordination among GPs and ancillary healthcare service organisations. This perspective was articulated by Arnold.

> *"….. And it all happened on top of each other. I mean, I was obviously, you know, I was rushed to hospital, basically, through the GP, urm now that is always a very good system, if you are ill, urm get your GP because the GP can pick up the phone, ring ahead to the hospital and refer you, that is the word, they can refer you. And that gets you in quickly. Urr and say, you can get the medical attention"* (Arnold, Ln 274).

Furthermore, older people living with frailty emphasised the importance of sufficient consultation time with their GPs to discuss healthcare issues and broader life circumstances. Direct engagement with healthcare professionals, especially face-to-face interactions, significantly enhanced their care experiences. Despite occasional delays, some older people living with frailty reported generally easy access to their healthcare providers, which facilitated their ability to discuss health concerns, including pain management, and to connect with additional healthcare services. This accessibility was particularly reassuring, as it fostered confidence in older people living with frailty in their ability to manage their health with appropriate support from their GPs.

> *"….you have got to be patient, because of course we have got to wait because everything is so long now. Probably very important at the moment. I have been waiting since… the first of April, I suppose, for my rheumatology appointment, and I was told it would be no later than the first of April, and I have not heard a word yet, and I just think, ah I cannot be bothered to phone them, you know. I have got a good GP – if I did not have a good GP, what would I be doing? I do not know"* (Kate, Ln 790).

At the Day Hospital, many older people living with frailty received rehabilitation services from various professionals, including nurses, physiotherapists, and therapy assistants. These services primarily focused on physiotherapy and involved a series of gym exercises conducted over several appointments. Healthcare professionals at the Day Hospital also provided patients with booklets featuring various exercises and detailed instructions for home practice. These exercise sessions proved particularly beneficial for older people living with frailty in managing health conditions such as Parkinson's disease and issues related to physical balance. Additionally, some sessions--especially group activities like Parkinson's classes--created opportunities for older people living with frailty to connect and support one another, which was deemed valuable for enhancing social interaction and mental stimulation. Lynnet, an 82-year-old female participant, emphasised this important aspect.

> *“Oh no, there is always someone urm… there is one of the hospital staff running the classes, I think they are physiotherapists. Oh yeah, if we did not want to do something, we could have said, I do not want to do this. Or I cannot do this…....well, they (clinicians) would say, you know, just give it a little try, and if you cannot, you know, they were all really good like that. Because we had, I think it was *name* who was there all the time, and then she was away because her daughter had COVID or her daughter’s school had COVID, and that day we had… I think a trainee and a trained staff member, so we did see three staff members from the physiotherapy side while we were there in the six weeks. So that was quite good, and they were all really positive and nice. And would explain what we were doing, and why we were doing it”* (Lynnet, Ln 250).

Many older people living with frailty expressed that the rehabilitation they received at the Day Hospital helped them remain agile and maintain control over their health. Additionally, care service organisations were crucial in offering practical support that facilitated easier access to healthcare services. For instance, some older people living with frailty reported receiving assistance with hospital transportation, while certain healthcare professionals aided them in scheduling appointments with various healthcare service providers and in monitoring their health after discharge.

> *“And the doctor arranged for me to go in hospital transport because obviously, I cannot see to drive. And you could not ask anyone to take you because it was the beginning of lockdown. So, they could not go to the hospital, they could not go to the shops because there was nowhere to go. Yeah, so I went by [hospital] transport, which was fantastic”* (Lynnet, Ln 64).

Similarly, some older people living with frailty were provided with assistive devices, including wheelchairs and specially designed footwear, to enhance their mobility. This support facilitated their physical movement and fostered a greater sense of confidence in their interactions with the healthcare system.

The results indicate that access to healthcare services, particularly GPs, is crucial for effective healthcare management among older people living with frailty. GPs are vital in the healthcare system as the primary contact point for health-related issues and referrals. It is crucial for older people living with frailty to have sufficient time to discuss their health and personal matters with their GPs. Easy access to healthcare professionals, especially through in-person visits, significantly improves care experiences. Furthermore, rehabilitation services available at Day Hospitals are beneficial for older people living with frailty by promoting control over their health. Similarly, group exercise classes also assist these individuals by encouraging social connections or togetherness and offering mental engagement.

While some older people living with frailty reported largely positive experiences with accessing healthcare services, many participants had encountered negative experiences, which I will explore in the following section.

5.3.1.2 Negative experiences

The study identified several challenges faced by older people living with frailty when it comes to accessing healthcare services, which negatively impacts their sense of control over their healthcare. Although participants expressed a desire for positive experiences, many of those interviewed reported difficulties in reaching healthcare providers, particularly GPs, to address their health concerns. A few older people living with frailty noted that accessing care service organisations, such as exercise centres, was financially burdensome due to high public transport fares. Additionally, some participants, especially those living with Parkinson's disease, felt there was a shortage of experts available to explain the causes and potential progression of their condition, leaving their health status feeling unpredictable. Furthermore, those who could access healthcare organisations often faced long wait times to see professionals and utilise services such as ambulances. They had to navigate a rigid system that offered little to no flexibility, generating further frustration.

> *"I think the… problem is getting it through to the GP that you really need some sort of pain relief. Urm, frequent pain relief comes at a price, and that can cause other problems like constipation, for example. And that is critical. In my case now, I have been constipated now far too many times. I am taking urr laxatives, but painkillers cause constipation, and that is looking to be very embarrassing. You cannot go out without fear that you*

> *might have an accident, or you know, next time you go to the toilet, you cannot pass anything because you are bound up. Urm… [unable to discuss this with the GP] because of the difficulty getting an appointment, I have to wait two weeks to get a phone conversation and being an impatient fella, I find that irritating. It is the frustration of actually [not] being able to speak to them. I have only seen him once since I took up the doctor here"* (Brian, Ln 228).

The Day Hospital staff echoed the frustrations regarding access to healthcare service organisations, noting that it can be particularly challenging to reach out to fellow professionals, especially GPs, to address concerns related to older people living with frailty. These professionals reported difficulties in contacting their colleagues, often due to systemic communication barriers and a shortage of healthcare workers. As Stella, a nursing staff, pointed out, the lack of easy access to GPs adversely affected care coordination, particularly in terms of information exchange.

> *"I have the same problems as a professional. I cannot always get through to the GPs. I am put in a queue, or they just hang up because there is no queue, there are too many people in the queue. Urm, only last week, I had a patient that I needed to talk to their GP because I felt they might need some antibiotics…….. So urm…over the course of the day, I phoned their GP four times, and I could not get through. I was not even on, you know, in a queue. So, I went on the website because I can, but my patients cannot. But I went onto the website and found an email, a receptionist*

> *email, and I am not really sure how I managed to find that actually, probably persistent. Urm so wrote an email saying, dear duty doctor, blah, blah patient's details, etc, I got an email back saying, 'Do not use this email for clinical purposes, please use our telephone number' okay 'or do an e-consult'. Well, I cannot do an e-consult because I am not a patient. Only the patient can do that, 'or phone 111 or 999'. So, that particular surgery was not open to me as a health professional or to my patients. Many patients have told me how frustrated they are; being unable to talk to your GP is frustrating. On the other side, I understand that more patients need more services with fewer health professionals to provide those services. And unfortunately, that pressure creates inward pressure in all professionals. Because, and then they start leaving, so then there is less of us, even less of us needing to do more work. And it is a downward spiral if we are not careful"* (Stella, Ln 324).

Older people living with frailty, along with the Day Hospital staff, reported that the COVID-19 pandemic further limited access to healthcare services. The pandemic compelled many healthcare professionals to move to larger hospitals, leaving Day Hospitals with fewer staff to attend to the needs of older people living with frailty. Additionally, the pandemic disrupted healthcare processes, further restricting access to various services. Consequently, many older people living with frailty could not engage in health activities, such as rehabilitation exercises at the Day Hospital, as they had previously. The exercise sessions at the Day Hospital provided essential outdoor activity for these individuals, but the restrictions imposed by the pandemic severely hindered these opportunities.

The Day hospital staff also observed that the pandemic significantly impacted how they supported older people living with frailty. The number of sessions with clients was limited to just four, given the reduced number of clients seen at the Day Hospital. This restriction complicated the management of frailty, as many clients were seen in their homes through outreach services. While this approach had some positive aspects, healthcare professionals felt it hindered multi-disciplinary collaboration and diminished their control over the care process. Meeting clients outside the hospital meant they could not fully utilise the various specialists available. Additionally, certain support equipment could only be accessed and utilised within the hospital setting, making it challenging for healthcare professionals to provide adequate support to older people living with frailty outside of the Day Hospital.

Therefore, the challenges in accessing healthcare professionals significantly negatively impacted the quality of care for older people living with frailty. Some of them expressed that, due to the difficulties in seeing healthcare providers, they felt compelled to refrain from criticising the services they received or questioning the professionals' authority. As Kate noted, *'you feel so grateful that you're getting some help and some treatment that you've got to do what they say and not challenge them'* (Ln 304). Furthermore, these access challenges resulted in delays in starting treatment and created obstacles in managing health issues, particularly pain, as highlighted by Brian, who struggled with shoulder pain.

> *"The treatment I have had from the hospital has been less than satisfactory. The x-ray that was taken at XXXX Hospital revealed that it was broken [spine], but I was told there was nothing wrong with it. It was not until some weeks or months later that I had a phone call from them explaining that the T12 was fractured. I have had no treatment for the pain, urm, and I have had difficulty getting through to the GP practice"* (Brian, Ln 28).

The study highlights several challenges that older people living with frailty face in accessing healthcare services. Key issues include difficulties in reaching healthcare providers, particularly GPs, to discuss their health concerns, as well as long waiting times and insufficient information regarding the causes and potential progression of conditions such as Parkinson's disease. Furthermore, the study indicates that both older people living with frailty and healthcare professionals experience communication barriers, which hinder care coordination and the exchange of information. The COVID-19 pandemic exacerbated limited access to healthcare services and disrupted healthcare processes, negatively impacting essential health activities such as rehabilitation exercises for older people living with frailty.

In summary, category 1 highlights that older people living with frailty have mixed experiences accessing healthcare services. Positive aspects include access to GPs, who provide practical and emotional support, which enhances reassurance. In addition, rehabilitation services at the Day Hospital promote physical health and social connection, emphasising that healing involves emotional and social aspects. These experiences reflect a deep connection between people living with frailty and their healthcare journey, allowing them to define their identities beyond the frailty.

However, accessibility challenges persist, particularly regarding limited interactions with GPs and other specialists, which can lead to feelings of helplessness, especially for those with conditions like Parkinson’s Disease. The COVID-19 pandemic further hindered access to healthcare services and communication, resulting in distress and anxiety. In this context, accessibility transcends mere practical considerations and enters the existential realm, focusing on deeper human needs for connection and recognition.

Overall, the healthcare experiences of older people living with frailty highlight the subjective nature of a sense of control and well-being. Positive accessibility aspects coexist with frustrations like long wait times and bureaucratic barriers. Genuine engagement with healthcare professionals enhanced their sense of identity and autonomy, while communal activities at Day Hospitals fostered a feeling of belonging. Therefore, older people living with frailty seek not only practical healthcare assistance but also an acknowledgement of their experiences. This perspective underscores that access to healthcare services is influenced by both practical and emotional aspects, including the importance of feeling valued and welcomed.

5.3.2 Category 2: Welcoming atmosphere

Most of the older people living with frailty expressed high satisfaction with the quality of the healthcare services, attributing this largely to the welcoming atmosphere fostered by certain healthcare organisations. The significance of a warm reception was underscored, with emphasis on the need for patients to be informed about procedural expectations upon arrival. Notably, the Day Hospital was frequently referenced as an exemplar of a supportive environment, wherein patients reported feeling both valued and attended to. This nurturing atmosphere was manifested through informal exchanges regarding daily life and through empathetic and kind gestures from healthcare professionals, such as offering a cup of tea. Such interactions not only enhanced the patient experience but also contributed to a sense of belonging and care within the clinical setting.

> *"Everybody right from walking in the door urm, there is a nice atmosphere in there [Day Hospital], there's a lot so of people urm… moving around, doing whatever it is they are doing, the receptionist, when I went in, urm… asked my name and the time of my appointment, and directed me to the waiting area and urm, somebody would be along to see me in a few moments. I think she was a physiotherapist, the one who was looking after me originally. Urm… and then on further occasions, I have been and seen by XXXX there. And again, she is very welcoming urm, she makes you feel comfortable, I can talk to her about any of my problems, and she is very understanding. She comes up with answers…….anything I have problems with, she will come up with suggestions…. of how we can get around"* (Emily, Ln 76).

The healthcare professionals at the Day Hospital highlighted the significance of fostering a comfortable and respectful environment to enhance the sense of control for older people living with frailty. This approach involved being flexible and allowing patients to participate in care meetings with family members if they wished. It also emphasised giving them ample time, especially during home visits. Additionally, creating a welcoming atmosphere included acknowledging the power imbalances present in caregiving relationships and actively working to minimise them, thereby granting older people living with frailty greater control over their healthcare decisions. Justine, a therapy staff, elaborated on this perspective.

> *“Okay, so urm, when you initially meet [the client] and introduce yourself, you explain who you are, why you are there, and you ask them what they like to be called because some do not like to be called by their first name, or they have got another name they like to be called. Urm, because you are in somebody’s home, I always ask whether I should take my shoes off. You are a guest in their home, so just making them feel comfortable and more in control: where would you like to talk, urm, where would you like me to sit? So, giving them that control, not kind of dominating, just being this two-way thing, but not making them feel uncomfortable, and that initial bit is so important just for reassurance really, and make them feel comfortable talking to you…. But then, as I said, it is giving them time to talk and being aware of time. You have to be aware of time because many of them just want to talk and talk because they are on their own. And that is actually a goal in itself; it is the isolation goal. But it is having a bit of a balance with that. But just treating them, you know, not like you are this*

> *white-coated clinician urm treating them like, making them feel comfortable throughout. And respect their wishes, yeah''* (Justine, Ln 246).

Older people living with frailty conveyed similar feelings about their care. They found the health professionals to be reassuring, comforting, and supportive. These individuals felt listened to and well cared for by the Day Hospital staff, who demonstrated expertise and treated them as unique individuals. This was especially evident in the extra attention and interest that nurses and physiotherapists devoted to providing personalised care. Such an approach helped maintain a sense of identity in older people living with frailty and significantly enhanced their healthcare experience. Consequently, the welcoming attitude of the healthcare professionals proved invaluable in fostering hope and a sense of purpose for older people living with frailty during times of disruption in their lifeworld. This perspective was particularly emphasised by Barbra, an 85-year-old female participant.

> *''Oh, wonderful, it (Day Hospital care) was enlightening to me the care from the nurses and various other people, it was just uplifting, you know- You felt important, and you felt loved almost. They looked at you as a person, you know, and everyone was an individual, and I think there were eight in our class, and it was very simple, you have seen the exercises that they do and one of them, I will never forget, and I tell it to everybody, is to avoid falling, that was one of the reasons I was sent to this group because I had had one bad fall, did not break anything, you know, wasn't a bad fall, but that was the reason the doctor set it going, and because so many of the*

> *other people on the course, there were about ten of us, were a lot more… incapable than I was, in fact, urr, I think it was the physio who used to say to me, you know because we had walking practices sort of thing, she said, 'you have got such good posture, were you a ballet dancer?' You know. And these sort of give you belief in yourself as an individual"* (Barbra, Ln 432).

The findings under category 2 highlight that fostering a welcoming and respectful atmosphere in healthcare services is vital for enriching the healthcare experiences of older people living with frailty. This practice goes beyond mere comfort and taps into the deeper psychological and emotional layers of how these individuals perceive their healthcare encounters. Older people living with frailty reported feeling genuinely satisfied when they entered healthcare environments that prioritised their comfort and clarified what to expect. Healthcare professionals, in reflecting on their practice, underscored the importance of cultivating a comfortable and respectful caring atmosphere. This practice not only enhances the feelings of control in older people living with frailty but also affirms their individuality and personal journeys amidst the challenges of frailty. Simple practices, such as actively involving patients in care meetings and allotting ample time during home visits, resonate deeply with the yearning for a sense of control in healthcare. Furthermore, older people with living frailty expressed gratitude for the reassuring, comforting, and supportive demeanour of healthcare providers, which preserved their sense of personhood and dignity. This dynamic is crucial as it highlights the significance of human connection and empathy in healthcare, profoundly impacting their overall sense of control and well-being. A hospitable environment thus becomes more than a backdrop--it is pivotal in enabling older people living with frailty to seek healthcare services with a renewed sense of hope and meaning. Furthermore, this nurturing atmosphere lays a foundation for building trusting and caring relationships between older people with living frailty and their healthcare providers.

5.3.3 Category 3: Trusting relationships with healthcare professionals

Most older people living with frailty held a positive view of healthcare professionals. They regarded them as diligent and supportive, feeling at ease in their interactions as everything seemed to align seamlessly. This positive perception stemmed from the strong relationships they developed with these professionals. Two key elements were essential in fostering these good and trusting relationships: a welcoming and friendly attitude, as previously emphasised, and the knowledgeable, competent practices demonstrated by healthcare professionals.

Older people living with frailty placed significant trust in their healthcare professionals, particularly the Parkinson’s specialists at the Day Hospital, to enhance their health. They found these professionals skilled in conducting assessments, making diagnoses, and providing valuable advice. Moreover, older people living with frailty felt confident in their ability to easily reach out to the Day Hospital staff whenever issues arose, which were typically resolved promptly. These positive healthcare experiences bolstered the trusting relationships they developed and empowered them to engage in healthy self-care practices, such as exercising at home and adhering to prescribed treatments. When evaluating care services, older people living with frailty often compared different organisations, especially when certain services did not meet their expectations.

> *"……..Urm, my experiences with Hospital B was the staff had always been very pleasant to talk to urm… they have been very caring in their attitude. Urm, the nursing staff, for example, when I was having problems with my skin cancer, and the dressing was being changed on a regular basis, they were absolutely first class. I could not wish for better service from the nursing staff* (Brian, Ln 282).

A key element in fostering trusting and caring relationships was the open, honest, and respectful communication between healthcare professionals and older people living with frailty. The healthcare professionals emphasised that respectful communication allowed them to understand each individual's perspective and care preferences, making older people living with frailty feel more at ease. This rapport enabled the professionals to access the person's lifeworld, gaining insights into what truly mattered to them. Consequently, the healthcare professionals felt empowered to discuss honestly whether the system could adequately meet the individual's care needs and to present alternative options. This perspective was shared by Lilian, a therapy staff.

> *"I think when you have an initial consultation with somebody, it is important to establish what the issues are and what is going to be addressed because it might be that someone has pain and to them, that is the biggest thing on their mind, the pain is unbearable, we have got to do something*

> *about the pain. And the GP refers them to the Day Hospital. And then the person from the Day Hospital goes in and says, 'oh, you know they have got problems walking, they have got problems… cooking, they have got problems, you know, with various things in life', and starts to plan around those things and maybe does not take on board that the pain is a big thing and needs to be part of the plan. Or it might be that… the feeling is the pain is an old problem, that we cannot address, and people go on with the things that they feel they can address, and the pain gets kind of ignored….not necessarily deliberately, but you know—people think, oh this lady has pain, she is got pain, I am only the physio I do not know what to do about it, she has had it for two years, a GP does not seem to be able to treat it, what can I do about it, and then people kind of push on with what they feel they can do, and there might not be an honest, in-depth understanding of what people have got. So, really, in a way, patients should know what is in the plan, and if they should say, 'I want you to address my pain', then at least there will be an honest conversation about whether you can or you cannot''* (Lilian, Ln 126).

Older people living with frailty also underscored the importance of communication in their healthcare relationships. They desired consistent contact with healthcare professionals, noting that *'being listened to is half the problem, even if it's by a receptionist and not a doctor'* (Teresa, Ln 495). These individuals highlighted that their communication with healthcare providers encompassed everything from casual conversations to in-depth discussions about health and medications through various channels such as in-person meetings, emails, phone calls, and letters. This consistent communication is crucial, as it ensures that those seeking healthcare services are recognised as individuals rather than merely being treated like another patient in a queue--‘*not just piling drugs and saying next customer, please’* (Teresa, Ln 497). Moreover, effective communication within healthcare relationships significantly impacted care services. It empowered older people living with frailty to take control of their healthcare, enabling them to ask questions, share their feelings, and seek support.

> *“... Urr, because you need to talk about how you feel because… what you think… or how you are and how the healthcare professionals see you are probably two different things”* (Emily, Ln 518).

However, when older people living with frailty experienced inadequate communication with healthcare professionals or lacked opportunities to express their concerns, it negatively affected their trust in their healthcare providers. This issue was especially pronounced among those who had undergone inpatient care and felt they did not have sufficient opportunities to talk to clinicians in the hospital, particularly the nursing staff.

> *“………At Hospital A, it is almost as if there is a lack of communication from possibly the patient to the specialists. I am speaking of my own situation rather – I have tried to get through to hospital staff when I am experiencing pain, and I get more or less dismissed. It is not their concern. I am frustrated because I am not getting anywhere. If I was getting*

> *somewhere, I would be much happier… So, from that point of view, it was excellent. It is possible that I'm expecting too muc*h*"* (Brian, Ln 282).

The COVID-19 pandemic brought to light the detrimental impact of inadequate communication between healthcare professionals and older people living with frailty. During this period, many older people living with frailty faced significant challenges in reaching their healthcare providers due to the obstacles imposed by the pandemic. As the number of sessions at the Day Hospital decreased, so did the opportunities for meaningful interaction and communication between older people living with frailty and healthcare professionals. These changes hindered the development of professional relationships and the continuity of care. Moreover, using personal protective equipment (PPE), such as face masks and visors, posed additional difficulties for older people living with frailty, particularly those with hearing impairments, as it sometimes became harder to understand the clinicians' messages. This issue was further exacerbated by the restricted physical and social contact, forcing many older people living with frailty to engage with their healthcare providers behind glass barriers. These perspectives were highlighted by Teresa, a 65-year-old female participant who lived alone.

> *"Oh, my goodness, when you phone up the GP, for example, and you have to go through the woman going on about COVID-19, and then you have to press various buttons, and then you get the receptionist, and I think a receptionist can change your life because she can either give you a good day or a bad one. Urm, yeah, and when I was… deeply depressed, I could not access anything. I could not even phone up the doctor or anybody.*

> *Urm… so I think… yeah… the more barriers they put in with the long COVID-19 spiel and all the rest of it, you need to be able to access someone……. Yeah…..I find it frustrating, and it has happened a lot. I phoned up the hospital, like the Day Hospital, and they have phoned me back on a number that you cannot ring back on. That, I think, is ridiculous. And I found that health professionals do that a lot; they ring on a number you cannot call back on, and you do not know who it is. And because as a person with a need, you are slowly getting to your phone, and when you have got to your phone, and you have non, you have knocked them out accidentally, and then you cannot ring back, it is very frustrating. So urm, yeah… yeah"* (Teresa, Ln 323).

Furthermore, some older people living with frailty expressed that healthcare professionals occasionally dismissed their concerns and responded with condescension, particularly when minor mistakes were made during care sessions. This sentiment was especially prevalent in interactions with Healthcare Assistants on the wards, where some older people living with frailty perceived a dictatorial and ageist attitude. Such care practices were viewed as depersonalising, which diminished the quality of their care and discouraged older people with frailty from seeking necessary healthcare services.

> *"…..this is something that really ought to be addressed by hospital management; after you have your nurses and so on, you have those what they call healthcare assistants……they are not qualified nurses, and they are not actually qualified…..But most of them have a mouth on them, and*

> *they should not be in a position to start diagnosing what is wrong with you and how long you are going to live. Because what they do, they frighten you… And then, a lot of them can be absolute know-alls and actually do not have any knowledge at all. Now, these are people that cause a lot of anxiety to patients because they are rumour-mongering and they are urr, dictating themselves to the patient because they know somebody's bedridden, they can be a bit sort of, well literally, like a dictator. If you like trying to ask them, get you a glass of water, or try to ask them if they can do anything at all. For example, many healthcare assistants bring the food onto the trays on the bed when you are having your lunch. And invariably, they will forget a spoon or a knife and fork or salt and pepper, and you ask them for it, and generally speaking, you get a sort of, 'oh, I have not got time', or 'I, you know, you will have to be patient or', that sort of thing, and then they forget. Urm, and or, you know either that or they will not do it or provide it. And I find that you are constantly having to remind them, over and over again, that you actually want, what you need''* (Arnold, Ln 429).

Healthcare professionals identified time constraints as a significant factor contributing to communication challenges in patient encounters. For instance, due to the impacts of COVID-19, patients at the Day Hospital were restricted to a maximum of four sessions. As a result, older people living with frailty often found it difficult to convey all their concerns, which hindered healthcare professionals' ability to fully understand their challenges. Moreover, given the limited time available, healthcare professionals felt compelled to exercise caution in communicating with patients. They sometimes refrained from engaging in deeper conversations for fear that it could *'open a box that might fly open and present loads more problems when we only have two more sessions to see a patient'* (Stella, Ln 610). This perspective suggests that their reluctance may stem from factors beyond just time constraints and organisational limitations. One potential factor could be a lack of skills, confidence, or cultural understanding on the part of the professionals in handling such complex discussions within time-limited situations. Ultimately, these time limitations impeded effective communication and meaningful care relationships, as highlighted by Stella, a nursing staff.

> *"Yeah, so … targets are… urm, they are driven from up there, …from the government, all the way down, for instance getting people out of hospital quick, quick, quick, you have to get them out within a certain amount of time, you have to see them within a certain amount of time. Time targets are the worst ones, really, I feel, that stop people… just trying to manage all of the flow of people. Yeah, you cannot [develop therapeutic relationships]….the other thing I am not sure that a lot of management understands is when we are talking about frail, elderly people, they need more time. Just walking into a room and getting themselves comfortable can take five minutes. It can take longer if they have got Parkinson's or disabilities. So, you know if we have got ten minutes, let us say we have got half an hour to see then, takes ten minutes to get them in the room, let us say--Ten minutes to sit down, get their story and they have got to repeat it all, perhaps, because it was not me that saw them last time. Urm, and*

> *then I have to write my notes at some point because that's a legal responsibility on my head. And urm… so, yeah, we have to, and then, pre-pandemic, we were having to see patients every half an hour, post-pandemic there is a little bit more leeway, but then the leeway is given because we need to clean down in between…. but then there is still no time for the notes *laughs* you know. Urm… so yeah, time and targets are the things that get in the way I feel"* (Stella, Ln 543).

The experiences outlined above indicate a significant gap in effective communication at the interpersonal level. Due to time constraints, healthcare professionals often prioritise meeting targets over addressing patients' emotional needs. For older people living with frailty, accessing healthcare services frequently involved navigating communication barriers within the healthcare system. This inadequate interaction between patients and specialists meant many older people living with frailty sometimes hesitated in seeking necessary care because they felt they were receiving a favour and needed to manage their expectations. This mindset contributed to feelings of frustration among older people living with frailty, who felt that their healthcare journey was stagnating, ultimately resulting in a diminished sense of control over their healthcare services.

Effective communication hinges on understanding each other's preferred methods of communication. This was particularly emphasised by older people living with frailty, who found that recognising these preferences enhanced their communication with healthcare professionals during times of need. For instance, Nicole underscored the significance of having a clear and mutually agreed-upon communication method.

> *'In case something was wrong, or if I were to run out of tablets, or if they had given me the wrong tablets, I would send her [healthcare professional] an email. She prefers email because it allows her the time to address the issue rather than telephoning'* (Nicole, Ln 956).

Additionally, both older people living with frailty and healthcare professionals emphasised the significance of language in fostering caring relationships. They underscored that effective communication is vital for building rapport in care settings. However, the use of technical jargon in healthcare can often be difficult for laypeople to grasp, hindering patients' understanding of what healthcare professionals convey. Healthcare professionals also encountered challenges when working with clients with hearing impairments or who did not speak English as their first language. These obstacles can affect the quality of rapport, relationship building, and clients' ability to engage in their healthcare actively. Therefore, it is essential to tailor verbal and written communication to align with each individual's needs, abilities, and beliefs. In some cases, involving family members to facilitate communication in the caregiving relationship was also deemed beneficial, as one therapy staff noted:

> *"I think the language needs to be tailored. We are so used to using it [medical language]. It becomes part of our vocabulary that I think we need to be aware that we are talking to people who are not, maybe not medical,*

> *or have not worked in a hospital. So, we need to be aware of that and tailor it so that it is understandable and kept simple, not complex. So that, and just… You know what to say to them. If you have any questions or if you want me to repeat anything in a different way, please feel free to do that. Just be open, and make sure they understand the information is really important"* (Justine, Ln 360).

Another important element in establishing professional relationships within healthcare services is continuity of care. For instance, older people living with frailty emphasised the significance of being supported by familiar healthcare providers to foster trusting and caring relationships. This continuity of care was crucial, as it saved time by eliminating the need for patients to revisit their entire medical history with each healthcare encounter. As Tom expressed, care continuity was key in cultivating a trusting relationship between older people living with frailty and their healthcare providers.

> *"And also, when I go back there, I see the same ones, and you form a relationship with them- And they know where they are with you, and they carry on step by step, rather than going to see a doctor who is not going to be the same as the doctor you saw last time, is not going to be the same as the doctor you saw next time….."* (Tom, Ln 737).

The COVID-19 pandemic had a significant impact on the continuity of healthcare services. Many staff members at Day Hospitals emphasised that maintaining care continuity is essential for fostering patient trust. However, the pandemic disrupted work schedules, making it challenging for patients to consistently see the same healthcare professionals. The shortage of healthcare personnel during this period further complicated the process of building therapeutic relationships. As a result, healthcare professionals expressed a desire to return to a system that would ensure greater continuity of care, ultimately aiming to improve patient outcomes, as Beth, a therapy staff member, highlighted.

> *"Yeah, and that [clients seen by the same healthcare professional] is what we used to have. I think COVID has got a big part to play in that, yeah, but urm, we have kind of moved over logistically to timetabling people to shift work, weekend work, which means that patients who do come into the Day Hospital do not always see that same face. You do not build a therapeutic rapport by doing that, and what we used to have was always, you know, you saw the same person. They got to know you, we got to know them, so that when you're doing intimate things, like if you mood screen with them or looking at anxiety or depression, all those sorts of things, they're much more likely to converse with you if you have got that kind of relationship therapeutically, where they feel comfortable. It is a shame that we have moved away from that. Yeah, continuity is lost, I think, yeah, I can absolutely see that. That is one major problem"* (Beth, Ln 304).

Category 3 suggests that older people living with frailty often have a positive view of healthcare professionals, largely due to strong, trusting relationships built on a welcoming attitude and demonstrable expertise. Their experiences with frailty shape their interactions with the healthcare system, influencing their expectations and fears. Trust in specialists, particularly in the Day Hospital context, reflects a reliance on these professionals to navigate health challenges. This trust goes beyond technical skills and also hinges on empathy and understanding. Many older people living with frailty shared positive experiences that highlighted the healthcare professionals' warmth and attentiveness, reinforcing the significance of human connection during serious health challenges, such as Brian's experience with skin cancer care. This relational dynamic transforms the healthcare experience from a purely professional interaction to an interpersonal journey, embodying shared experiences and mutual understanding, where older people living with frailty feel valued and cared for.

Trusting caring relationships are reinforced through effective communication and continuity of care, both of which must be perceived as authentic rather than merely functional. Communication serves as a critical bridge between older people living with frailty and healthcare providers. Open dialogue allows older people living with frailty to express their concerns and preferences, fostering a sense of agency in their healthcare. However, breakdowns in communication can create significant barriers, undermining the fragile bond of trust established. Lilian, a therapy staff, illustrates the potential misalignment in care that can occur when communication falters. Her reflections stress the importance of recognising the complex nature of health concerns--such as pain--rather than reducing patients to mere symptoms. This perspective highlights the need for a shared understanding of care plans, where patients feel heard and their needs validated.

Overall, building trusting relationships with healthcare professionals is vital for improving outcomes for older people living with frailty. It is essential for healthcare systems to prioritise relational aspects alongside clinical skills to empower patients to navigate healthcare processes with dignity and confidence. Effective communication fosters individuality and strengthens trust, forming the foundation for all care aspects, including information sharing.

5.3.4 Category 4: Information sharing within healthcare systems

The findings highlighted that information sharing significantly influenced the control and well-being of older people living with frailty, particularly at the systemic level. Many older people living with frailty reported that having easy access to information about their healthcare services was essential; without it, they felt as though they were '*going round and around forever'* (Priscilla, Ln 166). Access to information was also vital for empowering these individuals to manage their healthcare effectively. It fostered a better understanding of various healthcare aspects, including illnesses, diagnoses, and interventions, ultimately enhancing the sense of control over healthcare among older people living with frailty.

Inter-organisational and inter-professional communication were also considered important in facilitating healthcare information sharing. This practice involved healthcare professionals obtaining background information about individuals before engaging in personal interactions. Healthcare providers often facilitated this information exchange through established organisational practices, such as assessments and clinical and referral notes. Such information sharing was crucial in minimising client confusion and preventing patients from repeatedly recounting their experiences, especially when interacting with different professionals and care organisations. For example, the Day Hospital staff offered older people living with frailty a ‘record of communication’ that enabled them to connect with other healthcare professionals, monitor their health, and involve their relatives in the healthcare process.

> *“So, before COVID, patients had a record of communication. It was a very small booklet that was given to them at the point of assessment. The first few pages were about what we do as OTs, physios, and nurses. Then, the following pages contained records of communication between the patient and us. So, it was given to them at assessment, and they were told to fill out anything that was of concern to them. Then, for their first visit, the clinician would look at that record of communication and look at the patient’s concerns. This is on top of the assessment to make sure everything’s okay and on track, and then at the end of that first session, write the patient a note as to what had happened during that session so that if they had any cognitive impairment, or if the family wanted to have any involvement, there was a written communication that was kept with the patient, that allowed that record to be visible for anyone, for the patient or the relative. Again, this is also about involving the relatives, isn’t it? Urm, and then we would go away and leave that patient. The patient would be encouraged to write down anything in the week or so that goes by that’s of concern for them that they think, ‘oh, that’s bothering me’, Next week, the clinician goes in, they look at, yeah. So that was a really good thing, and it was before COVID. We have to get back to that, we have to, to be able to get back to some sort of normal”* (Beth, Ln 691).

As mentioned in Category 3, effective communication is crucial in facilitating information sharing within healthcare processes. For example, older people living with frailty reported that nurses and other healthcare professionals provided them with essential information regarding treatment decisions, interventions, and various exercise routines. They also felt adequately informed about what to expect next and received clear explanations of their medical procedures, along with answers to their questions. Access to healthcare information helped these individuals feel more relaxed and at ease, particularly during their initial sessions, alleviating their concerns about the unfolding process.

> *"…..I think urr I was on a learning curve because I did not know what to expect, urr and urr urm… I felt that urr… they were keeping me informed, and at the end of the day, I had this folder, and at the end of the session, they wrote in the folder, urr, something about urm… urr… what we did during that session. So, they were urm… when I got home each day, after that, the first thing my wife said was urr, 'well tell me about it, what did you do'……So, as I said earlier on, I thought they were faultless. Urm, they kept me advised of what was happening, which is always important. We are going to do this next. I think that is very important. I think you feel more relaxed, urm, you do not worry about what is happening"* (Mark, Ln 353).

The staff at the Day Hospital ensured that they communicated information with precision, particularly when outlining the proposed course of action, all while respecting the patient's autonomy. This approach empowered patients to make informed decisions regarding their care. Additionally, the staff tailored their communication for older people living with frailty through various means, including verbal explanations and written documentation such as assessment forms and discharge letters. They often adjusted their communication methods to accommodate individual needs, employing different languages or interpreters for those facing cognitive challenges or who did not speak English as their primary language. In sharing information, clinicians aimed to maintain an appropriate balance, carefully considering the nature of the information to avoid overwhelming the person. Importantly, the Day Hospital staff recognised that a coordinated information-sharing system was essential to support effective care practices, including referrals. They emphasised that referrals should encompass comprehensive details about the patient and their history, beyond just medical records, to enhance the quality of care.

Despite the initiatives mentioned above, many older people living with frailty expressed dissatisfaction regarding the limited sharing of information related to their healthcare. They encountered challenges obtaining details about referrals, dietary options, and the trajectory and prognosis of certain illnesses, particularly Parkinson’s. Moreover, older people living with frailty often perceived Parkinson’s as ambiguous concerning its significance, manifestations, and progression. The scarcity of information about the condition left some of these individuals feeling a lack of control over their health, which was distressing. Additionally, some older people living with frailty noted that many healthcare professionals did not appear to be well-informed about Parkinson’s, leading to their frustration. They emphasised the importance of having a guide to help navigate their healthcare journey. Furthermore, several older people living with frailty reported receiving inadequate information about their medicines, as they felt that information sharing was mainly concentrated at the professional level, with less input from service users. Consequently, the challenge of seeking essential information felt akin to *'looking for something that was not there'* (Hughes, Ln 217), limiting the sense of control that many older people living with frailty had over their healthcare.

> *"I think… well, like I asked for the doctor's referral for exercise… but I had to ask for it. Yeah, I should not have to ask for it... it should be offered, you know? I asked for help with my diet because some people believe that your diet-….your gut, you know it [Parkinson's] comes from the gut and not from the brain, some people believe. So, I asked if I could see a dietician. There are dieticians trained as dieticians, but I have never been offered that. I do not know why you are not offered things that are helpful. Nobody, for example, mentioned that Re-Gen place in Italy. And yet, we do not have one in- in the UK. Urm yeah. It has been a journey of urm… it feels like I have been fighting for the answers. But actually, there are very few answers. And… yeah……it is difficult because you have to go to the expertise of the field, you know, for Parkinson's, you cannot just go to the doctor. Because he… is not informed enough. But he should be informed enough to say… 'hey, you know-how about… I get you into a gym, and you do six weeks in a gym? I think they should be more informed. At least to point you in the right direction, like somebody should be pointing out that place. You should not be delving around looking for it yourself. So, I guess*

> *in your role, there should be, you know, if you have got his disease or condition, then you can look at the list of possibilities. That might be helpful''* (Teresa, Ln 403).

The findings seem to point to a struggle for information within the healthcare system for some older people living with frailty. This challenge was exacerbated for those experiencing advanced frailty, who often encountered difficulties comprehending critical healthcare-related information. To mitigate this issue, some older people living with frailty suggested the establishment of information centres dedicated to providing reliable resources on various healthcare conditions, with a particular emphasis on Parkinson's disease. Furthermore, it was considered paramount for older people living with frailty to adopt a proactive stance in seeking information related to their health to maintain control over their healthcare. As articulated by Nicole (Ln 863), *'you are in control…if you know what is going on.'* This proactive approach was primarily facilitated through consultations with clinicians and, at times, engagement with private consultants to obtain nuanced details that ensured the efficacy of their healthcare management. Additionally, incorporating technology into healthcare practices played a crucial role in the experiences of older people living with frailty. Many utilised the internet to communicate with healthcare providers, stay informed about health-related developments--including available specialists and treatment options--and engage in home-based exercises to support their health and well-being.

The descriptions provided under category 4 underscore the crucial role of information sharing in enhancing the control and well-being of older people living with frailty, revealing an interplay between systemic healthcare practices and personal experiences. Access to healthcare information emerged as a fundamental need for these individuals, allowing them to navigate their conditions with greater autonomy. Many reported feeling lost without such information, illustrating a profound sense of helplessness that can accompany living with frailty in healthcare systems. As a result, effective information sharing transformed the healthcare experience from a passive encounter to an empowered engagement, fostering a perception of control over their healthcare.

Similarly, inter-organisational and inter-professional communication and information sharing create a cohesive care ecosystem, allowing older people with living frailty to navigate the complex landscape of healthcare services more easily. The example of the Day Hospital staff providing a ‘record of communication’ embodies a personalised care approach that values the patients’ narratives, creating a tangible link between different healthcare interactions. Similarly, Beth’s account illustrates the relational dynamics at play where the continuity of communication is not merely procedural but deeply ingrains a sense of partnership and support. Encouraging patients to document their concerns acknowledges their lived experiences and cognitive challenges some may face, fostering an environment where patients feel seen and heard, enabling them to engage more actively in their care. In this light, effective communication and information sharing transcend mere exchanges and become a conduit for care, weaving together the threads of dignity, empowerment and agency, enhancing the sense of control and well-being in older people living with frailty.

Furthermore, Mark’s reflections highlight the psychological comfort derived from being adequately informed, emphasising how effective communication and information sharing can alleviate anxiety surrounding healthcare procedures and empower patients to engage meaningfully with their care, reinforcing their autonomy. Similarly, for other older people living with frailty, technology transcends its role as a mere tool and emerges as a vital bridge for accessing healthcare-related information. This technological engagement not only enhances their daily experiences but also fortifies their sense of agency in managing their health and well-being. The reliance on technology reveals a deeper relational dynamic in which older people living with frailty view themselves as proactive participants rather than passive recipients of healthcare services. Furthermore, it highlights the necessity for a comprehensive exploration of the digital world for this demographic to gain a nuanced understanding of their healthcare experiences.

In summary, information sharing within healthcare systems goes beyond simply transferring data; it is a relational practice that enhances agency, reduces anxieties, and ultimately improves the healthcare experience. Therefore, promoting communication and information sharing in healthcare processes can empower older people living with frailty to make informed choices about their health, affirming their role in the continuum of care.

5.3.5 Category 5: Experience of having choice in healthcare services

Older people living with frailty emphasised the importance of having choices in their healthcare services. As a result, most preferred collaborating with care organisations that provided various options, including appointments and medication. Many older people living with frailty noted that their ability to exercise choice in various aspects--such as referrals and interventions like exercise--boosted their confidence in the healthcare system. For example, some mentioned that they could choose which hospitals to be referred to. Additionally, some individuals opted out of certain exercises, particularly when they experienced discomfort or pain during those activities. This sense of choice explains why many older people living with frailty felt empowered to decline certain healthcare interventions, such as particular exercises or medication, as illustrated by Nicole.

> *“Urm, they, urr, I have not really seen *the Day Hospital nurse*, I have only seen her once, but *another Day Hospital nurse* lets you, she asked you what you wanted, what do you want from us now? Urm, and of course, when she retired, I had all the trouble with my blood pressure. The doctor sorted that out, not the Parkinson’s [Day Hospital]. I suspect in the future, I still go to Parkinson’s [Day Hospital] rather than a GP. Urm, because they presumably will continue the same way and ask me what I want from the system. Urm, because I do not really demand very much at all. Urm, only the tablets, keep the tablets going; that is about all I need. She used to say, ‘well, we can do so-and-so, or we can try so-and-so?’ or, ‘Oh, you’re going out to Dubai in three weeks’ time. Let us do it when you come back’.*

> *Urm, just little things that you know, makes you, makes me feel in control….. Urm, yeah, the specialists at the Parkinson's group are good because you think, oh, there is someone on my side, urm, I am not doing it on my own, there are choices that I can make, and I have been allowed to make…. It gives you the confidence, of course, to know that… even if they do not get it right or the tablet does not work, at least they have tried, they have had the gumption to try, you know, advise you to try it. Urm, so it gives you confidence as well…."* (Nicole, Ln 968).

The descriptions above highlight the positive experiences many older people living with frailty had with healthcare professionals at the Day Hospital. They reflect the personalised care and attention that patients receive, which empowers them and instils confidence in their healthcare decisions. Older people living with frailty deeply value the expertise of the specialists at the Day Hospital, who offer options and support even when situations do not unfold as expected.

However, some older people living with frailty expressed that the healthcare system offered limited choice, which sometimes put them at odds with it. This lack of options was often tied to accepting only what healthcare professionals could provide, particularly regarding interventions and medications. For instance, to obtain exercise equipment at the Day Hospital, older people living with frailty had to apply and navigate a process to determine their eligibility, leaving them uncertain about the outcome. Likewise, some felt pressured to accept certain medications against their preferences, which led them to hesitate in seeking healthcare services.

> *“Again, I think it is down to your doctor……I get on with my doctor. I did not get on with my last doctor. Consequently, I did not go because I did not like him. I do not think he liked me either, personally. Because I argued with him, he wanted me to take some pills, and I said I am not going to take them. And he said, ‘I am the doctor, you will do as you are told’. And I said, well, you cannot make me take them; you can prescribe them for me, but if I do not want to take them, I will [not] take them, and I thought I had a choice. So, we did not get on at all. Well, I was annoyed. And then I changed my doctor, and I said, well, I have been trying to get with you for the last three years. And he said, ‘What do you mean?’ I said, oh well, I have asked, and they have always said you are full. He said, *tuts*, so he changed me over to him. And I said to him, before we start, you will see on my notes that I have refused to take statins, I am still refusing. He said, ‘that is up to you’. He said, ‘You know if you want them, if you need them, I will tell you that it will be a good idea for you to take them, but I cannot make you take them. Yeah, so, I do not take them”* (Lynnet, Ln 767).

The staff at the Day Hospital emphasised the importance of enhancing the sense of control of older people living with frailty over their healthcare by offering them choices on different aspects of care. Recognising that many healthcare interactions, such as visits to the emergency department, are often outside the control of these individuals, healthcare professionals advocated for allowing service users to exercise choice in various aspects of their care. Although clients occasionally declining professional advice presented challenges for healthcare professionals, they maintained that honouring the individual’s choice was paramount. Healthcare professionals prioritised elucidating the implications of each choice on the individuals’ health outcomes rather than coercing them into compliance with recommended interventions. Additionally, they observed that some older people living with frailty exhibited diminished personal autonomy at the household level, often attending healthcare facilities at the behest of family members rather than out of a personal desire for care. Consequently, there is a critical need to reaffirm to older people living with frailty that they have a choice in their healthcare encounters. Respecting the healthcare preferences of older people living with frailty entailed empowering them through a nuanced understanding of their concerns and preferences, thereby equipping them with the necessary tools to manage their lives. Enhancing the sense of choice was also achieved through simple, reciprocal communication aimed at encouraging acceptance of proposed interventions by highlighting their potential benefits, as articulated by a nursing staff.

> *“So, it can be frustrating [when patients do not take the prescribed medication], it can be, urm, because we know that if you are diabetic and you do not take the medication, it can make you very poorly. If you have got high blood pressure and you don’t take your medication, you could end up having a stroke, so urm yeah, but… the only way people can make decisions is if they are informed of that, so I try and talk to them about what could happen if they do not take it. Not to come from a place of fear but so that they know that that is an option that could occur down the road. Urm,*

> *I have talked to patients about making lifestyle changes because otherwise, they will end up in the hospital, urm, yeah. It depends on the patient, really, and what barriers are giving you. And if they have already thought that through and do not want to, it is their choice after all……. I am confident enough to know that I do know. I can tell them what the alternatives might be for them, but I am also very passionate from a personal point of view about freedom of choice. It is important. Although we, you know we, want everybody vaccinated [against COVID-19], if they do not want to be vaccinated, for instance, urm… that is their choice… after all, I should not have to make them, and I do not believe that anybody should make them. As long as they have got the proper information, proper scientific information, then that, and maybe that is my job to give them the science because they have not got that, might be"* (Stella, Ln 735).

Healthcare professionals interpreted these practices as emblematic of client-centred care, highlighting the importance of client choice in setting healthcare goals.

Category 5 explores the crucial role of choice in healthcare services for older people living with frailty, highlighting how this autonomy significantly impacts their confidence and sense of agency within the healthcare system. Many individuals expressed a preference for collaborating with care organisations that offered a variety of options, allowing them to make informed decisions about their treatments and interventions. This experience of care personalisation not only empowered older people living with frailty but also fostered a collaborative relationship between them and healthcare professionals, as illustrated by Nicole's account of her experiences with the Day Hospital. She emphasised the importance of having her preferences considered, which gave her a sense of control, even amidst the unpredictability of her health condition. This collaboration fosters an interpersonal dynamic vital for older people living with frailty, allowing them to engage more meaningfully in their healthcare services.

Empowerment through choice can be seen as a fundamental healthcare aspect for older people living with frailty. This cohort places significant value on the ability to make choices regarding their care, which they perceive as a pathway to regaining control over their often vulnerable circumstances. The ability to choose which hospital to be referred to or which interventions to accept shapes their identity and fosters a sense of worthiness in a system that often views older people as passive recipients of care. In contrast, when the healthcare system limits options for these individuals, it creates a profound sense of dissonance, frustration and powerlessness, sentiments expressed by Lynnet in her conflict with a previous doctor. The lack of choice highlights the tension between an individual's desire for agency and the reality of navigating a healthcare system that can sometimes impose decisions rather than collaborate. In such instances, they may be compelled to disengage from seeking necessary healthcare services, highlighting a paradoxical situation in their quest for health and well-being as the structures designed to aid them can inadvertently alienate them.

Overall, category 5 underscores the crucial need to enhance the sense of control among older people living with frailty by actively providing them with options in various facets of their care. It also reveals that choice is not merely about options but is intricately connected to identity, self-efficacy, and the quest for meaning in one's healthcare service use. These perspectives not only align with the recognition that choice is a vital ingredient in the quest for dignity and self-determination in healthcare but can also be seen to facilitate participatory healthcare decision-making.

5.3.6 Category 6: Experience in making decisions in healthcare services

Decision-making is a vital aspect of the healthcare experience for older people living with frailty. Those in this demographic expressed that feeling in control meant having the autonomy to make everyday choices without external influence. They also anticipated that healthcare professionals would actively seek their input and support them in decision-making. This viewpoint was especially pronounced among moderately frail and relatively independent older people, exemplified by an 82-year-old female participant who lived alone and was still capable of managing many facets of her healthcare.

> *"I expected them to do that [seek patients' opinion]. That is the sort of thing I used to do when I was working at college, so I expected that. Urm, I do not expect them to take notice of all of us because it obviously has to fit in with the hospital plans. And it depends on the number of staff available, doesn't it?"* (Lynnet, Ln 234).

Therefore, the aforementioned dimensions of effective communication and information-sharing are crucial in facilitating the engagement of older people living with frailty in healthcare decision-making.

However, the level of involvement in healthcare decision-making varied among individuals. Most older people living with frailty felt that healthcare professionals were respectful and inclusive, actively involving them in the decision-making process. This approach included seeking their opinions regarding their preferences and wishes rather than unilaterally making decisions on their behalf. Many reported that healthcare professionals were receptive to their suggestions and needs, particularly in the Day Hospital setting. The professionals provided recommendations outlining the advantages and disadvantages, enabling older people living with frailty to make informed healthcare decisions. These decisions often centred around continuing certain medications or exercises, as noted by Denis, an 81-year-old male participant.

> *"Urr, they [healthcare professionals] ask what you want, they do ask you, they do not just get on and do it willy-nilly. You know they ask you, how you feel, you know?"* (Denis, Ln 513).

Additionally, older people living with frailty often felt supported by their healthcare providers, even when they chose not to follow professional advice. This support contributed to a greater sense of independence. Furthermore, some older people living with frailty had established a strong trust in their healthcare providers, allowing them to feel comfortable with professionals making healthcare decisions on their behalf. Consequently, older people living with frailty regarded the respect shown for their healthcare decisions as a reflection of their control over their healthcare, resulting in a fulfilling experience.

> *“They [Day Hospital staff] were very open to whatever I wanted to do. They told me what they thought should happen, made strong recommendations that this would help, and told me the downsides and upsides. And so, I was comfortable with the control they gave me and [felt] empowered to make the decision I wanted. I felt good about that. In fact, we still talk about it because the nurse I speak to on a sort of monthly basis is very friendly. She does not understand my Christianity, but she respects it. She’s fine. Absolutely fine. She probably thinks I am an idiot, and I happily accept that. But urm, no, she’s great, and she’ll talk about it, and she is just very, very pleasant person and accepting my… ways of thinking of things which again are important to me, but she is very respectful of them. But she’ll tell me her points of view and tell me that, as a healthcare professional, she believes in her experience, which is important, and that gives you a chance to decide, but the decision was always left in my hands.…It is the way that I like it. In my point, I do not know if you need to be a little bit more insistent sometimes. I am not a healthcare expert, I just know, in my case, it felt very empowering that whatever I wanted to do, it was in my behest. Now, sometimes I am sure it is not always like that. But that was what I needed in my circumstances”* (Peter, Ln 455).

The Day Hospital management occasionally invited older people living with frailty to participate in management meetings, allowing them to offer feedback on services and contribute to broader organisational decision-making processes. This approach to participatory decision-making fostered a sense of appreciation and value among older people living with frailty, reinforcing the belief that their input could enhance healthcare processes.

> *“And then she [Day Hospital staff] asked me if I would be interested in participating in what they call a patient input scheme where I would attend meetings with the nurses, doctors, consultants, blah, blah, giving the patient point of view on the various policies. Or urm, because that was the one thing they had not got, they had not got a patient input….I had been in hospital for six weeks, which was quite a long time….And that experience was something they felt very valuable, and they wanted to know how I felt about that…..And urm, so anyway, I said to the *lead clinician*, yes I would be able to participate, because I said, look, I survived this, and if I can ever do anything to help other people down the line, then I would be very happy to do so. And urm, urr, and so she also said, would you be prepared to help them down at xxxxxxx [hospital]? And I said, yes, I would. And I do remember the senior manager of xxxxxxx [hospital], I remember being in his office, sitting around a conference table with all these, it was really funny with all these specialist people, doctors and physiotherapists and goodness knows what. I could not understand what on earth they were talking about, and *laughs* I said to him, do you really want me here? I*

> *said, I can hardly compete with all your experts. He turned to me and said, 'you are the most important person in this room. None of us in this room have been in the hospital for more than a couple of days. You have been in the hospital for six weeks. We do not just want to know about that, we need to know about that to help to make life easier for other patients coming down the line'. Urm, I was speechless, *laughs* my jaw dropped, and I said to myself, really?! And then he explained why, and then I understood that urm, so it was not a waste of time …..Well, it made me feel that maybe I can contribute something here to the welfare of other patients coming down the line. So, if I could recount my experience over that six-week period, then maybe we can get something across to help them with their policies and what-have-you. Do you see what I am getting at?"* (Arnold, Ln 192).

Furthermore, many older people living with frailty expressed a preference for making healthcare decisions in collaboration with their informal caregivers, especially family members. They emphasised the importance of healthcare professionals involving their families in these decisions, as informal caregivers played a crucial role in coordinating care, including scheduling appointments and managing medications. This perspective was shared by Robert, an 85-year-old married participant who lived with his wife.

> *"Because she [wife] can remember dates and keeps a diary…She is good on the phone because that was part of her job. Audiology, wasn't it?"* (Robert, Ln 562).

In situations where older people living with frailty perceived a lack of involvement in healthcare decisions, it significantly diminished their sense of autonomy. For example, some individuals reported that healthcare professionals tended to dominate the healthcare encounters, resulting in a scenario where decision-making was effectively removed from the patient's hands, *'and they just did what they were told'* (Denis, Ln 187). This dynamic led some older people living with frailty to feel as though they were simply complying with directives, thereby undermining their healthcare decision-making power. Similarly, some older people living with frailty expressed concerns that healthcare professionals sometimes required them to engage in certain exercises without adequately taking into account their physical limitations. This disempowerment had a profound implication for the sense of control and well-being of older people living with frailty.

Furthermore, some older people living with frailty shared that certain healthcare professionals, including occupational therapists and therapy assistants, made modifications to their homes without fully comprehending how these changes impacted them personally. Additionally, many older people living with frailty found it challenging to engage in decision-making due to inadequate information sharing during healthcare interactions. In some instances, the very structure of the healthcare system hindered professionals from having the autonomy needed to promote participatory decision-making in major healthcare interventions. This issue was particularly prevalent when the system required healthcare professionals to adhere to a standardised or uniform care approach. As a result, many older people living with frailty felt that their choices were overlooked and that their trust in healthcare professionals was deteriorating, as expressed by Jessica, a 71-year-old woman.

> *"Being open and honest with you, however bad what it is they have to tell you. Urm… and I think when they operated on my legs, they really did not do me any favours. I wish I had never had it done. I think the pain I was getting before they operated was considerably preferable to the lack of ability I have now got, or my lack of mobility. So, yeah, Urr, because since I have had them done, I have found there have been quite a few people I have met where it has not been terribly successful, and I would not say this is successful. Particularly not taking about two or three centimetres off one leg. Urm… so, mistrust has crept in, which is what I felt anyway with urm medical people. Urm… and I had a lot of trouble having babies, urm. I had *a son* in my ninth pregnancy, and I have lost eight babies. And urm… there was always a bit of hope because I was conceiving, and some people were going to the hospital and could not conceive at all"* (Jessica, Ln 123).

The staff at the Day Hospital highlighted the importance of involving older people living with frailty in healthcare decision-making. They believed empowering these individuals meant offering them choices and allowing their input on matters directly affecting their well-being. According to most of the healthcare professionals interviewed, they supported this process by providing older people living with frailty with adequate information to make informed and independent decisions. This approach included activities like exercises designed to motivate individuals to set and pursue their personal goals. Engagement in care decisions for older people living with frailty was facilitated through a simple two-way communication process. Moreover, healthcare professionals expressed their commitment to respecting the decisions made by these individuals, even when they deviated from professional recommendations. However, they noted that factors such as mood swings and cognitive impairments could sometimes hinder participation in decision-making for older people living with frailty. Additionally, informal caregivers may occasionally disregard the older person's autonomy, often making decisions on their behalf. As a result, healthcare professionals emphasised honouring the right to decision-making for older people with frailty, particularly when they can make their own choices. This principle extended to allowing older people living with frailty to decide when to involve their family members in the care process, as illustrated by Justine, a therapy staff.

> *"I think we are all very different in how we work. Urm, because we are all individuals as well. We all are aware that we need to involve the patient in the decision-making process because it is them that we are trying to help. Urm, so yeah, we have the standardised paperwork which we go through, which goes through urm all the activities of daily living, urm… so such as washing and dressing, kitchen work. It also goes through how they manage their walking, stairs, steps, urm, getting on and off things. And also, the sort of medical side, like if they have a skin condition or are vulnerable to their skin. Urm, whether they are eating well or having enough nutrition. Having enough fluids is another big thing, as well. So that, from that, we*

> *can sort of, at the end of our assessment, ask what they feel is important to them, but also from what we have seen, physically and what we have talked about, kind of give an idea of how we can help them as well and then come to a decision, an agreement about the goals. So, it might be that by the end of the assessment, they feel they will not cope with it, and it will be too much for them. So that is also fine if they decide no, it is not for them after all; we totally respect that. We might provide them with some equipment and some paperwork, advice, you know of other services"* (Justine, Ln 172).

In summary, category 6 indicates the intrinsic value older people living with frailty place on their participation in healthcare decision-making. Many expressed a deep-seated desire for their voices to be heard, viewing healthcare decisions not merely as a series of choices but as integral to their healthcare experience. This desire for autonomy often manifests through effective communication and collaborative exchanges with healthcare professionals. For instance, Lynnet highlighted her expectation for professionals to seek patient input, reflecting a broader need for respect and acknowledgement within healthcare settings. This collaborative approach fosters an environment where older people living with frailty feel supported and validated.

However, the degree of involvement in healthcare decision-making processes varied among individuals. While many experienced inclusivity and genuine consultation, as Denis noted, others found comfort in the support offered by healthcare providers, even when their choices diverged from professional recommendations. This duality suggests that the experience of control is not merely the presence of guidance in healthcare decision making processes but rather a nuanced relationship where patients feel empowered by respect for their decisions, even in moments of uncertainty.

Moreover, descriptions like Peter’s illustrate how trust in healthcare professionals can foster a sense of empowerment. The decision-making process emerges as a shared journey where healthcare providers articulate their expertise while respecting the patient’s values and beliefs. This dynamic underscores the understanding that the experience of making decisions about health is deeply personal, shaped by individual contexts and relationships. Additionally, the involvement of older people living with frailty in management meetings at the Day Hospital exemplifies an innovative approach to participatory healthcare decision-making. This practice resonates deeply, fostering a sense of appreciation and belonging. The initiative not only validates the experiences of older people living with frailty but also underscores the potential for their insights to inform broader healthcare practices. Being invited to contribute enhances their sense of value and agency, reinforcing the belief that their perspectives can lead to meaningful improvements in care. This participatory approach goes beyond mere consultation, recognising their lived experiences and wisdom as invaluable assets to the healthcare system.

Therefore, category 6 suggests that facilitating decision-making for older people living with frailty requires creating a nurturing environment where they can navigate their healthcare decisions without fear of negative repercussions on their care or relationships with healthcare providers. This safe space honours their autonomy and affirms their dignity, allowing them to engage fully in their healthcare services with a sense of shared purpose.

Theme Two emphasises the intricate relationship between practical and emotional aspects of healthcare services that impact older people living with frailty. A crucial element of these experiences is the vital role of GPs, who provide practical support and emotional understanding. Easy access to healthcare professionals enhances the sense of control and well-being of older people living with frailty, allowing them to define their identities beyond health conditions. However, barriers such as limited access and poor communication can lead to feelings of helplessness and diminish the quality of interactions with healthcare providers. Creating a welcoming and respectful atmosphere in healthcare settings is thus essential for improving the experiences of older people living with frailty. When healthcare environments prioritise comfort and clarity, these individuals report greater satisfaction and a stronger sense of individuality. Everyday interactions with healthcare providers greatly influence how older people living with frailty feel recognised as unique persons rather than just patients within the system. Simple practices, such as involving patients in care discussions and allowing ample time during home visits, enhance their sense of control. This supportive environment fosters human connections and empathy, which are critical for preserving the dignity and well-being of older people with living with frailty and forming trusting relationships with healthcare providers. Trust is established through open and respectful communication, which is vital for facilitating caring practices, including information sharing, choice, and shared decision-making that empower these individuals. Breakdowns in these areas can significantly undermine the fragile caring relationship that has been developed. Therefore, the insights from Theme Two of this study highlight the importance of combining practical accessibility with relational and emotional support in healthcare. It underscores that older people living with frailty require acknowledgement and validation of their experiences to enhance their overall sense of control and well-being. The quality of relationships and interactions within the healthcare system serves as foundational elements that can meaningfully expand their sphere of influence. These relationships are nurtured through the interactions of older people living with frailty with healthcare professionals, both in the hospital and at home.

5.4 Theme Three: The home as a secure base for navigating an insecure future

The current theme highlights the significance of older people living with frailty remaining in their homes for as long as possible to maintain their sense of control amid an uncertain future. I have divided this theme into three categories: uncertainty about future healthcare, sense of control and future health-determined plans, and negotiating control over healthcare within the home environment.

5.4.1 Category 1: Uncertainty about future healthcare

Many older people living with frailty, as highlighted in the interviews, expressed feelings of uncertainty regarding their future healthcare and a general sense of limited control over what lies ahead. They specifically voiced concerns about their physical and cognitive functionality, with several participants anticipating further decline in their conditions. Likewise, some older people living with frailty hoped *'they would not become very frail, immobile, or lose their memory'* (Kate, Ln 653). They referenced others with similar conditions who had faced more severe declines. Additionally, there were concerns that their medications might become less effective in managing their health, particularly for those living with Parkinson's disease or other terminal illnesses such as cancer.

> *"….as you become ill, you get to know more people who are ill as well, and most people seem to go downhill, and they accept the condition, and they lose a lot of hope, and they lose a lot of doing things, and this is one thing I am wondering what happens in the future. Because uncertainty is the future, well, anybody's uncertainty is the future because you do not know what will happen this afternoon. But with this disease of Parkinson's, there is the great not knowing because the medication only has a sort of shelf life because it loses its poignancy, its potency, its power with time. So urm… so you can get caught up in that. But generally speaking, Parkinson's creates uncertainty about your physical situation because there is a phase in Parkinson's where you get what they call freezing, i.e., the messages from the brain do not reach the leg. So, you are standing at the dishwasher, for example, you are unloading the dishwasher, and then emptying it, you are bending over, you are trying to get your balance because balance can go as well with Parkinson's, and then suddenly you*

> *need to move your left leg just to get the balance –Or to move around, and it does not move. Then it is stuck. So, you lose your balance. Yeah, I am already at that stage"* (Peter, Ln 303).

The decline in health, combined with an uncertain future, often resulted in heightened anxiety among older people living with frailty. They tended to adopt a short-term perspective on life rather than considering the long-term. This time-limited viewpoint stemmed in part from the belief that their health conditions were likely to deteriorate further, leading them to feel they might not have much time left. They hoped to be fortunate enough to avoid certain complications and limitations, and if such issues did arise, they wished for them to be manageable. This mindset not only increased their worries about their own future healthcare and well-being but also prompted concerns for their loved ones.

> *"I was at the Bridge yesterday afternoon, and a piece of cake went the wrong way, which is very prone to happen with Parkinson's. That worries me because that means that sooner or later, I am going to have to have a tube put in my stomach, I expect. But with a bit of luck, it will not happen to me. Just because it happens to one does not mean. So, I was embarrassed by that because half the people there did not even know I had Parkinson's. I had not told anybody"* (Nocole, Ln 718).

However, some older people living with frailty displayed a positive outlook and maintained high hopes for the future despite their concerns. They expressed contentment with life as it unfolded and were poised to confront any challenges that arose. Additionally, they felt a deep sense of gratitude for their experiences thus far and chose to approach the future one day at a time. Some actively sought to assert control over their future health and well-being by adopting healthy lifestyles, such as refraining from smoking, moderating alcohol consumption, and engaging in regular exercise. Likewise, several older people living with frailty intended to engage in *'brain work'* to cope with their condition, as they believed they were *'not ready to die yet'* (Julian, Ln 307).

Moreover, although many older people living with frailty sensed they were nearing the end of their lives, they successfully came to terms with this reality and took steps to address various end-of-life matters. They expressed a willingness to *'jog along whatever was handed out'* (Jessica, Ln 520) rather than *'sitting around all day worrying and crying'* (Lyndsey, Ln 858). This mindset was prevalent among those facing terminal and incurable illnesses, such as multiple myeloma. These individuals relied on effective pain management and held onto the hope that their conditions might improve. In preparation for the future, they made crucial decisions about their end-of-life care, including preparing wills and powers of attorney.

> *"What else annoyed me as far as health goes? I am not even annoyed urm that I have got blooming Parkinson's. I have signed I do not want to be resuscitated, and I do not want to be artificially fed. In other words, I do not want anything jammed down my throat to stop me in the hope that I will start breathing again because I will be a cabbage anyway, and I do not want to be a cabbage. But urm… my daughters already pointed out that if*

> *you have anything likely to cause me to stop breathing, I would have called an ambulance or something by then. The first thing is to keep you alive and then look at the paperwork, so the doctor signed it for me, and I have got it written out by hand in my handbag"* (Nicole, Ln 554).

Category 1 reveals a complex interplay between anxiety, uncertainty, and resilience in facing future healthcare among older people living with frailty. Many of them expressed a profound sense of helplessness regarding their declining physical and cognitive abilities, often projecting fears of further physical and mental deterioration. This existential anxiety is particularly pronounced among those with chronic conditions like Parkinson's disease, where symptoms such as freezing can lead to a disembodied experience of their bodies, creating feelings of loss and instability. As Peter described, the sensation of being unable to move his leg while standing reflects a deeper fear of being trapped within one's own limitations, evoking feelings of vulnerability and a yearning for control. Despite these challenges, some older people living with frailty maintained a hopeful outlook, demonstrating a remarkable capacity to adapt to their circumstances. This positivity can be seen as a form of resilience, as they strive to embrace life one day at a time. Their efforts to engage in healthy lifestyles and 'brain work' signify a desire to exert some control over their future healthcare, reflecting the human inclination to seek meaning even in the face of decline. Julian's sentiment of not being 'ready to die yet' illustrates a persistent will to live, highlighting a tension between accepting one's condition and wanting to defy it. Similarly, many older people living with frailty appeared to reconcile with their mortality, addressing end-of-life issues with a sense of pragmatism. The readiness to make decisions about resuscitation and palliative care reflects a conscious engagement with their health trajectory. This acceptance of life's unpredictability can foster a sense of peace, as expressed by Jessica's contentment with whatever life offers. This category underscores a perspective on ageing, wherein personal experiences of frailty are not just marked by loss but also by strength, resilience, and a profound relationship with their evolving selves and futures. In this way, the experience of living with frailty becomes not merely about decline but about navigating the complexities of existence in the face of uncertainty. Many older people living with frailty feel that staying in their homes for as long as possible might be the best way to achieve this.

5.4.2 Category 2: Sense of control and future health-determined plans

Most of the older people living with frailty who were interviewed expressed a strong desire to remain in their own homes for as long as possible rather than transition to institutional care facilities such as nursing homes. They anticipated that their family members would honour this wish, with some individuals being quite firm about it, saying, *'I want to stay here…yeah, I do not want to go into care until it takes me screaming and shouting if I would go'* (Lyndsey, Ln 580).

There were several reasons why older people living with frailty preferred to remain in their own homes. Firstly, many wished to stay close to family, benefit from their support, and *'…feel as though they were still normal for as long as they could'* (Lyndsey, Ln 587). Additionally, the home environment offered a safe and supportive space for managing various health-related challenges. Peter, who lived with Parkinson's disease, described his home as *'my world'*. He expressed that it is *'a place I know and feel safe, the place that I can retreat to'* (Ln 616). For most older people living with frailty in this study, the home was a familiar sanctuary where they could *'go away from... but liked to come back to'* (Peter, Ln 628), granting them the freedom to live as they wished.

Additionally, certain homes offered features such as stairs that enabled older people living with frailty to exercise and stay active. Likewise, some locations provided convenient access to essential services, including public transportation, pharmacies, hospitals, and community centres, where older people living with frailty could easily connect with friends and neighbours. Moreover, several homes were ideally situated near natural attractions like rivers and forests, encouraging outdoor activities like walking. Proximity to these amenities allowed older people living with frailty to *'feel like they were still in something'* (Lynnet, Ln 620) and at ease, which was essential for their overall well-being.

Older people living with frailty expressed a desire to maintain a sense of familiarity by staying aware of their surroundings so as to '*not lose themselves somewhere along the way'* (Lyndsey, Ln 594). Caregivers, such as spouses and children, along with practical aids like electric chairs and walkers, enabled them to retain control and confidence within their home environment. Furthermore, many older people living with frailty preferred to remain in their homes due to their experiences with the drawbacks of institutional care. Having previously stayed in a care home, some had encountered a loss of autonomy, neglect, and other unfavourable care practices. Consequently, some older people living with frailty were saving money to avoid selling their homes in the future and having to resort to institutional care.

> *“from the hospital, they put me into a nursing home……..the [nursing] home I was in urm… I did not have a hair wash, I did not have a shower, it was disgusting….. And, of course, I was not allowed visitors at night; you had to ring and make an appointment for a visitor - one visitor. I have three children and great-grandchildren, who all want to come and see me, but no. So, we accepted that, and this day, I had not got any visitors, and I was just sitting in my room watching my television, and Paul [son] came knocking at the window, like outside…..and he said…mum, get yourself packed up, pack up all your bits and pieces, he said, we are coming to take you home. I said, you what? I said, you cannot do that, he said, can’t we?....he said, go and pack all your bits and pieces together, and we are taking you home. [I felt] Astonished, I could not believe it and anyway, they did, they got a wheelchair, took me down to reception where all the staff was and urm… they loaded the car up, put me in the car….. And I could not wait to get home, and when we got here, I told the boys, that is it, you can put the kettle on, make yourself a cup of tea or coffee. I said, I am going in the shower, and I shall be there sometime because I am going to shower several times, *laughs* ….”* (Julian, Ln 426).

The above finding suggests that some older people living with frailty preferred the option of a live-in carer over residing in a nursing home, as the latter can be quite intimidating--*‘they frighten the bloody life out of me’* (Alex, Ln 123). This sentiment was further reinforced by the perception that staying in a hospital or nursing home diminishes their sense of control, as they must depend on nursing staff for essential needs like meals and medication. Additionally, negative interactions with certain care staff contributed to this viewpoint. Overall, these findings indicate that the standardised structures and routines inherent in formal care, such as designated meal times common in nursing homes, can significantly impact the autonomy of older people living frailty, making them prefer to continue managing their healthcare in the home environment.

> *"I mean, it is unbelievable [difference between living in a nursing home and staying at home]. Yeah, because urm… there, you have got to rely on them [nursing staff] coming around with your tablets. [Yet] you are used to taking your tablets yourself. You know what to take. Urm… and it is the same with, like, when you have something to eat, urm, they always come around with a menu….*(Julian, Ln 473).

Many older people living with frailty adapted their living environments to better suit their needs as they aged and became more frail. These adjustments aimed to enhance their sense of control by addressing current and potential future limitations, enabling them to remain in their homes for as long as possible. Key modifications to create a more suitable home environment included replacing bathtubs with showers and wet rooms, as many older people living with frailty found it increasingly difficult to step into a tub. Other changes included opting for higher double beds, installing grab rails in bathrooms and staircases to prevent falls, and adding garden ramps to accommodate mobility aids such as scooters.

Moreover, some homes were enhanced by acquiring appropriate chairs that facilitated easy sitting and standing and securing large wardrobes that could be used for support when getting up from bed. Finally, older people living with frailty often created extra space in their homes, including a downstairs bedroom and bathroom, in anticipation of future challenges. They planned to relocate downstairs when they could no longer manage the stairs, as illustrated by Priscilla, an 80-year-old participant who lived with her husband.

> *"No, I do not really think about it [moving away from home]. I mean this, this is our home, this is where – we will not be moving again. Urm and I shall live here as long as possible. One of the reasons we bought this house is because there is a bedroom and a bathroom upstairs, and a bedroom and a bathroom downstairs. And we have got all, as you can see, plenty of space. So, if it came to me that I could not manage the stairs, I would move downstairs to the downstairs bedroom and bathroom. So, it is not an issue"* (Priscilla, Ln 342).

Some older people living with frailty chose to purchase homes close to essential services, such as pharmacies, supermarkets, and hairdressers, in anticipation of future challenges. Additionally, others planned to invest in services that will assist them as their ability to remain at home declines. As Nicole expressed, *'If I cannot do it myself, I buy help in'* (Ln 591). This aspect includes hiring professionals like gardeners, decorators, and plumbers to make necessary modifications to their homes at the appropriate time.

However, some changes in the living environment, such as the addition of ramps, impacted the sense of control among older people living with frailty, particularly those who struggled to use mobility aids. Likewise, many older people in this demographic expressed a desire to modify their homes to enhance their sense of autonomy, such as by installing stairlifts. However, financial limitations often posed challenges to implementing these improvements. Furthermore, some older people living with frailty felt that their home environment undermined their sense of control and influenced how others perceived their autonomy. For example, older people residing in residential houses may be viewed and treated as elderly simply due to their living circumstances, as highlighted by Barbra, who resided in a residential house.

> *"It is very, very simple, actually, it is how people treat you. I have had urm, people decorating and doing jobs for me in the properties I have had on my own, urm… and… it has been very balanced, but there [retirement homes], because they are coming, this is my submission, that they are coming into a flat full of old people, they treat you like an old person. Like you do not have a mind of your own and do not have opinions of your own, they try to railroad you into having the kitchen renovated, and you know, bang, bang, bang, bang, and I know it is their job, and you know it is stopped for COVID, but I have been made aware of the age thing from that point of view"* (Barbra, Ln 494).

The above findings suggest that economic disparities may influence the progression of frailty and subsequently affect the well-being of those living with it.

Furthermore, some older people living with frailty expressed concerns that the rules in residential houses significantly impacted their independence. This viewpoint sheds light on why some individuals in retirement homes felt a greater sense of autonomy; their ownership of these homes contributed to this feeling, a privilege not granted in residential or nursing homes. Additionally, some older people living with frailty reported a lack of safety in their residences, often worrying about leaving windows and doors open. This anxiety stemmed from a diminished trust in others, especially the neighbours, which contributed to their discomfort. Moreover, certain features within their home environment, such as doors, imposed additional limitations on older people living with frailty. For instance, some individuals felt unable to leave their homes without assistance to open the door and ensure it would not inadvertently close behind them.

> *"I do not [move in and out of the door] unless someone is with me. It is as it is, if I want to get in, I want to have someone with me….if I go out with Adam [son], he will always open the door for me and make sure it does not close on me"* (Jessica, Ln 469).

In summary, category 2 reveals the strong desire of older people living with frailty to remain in their homes instead of moving to institutional care facilities. This preference stems from a deep attachment to personal autonomy, familiar settings, and social support. The findings highlight a commitment to independent living, viewing their homes as vital spaces that preserve their identity and freedom. Key factors influencing this preference include proximity to family, which provides emotional security and support during health challenges. The home is also seen as a safe and familiar environment that allows individuals like Peter, who lives with Parkinson’s, to maintain some control over their lives. Acknowledging the home as a comfortable place to return to reinforces the significance of familiarity in promoting a sense of control and well-being in older people living with frailty. Furthermore, home environments often contain features that encourage active lifestyles and social engagement, such as easy access to community services and nature. In addition, the negative experiences with institutional care, including neglect and loss of autonomy, foster a fear of nursing homes. The contrast between the rigid schedules of such facilities and the freedom of home life underscores the fundamental human desire for control and dignity, which many older people living with frailty feel can be jeopardised in institutionalised care settings.

Overall, category 2 emphasises the need for caregivers and policymakers to recognise the importance of supporting older people living with frailty in maintaining their autonomy. By fostering ageing in place, healthcare services can enhance their sense of control and well-being. This perspective reinforces the notion that the home is more than just a physical space but a vital aspect of their identity and life satisfaction. Consequently, healthcare services need to support older people living with frailty so they can remain in their homes for as long as feasible. To achieve this, healthcare professionals may collaborate with them to create a home environment that fosters their sense of control rather than hinder it.

5.4.3 Category 3: Negotiating control over healthcare within the home environment

Many older people living with frailty expressed a preference for receiving healthcare services within the comfort of their own homes. This choice is particularly significant for those unable to leave their residences. For some participants, the home environment fostered a sense of control over their healthcare, although it also presented certain challenges for others. Ultimately, the safety, comfort, and convenience of their home settings were critical factors influencing the decision of older people living with frailty to receive healthcare at home.

> *"Well, it would be helpful if they [healthcare providers] come to me to take blood tests and things instead of always having to get someone to come and take me across the road [to the hospital]. Urm… but I think they are arranging that because I am down as housebound. This is not strictly true because, well, I went out today. It is less effort [healthcare professionals coming over] on my part. Because it does make my legs ache walking around, and they are the ones pushing to do it, too. So okay"* (Jessica, Ln 544).

Older people living with frailty engaged in various sessions with healthcare professionals, including nurses, physiotherapists, and therapy assistants, in the comfort of their homes as part of their rehabilitation and treatment. Additionally, some of them had exercise equipment at home to maintain their physical activity and engagement. Jessica, a 71-year-old woman who lived alone, shared her experiences regarding this approach.

> *"It [treadmill] is there in case I can use it because I used to go on it every day. Urm, but I cannot walk fast enough to go on it yet. So, I am running it, and then I look at how fast I have to walk to get on it, and then I practice walking at that speed. I am determined; eventually, I will be able to get on it again, so - hence doing the cubii work"* (Jessica, Ln 411).

Healthcare professionals collaborated with older people living with frailty at home to implement care interventions aimed at helping them remain in their homes and avoid hospitalisation. Many of these professionals emphasised the importance of early healthcare intervention and prevention strategies to keep individuals out of the hospital. They viewed control and independence as vital, focusing on what matters most to the patient in maintaining their happiness at home. This perspective stemmed from the understanding that visiting a hospital, particularly the Emergency Department (ED), often resulted in a loss of autonomy for older people living with frailty. During the COVID-19 pandemic, Day Hospital staff enhanced their home care engagement with older people living with frailty by conducting home visits and community outreach programmes. Healthcare professionals deemed this approach critical, as it granted older people living with frailty greater control and convenience by eliminating the need to travel to the hospital during challenging times. Additionally, seeing older people living with frailty in their own homes allowed healthcare professionals to gain deeper insights into their lives. As Boris noted, *'they are different people when they are here* *[hospital] and at home'* (Ln 573), highlighting how individuals feel more in control in their home environment. Moreover, this direct observation enabled healthcare professionals to identify the specific challenges and resources present within the home setting. As a therapy staff pointed out, understanding this context was considered essential for providing appropriate support and fostering independence.

> *"……at present, we have referrals from GPs urr other professionals. Urm, you know we get lots of different referrals and consultants, things like that. So, what happens is the admin people process them, and then they book an assessment for the qualified staff; the qualified staff will go out, and at the moment, it is assessing them in their home - so, it is a good way to see someone in their own home, to see what the problems are. They are much more relaxed, which is more true than having it in a clinical area. Then, we will decide whether we have any goals for them, which might be to stop them from falling, help their mobility, help their transfers, and look at their cognition and mood. We set the goals to decide how many sessions they need urm, if possible. Now, we are having them come up to a maximum of four sessions at the Day Hospital here, or urm, if, for some reason, they would be better to be seen in their own home, for example, if they have memory issues, then we will see them at home……we decide on the complexity of their problems, and whether they need to be seen by a rehab assistant or a [more] qualified one"* (Justine, Ln 58).

However, home visits can present challenges in the provision of healthcare services. Feedback from healthcare professionals suggested that older people living with frailty may perceive these visits as intrusions into their personal space and privacy. Some professionals observed that these individuals sometimes feel like *‘their homes are no longer their own’* (Lilian, Ln 109), as they frequently experience a steady stream of uniformed individuals entering and exiting. This perception can negatively affect their attitudes toward home-based healthcare. Consequently, it might be essential to educate healthcare professionals about the significance of personal space and privacy, as well as the necessity of approaching these situations with sensitivity.

Additionally, many healthcare professionals believed outpatient care was less effective than inpatient or hospital care. This perception was partly influenced by the sometimes unsafe home environments where discharged patients were occasionally *‘left overnight [by the paramedics], stuck in the bed or in the chair until someone came the next day’* (Justine, Ln 130), particularly for those living alone. Consequently, the healthcare professionals noted that the Day Hospital offered a safer treatment environment for older people living with frailty than their homes. This perspective is also linked to the fact that the Day Hospital has a range of specialised exercise equipment that can support older people living with frailty, which is often not available or practical in a home setting. Likewise, some healthcare professionals encountered difficulties working in clients’ homes due to factors such as location, social circumstances, or the clients’ discomfort with the clinician’s recommendations.

Moreover, during home visits, healthcare professionals occasionally found themselves at odds with informal caregivers, undermining the professionals' influence and straining the overall care relationship. Consequently, to maintain their professional authority and use specialised equipment effectively, healthcare professionals preferred conducting client assessments at the Day Hospital rather than in their homes, as Angel, one of the therapy staff, explained.

> *"Urm and you kind of have a little bit more control in this [Day Hospital] environment, there are a few more sort of safety aspects associated with coming in here, whereas at home, you have got to keep risk assessing what you are doing and you are a bit limited, you cannot be tapping a balloon about everywhere *laughs*. You know, urm and people's homes are their homes. You cannot necessarily change the furniture around just to suit your therapy session. So, coming in here is much easier"* (Angel, Ln 433).

The above finding suggests that healthcare professionals desire control over the care process. However, this control becomes less defined when they provide care in clients' homes, as '*the boundaries are a bit more vague'* (Stella, Ln 434). As a result, there exists an underlying struggle for control as healthcare professionals strive to assert their authority outside their usual environment. For example, many older people living with frailty faced difficulties performing prescribed exercises at home due to the accompanying pain and exhaustion. Furthermore, some older people living with frailty felt that the adjustments suggested by healthcare professionals to their home environment did not align with their actual needs. A notable instance involved an occupational therapist bringing a soft bed for an older person with a fractured vertebra, which ultimately rendered it unusable. Similarly, other older people living with frailty found it challenging to utilise recommended mobility aids, such as a small wheelchair, in their homes. Other individuals felt uncomfortable with the idea of support aids, like bathroom rails and contraptions on the bed, as they perceived these as indicative of disability. They felt that healthcare professionals lacked understanding of how such changes would impact their lives. Nevertheless, healthcare professionals maintained that these interventions were essential for the well-being of older people living with frailty. This situation highlighted a clash of perspectives regarding what constitutes appropriate healthcare within the home environment, as discussed by Teresa.

> *"I was really upset when this one source or process was coming into the home and giving me aids in the home. So, i.e. I put up rails in the bathroom and some contraptions on my bed to help me get out of bed. I just stood in the middle of the room and cried. And then they moved in some kind of stool with a sitting up thing on it. I do not think that the people who came in urm… are aware of how that might affect a person when they are an able person and they are suddenly given things for a disabled person, and when they do not see themselves in that realm. It is very upsetting. So, I think I could still get by without the aids, but it is the way they would. I mean, they stayed on the two people who came stayed on when they saw I was distressed, but I think they should have more training in how to*

> *approach the whole situation. Urm… they cannot just breeze in … and make the alterations around the home without realising its profound effect on that person. Yeah, she [therapy staff] sees [in the home], and she says, oh, you need this, this, and this, and would you like this, this, and this? I did agree…. But then I did not realise how whacking big you saw the hold that, what did you call it, rails in the bathroom. Urm and they wanted to put urm, in my back path, in my back garden the step down was too large, so I managed to persuade them to make the step better rather than a path with a rail which would make me feel like I was heading for a wheelchair, and I do not feel I am. Or I do not wish to feel or think that way. But yeah, so it needs a bit more thought"* (Teresa, Ln 31).

To ensure that healthcare professionals effectively conduct home visits for older people living with frailty, it is crucial to negotiate for control with the older person in their home environment. This can be accomplished by respecting the autonomy of older people living with frailty and seeking their permission before accessing or making any changes to their homes. Encouraging older people living with frailty to actively participate in their care process is vital, as it enhances their sense of independence and helps prevent feelings of helplessness. Therefore, it is important to provide older people living with frailty with advance notice before visiting their homes, as they may have multiple visitors, including carers. This notice allows them to prepare for the healthcare professionals' arrival. Ultimately, home care should prioritise the aspects that older people living with frailty value and consider important for maintaining their independence at home, as highlighted by one therapy staff.

> *“Well, I think the first thing we all need to remember is that we are so used to just going in [patients’ homes] and just doing certain things, and we forget to some people that might feel… urm… difficult and alien that someone comes into your bathroom and… you know, starts to get you undressed. So I think it is important to say to people, you know, I am helping you with this, but would you like to do this bit yourself?” so that… it does not look like, do you know what I mean, like you are not doing everything, even if it is just taking the flannel and doing the face, even though it takes a few moments to get the flannel and give it to somebody, you know just some small part of the task that someone can join you in it, then it is good to let them join you in it, I think. So, I think that that helps. And we need to remember we are a visitor in people’s homes, you know, so you know, the importance of saying, is it all right if I go and look at your bathroom and your shower? Because I need to see whether I can suggest anything to improve it? you know it is important that we ask permission and that you know we do not just kind of move about the home as though…. Yeah, I am in a rush, and I just need to get this done, you know. And honestly, you are always in a rush, but you must give someone the impression that you have time. So, part of it is allowing people to join you in some of the things where it is possible, and having a discussion with people and saying, is it all right if, or saying, I can see, this is difficult, isn’t*

> *it, have you got any thoughts about how we can approach this better, so sometimes it is about trying to bring people into the situation, rather than be done unto if that is at all possible"* (Lilian, Ln 224).

Category 3 discusses the experiences of older people living with frailty as they navigate healthcare services within the intimate context of their homes. For many, home healthcare represents not just a medical service but a significant aspect of autonomy and control over their lives. The descriptions highlight a desire for comfort, safety, and convenience and a bittersweet recognition of physical limitations. Jessica's reflections reveal a duality; while the home setting can promote independence and lessen the physical burden of travel to hospitals, it also raises awareness of her frailty and the efforts required to remain active. The treadmill in her home symbolises hope and determination, embodying her struggle against the constraints of frailty while illustrating the inner drive to maintain a sense of normalcy. As a result, the home environment fosters a sense of self that is more intact compared to the clinical atmosphere of hospitals, where patients often feel stripped of control.

Furthermore, healthcare professionals perceive home visits as a valuable opportunity to engage with older people living with frailty in their true environments. Yet, they encounter challenges like disagreements over appropriate care and the potential for patients to feel their personal space is being violated. This scenario highlights the complex interplay between care and privacy, suggesting that the presence of healthcare workers can simultaneously provide support and disrupt the sanctity of home care. Justine's observations underscore the need for sensitivity and adaptability in home care settings, advocating for a tailored approach that respects the individuality and dignity of older people living with frailty.

Consequently, category 3 reveals that healthcare services within the home are not merely a care arrangement but a profound interaction where personal, existential, and professional dimensions converge. The home environment becomes a stage for negotiating personal identity, agency, and professional control, challenging healthcare professionals to recognise the nuanced relationship older people living with frailty have with their spaces and, ultimately, their sense of control. The overarching pursuit of dignity, control and well-being in healthcare practices takes on a deeper significance in the home setting as older people living with frailty strive to maintain their autonomy and privacy while adjusting to healthcare services.

In summary, Theme Three explored the concept of home as a sanctuary for older people living with frailty in the midst of an uncertain future. Many of these individuals envision a future marked by further decline and expressed fears of losing mobility or cognitive function. Despite the challenges, some older people living with frailty demonstrated remarkable resilience by adopting a positive attitude, living a healthy lifestyle, and modifying their home environment to make it more suitable for future declines. The findings indicate a strong preference among older people living with frailty to age in place rather than transitioning to institutional care settings such as nursing homes. Day Hospital staff provided care interventions to help them maintain this sense of place and avoid dislocation.

However, home care entails navigating control over the healthcare process. On the one hand, older people living with frailty sometimes perceive the care process as not responsive to their individual needs. On the other hand, healthcare professionals struggle to assert professional authority in the home environment as the professional boundaries often become blurred. These findings might suggest a greater burden of home caregiving on the part of healthcare professionals. They might find it more stressful to provide care for older people living with frailty in the home environment, impacting the well-being of the staff and individuals receiving care. As a result, healthcare professionals need to strike a balance by working closely with older people living with frailty and their families to deliver personalised care interventions in the home environment to help older people living with frailty stay independent and reduce the likelihood of needing to go to the hospital or move to institutional care.

5.5 Overall sense of control as a dynamic relational experience

The above section discusses the idea of control over healthcare services for older people living with frailty. It suggests that these individuals face challenges related to a shrinking sphere of influence in their daily lives due to physical changes and limitations. They may struggle to maintain independence and engage in everyday activities, reducing their sense of autonomy. The shrinking sphere of influence is further diminished by uncertainty about the future and challenges within the healthcare experience. However, the positive aspects of the healthcare experience, such as easy access to healthcare services and support to stay at home for as long as possible, enhance the sense of control for older people living with frailty and expand their sphere of influence, as summarised in Figure 2.

Figure 2: Model of a sense of control in healthcare for older people living with frailty

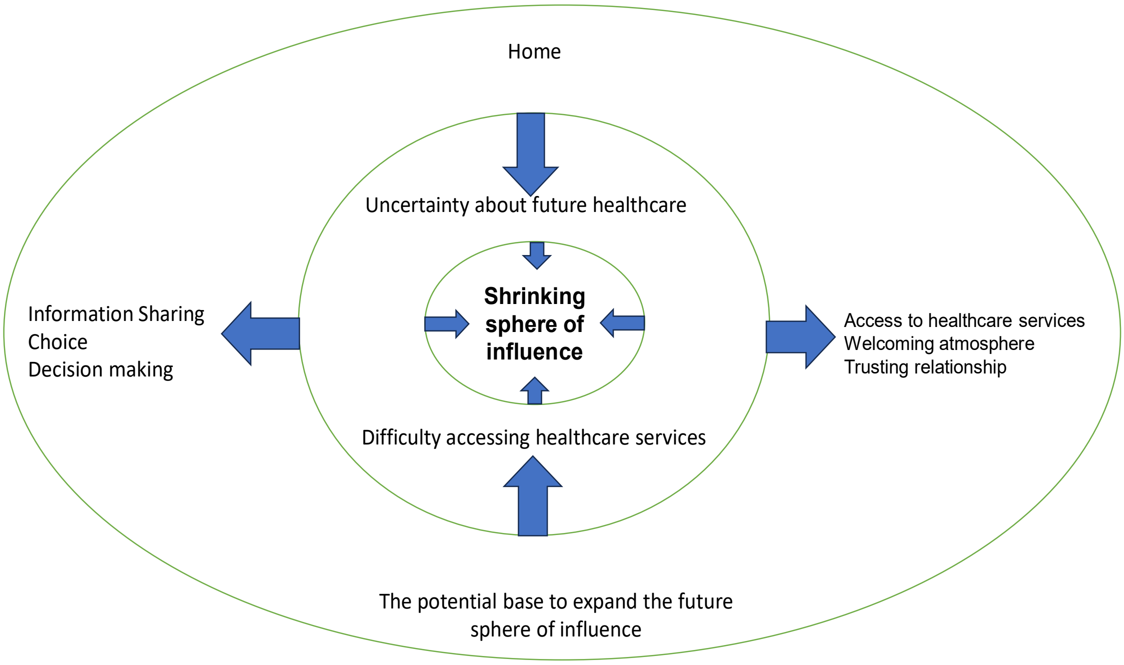


Figure 2 summarises the sense of control older people living with frailty have over their healthcare. The sphere of influence depicted in the figure is not fixed and changes depending on the healthcare experience of the older person living with frailty. When older people living with frailty face challenges in accessing healthcare services or are uncertain about future healthcare services, their sphere of influence shrinks. Conversely, their sphere of influence expands when they receive healthcare services that provide a welcoming atmosphere, trustworthy and caring relationships, information sharing, involvement in decision-making, and support to stay at home.

Chapter 6 Discussion

6.1 Introduction

In this chapter, I will discuss and synthesise the findings of my study, integrating them into the broader context of existing literature. I will also reflect on how my perspectives, values, actions, and biases influenced the research journey. Additionally, I will address both the strengths and limitations of the study, offering an assessment of its implications for research and practice. I will then link my findings to the current healthcare service context, highlighting their relevance and potential impact. Finally, I will outline key aspects of the study that I would approach differently in the future.

This qualitative study explored the lived experience of control and well-being of older people living with frailty in healthcare services in southern England. It aimed to provide new insights into this under-researched area by exploring the experiences of older people living with frailty and the views of their healthcare providers. The research uses a hermeneutic phenomenological approach to study the lived experience of control and well-being and reflect on its essence (van Manen 1997a). Figure 2 above shows that there are many factors at play. I have discussed these themes using the lifeworld framework, considering dimensions such as embodiment, spatiality, intersubjectivity, temporality, and mood that shape a sense of control and well-being in older people living with frailty. Where appropriate, I have also referred to the dimensions of the humanising care framework.

I am going to discuss the embodied experience and diminished sphere of influence in older people living with frailty, the impact of healthcare relationships on intersubjectivity and sphere of influence in older people living with frailty, the influence of temporality on the sphere of influence for older people living with frailty, the influence of spatiality on the healthcare sphere of influence and the impact of mood on the sphere of influence in older people living with frailty. I chose these aspects in order to discuss my findings in the context of the lifeworld framework.

6.2 Embodied experience and diminished sphere of influence in older people living with frailty

The findings of the study indicate that older people living with frailty have a diminished sphere of influence due to age and disease-related declines. The declines were primarily manifested in bodily deterioration, which affected their everyday activities. The body is central to our experience of the world and allows us to engage in daily activities and interact with others (van Manen 1997a; Galvin and Todres 2013). Our experiential well-being is also linked to our bodily experiences in the world, as the body helps to communicate authentically about ways of living in the world (Todres and Galvin 2010; Galvin and Todres 2011). The body can be understood from two perspectives: the lived body *(Leib)* experienced from the first-person perspective, and the corporeal body *(Körper)* experienced from a third-person standpoint (Grīnfelde 2018; Fernandez 2020). Therefore, it is crucial to understand people’s embodied experiences by looking at the body from these perspectives (Grīnfelde 2018).

Humans have different embodied experiences often shaped by illnesses and interactions with others, including healthcare providers (Fernandez 2020). In other words, embodiment is a form of awareness people hold as uniquely connected to themselves, others, and the world (Pound and Jensen 2018). However, the body's being-in-the-world is sometimes marked with experiences of disruptions related to pain, discomfort, and loss of function manifested in the form of falls and changes in the pace of doing things, which signify the fragile limits of human embodiment (Todres et al. 2009; Svenaeus 2011). The current study's findings indicate that physical declines and restrictions in the body can lead older people living with frailty to forfeit daily activities and depend on others. These findings support previous research that shows how age and disease-related declines impact physical functioning in old age (Kim et al. 2017; Makizako et al. 2017; van Rhyn et al. 2020, 2021b). The declines limit one's sense of control and autonomy over bodily functions and daily activities, negatively impacting dignity and quality of life (Rodríguez-Prat et al. 2016; Busch et al. 2019).

The body is often taken for granted until changes occur that may affect a person's ability to interact with the world (Martin and Twigg 2018; van Rhyn et al. 2020). These changes, often arising from illness and pain, create a feeling of *"unhomelikebeing-in-the-world"* (Svenaeus 2011, p.335). As a result, the disruption of the seamless integration of the body and the lifeworld makes people pay more attention to the body and become more aware of the relationship between the body and the world (Thomas and Wardle 2014; Dahlberg 2019; Fernandez 2020). Ellis-Hill et al. (2000) suggest that stroke survivors often feel detached from their bodies, leading to a loss of bodily control and reliability, and this split between self and body becomes a focus of their lives for at least a year after stroke, as individuals struggle to regain control over their bodies.

The focus on the body, which is occasionally gradual, highlights the ‘bodily dys-appearance,’ as the body, once a medium of action and experience, now presents a challenge, bringing the silent body into our awareness (Fernandez 2020). Carel (2012) argues that the previously taken-for-granted body becomes saliently thematised as the problem as people become more concerned and anxious due to bodily changes and environmental limitations. For example, many older people living with frailty in the current study highlighted how they had modified their home environment, such as installing grab-rails in the bathrooms and staircases to prevent falls. Such changes occur because the experience of illness or disability alters an individual’s perception of their body within the environment, transforming previously supportive aspects into perceived obstacles that impede functioning (Fernandez 2020).

However, bodily disruptions are perceived not only from an individual’s perspective but also through societal views of our bodies (Groven et al. 2013). The findings indicate that older people living with frailty, especially those with Parkinson’s disease, often feel embarrassed by their tremors during social gatherings. The fear of embarrassment can lead them to avoid social events altogether, resulting in a sense of their bodies becoming invisible within society. Such an objectifying perception from others contributes to the experience of ‘social dys-appearance’ in social interactions (Fernandez 2020). Therefore, from a humanising care perspective, it is essential to acknowledge the insiderness of human embodiment, which is defined by the uniqueness of each person's body and their varied positive and negative social, cultural, and familial experiences in the world (Scammell and Tait 2014; Todres et al. 2014; Ozolins et al. 2015).

Recognising insiderness is vital because a reductionist view of the body that emphasises the bodily parts, signs, and symptoms, including diseases, may mean overlooking the broadest and most complex social, psychological, and environmental embodied relationships (Todres et al. 2009; Galvin et al. 2018; Pound and Jensen 2018; Galvin et al. 2020). Similarly, the objectification of others, often through the body-object gaze, takes the body's uniqueness away and affects the self-esteem and perception of people experiencing social dys-appearance, which is potentially dehumanising (Todres et al. 2009; Todres et al. 2014). Consequently, such reductionist and objectifying experiences often lead to isolation, hinder empathy and human connectedness and impact people's sense of belonging and embodied dignity (Todres et al. 2009; Galvin and Todres 2015).

Additionally, there exists a link between embodiment and achieving desired outcomes in old age (Lynch et al. 2023). However, this relationship is affected by both disease and age-related physical changes, especially as individuals grow older. In the current study, many older people living with frailty perceived their bodies as less significant, even during the performance of simple daily tasks within their home environment. This perspective has important implications for older people's sense of control. As older people encounter challenges in engaging in daily activities due to physical limitations, they frequently experience a diminished sense of primary control, which in turn leads them to depend more on compensatory secondary control strategies (Hall et al. 2010). This observation explains why older people who possess greater confidence and satisfaction in their bodies often exhibit a higher sense of primary control (Watt et al. 2017). Such individuals are more adept at engaging in behaviours that enable them to influence their environment to fulfil their physical, physiological, and social well-being needs (Haynes et al. 2009). These behaviours may encompass self-care activities, such as exercising and seeking healthcare services, which ultimately help to expand their sphere of influence.

6.3 The impact of healthcare relationships on intersubjectivity and sphere of influence in older people living with frailty

The lifeworld perspective suggests that reality is always in relation to others, and individuals coexist with others in a mutually intelligible way (Todres et al. 2007). Intersubjectivity as a lifeworld dimension refers to the interactions and relationships people develop in their everyday lives (Galvin 2010; Ashworth 2016). This experience is linked to interpersonal dignity, emphasising one’s interpersonal value and worthiness, where individuals gift one another as intrinsically ‘mattering’ to each other within a community (Galvin and Todres 2015).

Research indicates that older people are often less visible in society and experience a diminished sense of control and sphere of influence in their lives (Scharf et al. 2005; Walkner et al. 2018; Menezes et al. 2023). Likewise, older people living with frailty frequently report feelings of isolation and encounter negative stereotypes that hinder access to essential services (Todres et al. 2009; Galvin and Todres 2013). The findings from the current study reveal that this challenge was exacerbated during the COVID-19 pandemic, as older people faced a heightened risk of isolation and neglect due to assumptions regarding their vulnerability. Physical limitations further restricted their ability to engage in social activities, and many felt anxious about navigating unfamiliar environments. Unfortunately, some of the individuals they interacted with lacked empathy for their challenges, perpetuating negative stereotypes associated with ageing. These findings align with other research indicating that forming social connections and participating in group activities can be particularly difficult for older people, often due to adverse life experiences and concerns about visibility and exclusion in social settings (Willis et al. 2022). This perspective can foster feelings of exclusion, adversely affecting social well-being and interpersonal dignity, contributing to social frailty (Galvin and Todres 2013; Galvin and Todres 2015; Nagai et al. 2020; Bessa et al. 2021). However, the current study indicates that accessing healthcare services can help older people living with frailty expand their sphere of influence by facilitating additional interpersonal support. This is evident in programmes such as the Day Hospital exercise sessions and Parkinson’s support group meetings.

Healthcare provision is fundamentally a relational activity, and the interpersonal relationships between healthcare professionals and patients play a crucial role in determining the quality of care and patient autonomy (Rørtveit et al. 2015; Molina-

Mula and Gallo-Estrada 2020; Lamph et al. 2023). This aspect is particularly important for older people, who need to establish a trusting relationship with their healthcare providers to improve their care experiences (Rushton and Edvardsson 2018; Oliver 2020). The quality of caring relationships is influenced by a range of factors, from systemic elements to individual traits (McGilton and Boscart 2007; Scheffelaar et al. 2018). The findings indicate that positive relationships between older people living with frailty and their healthcare providers are fostered through a welcoming, kind, and comforting attitude. Such a caring approach acknowledges the individual's insiderness, values, and preferences, promoting a two-way dialogue (Todres et al. 2009; Borbasi et al. 2013; Todres et al. 2014). Previous studies have highlighted the importance of healthcare professionals exhibiting warm, friendly, and respectful attitudes as essential for building a trusting professional relationship (Koskenniemi et al. 2015; Tuominen et al. 2020; Sarkar 2022).

Participation in healthcare decision-making is another critical aspect that strengthens the relationship between healthcare professionals and older people living with frailty. When involved in decision-making about their health, older people feel that their sense of agency is enhanced, reducing any potential power imbalances between them and their healthcare providers (Borbasi et al. 2013; Angel and Frederiksen 2015). For instance, some older people living with frailty in the current study highlighted that they were involved in care decision-making by their healthcare professionals both at the individual and organisational levels. This inclusive approach has been associated with increasing patients' sense of control, addressing their fears, and fostering a safe and encouraging environment, all of which are vital for promoting engagement in rehabilitation services (Brighton et al. 2020a).

Another important aspect of establishing therapeutic relationships in healthcare encounters is continuity of care (Schwarz et al. 2019; Ljungholm et al. 2022; Khatri et al. 2023). The findings of the present study revealed that older people living with frailty preferred to receive care from the same healthcare professionals. This care continuity facilitated the development of a personal connection with their healthcare providers, enabling individualised care that honours their uniqueness and personal journeys (Todres et al. 2009; Galvin and Todres 2013). However, continuity of care should prioritise the quality of relationships in healthcare interactions rather than simply focusing on the repetition of seeing the same healthcare professionals (Ljungholm et al. 2022). Vicente et al. (2021) highlight that such relational continuity is crucial in healthcare encounters, as it involves regular contact between healthcare professionals and patients, fostering a strong rapport, trust dynamics, and fluid communication. In addition, relational continuity establishes a foundation for a sustained therapeutic relationship between a patient and one or more healthcare providers (Ljungholm et al. 2022). This continuity promotes shared decision-making and recognises the impact of personal qualities and individual perspectives on daily care practice, fostering a lasting sense of responsibility (Haggerty et al. 2003; Uijen et al. 2012). Therefore, continuity is essential in care, especially for homebound patients, who greatly benefit from individually tailored and supervised exercise interventions that can enhance their sense of predictability and coherence (Haggerty et al. 2003; Boxall et al. 2005; Brighton et al. 2020a).

Both older people living with frailty and Day Hospital staff highlighted the importance of open and respectful communication in healthcare interactions to build trusting relationships. Effective communication provided opportunities for older people living with frailty to express their concerns about vulnerabilities, collaboratively plan their care, exchange healthcare-related information, and discuss various options and future possibilities. In addition, older people living with frailty noted that healthcare professionals at the Day Hospital provided guidance and demonstrations on how to utilise the exercise equipment both at the hospital gym and at home. Such interactions enhanced the caring relationship between staff and patients. Moreover, exercise sessions created opportunities for older people living with frailty to connect and support one another, underscoring the importance of human interconnectedness (Galvin 2010; Ashworth 2016; Killingback et al. 2022). Brighton et al. (2020a) highlight that establishing trusting relationships and therapeutic alliances between service users and healthcare professionals can promote engagement and adherence to exercise-based interventions. This sense of togetherness fostered a feeling of belonging among older people living with frailty, which was crucial in alleviating feelings of isolation and encouraging them to expand their sphere of influence and make the most of life (Todres et al. 2007; Todres et al. 2009; Hemingway 2011; Galvin and Todres 2015).

However, when older people living with frailty felt communication was inadequate--such as feeling dismissed or excluded from decisions--they experienced a sense of passivity. According to Kwame and Petrucka (2020), poor communication within healthcare settings adversely affects the quality of care, nursing practices, and patient safety. It may lead healthcare professionals to overlook patient needs and concerns, thereby damaging relationships in clinical encounters (Cuevas et al. 2016; Kwame and Petrucka 2020). For example, patients, especially those facing terminal illnesses, sometimes report that healthcare professionals deliver vague and contradictory information when discussing an uncertain future, which affects their existential knowing (Friberg and Öhlen 2007). This communication challenge often leaves patients feeling powerless, leading them to completely defer decisions to healthcare providers and hindering their active participation in the healthcare process (Belcher et al. 2006; Todres et al. 2009). As a result, when patients sense a decline *in ‘‘mutual intrinsic valuing’’* during their interactions with healthcare professionals, it negatively affects their sense of interpersonal dignity (Galvin and Todres 2015, p. 413). This dynamic underscores the critical importance of fostering a collaborative environment within healthcare settings and the necessity of enhancing communication competencies among healthcare professionals to improve patient engagement (Fleischer et al. 2009; Cubaka et al. 2018; Amoah et al. 2019).

Additionally, establishing trustworthy relationships with healthcare providers can be challenging due to service users’ distrust (Jaiswal 2019; Griffith et al. 2021). Many older people living with frailty expressed concerns that healthcare professionals frequently made modifications to their homes without considering the potential impact on their daily lives. Furthermore, some older people living with frailty reported that healthcare assistants often failed to exhibit sensitivity to their needs, which ultimately contributed to a diminished trust in the healthcare system. These practices complicate the establishment of a solid relationship between healthcare providers and patients. This finding aligns with the research conducted by Brighton et al. (2020b), which suggests that mistrust stemming from uncertainty regarding care and disagreements about appropriate support can lead to fractured relationships within the healthcare system.

Despite the above concerns, both older people living with frailty and healthcare professionals emphasised the significance of fostering a trusting and caring relationship. Such a relationship entails healthcare professionals viewing patients as unique individuals, a concept that ties into the notion of humanising care (Todres et al. 2009; Galvin and Todres 2013). Moreover, relationships and social support are crucial as they provide individuals with a sense of belonging, connection, and emotional support, which in turn contributes to enhanced life satisfaction and overall well-being (Forgeard et al. 2011; Huppert and So 2013; Harrison et al. 2015). Consequently, interpersonal relationships in healthcare encounters can provide reassurance to patients by creating opportunities to address their concerns and expand their sphere of influence.

6.4 The influence of temporality on the sphere of influence of older people living with frailty

Temporality as a lifeworld dimension relates to how people perceive and experience time and events in their everyday lives (Ashworth and Ashworth 2003; Ashworth 2016). It encompasses both the continuity and discontinuity of time as experienced by humans (Todres et al. 2007). In other words, temporality includes memories of the past, opportunities from seasonal rhythms and the impact of time constraints (Hemingway 2011; Hemingway et al. 2015).

Time perception differs from person to person and is shaped by individual experiences (Gergel 2013). The perception of time among older people living with frailty is a vital aspect of their healthcare experience. This is because age and disease-related changes significantly influence how people perceive time, impacting their temporal experiences (Leder 2021). During the experience of illness, time is perceived in a multidimensional way (Robertson 2015). Jowsey (2016) identifies four essential temporal structures relevant to the experience of illness: biographical time, inner time and rhythms, past-present-future time, and calendar and clock time. Biographical time pertains to the disruptions in one’s life story caused by illness, which can challenge an individual’s sense of identity and continuity. Inner time and rhythms are primarily understood through bodily experiences, influencing how individuals perceive and manage their symptoms and treatment. The dimension of past-present-future time affects how individuals living with illness reflect on their past, manage current symptoms, and navigate future plans. Calendar and clock time shape the experiences of illness, influencing concerns like waiting times for appointments, travel time to healthcare facilities, and adherence to medication schedules (Jowsey 2016). These temporal structures interact to shape how individuals comprehend their illness experiences and deal with the complexities of living with various health conditions (Jowsey 2016).

The experience of illness can significantly alter individuals' perceptions of time, distorting their usual experiences and expectations regarding temporal rhythms (Jowsey 2016). These disruptions impact a person's capacity to find solace in the past and present, as well as to foster hope for the future (Leder 2021). In the context of the present study, several older people living with frailty reflected on their past enjoyment of activities, such as walking, which they could no longer engage in due to age-related declines and health challenges. In addition, older people living with conditions like Parkinson's disease expressed feelings of despair and hopelessness as they perceived their irreversible declines as likely to intensify with time. Moreover, the experience of living with Parkinson's introduced a level of temporal uncertainty attributable to the unpredictable nature of symptoms that manifested at varying intervals. The unpredictability and episodic nature of pain complicate patients' ability to accurately recall and narrate their pain histories, affecting communication and making it challenging for healthcare professionals to understand their condition (Nilsen and Elstad 2009). Leder (2021) suggests that illness can create a sense of time that is stagnant, fragmented, or elusive. The coexistence of multiple diseases introduces additional complexities, as illness trajectories can intersect and manifest differently, according to individual temporal rhythms (Jowsey et al. 2016). Therefore, it is essential to recognise how time affects individuals' experiences of illness symptoms, as patients with chronic pain may experience what is termed *"temporal confinement,"* where their pain diverts their focus from the calendar and clock time (Nilsen and Elstad 2009, p.58; Robertson 2015).

Furthermore, the experience of time takes on a distinct significance for individuals confronting time-limited illness and the prospect of impending death (Elstad and Torjuul 2009; Ellingsen et al. 2015; Robertson 2015). For such individuals, time significantly influences their experiences, often prompting a heightened focus on the present moment (Ellingsen et al. 2015). Similarly, living with life-limited illnesses often brings existential uncertainty about disease progression or regression (Friberg and Öhlen 2007; Nilsen and Elstad 2009). Robertson (2015, p. 72) argues that illness can distort temporal perception, leading to *"temporal inertia,"* where individuals nearing the end of life are caught up in a *"waiting game"* lacking a clear future outlook. As a result, discussions about the future tend to highlight one's limitations and vulnerabilities imposed by such illnesses (Ellingsen et al. 2013). In the present study, older people living with frailty and other incurable illnesses such as cancer expressed concern regarding the unpredictable nature of their illnesses, choosing to focus on present and short-term goals rather than long-term aspirations. The Heideggerian theory of temporality provides insight into how illness alters people's perception of time, drawing their attention more toward the present (Gergel 2013). This temporal shift may alter one's identity and established temporal relationships, potentially undermining the existential quality of life (Gergel 2013; Trevino et al. 2019). Consequently, healthcare professionals need to understand the impact of life-limiting illnesses on the temporal perception of patients to provide appropriate support that enhances well-being (Hole and Salem 2016; Schoenborn et al. 2017; Botta et al. 2019; Trevino et al. 2019).

However, the reorientation of hope towards the maintenance of comfort and quality of life in the present can significantly enhance future time and experiences for individuals facing life-limiting illnesses (Strada 2008). For certain individuals, the concept of the ‘transcendental horizon: future time’ serves as a source of hope and meaning that transcends their current circumstances, while others reconcile with the inevitability of death by adopting an optimistic perspective toward a predictable future (Robertson 2015). The limitations imposed on anticipation by progressive illness or the ageing experience prompt people to engage in a practice of ‘presencing,’ enabling them to fully appreciate the gift of the present moment (Leder 2021). In the current study, the phenomenon of living in the moment is characterised by the pursuit of contentment, effective pain management, and the maintenance of familial bonds within the home environment, all of which contribute to comfort. Living in the present is closely linked to existential time, highlighting how our understanding of time evolves in the face of mortality, leading individuals to perceive time less as a chronological sequence and more as a concept of deeper existential meaning (Ellingsen et al. 2015). Consequently, fostering positive experiences for patients in the present necessitates support in preserving a connection to their values, beliefs, and identities while facilitating a reconnection with elements of their personhood and sense of self amid the turmoil of illness and death (Strada 2008).

Time perception is intricately linked to how individuals perceive and experience their bodies during illness, as bodily-generated rhythms guide their interaction with the external world (Gergel 2013; Jowsey et al. 2016). The embodied experience of time, influenced by bodily rhythms and practices (inner time and rhythms), becomes more pronounced during illness and shapes how individuals manage their daily routines and self-care (Ellingsen et al. 2013; Jowsey 2016). Ellingsen et al. (2013) assert that the body, rather than the clock, structures and controls daily activities for those who are ill. In the current study, older people living with frailty emphasised that bodily changes significantly influenced the timing of their everyday activities, with physical pain rendering simple tasks, such as cooking, laundry, and preparing to leave the house, significantly more time-consuming. As the progression of embodied illness increasingly restricts opportunities for engagement in daily life, the significance of clock time diminishes, even as individuals remain aware of its importance in social contexts (Ellingsen et al. 2013). Similarly, the relationship between the body and time is dynamic, shifting over time and affecting how individuals manage their daily routines (Leder 2021). As demonstrated in the present study, when an individual is unwell, their body develops its temporal rhythms, necessitating a balance between their internal sense of time and the external temporal structures required to manage daily tasks (Jowsey et al. 2016). For example, although some older people living with frailty in this study looked forward to maintaining their routine activities, such as travelling to visit family abroad for Christmas, they constantly reevaluated such plans in light of their physical decline. Heidegger’s concept of ecstatic temporality highlights that past and present experiences influence our future orientation, but illness may lead to the body’s internal perception of time taking precedence (Ellingsen et al. 2013). This shift can alter an individual’s understanding of their biographical time, prompting them to reassess their life goals and direction (Jowsey et al. 2016).

Additionally, temporal experiences play a significant role in influencing responses to medical treatment and health outcomes (Gergel 2013). Illness poses challenges to both our understanding of ‘healing time’ and ‘healing over time,’ particularly when individuals seek healthcare services to improve their condition (Strada 2008; Leder 2021). The healthcare experience often presents temporal challenges; for instance, long waiting times can adversely affect how patients perceive their experiences. The anticipation of future events, such as medical appointments or potential treatments, can have a profound impact on an individual’s perception of time, instilling either hope or a sense of stagnation (Leder 2021). The present study found that older people living with frailty faced notably long waiting periods to see healthcare providers such as GPs, especially during the COVID-19 pandemic. This situation arose particularly from structural changes within the healthcare system, staff shortages, and a surge in patient numbers. Similar observations have been noted in other research, indicating that patients often experience lengthy waits to consult healthcare professionals, and once they do, their contact time with these professionals is often limited, impacting both satisfaction and well-being (Pillay et al. 2011; Oche and Adamu 2013). Robertson (2015) adds that prolonged waiting times for healthcare assistance can be particularly frustrating for patients and negatively affect their mood. Such challenges make patients frequently feel at the mercy of a rigid healthcare system and unyielding temporal structures, which impede their ability to receive timely care (Jowsey et al. 2016). Consequently, minimising waiting times within healthcare service organisations has become essential for assisting patients in addressing their concerns regarding clock time (Jowsey 2016).

Similarly, the findings revealed that older people living with frailty require ample time with healthcare professionals. However, these professionals often face competing demands, resulting in shorter patient interactions. In the current study, it was reported that during the COVID-19 pandemic, Day Hospital patients were restricted to a maximum of four sessions. This limitation posed significant challenges for patients in fully articulating their healthcare concerns. Likewise, during home care visits, healthcare professionals acknowledged that time constraints hindered their capacity to effectively implement participatory healthcare interventions. Consequently, they struggled to ensure proper coordination and continuity of care, as the limited opportunities for establishing therapeutic relationships impeded the effective management of illness and its temporal aspects (Jowsey et al. 2016). Elstad and Torjuul (2009) highlight that temporal continuity is crucial in healthcare practice, especially for long-term patients and those undergoing invasive treatments. It involves recognising the episodic nature of (persistent) pain and allowing patients time to communicate their complete pain history since pain develops through various stages (Nilsen and Elstad 2009). Furthermore, it emphasises the importance of providing ongoing support, monitoring, and care throughout the patient's illness trajectory to ensure that they receive consistent and holistic care, minimising disruptions and enhancing treatment outcomes and overall well-being (Elstad and Torjuul 2009; Galvin 2010). Thus, temporal continuity is vital for understanding complex temporal processes and acknowledging the various time dimensions of individual illness, allowing healthcare professionals the time, flexibility, and closeness to respond effectively to patients' needs (Nilsen and Elstad 2009).

In summary, phenomenological temporality in healthcare is vital for understanding how individuals perceive illness and time, which can influence health outcomes and the development of personalised interventions (Todres et al. 2007; Galvin and Todres 2013). Healthcare professionals ought to respect patients' unique temporal perceptions, especially those with limitations or reduced life expectancy (Ellingsen et al. 2015). Continuity of care and empathetic communication can foster a *"temporally continuous perspective"* that can enhance the care experience and understanding between patients and healthcare professionals (Elstad and Torjuul 2009; Nilsen and Elstad, 2009, p. 60). In addition, storytelling has emerged as a therapeutic tool for individuals with chronic illness, helping them reflect on their experiences, make sense of their illness narratives, and create continuity in their lives (Chelf et al. 2000; Akard et al. 2015; Galvin et al. 2020). This phenomenon aligns with Heidegger's concept of 'ecstatic temporality', where time is seen as a dynamic interplay of past, present, and future that shapes our sense of identity and existence in the world (Morris 2008). Moreover, addressing concerns related to clock time, such as reducing waiting time, and understanding the distinction between clock time and subjective time can deepen healthcare professionals' insights into patients' varied embodied time and illness experiences (Elstad and Torjuul 2009; Ellingsen et al. 2013, 2015; Jowsey 2016). Finally, each phase of an illness can shift individuals' perceptions of time, often subdivided into periods before or after diagnosis (Ellingsen et al. 2013; Jowsey 2016; Jowsey et al. 2016). Therefore, grasping individuals' temporal experiences is critical in determining the most opportune moment for healthcare interventions, termed *'kairos'*, which is carefully sought in the individual trajectory of the patient (Jowsey 2016; Jowsey et al. 2016; Schaepkens and Coccia 2022). By acting at the right moment (*kairos*), healthcare professionals can improve patient outcomes and enhance care quality (Elstad and Torjuul 2009; Niles et al. 2021).

6.5 The influence of spatiality on the healthcare sphere of influence

Spatiality relates to the ways in which individuals experience and engage with physical spaces within their lifeworld, encompassing both their immediate environment and their broader geographical context (Ashworth and Ashworth 2003; Ashworth 2003; Galvin 2010; Hemingway et al. 2015). It represents a dimension of the lifeworld that emphasises lived space, including the meaningful places and objects that hold significance in one's life (Todres et al. 2007).

This study highlights the significant influence of the home environment on the sense of control and well-being of older people living with frailty. It highlights that the home served as a secure spatial and temporal foundation, enabling these individuals to navigate the uncertainties of the future (Friberg and Öhlen 2007). The concept of 'home' is intricately linked to spatiality, which pertains to individuals' qualitative perceptions of space and distance, which in turn impacts their dignity and well-being (Galvin 2010; Hemingway 2011; Galvin and Todres 2013; Hemingway et al. 2015). The notion of spatial dignity underscores the necessity of feeling dignified within one's environment and fostering a positive relationship with one's surroundings, which involves feeling a sense of support derived from valued continuities within the environment (Galvin and Todres 2015). In addition, spatial mobility contributes to existential well-being by affording individuals the opportunity to develop both a sense of home and the spirit of adventure (Todres and Galvin 2010; Galvin 2021).

The findings of the present study indicate that older people living with frailty often derive meaning and satisfaction by concentrating on the present moment and discovering new value in everyday activities and hobbies, such as cleaning, cooking, needlework, and reminiscing about past experiences. When engaged in these activities within their home environment, older people can develop a sense of resilience, empowering them to navigate challenges and maintain a degree of independence (Aléx 2010; Van Kessel 2013; Voie et al. 2024). Galvin and Todres (2015) add that when individuals perform daily tasks in a familiar space, they experience a profound sense of appropriateness and significance in the connection between their actions and the supportive environment, suggesting that the surrounding space enhances and dignifies their activities. Although many older people living with frailty in the present study had concerns about the future, their home offered a source of comfort and contentment in the present moment. Indeed, despite their declining health and age, these individuals were still capable of finding joy and gratitude in their daily lives, even while acknowledging the limited time they may have had remaining in their homes (Ness et al. 2014).

Additionally, many older people living with frailty in the current study viewed their homes as spaces that allowed them to maintain control over an uncertain future. They considered their homes to be their ‘world’--environments that offered comfort and safety, which are essential for navigating age-related declines, as illustrated by Peter, a 70-year-old participant. According to Ness et al. (2014), homes play a vital role in providing older people with a sense of security and freedom, where they can find strength and peace, especially during health declines or following disease events. The home environment is even more beneficial when located near essential amenities, such as hospitals and shops. Consequently, most older people living with frailty in this study preferred to remain in their homes for as long as possible. Some even modified their living spaces by adding ground-floor bathrooms in anticipation of potential future mobility challenges. These findings align with previous research highlighting older people’s preference for ageing in place rather than transitioning to institutional care (Bjornsdottir 2018; Fæø et al. 2019; Søvde et al. 2022b).

Furthermore, Ness et al. (2014) suggest that the home serves both as a physical space and a state of being, enabling older people to exercise self-determination and maintain connections with their past, thereby fostering a sense of continuity and familiarity. The experience of ‘at-homeness’ is consequently linked to well-being and living a meaningful life despite the challenges posed by frailty (Søvde et al. 2022b). When this personal and collective sense of belonging is disrupted, or when familiar continuities are diminished or lost, individuals may experience indignity (Galvin and Todres 2015).

However, our physical space can sometimes contribute to feelings of loneliness and isolation. In the current study, it was revealed that some older people living with frailty, particularly those who reside alone, faced social limitations due to their physical challenges. Their sense of loneliness was further intensified by COVID-19 restrictions, which hindered their ability to engage with others and left them feeling confined at home. Existential loneliness is a prevalent issue among older people living with frailty who live alone, resulting in feelings of isolation and disconnection from life (Sjöberg et al. 2018; Edberg and Bolmsjö 2019). Consequently, healthcare professionals should approach each older person living with frailty as an individual and recognise the significance of their role as social contacts, as they may be the only regular visitors to these home-bound individuals (Ness et al. 2014).

According to Bjornsdottir (2018), older people living with frailty at home often receive assistance from family members, home care nursing services, and technology. In the current study, it was discovered that some of these older people had exercise equipment at home, with staff from the Day Hospital, including physiotherapists, visiting to provide rehabilitation support services. This observation is consistent with earlier research by Ness et al. (2014), which indicated that nurses deliver both practical and psychological support through home nursing care, allowing older people to feel confident that they can access the support they need when required. In addition, the healthcare professionals who visit patients at home foster opportunities for human connection, which is vital for maintaining well-being and a sense of homeness, as these interactions play a crucial role in linking home-bound older people to the outside world, instilling a sense of vitality and purpose (Søvde et al. 2022b).

Ness et al. (2014) add that healthcare professionals, particularly nurses, play a crucial role in supporting older people to maintain their independence at home by recognising and nurturing their inner strength. However, the current study revealed that home visits can sometimes lead to tensions, especially when healthcare professionals feel a lack of control over the care process in an unfamiliar environment. This finding aligns with existing research highlighting power struggles between patients and healthcare professionals in home settings (Eilertsen and Kiik 2016; Fatemi et al. 2019; Olsen et al. 2019). To mitigate these tensions, healthcare professionals employed various strategies, such as respecting the older person's preferences and focusing on what mattered most to them at home. This approach helps negotiate control while ensuring that home-based care fosters a sense of autonomy and well-being for older people living with frailty. Bjornsdottir (2018) suggests that building relationships between older people and healthcare professionals during home visits can be an effective starting point for creating a reassuring and supportive environment essential for delivering care at home.

In contrast to the findings of the current study, some research has indicated that older people living with frailty may be open to the idea of institutional care, particularly due to the increasing difficulties of remaining at home, such as health issues, grief, and loneliness (Hatcher et al. 2019; Søvde et al. 2022b). Health challenges can disrupt the sense of homeness, making it increasingly difficult for older people living with frailty to derive meaning from their lives within the altered and silent home environments (Svenaeus 2011; Søvde et al. 2022a). While these individuals may consider moving to nursing homes, they often grapple with this decision as they yearn for the familiarity and ‘at-homeness’ of their own homes. This dynamic reflects the ambivalence felt by older people living with frailty regarding the prospect of relocating to institutional care as they balance the complexities of managing life at home against the limitations imposed by frailty (Søvde et al. 2022b).

Overall, the home plays a vital role for older people, providing emotional attachment, safety, and space for cherished possessions and opportunities (Tanner et al. 2008; Ness et al. 2014; Hatcher et al. 2019; Coleman and Wiles 2020; Dalistan et al. 2023). In the present study, the experiences of older people living with frailty in relation to their homes varied significantly. Some individuals felt that their homes required modifications to accommodate their current and future limitations, while others deemed their residences comfortable enough to navigate the uncertainties ahead. These experiences highlight the existential challenges that older people living with frailty face in maintaining a sense of at-homeness and well-being. They also underscore the importance of addressing individual needs to provide humanising care that supports their well-being (Todres et al. 2009; Galvin and Todres 2013; Søvde et al. 2022b). Consequently, there is a need for personalised care and resources to support older people living with frailty in remaining in their homes for as long as possible (Ness et al. 2014; Søvde et al. 2022b).

6.6 The impact of mood on the sphere of influence in older people living with frailty

Mood is an aspect of the lifeworld that relates to emotions that influence lived experiences (Todres et al. 2007; Hemingway 2011; Galvin and Todres 2015; Ashworth 2016). It is linked to hedonic well-being, which encompasses the variability of people's emotional states, such as happiness or sadness (Deci and Ryan 2008; Gallagher et al. 2009; Dodge et al. 2012). Emotions, which are particularly sensitive to mood fluctuations, can be derived from both past experiences and present circumstances (Wildschut et al. 2006; Keren et al. 2021). This relationship is notably pertinent among older people living with frailty, as their emotional experiences can oscillate between states of happiness, sadness, anxiety, depression, and frustration (Rolfson et al. 2006; Bravell et al. 2011; Sugie et al. 2022). Mood, however, is not just an internal mental state but also serves as a powerful indicator of the existential meaning attributed to various situations, thus reflecting individuals' openness to their surroundings and their subsequent responses (Carel 2011; Van der Meide et al. 2015). Consequently, mood is intertwined with other lifeworld dimensions and cannot be considered in isolation from its context (Todres et al. 2007; Hemingway 2011; Hemingway et al. 2015; Ashworth 2016).

Mood significantly shapes how older people living with frailty perceive and interact with their world, influencing their experiences and overall well-being (Van der Meide et al. 2015). The findings from the present study suggest that older people living with frailty experience heightened levels of fear, anxiety, and frustration attributable to a diminished sphere of influence. These emotional responses may emerge from limitations imposed by daily activities, such as challenges with walking or engagement in hobbies like gardening, leading to feelings of incompleteness and increased dependency. In addition, the loss of control over daily routines, including disrupted sleeping patterns, frequently contributed to anxiety, particularly among those living with Parkinson’s Disease. Moreover, uncertainty about their health trajectory and the unpredictability surrounding their futures also contributed to feelings of anxiety and disconnection with the future, especially for those with terminal illnesses (Friberg and Öhlen 2007; Van der Meide et al. 2015). Such findings resonate with other studies, which underscore the detrimental impact of age-related declines on the emotional well-being of older people (Lyndon 2015).

The findings also indicate that healthcare experiences evoke mixed emotions among older people living with frailty. Many of these individuals expressed feelings of frustration stemming from long wait times to see healthcare professionals and a lack of sufficient information regarding health conditions and treatment options (Naidoo and Van Wyk 2019). Despite facing such challenges, many older people living with frailty in this study experienced joy and comfort through their involvement in healthcare decision-making processes and their ability to remain in their own homes. This satisfaction with staying at home was primarily attributed to the social support they received from family and community members, which had a positive effect on their emotional well-being. However, the existential anxiety surrounding the potential necessity of transitioning to institutional care as health declined was a significant concern for many older people living with frailty (Søvde et al. 2022b). Similarly, the sense of 'homeness' was often disrupted when healthcare professionals made changes to their living environments without prior engagement, causing distress, especially when these changes were perceived as linked to disability (Dalistan et al. 2023). Such healthcare practices adversely affected their sense of insiderness and uniqueness, leaving them feeling frustrated (Todres et al. 2009; Galvin and Todres 2013; Todres et al. 2014).

Furthermore, an individual's ability to achieve goals and realise their full potential is closely linked to their mood (Hemingway 2011). Mood influences people's being-in-the-world and influences how they perceive and interact with their surroundings, thus shaping their experiences and relationships (Todres et al. 2007; Hemingway 2011; Ashworth 2016). In essence, mood can either motivate or demotivate purposeful action and possesses an organising power that determines people's priorities and activities (Todres et al. 2007). In the present study, older people living with frailty frequently encountered distress as a result of life disruptions. As a result, many struggled to come to terms with their circumstances, which ultimately fostered a sense of resignation. This struggle often led to a loss of motivation and a reluctance to participate in several everyday activities, primarily due to anxiety about their physical limitations, particularly in unfamiliar settings.

Similarly, older people living with frailty tended to resist being labelled as frail, as this label was often associated with the loss of independence and other negative emotions (Archibald et al. 2020; Durepos et al. 2022). This discomfort may explain why physical changes linked to ageing and frailty, such as tremors and the use of mobility aids, evoked feelings of discomfort and social embarrassment in individuals, especially when attempting new activities. Such feelings stem from their difficulty in accepting their physical losses and a desire to avoid being identified as frail. Indeed, older people living with frailty often prefer to view frailty as an emotional state, one that ‘feels’ more personal, rather than ‘being’ a physical condition that is perceived as a medically imposed classification (Pickard et al. 2019; Archibald et al. 2020). These observations align with previous research indicating that older people tend to resist the labels of ageing and frailty, as these designations typically evoke feelings of sadness and discomfort (Warmoth et al. 2016).

As people age, they may face the unfortunate reality of declining health and the inevitability of life’s end. Nevertheless, research indicates that older people who come to terms with these changes often experience greater contentment and reduced anxiety. Harbaugh and Vasey (2014) assert that acknowledging the things we are grateful for can elevate our mood and have enduring effects on our well-being. Such positive emotions have been associated with improved coping strategies when facing health challenges among older people (Preston et al. 2007). The findings of the current study show that some older people living with frailty maintained a positive outlook despite their concerns. They found contentment in their lives as circumstances unfolded, embraced challenges, and expressed gratitude for some of their experiences. Previous research has shown that individuals who display traits such as emotional stability, optimism, and positive emotional states--especially gratitude--are more likely to flourish and achieve higher levels of well-being (Sheldon and Lyubomirsky 2006; Wood et al. 2009; Huppert and So 2013). This feeling is associated with what is termed 'mood dwelling,' characterised by a sense of tranquillity despite life's challenges, fostering a sense of 'letting-beness,' which is also experienced as a form of mood well-being (Galvin and Todres 2011).

It is essential to recognise that both positive and negative emotions are intertwined with the concept of 'mood dignity,' wherein individuals value being in their vulnerable states. Galvin and Todres (2015) define mood dignity as a fundamental characteristic of any experiential moment that possesses dignity across various moods--be it solemn sadness, celebratory joy, or poignant love. This concept embodies a complex emotion of 'honour-wound,' which balances the recognition of human vulnerability with inherent value (Galvin and Todres 2015). According to Galvin (2021), in all circumstances, there remains a degree of possibility and vulnerability. However, human vulnerability is both relational and dynamic, shaped by the interplay between the embodied individual, their social connections, daily experiences, and the care environment (Van der Meide et al. 2015). In the present study, the emotions experienced by older people living with frailty within their daily lives and healthcare situations revealed how their insiderness or feelings filtered their sense of control and well-being (Killingback et al. 2022). By understanding the full spectrum of both positive and negative emotions that older people living with frailty encounter, we can gain deeper insights into their feelings of happiness, anxiety, sadness, and frustration. This understanding of diverse emotions can aid in the creation of a more supportive and inclusive healthcare environment that values the inherent possibility and vulnerability of human existence, thereby enhancing dignity and well-being (Forgeard et al. 2011; Oades and Mossman 2017; Galvin 2021; Killingback et al. 2022).

Consequently, as people age, they frequently experience emotional wounds associated with factors such as illness, the loss of loved ones, and increased dependence on others (Mathiesen et al. 2023). Understanding the emotional experiences of older people living with frailty is essential for creating more empathetic and effective healthcare experiences. Carel (2011) contends that mood serves as a significant existential category that profoundly influences patients’ experiences of illness and their long-term emotional adaptation. Attending to a patient’s mood and mental well-being is crucial for enhancing their existential care (Mathiesen et al. 2023). To achieve this, healthcare professionals ought to develop competencies, including emotional intelligence and empathy, within healthcare settings (Pérez-Fuentes et al. 2020; Meléndez et al. 2022). As a result, rehabilitation services for older people living with frailty should concentrate not only on improving physical health but also on addressing the emotional and experiential aspects of healthcare (Cowley et al. 2021; Killingback et al. 2022).

6.7 Reflexivity

Reflexivity is essential to experiential qualitative research, particularly within the framework of hermeneutic phenomenology (Finlay 2003, 2008, 2009; Shaw 2010). It entails a continuous examination of our interpretations of both our experiences and the phenomena being studied, allowing us to transcend the limitations of our preconceived understandings (Finlay 2003). Reflexivity differs from mere reflection or introspection, as it is a constructivist-driven process that emphasises a comprehensive evaluation by the researcher while engaging with the research world in a socially-oriented context. In contrast, introspection is rooted in a more positivist perspective, concentrating primarily on validating and confirming the accuracy of the participant's account and measurements represented (Shaw 2010).

Reflexivity entails self-awareness and openness on the part of the researcher, along with a conscious acknowledgement of the biases, values, and experiences that could influence the research (Creswell 2007). By actively engaging in reflexivity, researchers can critically evaluate their own perspectives, values, and behaviours, leading to a more rigorous and credible research methodology (Clancy 2013). This process of self-examination is essential to minimise the impact of personal characteristics, prejudices, and biases on the research outcomes (Finlay 2003; Clancy 2013). Richardson (2000, p.15) emphasises that researchers must *“hold themselves accountable to the standards of knowing and telling of the people they have studied.”* However, researchers should avoid focusing solely on their own experiences and emotions during the reflexivity process (Finlay 2009). Instead, they should consider how their involvement in the lives of others--for example, through language, stories, and experiences--influences the research process, ultimately enhancing the quality and credibility of their research (Finlay 2009; Shaw 2010; Clancy 2013).

In the following section, I present a reflective analysis of my study on the sense of control and well-being among older people living with frailty in southern England. The insights conveyed here were primarily drawn from a reflective field journal that I maintained throughout my research project (Clancy 2013; Alsaigh and Coyne 2021). I have organised this analysis around four key themes: approaching the research, fostering relationships, collecting data, and analysing data (Finlay 2003).

6.7.1 Turning to the nature of the lived experience

My research on the sense of control among older people living with frailty has been shaped significantly by both my personal and professional interests. As a qualified social worker from Uganda, I have always found the concept of a sense of control in older people to be particularly fascinating. This interest stems from the dominant policy discourse within social work that emphasises supporting older people in maintaining their independence for as long as possible. In Uganda, the care services for older people differ markedly from those in the Western world, including England. Uganda typically employs a more community-based care system, whereas the English care system is predominantly institutionalised. Additionally, the strong sense of community in Uganda often allows older people to seek support more readily. In contrast, in the UK, many older people appear to aspire to a lifestyle characterised by independence and self-sufficiency, which can sometimes make it difficult for them to seek help. These contrasting approaches have significant implications for older people's views on control and independence. Consequently, I sought to explore the sense of control among older people living with frailty in England and its impact on their well-being.

When I decided to pursue a PhD, one of the first challenges I faced was formulating a research question (Mantzoukas 2008; Fandino 2019). This daunting task required me to deepen my understanding of my chosen topic and clarify my preconceptions and assumptions (Adams and van Manen 2017; Ray and Locsin 2023). It took me nearly ten months to narrow my interests and develop specific research questions that aligned with the emerging gaps in the literature, my personal interests, and the objectives of the InnovateDignity project. I conducted a scoping review and participated in meetings with my academic supervisors to further refine my ideas. Ultimately, I established two closely related research questions*: 'What is the lived experience of control and well-being for older people living with frailty in their healthcare service use?'* and *'What are the experiences of service providers regarding control and well-being for older people living with frailty in healthcare service provision?*' These questions were designed to encourage participants to share their experiences related to the phenomena under investigation (van Manen 2012; Ray and Locsin 2023). The emphasis was not merely on the meaning of words in the questions but on exploring the lived experiences that warranted investigation (Adams and van Manen 2017).

At this stage, I also held certain preconceptions about older people living with frailty. I assumed that they had diminished control over their daily lives and that healthcare professionals played a crucial role in supporting them to regain or maintain this sense of control. The literature review further highlighted that frailty is one way in which old age is problematised, revealing that many older people living with frailty possess a low sense of control. Recognising that lived experiences frequently lack clear boundaries of beginnings and endings, I aimed to remain as open as possible to the experiences of others (Adams and van Manen 2017; Zahavi and Martiny 2019). Likewise, to prevent my assumptions from biasing the research process, especially regarding older people living with frailty, I crafted an interview schedule guided by the research questions, with the first question being broad and non-directive (Zahavi and Martiny 2019).

Additionally, I explicitly distinguished between the main phenomenological question--*'What is the lived experience of control and well-being of older people living with frailty in healthcare service use?'*--and the subsequent questions posed during the interviews that aimed to elaborate on this main question, such as *'How much control did you feel you had over this process?'* (Adams and van Manen 2017; Sholokhova et al. 2022). Formulating a research question not only enhanced my understanding of its importance in qualitative research but also clarified that research questions provide direction for the study. They establish a foundation for assessing the rigour of the research, offering a basis against which the study’s conclusions can be evaluated (Mantzoukas 2008).

As a social worker conducting research with older people within the healthcare system, I had to carefully consider my positionality and identity (Dwyer and Buckle 2009; Pringle et al. 2011a; Kerstetter 2012). While I was an insider as a professional social worker, I also occupied an outsider position due to my lack of direct involvement in healthcare services and my unfamiliarity with the culture surrounding healthcare service provision. My background in working with older people allowed me to understand the challenges faced in social care services. However, I was removed from the specific challenges and opportunities that healthcare providers encounter when working with older people. This ‘space between’ my insider and outsider positionality significantly influenced the entire research process, including the formulation of the research question (Dwyer and Buckle 2009; Pringle et al. 2011a; Kerstetter 2012).

On one hand, my insider perspective, grounded in my extensive experience with older people, facilitated the development of trusting relationships, enabled me to recognise subtle signs of distress, and allowed for controlled emotional involvement during interviews with older people living with frailty. On the other hand, my outsider status ensured that my personal experiences, interpersonal relationships or subjective viewpoints did not limit the study. This distance also meant that participants did not perceive me as part of their clinical team, which may have contributed to reducing power imbalances and participant vulnerability, thus allowing them to express themselves freely without concern about the potential impact of their participation on their care (Clancy 2013).

Reflecting on my positionality in this study has deepened my understanding of the often-overlooked influence of a researcher's identity--not only on interactions with participants but also on the overall dynamics of the research. Consequently, qualitative researchers need to consider their positionality early in the project design phase.

I also undertook a PPI exercise to ensure that my research question and design remained aligned with the needs of the target community. This initiative allowed me to gather insights from older people with firsthand experience of healthcare services, which in turn helped me refine my research design. Additionally, it assisted me in navigating my 'insider-outsider' identity and ensured that both the research question and design were relevant to the intended research group (Kerstetter 2012). This experience marked my first opportunity to learn about and implement the principles of PPI in a research project. One of the key lessons I learned was the importance of being receptive to feedback from those directly impacted by the research topic. PPI offers a unique and invaluable perspective on research design that may not be readily available from professional peers. Consequently, ensuring diversity and inclusion within PPI groups is essential for obtaining rich and varied insights.

After formulating my research questions, I needed to determine the appropriate research approach. The literature emphasised the direct relationship between phenomenology and the study of people's experiences, leading me to choose this approach. However, selecting the most suitable phenomenological approach was challenging due to the necessity of understanding the various philosophical assumptions and their applicability to research. As a novice researcher, the decision between descriptive and interpretive/hermeneutic phenomenology was particularly daunting. I also recognised that phenomenology functions as both a philosophical and methodological framework, which complicated the task of translating its philosophical assumptions into a coherent, step-by-step process for conducting phenomenological research.

To address these challenges, I conducted extensive consultations and reviewed the literature to ensure that my chosen method aligned with my research ideas and current evidence (Dibley et al. 2020). Ultimately, I opted for hermeneutic phenomenology while remaining open to other phenomenological perspectives (Matua and Van Der Wal 2015; Öhlén and Friberg 2023). My choice of hermeneutic phenomenology was partly influenced by my realisation that fully bracketing my beliefs and presuppositions regarding the research was difficult. Additionally, I believed that hermeneutic phenomenology was best suited to effectively address my research questions (Adams and van Manen 2017).

Before embarking on my PhD journey, my knowledge of research methods was limited to a general understanding of the applicability of quantitative and qualitative research. However, by the end of this research project, I significantly deepened my understanding of the theoretical perspectives (ontology, epistemology, and methodology) that underpin qualitative research. I also gained greater confidence in evaluating and clarifying the relevance of various qualitative research approaches, particularly within phenomenology.

Importantly, throughout the research process, I engaged in self-reflection by documenting my thoughts, biases, and assumptions in a reflective field journal. I later integrated these reflections into the interpretive process during the analysis stage (Laverty 2003). This process underscored the importance of recording spontaneous ideas that emerged during my research. I found that during my PhD journey, random thoughts frequently crossed my mind, and without the practice of writing them down, I struggled to retain them. My supervisors also encouraged me to capture any relevant insights that arose randomly in my daily life. Often, these revelations occurred while I was engaged in academic reading, collecting data, or even during conversations with colleagues and family. These ‘rough’ notes were invaluable in clarifying my interpretations and fostering critical reflection on both the strengths and limitations of my project, ultimately enhancing its overall robustness.

6.7.2 Developing relationships during the research process

The phenomenological research process unfolds within the context of relationships, which play a crucial role in determining the final outcome (Laverty 2003). In my study, I maintained strong relationships with both the recruitment site and the participants. To foster rapport with the participants, I engaged in informal conversations, demonstrated genuine interest in their concerns, and accommodated their routines. Additionally, I practised flexibility by allowing participants to take breaks during the interviews and expressed sincere gratitude and interest in their conversations before and after the sessions. These efforts were essential in facilitating recruitment. Moreover, the rapport I established with the participants positively influenced the data I gathered. This comfort level during interviews enabled participants to articulate their experiences more engagingly, ultimately enhancing the trustworthiness of the data (van Manen 2012).

As I conducted most of the interviews with older people living with frailty in their homes, it was essential for me to build relationships with their informal caregivers, such as children and spouses. These caregivers played a crucial role in assisting with the scheduling of interview appointments, helping participants comprehend information sheets, completing consent forms, and occasionally serving as interpreters. Therefore, I made a concerted effort to maintain positive relationships with informal caregivers by being respectful, adhering to scheduled times, and clearly articulating their role in the interview process. The support from the caregivers was essential in facilitating the participation of some older people living with frailty in my study. For instance, during an interview with Alex, an 87-year-old man who was partially deaf, I depended on his daughter for assistance as she acted as an interpreter.

However, the involvement of informal caregivers in the study had a notable impact on the data collected. This effect was particularly evident when they acted as interpreters. For example, during the interview with Alex, the interpretation provided by his daughter may have influenced his responses. Such influence may have introduced biases that affected the credibility of the participant’s answers. Additionally, the interview felt less spontaneous, and delving deeply into Alex’s responses occasionally proved challenging. It was also sometimes difficult to connect the participant's non-verbal expressions with their spoken words. To minimise the impact of these factors on the data collected, I briefed the participant on the interpreter's role at the beginning of the interview. I also arranged a triangular seating position that allowed us to see each other clearly, which helped me maintain control of the interview (Plumridge et al. 2012). One of the key lessons learned from the experience of working with informal caregivers as interpreters is the importance of researchers proactively planning how to address interpretation challenges. This consideration may involve engaging professional interpreters who can provide valuable support throughout the research process.

In conclusion, the relationships between the researcher, participants, informal caregivers, and the research setting played a crucial role in shaping the data generated and interpreted in this study (Laverty 2003). Therefore, it was vital to foster positive relationships with all parties involved in the research to achieve meaningful outcomes.

6.7.3 Data collection

My background in social work significantly influenced my approach to data collection. When researching a topic that is linked to one's personal or professional experiences, preconceived ideas and biases can emerge. For example, during my study, I found myself assuming that older people have diminished control over their lives. This bias stemmed from my personal experiences in caring for older people, as well as my professional interactions with them. Consequently, my social work background shaped the data I collected, reflecting my preconceived beliefs about older people’s sense of control. Interestingly, the data sometimes presented a different reality.

During the data collection stage, I collaborated with clinicians at the Day Hospital, who acted as gatekeepers and facilitated the recruitment of participants. The objective was to identify individuals who met the inclusion criteria and could provide valuable insights to help address my research questions. The gatekeepers were accommodating in their support, which greatly aided me in reaching my recruitment targets. As experienced participant recruiters, they offered valuable advice on how to encourage participation in the study. Consequently, I was able to enhance the number of potential study participants by utilising the gatekeepers alongside other recruitment strategies, such as using posters and building rapport (Jessiman 2013; Negrin et al. 2022).

Moreover, to encourage potential participants to take part in the study, I provided them with sufficient information related to the research. I presented this information in clear and straightforward language, which was particularly beneficial for older people living with frailty (Provencher et al. 2014; Ennis and Wykes 2016). Similarly, the participant information sheet included my photograph as the researcher, fostering a personal connection with potential participants and building trust and transparency. I also allowed participants to determine the time and location of their interviews, making the process more convenient for them. Insights from the PPI team were valuable in ensuring that the information in the study documents was both clear and relevant to the target audience while conveying all necessary details about the study (HRA 2023). Furthermore, I arrived early at the Day Hospital to meet participants who had agreed to hold interviews there, eliminating the need for them to inquire about my whereabouts at the hospital reception. This approach helped alleviate the anxiety of searching for a ‘stranger’ in a public space and enhanced my credibility as a researcher.

Prior to commencing data collection, I reviewed the interview schedule with my supervisory team to explore various methods of posing questions, particularly when engaging with older people. This practice proved invaluable, as it enabled me to anticipate potential challenges in encouraging participants to articulate their experiences and formulate adaptive probing questions tailored to their individual narratives, thereby enhancing the data collection process (Adams and van Manen 2017). During the interviews, I focused on asking open-ended questions while incorporating a few direct questions. This strategy was essential in enabling the interview to stay as close to the participants’ lived experiences as possible, allowing them to recount their experiences from the inside out (Laverty 2003). Additionally, I remained attuned to non-verbal cues, including periods of silence, which helped me uncover the often-overlooked dimensions of the participants’ lived experiences (van Manen 1997a; Laverty 2003).

Importantly, I conducted the majority of interviews with older people living with frailty in their homes, a decision made at the outset of the study and consistently maintained throughout (Laverty 2003). This is because most of the participants dealt with health-related challenges, making the home interviews convenient and preferable to meetings at the Day Hospital or other locations. This approach also fostered a sense of safety, trust, and comfort for the participants. Additionally, it allowed them greater control over the interview process since they could select the location (whether inside the home or in the garden), date, and time, based on their comfort levels (Diffley 2020). Moreover, it provided me with valuable insights into their living situations, enabling a better understanding of the challenges and opportunities within their living environments.

However, conducting interviews within the participants' home environment presented several limitations. One main challenge encountered was the geographical distance between interviewees. On several occasions, I conducted two interviews in a single day, necessitating travel to disparate locations that were occasionally quite far apart. Nevertheless, this logistical constraint did not compromise the data collected, as I ensured that each participant was afforded ample time to articulate their experiences, thereby facilitating the generation of rich experiential data.

A further challenge involved the presence of informal carers during the interviews. In four instances, older people expressed a preference for having their informal carers present in the house as it fostered a sense of comfort. However, in two of these cases, the informal carers' insistence on being present during the interview resulted in observable discomfort for the participants. During these sessions, informal carers intermittently interrupted the dialogue, often diverting the conversation to unrelated topics. Such interruptions suggested a potential lack of agency on the part of the participants, which may have adversely influenced the validity of the data collected. This dynamic was particularly pronounced in the interview with Lyndsey, a 73-year-old female participant, during which her husband frequently interjected, disrupting the intended flow of the interview.

To minimise the above effect, I consistently communicated to participants that my primary focus was on their individual narratives and perspectives regarding the topics discussed. I indicated that while it was permissible for their relatives to be present, their involvement could be more beneficially served by opting to leave the room, thereby allowing for an environment conducive to open dialogue. I acknowledge that suggesting such arrangements could be sensitive or challenging, as participants may have felt uncomfortable requesting their informal carers to withdraw from the interview setting. Consequently, the presence of informal carers may have inhibited some participants from expressing their thoughts freely. In conducting the data analysis, I took these complexities into account, giving particular consideration to the interviews conducted in the presence of informal carers and prioritising them only in the latter stages of analysis. This approach was crucial in ensuring a nuanced understanding of the data while recognising the potential impact of these dynamics on the participants' narratives.

It is also essential for me to reflect on both the positive and negative aspects encountered during the data collection process. On the positive side, I was pleasantly surprised by how warmly the participants embraced me as a researcher, particularly in their homes. Older people living with frailty were incredibly kind and hospitable, often offering me a cup of tea or a glass of water. Some even took the time to show me around their homes, which helped foster a stronger rapport. Additionally, I was struck by the enthusiasm most participants displayed towards the study, especially regarding recruitment and the potential impact of the research. Several participants reached out to me ahead of the interviews to confirm the scheduled time and to remind me about the necessary study documents I needed to bring. A few even requested the information sheet to share with friends they thought might be interested in learning more about the study. These actions indicated that the participants were genuinely interested in me as a researcher and found the research topic both engaging and relevant.

On the other hand, I found myself surprised at times by my inability to manage my emotions, particularly when participants shared the more poignant aspects of their experiences or became visibly emotional while recounting them. For instance, it was occasionally challenging to listen to individuals speak about the loss of loved ones and their experiences with bodily pain and how these factors profoundly altered their perspectives on everyday life and the future, especially for those facing terminal illnesses. During the interviews, I relied on my social work training and skills, particularly the principle of controlled emotional involvement, which allows professionals to engage empathetically in professional relationships without becoming overwhelmed (Sewell 2020). After the interviews, I discussed these concerns with my supervisory team, who provided additional support. However, these emotional challenges did not affect the data collected.

Finally, I conducted interviews during the COVID-19 pandemic, specifically when the UK was under a nationwide lockdown. During this time, I had to delay my data collection due to the restrictions in place, which affected my research plan. In addition, some participants were classified as clinically vulnerable and were, therefore, unable to take part in the study, which may have resulted in the loss of valuable insights. The restrictions also impacted the daily lives and activities of older people living with frailty, including their ability to exercise, socialise, and access healthcare services. This situation could have influenced their perspectives on their sense of control. Consequently, the timing of the data collection may have affected the participants' responses. However, one of the key insights I gained from conducting research during the COVID-19 pandemic is the unpredictability inherent in the research process. It became clear that flexibility and pragmatism are essential attributes for researchers, especially when confronting unprecedented circumstances. This adaptability enabled me to navigate the complexities and challenges that arose during the pandemic, leading to a more effective approach to the study.

6.7.4 Data analysis and my overall interpretation

As I previously noted, one of the main challenges I faced during my research was identifying a clear, step-by-step method for conducting phenomenological research, particularly in terms of data analysis. I chose to apply a hermeneutic phenomenological method to guide my interviews and data analysis, primarily due to its emphasis on the participants' lifeworld (van Manen 1997a, 1997b). In the initial stages, however, I struggled to comprehend how to effectively implement this method in practice and ensure rigour in my analysis. van Manen's (1997a) principles for conducting phenomenological research can be difficult to apply, especially for novice researchers like myself. Nevertheless, I dedicated significant effort to grasping how to utilise a hermeneutic phenomenological approach and the key aspects necessary for maintaining rigour. To assist in this, I reviewed the literature to see how other researchers had approached their data analysis using this methodology (Adams and van Manen 2017). I also engaged with fellow PhD students who employed various phenomenological approaches for data analysis. Through this process, I began to appreciate hermeneutic phenomenology and recognise the significance of its core tenets, such as phenomenological reflection. van Manen's principles of hermeneutic reflection became increasingly clear to me, and I utilised them as a framework for guiding my data analysis (van Manen 1990, 1997a; Adams and van Manen 2017).

It is crucial to highlight that van Manen (1997a) cautions against the use of analytical software packages for analysing hermeneutic phenomenological data. Therefore, I opted to manually analyse my data to uncover the experiential structures related to the phenomena under investigation (Errasti-Ibarrondo et al. 2018). Although this process was time-consuming, it provided substantial benefits by enabling a deeper engagement with the lived experiences of a sense of control and well-being in older people living with frailty. This method allowed for a *"slower and more meaningful interaction with the data,"* offering me the opportunity to examine, compare, and reflect on various perspectives (Maher et al. 2018, p.11; Mattimoe et al. 2021). Moreover, my extensive immersion in the data fostered a hermeneutic connection to the participants' experiences. Consequently, it became essential to present their narratives alongside my interpretations in a way that effectively conveys *''the wholeness of the experience''* for the reader, often through a first-person narrative style (Wertz et al. 2011, p.1).

To enhance confidentiality and anonymity, I employed data reduction techniques to eliminate any potentially identifiable information from certain participants' responses. Although this necessitated the removal of some specific details, I took care to preserve the credibility of the data by providing comprehensive contextual information about the interviews. This context allows readers to grasp my findings while ensuring that no identifying information is disclosed.

Furthermore, I established connections to various lifeworld existentials, including embodiment, spatiality, intersubjectivity, temporality, and mood, to inform my analysis (van Manen 1997a). These dimensions of lifeworld proved essential in offering frameworks that facilitated my existential reflection on the experiences of control and well-being among older people living with frailty (Gorichanaz et al. 2018).

The key lesson learned from engaging in data analysis following van Manen's principles of hermeneutic phenomenology is the importance of sustained interaction with the data. This stage proved to be the most complex and intellectually challenging aspect of my PhD journey. Analysing my data demanded significant time and effort to arrive at the final themes that would inform my writing-up phase. Consequently, researchers utilising this method must dedicate sufficient time to data analysis to achieve a deeper understanding and interpretation of the multi-layered nature of individuals' lived experiences.

In summary, reflexivity has significantly enhanced my learning by allowing me to critically evaluate my perspectives, values, and behaviours. This practice has fostered a deeper understanding of both myself and my research process. Through engaging in reflexivity, I have been able to identify and confront my influences and limitations, ultimately strengthening the rigour of my research.

6.8 Conclusion

The chapter has highlighted that older people living with frailty experience changes in their sense of control during healthcare encounters. These alterations are multidimensional, influencing various aspects of their lives. The interconnectedness among the various dimensions of their lifeworld significantly shapes their experiences of control and overall well-being. For example, their embodied and spatial experiences affect their perception of time and interpersonal interactions, subsequently impacting their mood. Through a discussion of these complexities, this chapter has endeavoured to provide a better understanding of the experiences of older people living with frailty. Furthermore, it highlights the application of the lifeworld approach in understanding the sense of control and well-being in this demographic, which stands as a significant strength of this research.

6.9 Strengths of the study

a) This study follows the philosophical principles of the lifeworld, providing vulnerable older people the opportunity to share their lived experiences--an aspect often overlooked in research (Hamaker et al. 2014; Lockett et al. 2019). The lifeworld framework transcends traditional healthcare models, such as patient-centred care, by emphasising the existential dimensions of healthcare provision (Dahlberg et al. 2009). Existentialism enables us to grasp the human condition by posing fundamental questions about key elements such as autonomy, well-being, ill-being, and our place in the world--concepts that are essential to our existence and healthcare service use (Van Der Bruggen and Widdershoven 2005; van Der Vaart and van Oudenaarden 2018; Galvin 2021). For older people living with frailty, it is vital to recognise their existential needs, which include effective communication, trusting relationships, choice, dignity, and participatory decision-making (Sjöberg et al. 2018; Bäckersten et al. 2024). As a result, the lifeworld framework has enriched our understanding of the significance and complexity of existential factors in healthcare provision for older people living with frailty.

b) In this study, I explored the lived experiences of control and well-being for older people living with frailty, drawing insights from both the perspectives of these individuals and their healthcare professionals. This multifaceted approach has facilitated a more comprehensive understanding of the topic compared to other studies that often focus solely on the perspectives of either older people or healthcare providers.

6.10 Limitations of the study

Although I implemented various measures to enhance the rigour of my research, it is essential to interpret the findings within the context of the following limitations.

a) The study comprised only white participants, as individuals seeking services at the Day Hospital in southern England are predominantly white. However, given that prior research has indicated that race influences perceptions of control, it would have been beneficial to include individuals from diverse ethnic backgrounds to gain a more comprehensive understanding of their experiences regarding a sense of control and well-being (Shaw and Krause 2001; Skaff 2007; Assari 2017).
b) Additionally, I conducted this study during the COVID-19 pandemic, which imposed various restrictions on people's daily lives, including limitations on social interaction and physical activity. Consequently, it is possible that some participants' perspectives on their sense of control were shaped by the prevailing, predominantly restrictive circumstances, particularly impacting older people.
c) Furthermore, I relied on clinicians' assessments of frailty rather than utilising validated tools when screening older people through the Day Hospital. This approach makes it challenging to objectively ascertain the levels of frailty these individuals experienced according to established dominant models of frailty.

6.11 Implications for practice and research

In this section, I will discuss the implications of the study findings for research and practice. This study presents several important implications for health and social care research and practice concerning older people living with frailty.

6.11.1 Practice implications and recommendations

a) Older people living with frailty have distinct perceptions of control within healthcare settings. As they navigate various services, these individuals encounter a range of factors that can either enhance or hinder their sense of control and overall well-being. It is essential to recognise that standardising care structures and processes may not always benefit older people living with frailty. This variation in perspective underscores the necessity for healthcare providers to understand the unique aspects of control relevant to this demographic and to identify suitable interventions that can strengthen their sense of agency.

b) Healthcare professionals and older people living with frailty share some common viewpoints, yet they hold differing perspectives on specific issues. One notable area of difference lies in the type and adequacy of health-related information exchanged. While healthcare professionals often believed the information was comprehensive and appropriate, older people living with frailty frequently perceived it as lacking or insufficient. This discrepancy can be attributed to a fundamental misunderstanding between the two groups. To address this issue, it is recommended for healthcare professionals and older people living with frailty to engage in group discussions about healthcare-related aspects. This participatory approach can help bridge the gap and foster improved communication and understanding.

c) Moreover, healthcare professionals seek greater control over their work to better serve older people living with frailty. The study indicates that these professionals often find themselves operating within a system that can constrain their work methods and ingenuity. To maximise the benefits of the study's findings, it is crucial to empower healthcare staff with more control over their work practices. This empowerment will foster a supportive work environment, allowing healthcare professionals increased flexibility and professional autonomy in their decision-making. Options such as choosing the number of client shifts can enhance their motivation and commitment to their work.

6.11.2 Research implications and recommendations

a) It is important to note that the study included only white participants, which may limit our understanding of the sense of control among individuals from other ethnic backgrounds. Therefore, it is essential for future researchers to broaden their investigations to encompass a more diverse range of ethnicities. Adopting this inclusive approach will lead to a more comprehensive understanding of the topic and promote a healthcare system that addresses the varied needs of older people living with frailty.

b) Additionally, a future participatory action study grounded in lifeworld principles involving older people living with frailty and healthcare professionals would be valuable. This research could explore how the findings from this study can be applied in practice and enhance service provision within healthcare settings.

6.12 Application of findings in the current healthcare services context

a) The Day Hospital represents a well-established healthcare organisation characterised by a robust service culture. However, it is imperative to consider the implementation of the findings in a more demanding, under-resourced, and fast-moving healthcare service environment. Despite the prevalent issues of excessive workloads and understaffing across many NHS-related healthcare organisations, staff can still prioritise the enhancement of older people’s sense of control and well-being by focusing on simple yet impactful elements such as the creation of a welcoming atmosphere, effective communication, and the practice of shared decision-making.

b) In a similar vein, these findings shed light on the often-overlooked existential dimensions influencing the sense of control and well-being among older people living with frailty. As a result, healthcare professionals may find these insights valuable in fostering a deeper understanding of the patient as a whole person. By elucidating existential factors related to control and well-being--such as embodiment, spatiality, and mood--this research endeavours to provide a significant starting point for healthcare professionals to access the individual’s lifeworld, thereby addressing genuine challenges rather than merely the presenting issues. Similarly, the findings highlight critical deficiencies within healthcare service provision, particularly in the realms of fostering trusting relationships, facilitating information sharing, and implementing shared decision-making practices. These elements can be improved through a humanising caring approach that does not necessarily rely on significant resource allocation.

c) Furthermore, the findings underscore the importance of considering the temporal dimensions of healthcare delivery, particularly emphasising the necessity for patients to have sufficient time to engage meaningfully in dialogue with their healthcare providers, alongside minimising waiting periods for appointments. Nonetheless, healthcare professionals frequently operate within systems constrained by limited time availability. Despite this limitation, the findings suggest that the quality of the healthcare interaction may hold greater significance than the mere duration of patient engagement. Therefore, it is possible for healthcare systems to navigate these temporal constraints while promoting aspects that enhance human dignity, thereby fostering a heightened sense of control and well-being among patients.

6.13 Aspects of the study that I would do differently

If I were to undertake this research again, I would implement the following strategies to enhance its quality and rigour.

a) I would interview a smaller number of older people living with frailty, specifically between 10-12. This approach aligns with recommendations found in some of the hermeneutic phenomenological literature (Rincón and Hollis 2020; Zelalem et al. 2021). As mentioned earlier, I interviewed 20 older people living with frailty because I assumed it would be challenging to engage this population group in lengthy discussions to gain in-depth insights into their experiences. However, during the analysis stage, I realised that I had accumulated a substantial amount of data, suggesting that a larger sample size may not be necessary for hermeneutic phenomenological studies involving this demographic.

b) Upon reflection, I realise that my study would have greatly benefited from including a more diverse participant group to ensure inclusivity. In future research, I intend to leverage the NIHR support services along with the INCLUDE framework and guidance on enhancing participant recruitment diversity to improve future studies (NIHR 2020).

c) I would also consider selecting a recruitment site that offers services to a broader range of older people living with frailty, which would enhance the transferability of the study findings. While the Day Hospital enabled me to reach my target population, it is essential to note that such facilities have become increasingly rare in the UK, impacting the transferability of my study findings. The experiences captured through wider GP and community services would likely be more applicable to other settings, such as older people's community teams or frailty teams.

Chapter 7 Conclusion

7.1 Introduction

In this concluding chapter, I provide a summary of my thesis and the novel insights obtained from the study. I also discuss the impact of the study findings on my current and future professional practice.

7.2 Summary of the thesis

This thesis highlights that a sense of control in older people living with frailty is not merely a static personal trait but rather a dynamic and relational position influenced by their lived experiences. Each older person possesses a unique sense of control that varies from high to low, contingent upon the specific lifeworld factors they encounter. Generally, older people, particularly those living with frailty, tend to experience a gradual contraction of their sphere of influence due to both physical decline and societal responses towards ageing.

A pivotal aspect of life for older people living with frailty is their engagement with healthcare services. When access to these services is effective, there is a notable expansion of the sphere of influence as older people living with frailty often enjoy enhanced physical capabilities and improved daily functioning resulting from the support received. However, access to healthcare services does not solely depend on physical availability; it is also significantly shaped by the impact that these services have on an individual’s lifeworld, sense of self, and perception of being acknowledged.

The current research underscores the critical importance of recognising the emotional and psychological dimensions of service provision, highlighting how these dimensions shape individuals' experiences and healthcare service use. When foundational human needs--such as insiderness and a sense of belonging--are duly met, a sense of togetherness emerges, facilitating improved information exchange, participatory decision-making, choice, and agency within healthcare services. This, in turn, fosters increased engagement with healthcare services, creating a virtuous cycle of improvement and support.

Additionally, it is essential to acknowledge that the sense of control is influenced by a person's specific lifeworld circumstances. Even seemingly minor existential vulnerabilities stemming from negative experiences can disrupt the virtuous cycle of improvement or hinder its initiation altogether. Employing a lifeworld perspective has illuminated the seemingly trivial existential dimensions of everyday life (van Manen 1990) and brought to light the often 'invisible' aspects of healthcare service delivery, emphasising their significance and influence.

Through an exploration of the lifeworld dimensions, including embodiment, intersubjectivity, temporality, spatiality, and mood, this study has yielded a deeper understanding of the sense of control and well-being among older people living with frailty. Additionally, it provides a language that researchers, practitioners, and service managers can draw upon to enhance the sense of control, optimise service delivery, and ultimately promote the well-being of this vulnerable population.

7.3 Summary of new knowledge from the study

In this section, I will summarise the new knowledge derived from exploring the lived experiences of older people living with frailty alongside the perspectives of healthcare professionals within the Day Hospital context, as informed by the findings of this study.

7.3.1 New knowledge about older people's experiences of control and well-being

The findings highlight that the humanising life-world approach enables older people living with frailty to express themselves more freely, thereby allowing practitioners to gain insights into their lifeworld. This understanding of the lifeworld provides healthcare professionals with the opportunity to concentrate on the existential aspects, which is essential for developing a deeper understanding of older people living with frailty and designing relevant interventions aimed at enhancing a sense of control and well-being for the person.

7.3.2 New knowledge on how healthcare professionals can support older people living with frailty to maintain control

The findings underscore the impact of time constraints on delivering quality and appropriate care, a concern that has been highlighted in previous research. However, they also reveal the potential benefits of lifeworld-led humanising care, which can empower healthcare providers to make older people living with frailty feel valued, even within time limitations. Often, the seemingly simple aspects--such as the perception of being valued and welcomed in healthcare settings--help older people living with frailty feel that their care meets them as human beings.

As demonstrated in the findings, these small yet significant aspects of care contribute to a sense of agency for older people living with frailty, allowing them to feel control over their healthcare. Consequently, healthcare professionals need to recognise that this sense of control is a dynamic relational aspect, heavily influenced by how they interact with the individuals in their care encounters.

7.4 The impact of the study findings on my current and future practice

The study emphasised key aspects that are directly transferable to health and social care practices for older people living with frailty. Currently, I am serving as a Research Fellow within the NHS, working on a research project aimed at enhancing the self-management skills of older people living with frailty and other long-term conditions, enabling them to safely manage their medicines after hospital discharge. The insights gained from my PhD work have been instrumental in helping me grasp the contextual factors that both facilitate and hinder the self-management abilities of older people living with frailty regarding their medicines management. Furthermore, my PhD research has broadened my understanding of the lifeworld-led humanising care approach, which is crucial in addressing various aspects of caring for older people living with frailty and other long-term conditions. This knowledge and experience will be vital as I develop my research career in this field.

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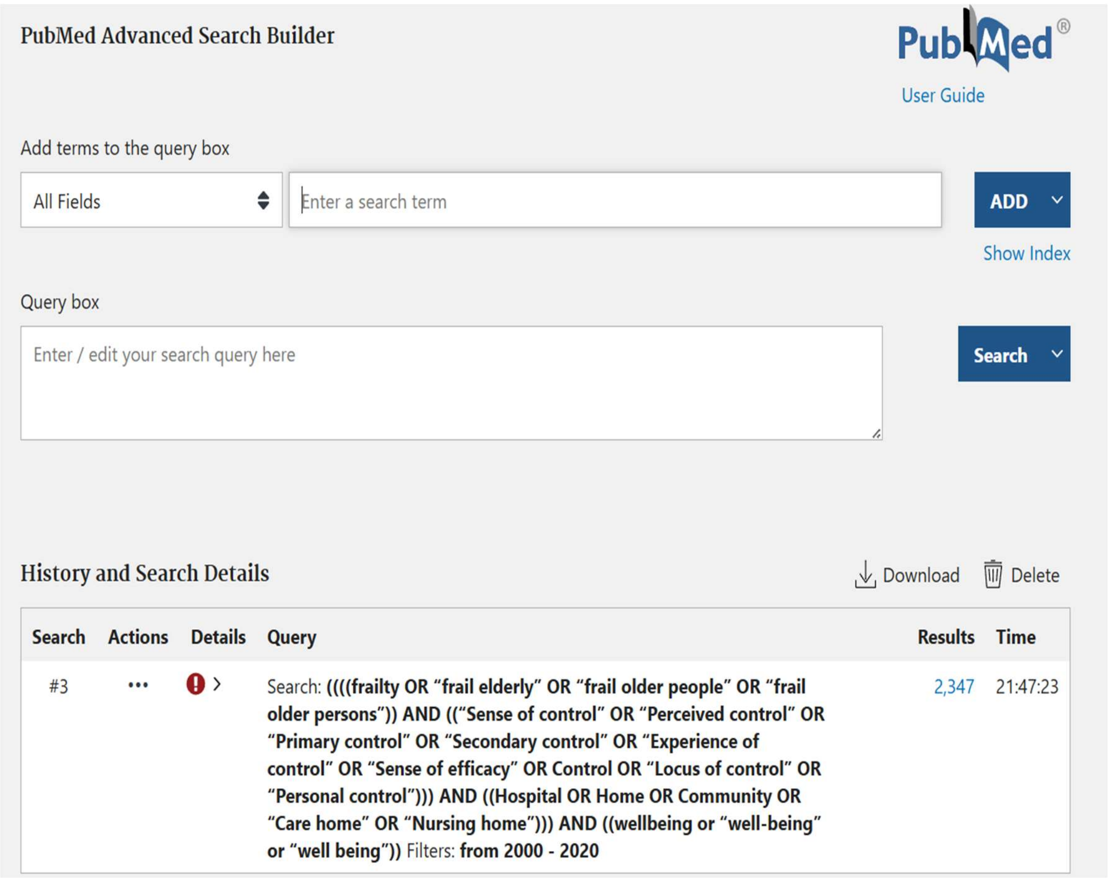
Appendices

Appendix 1: Example of a database search string (PubMed)



Search	Actions	Details	Query	Results	Time
#3	•••	! ›	Search: ((((frailty OR “frail elderly” OR “frail older people” OR “frail older persons”)) AND ((“Sense of control” OR “Perceived control” OR “Primary control” OR “Secondary control” OR “Experience of control” OR “Sense of efficacy” OR Control OR “Locus of control” OR “Personal control”))) AND ((Hospital OR Home OR Community OR “Care home” OR “Nursing home”))) AND ((wellbeing or “well-being” or “well being”)) Filters: from 2000 - 2020	2,347	21:47:23

Appendix 2: Participant Information Sheet (Older people)

Bournemouth
University

IRAS Version: 4.0
IRAS ID: 282540
Date: 24/06/2021

Participant Information Sheet (Older people)

1. Welcome and Introduction

Hullo, my name is Adam Nyende, and I am a research student at Bournemouth University.

I have learnt that it is easy to lose the feeling of control when you are an older person. In this study, I would like to find out more about your experiences. This will involve my coming to talk to you at home, or, if you wish, in another agreed place. However, if it is not possible to meet face to face, then the use of Skype/Zoom/Microsoft Teams or telephone will be considered. We would talk for up to 1 to 1 ½ hours and explore your experiences and views about your sense of control and well-being. It is up to you to decide whether or not to take part in the study.

Below you will find out more about this research project.

2. The title of the research project

An exploration of a sense of control and well-being in the lives of older people.

3. Invitation to take part

You are being invited to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

4. Who is organising/funding the research?

This research is being organised by Bournemouth University and funded by the European Commission under the Horizon 2020 (Marie Skłodowska-Curie Research Actions).

5. What is the purpose of the project?

The purpose of the study is to explore the experiences of control and well-being of older persons and to try and improve the care services for these people. Some research studies have shown that older people sometimes have a sense that they have less control in their lives, and so the researcher would like to see how this impacts on care services and how these services can be developed to support them better. The research is undertaken as part of doctoral degree requirements.

6. Why have I been chosen?

You have been contacted to take part as you have been assessed and treated as a patient at the Day Hospital, where you currently receive (part of) your care services and you are aged 65 years or over. Your age and personal experiences position you to provide valuable insights on the research topic. This study intends to recruit up to 20 (twenty) older people.

7. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. We want you to understand what taking part involves before you decide on whether to take part.

If you or any family member have an on-going relationship with Bournemouth University, e.g. as a member of staff, as a student or other service user, your decision to take part (or continue in the study) will not affect this relationship in any way.
Additionally, no element of your ongoing care at the Day Hospital will be impacted whether you take part or not.

8. What will I have to do if I take part?

If you agree to take part in the study, it would be expected from you to take part in a face to face interview with the researcher which is expected to last for no longer than 1 to 1 ½ hours to explore your experiences and views about your sense of control and how this has impacted your well-being. However, if it is not possible to meet face to face, then the use of Skype/Zoom/Microsoft Teams or telephone will be considered. There will be opportunities for short breaks in between the interview.

The interview will involve talking about what you feel about how much control you have got in your life, how care services affect this, and how they could be improved.

Generally, the questions will focus on your personal experiences and perceptions. If you feel uncomfortable about answering any questions, you do not need to answer them.

9. Where will this take place?

The interview will be conducted either at your home or in a private space at the Day Hospital, and this will be agreed in advance between you and the researcher. However, there is the flexibility to have the interview in another appropriate and mutually agreed venue. In case you decide to have the interview at the Day Hospital and require transport to get there, the researcher will cover the transport costs.

10. What measures are in place to protect against coronavirus?

The researcher will ensure that safeguarding measures such as hand washing, social/physical distancing and wearing facial coverings are in place to protect against coronavirus during the interviews.

11. Will I be recorded, and how will the recorded media be used?

The interview will be recorded using an audio-recorder. This is to make sure that the researcher does not miss any of your responses. People often say very helpful things in these discussions, and the researcher may not write fast enough to get them all down. Consequently, the researcher will transcribe the original recording into text.

The researcher will then analyse what you have said and some things that you say might be in the research report, conference presentations, journal publications and project official social media accounts, but nobody will know who you are.

The original recordings will be held securely and stored in a private, locked drawer at the researcher's office and transferred to electronic files (transcribed text) as soon as possible. The electronic files will then be stored on a Bournemouth University password-protected computer, and the original audio recordings securely deleted.

12. When will I have the opportunity to discuss my participation?

You will have the opportunity to discuss your participation before the start of the interview. You will be given a minimum of 24 hours to consider taking part in the study and also contact the researcher with any questions and/or concerns. At this stage, you will have the opportunity to raise any issues and concerns regarding your participation. Please note that you are also welcome to discuss any issues regarding your participation with the researcher at any stage of the study.

13. Can I change my mind about taking part?

Yes, you can stop taking part in the study activities at any time and without giving a reason. Your taking part in this study is voluntary, and if you choose to stop taking part in the study, it will not affect your ongoing care in any way.

14. If I change my mind, what happens to my information?

After you decide to withdraw from the study, the researcher will not collect any further information from or about you. As regards information already collected before this point, you will not be able to change or withdraw it once it has been included in the data analysis because nobody will know who you are. As personal details will have been removed, the researcher will be unable to identify which information is yours. The researcher needs to manage your information in specific ways in order for the research to be reliable.

Further explanation about this is in the Personal Information section below.

15. What are the advantages and possible disadvantages or risks of taking part?

Whilst there are no immediate benefits to you taking part in the project, it is hoped that this work will provide you with an opportunity to share your feelings and experiences and how these can contribute to improving caring services.

Whilst the researcher does not anticipate any risks to you in taking part in this study, it is possible that some of your responses could generate some form of stress since the entire interview will be about understanding your present and past life experiences. You may, therefore, find talking about parts of your experience stressful or upsetting.

However, if this happens, you can choose not to talk about these parts of your experience or stop the interview at any time without giving a reason and the researcher will check that you are ok. If you have any ongoing issues, the researcher will signpost you to further support.

16. What type of information do I need to provide and why is the collection of this information important?

This study seeks to obtain information related to your personal experiences, opinions and views relating to control and well-being in your life and how you get your care at the Day Hospital.

The information you will provide is important as your experiences, whilst unique, may share common patterns with others living in similar situations and contexts. Therefore, they will provide greater understandings as to appropriately support these individuals in enhancing their quality of life and improving their sense of well-being.

To achieve this, the researcher will need to use information from you and your medical records for this research project.

The personal information will include your;

- Initials
- Name
- Signature
- Age
- Gender
- Contact details
- Postcode

This information will be used to do the research or to check your records to make sure that the research is being done properly.

17. How will my information be managed?

Bournemouth University (BU) is the organisation with the overall responsibility for this study and the Data Controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university.

Undertaking this research study involves collecting and/or generating information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control use of information about identifiable individuals, but do not apply to anonymous research data: “anonymous” means that we have either removed or not collected any pieces of data or links to other data which identify a specific person as the subject or source of a research result.

BU’s Research Participant Privacy Notice sets out more information about how we fulfil our responsibilities as a data controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information.

Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet. To protect your rights in relation to your personal information, the researcher will use as minimal identifiable information as possible and control access to that information as described below.

a) Publication

You will not be able to be identified in any external reports or publications about the research. People who do not need to know who you are will not be able to see your name or contact details. Otherwise, your information will only be included in these materials in an anonymous form, i.e. you will not be identifiable, and your data will have a code number instead.

Once we have finished the study, we will keep some of the data so we can check the results. The researcher will write the research reports in a way that no-one can work out that you took part in the study.

The research results will be published in the form of a research report (thesis), journal articles, conference papers and social media blogs, and this will take place after the data collection and analysis stages.

b) Security and access controls

All the information collected about you will be kept safe and secure. The information will be held in hard copy in a secure location and on a BU password-protected secure network where held electronically.

Personal information which has not been anonymised will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified in the Privacy Notice. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations.

c) Further use of your information

The information collected about you may be used in an anonymous form to support other research publications in the future, and access to it in this form will not be restricted. It will not be possible for you to be identified from this data.

To enable this use, anonymised data will be added to the 'UK Data Archive': an online Research Data Repository where all the project data will be centrally stored and accessible to the public after the study.

d) Keeping your information if you withdraw from the study

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have if this has on-going relevance or value to the study or once this information has been included in the data analysis. This may include your personal identifiable information. This is because we need to manage your information in specific ways in order for the research to be reliable. However, if you have concerns about how this will affect you personally, you can raise these with the researcher when you withdraw from the study.

You can find out more about how we use your personal information, your rights in relation to your data and how to raise queries or complaints;

- by asking the researcher
- by contacting James Stevens, our Chief Data Officer at **dpo@bournemouth.ac.uk** or **01202 962472.**
- in the HRA data protection and patient information governance section.
- in the BU Research Participant Privacy Notice

e) Retention of research data

Project governance documentation, including copies of **signed participant consent forms:**

We keep this documentation for five (5) years after completion of the research, so that we have records of how we conducted the research and who took part. The only personal information in this documentation will be your name and signature, and we will not be able to link this to any anonymised research results. The consent forms will be transferred onto Bournemouth University's electronic hard drive/secure server, while the paper copies will be held securely and stored in a private, locked drawer (cabinet) at the researcher's office.

18. Research results:

As described above, during the course of the study, information collected about you as an individual will be anonymised (nobody will know who you are). This means your personal information will not be held in identifiable form after the research activities have been completed.

You can find more specific information about retention periods for personal information in our Privacy Notice.

We shall deposit the anonymised research data in an online research data repository after the study so that it can be used for other research purposes as described in Section 17*c* above.

19. Who will have access to the information that I provide?

Before the end of the research project, the information provided during the interview will only be accessed by the researcher and, in some cases, the research supervisory team during data analysis. The only exception is in instances where something is mentioned during the interview that has the potential to cause immediate harm to you or other people. In such cases, the university and/or Hospital’s safeguarding procedures will be followed, and the relevant people will be informed for safeguarding reasons. This will be the only exception to anonymity and confidentiality in this study.

20. How can I find out about the results of the study?

The researcher will be happy to provide you with a summary of the approved research results through post or email and can provide a soft copy of a full research report through email.

21. Contact for further information about the research

	If you have any questions or would like further information, please contact **Adam Nyende,** the **researcher** for this study. Email:anyende@bournemouth.ac.uk **or** Telephone: 07466-409939.

22. What if there is a problem?

The Patient Advisory Liaison Service (PALS) is a confidential NHS service that can provide you with support for any complaints or queries you may have regarding the care you receive as an NHS patient. PALS are unable to provide information about this research study.
If you wish to contact the PALS teams, please telephone**:** **01202 704886** or email: pals@rbch.nhs.uk.

If you wish to complain about any aspect of this study, you should contact **Professor Vanora Hundley,** Deputy Dean - Research and Professional Practice Bournemouth University-by email: **researchgovernance@bournemouth.ac.uk** or telephone: **01202 965206.**

23. Finally

If you decide to take part, you will be given a copy of the information sheet and a signed participant consent form to keep.

Thank you for considering taking part in this research project.

Appendix 3: Participant Information Sheet (Day Hospital staff)

Bournemouth
University

IRAS Version: **3.0**
IRAS ID: **282540**
Date: **24/06/2021**

Participant Information Sheet (Day Hospital Staff)

1. The title of the research project

Exploring the lived experience of control and well-being of older persons living with frailty within the care service provision in southern England.

2. Invitation to take part

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

3. Who is organising/funding the research?

This research is being organised by Bournemouth University and funded by the European Commission under the Horizon 2020 (Marie Skłodowska-Curie Research Actions). In this information sheet, we", "our" and "us" refers to Bournemouth University (BU).

4. What is the purpose of the project?

The purpose of the study is to explore the experiences of control and well-being of older persons and to try and improve the care services for these people. The research is undertaken as part of doctoral degree requirements.

5. Why have I been invited?

You have been contacted because of your professional experience of working with frail older people at the Day Hospital. Your professional knowledge, skills and experiences ideally position you in providing valuable insights on the research topic. This study intends to recruit up to ten (10) staff who have worked with frail older people for more than 6 months**.**

6. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a participant consent form. We want you to understand what participation involves before you make a decision on whether to participate.

If you or any family member have an on-going relationship with Bournemouth University or the research team, e.g. as a member of staff, as student or other service user, your decision on whether to take part (or continue to take part) will not affect this relationship in any way. Additionally, no element of your legal rights will be impacted whether you participate or not.

Furthermore, the researcher will provide refreshments such as tea and biscuits during the interview. Additionally, you will be provided with an Amazon cash voucher of £10 as a token of appreciation if you take part in the study in your own time.

7. What would taking part involve?

You will be asked to take part in a face to face interview with the researcher which is expected to last for no longer than one hour to explore your experiences, perceptions and opinions regarding sharing control with older people diagnosed with frailty and on how the care for frail older persons can be enhanced to support personal control and well-being. However, if it is not possible to meet face to face, then the use of Skype/Zoom/Microsoft Teams or telephone will be considered.

We shall be talking about your perception and experience of sharing control with frail older people and how this could be improved.

Generally, the questions will focus on your professional experiences and perceptions. However, if you feel uncomfortable about answering any question, you do not need to answer it.

8. Where will the interview take place?

The interview will be conducted at the Day Hospital by the researcher. However, there is the flexibility to have the interview in another appropriate and mutually agreed venue.

9. Will I be recorded, and how will the recorded media be used?

The interview will be audio-recorded. This is to make sure that I do not miss any of your responses. People often say very helpful things in these discussions, and I may not write fast enough to get them all down. However, the audio recordings of your activities made during this research will be used only for analysis and the transcription of the recording(s) for illustration in the research report, conference presentations and other research outputs. No one outside the project will be allowed access to the original recordings.

The original recordings will be held securely and stored in a private, locked drawer at my office and transferred to electronic files (transcripts) as soon as possible. The electronic files will then be stored on a Bournemouth University password protected H-drive and the original audio recordings securely deleted.

10. When will I have the opportunity to discuss my participation?

You will have the opportunity to discuss your participation before the commencement of any interview process. You will be given a minimum of 24 hours to consider taking part in the study and also contact the researcher with any questions and/or concerns. At this stage, you will have the opportunity to raise any issues and concerns regarding your participation. Please note that you are also welcome to discuss any issues regarding your participation at any stage of the study.

11. Can I change my mind about taking part?

Yes, you can stop participating in the study activities at any time and without giving a reason. Your participation in this study is totally voluntary and there will be no consequences as a result of your termination of participation from the study.

12. If I change my mind, what happens to my information?

After you decide to withdraw from the study, we will not collect any further information from or about you. As regards information we have already collected before this point, you will not be able to change or withdraw it once it has been included in the data analysis as it will be anonymous. As personal details will have been removed we will be unable to identify which information is yours. We need to manage your information in specific ways in order for the research to be reliable.

Further explanation about this is in the Personal Information section below.

13. What are the advantages and possible disadvantages or risks of taking part?

Whilst there are no immediate benefits to you participating in the project, it is hoped that this research will allow you the opportunity to reflect on your professional work and also contribute to improving care service provision for frail older people.

Whilst we do not anticipate any risks to you in taking part in this study, it is possible that some of your responses could generate some form of stress since the entire interview will revolve around understanding your professional experience. You may, therefore, find talking about parts of your experience stressful or upsetting.

If this happens, you can choose not to talk about these parts of your experience or stop the interview at any time without giving a reason.

14. What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?

This study seeks to obtain information related to your professional experiences, opinions and viewpoints. With the increasing number of frail older people in our communities, a more specific focus on understanding their quality of life and care is required to improve their well-being.

Therefore, it is crucial to gain the views/perspectives of their professional care providers on how the care service provision can be improved. Consequently, the information you will provide in the form of your professional experiences will be very valuable in achieving the study objectives.

To achieve this, we will need to use information from you for this research project.

The personal information will include your;

- Initials
- Name
- Signature
- Gender
- Contact details
- Postcode

People will use this information to do the research and to make sure that the research is being done properly.

15. How will my information be managed?

Bournemouth University (BU) is the organisation with overall responsibility for this study and the Data Controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university.

Undertaking this research study involves collecting and/or generating information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control use of information about identifiable individuals, but do not apply to anonymous research data: "anonymous" means that we have either removed or not collected any pieces of data or links to other data which identify a specific person as the subject or source of a research result.

BU's Research Participant Privacy Notice sets out more information about how we fulfil our responsibilities as a data controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information.

Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet. To safeguard your rights in relation to your personal information, we will use the minimum personally-identifiable information possible and control access to that data as described below.

a) *Publication*

You will not be able to be identified in any external reports or publications about the research. People who do not need to know who you are will not be able to see your name or contact details. Otherwise, your information will only be included in these materials in an anonymous form, i.e. you will not be identifiable and your data will have a code number instead.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

The research results will be published in the form of a journal article, thesis and conference papers and this will take place after the data collection and analysis stages.

b) Security and access controls

We will keep all information about you safe and secure. BU will hold the information we collect about you in hard copy in a secure location and on a BU password-protected secure network where held electronically.
Personal information which has not been anonymised will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified in the Privacy Notice. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations.

c) Further use of your information

The information collected about you may be used in an anonymous form to support other research projects in the future and access to it in this form will not be restricted. It will not be possible for you to be identified from this data. To enable this use, anonymised data will be added to the 'UK Data Archive' an online Research Data Repository where all the project data will be centrally stored and accessible to the public after the study.

d) Keeping your information if you withdraw from the study

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have if this has on-going relevance or value to the study or once this information has been included in the data analysis. This may include your personal identifiable information. This is because we need to manage your information in specific ways in order for the research to be reliable. However, if you have concerns about how this will affect you personally, you can raise these with the research team when you withdraw from the study.

You can find out more about how we use your personal information, your rights in relation to your data and how to raise queries or complaints;

- by asking the researcher
- by contacting James Stevens, our Chief Data Officer at **dpo@bournemouth.ac.uk** or **01202 962472.**
- in the HRA data protection and patient information governance section
- in the BU Research Participant Privacy Notice

e) Retention of research data

Project governance documentation, including copies of **signed participant consent forms:**

We keep this documentation for five (5) years after completion of the research, so that we have records of how we conducted the research and who took part. The only personal information in this documentation will be your name and signature, and we will not be able to link this to any anonymised research results.

16. Research results:

As described above, during the course of the study we will anonymise the information we have collected about you as an individual. This means that we will not hold your personal information in identifiable form after we have completed the research activities.

You can find more specific information about retention periods for personal information in our Privacy Notice.

We shall deposit the anonymised research data in an online research data repository after the study so that it can be used for other research as described in Section C above.

17. Who will have access to the information that I provide?

Before the end of the research project, the information provided during the interview will only be accessed by the researcher and in some cases the research supervisory team during data analysis. Additionally, the data you provide will not be used for your assessments/appraisal and you will not be vulnerable to your supervisors and/or managers.

The only exception is in instances where something is mentioned during the interview that raises issues of concern about practice such as potential criminal offence including professional malpractice or has the potential to cause immediate harm to you or other people.

In such cases, the University and/or Hospital's safeguarding procedures will be followed and the relevant people will be informed for safeguarding reasons. This will be the only exception to anonymity and confidentiality in this study.

18. How can I find out about the results of the study?

The researcher will be happy to provide you with a summary of the approved research findings and can also provide a full research report via email.

19. Contact for further information

If you have any questions or would like further information, please contact **Adam Nyende** who is the researcher for this study.

Email: anyende@bournemouth.ac.uk **or** telephone: **07466-409939.**

20. What if there is a problem?

If you wish to complain about any aspect of this study, you should contact **Professor Vanora Hundley,** Deputy Dean - Research and Professional Practice Bournemouth University-by email: researchgovernance@bournemouth.ac.uk or telephone: **01202 965206.**

21. Finally

If you decide to take part, you will be given a copy of the information sheet and a signed participant consent form to keep.

Thank you for considering taking part in this research project.

Appendix 4: Participant Consent Form (Older people)

IRAS Version: **3.0**
IRAS ID: **282540**
Date: **24/06/2021**

Participant Identification Number for this study:

CONSENT FORM-Older People

Title of Project: An exploration of a sense of control and well-being in the lives of older people.

Name of Researcher: **ADAM NYENDE**

Please initial box

1. I confirm that I have read the information sheet dated **24 June 2021** (Version **4.0**) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I confirm that I have been given access to the BU Research Participant Privacy Notice which sets out how my personal information will be collected and used (https://www1.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy). ☐

3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time or decline to answer any particular question(s) without giving any reason, and without my medical care or legal rights being affected. ☐

4. I understand and consent to the following activities;

   - Having either a face to face, online (Skype/Zoom or Microsoft Teams) or telephone interview with the researcher
   - Being audio recorded during the interview
   - My words will be quoted in publications, reports, web pages and other research outputs without using my real name.

   ☐

5. I understand that, if I withdraw from the study, I will also be able to withdraw my data from further use in the study except where my data has been anonymised (as I cannot be identified) or already incorporated in the analysis. ☐

6. I understand that my data may be included in an anonymised form within a dataset to be archived at ‘UK Data Archive’ online Research Data Repository. ☐

7. I understand that relevant sections of my medical notes may be looked at by individuals from the Day Hospital and Bournemouth University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

8. I understand that the information collected about me will be used to support future research publications, reports or presentations, and may be shared anonymously with other researchers. ☐

9. I understand that the information held and maintained by the Day Hospital about me may be used to help contact me or to provide information about my health status. ☐

10. I agree to take part in the above study. ☐

______________	______________	______________
Name of Participant	Date	Signature
______________	______________	______________
Name of Person taking consent	Date	Signature

Appendix 5: Participant Consent Form (Day Hospital staff)

IRAS Version: **3.0**
IRAS ID: **282540**
Date: **24/06/2021**

Participant Identification Number for this study:

CONSENT FORM-Day Hospital Staff

Title of Project: **Exploring the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England**

Name of Researcher: **ADAM NYENDE**

Please initial box

1. I confirm that I have read the information sheet dated **24 June 2021** (Version **3.0**) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I confirm that I have been given access to the BU Research Participant Privacy Notice which sets out how my personal data will be collected and used (https://www1.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy). ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time or decline to answer any particular question(s) without giving any reason, and without my legal rights being affected. ☐
4. I understand and consent to the following activities; ☐

- Having either a face to face, online (Skype/Zoom or Microsoft Teams) or telephone interview with the researcher
- Being audio recorded during the interview
- My words will be quoted in publications, reports, web pages and other research outputs without using my real name.

5. I understand that, if I withdraw from the study, I will also be able to withdraw my data from further use in the study except where my data has been anonymised (as I cannot be identified) or it will be harmful to the project to have my data removed. ☐

6. I understand that my data may be included in an anonymised form within a dataset to be archived at ‘UK Data Archive’ online Research Data Repository. ☐

7. I understand that the information collected about me will be used to support future research publications, reports or presentations, and may be shared anonymously with other researchers. ☐

8. I understand that the information held and maintained by the Day Hospital about me may be used to help contact me. ☐

9. I agree to take part in the above study. ☐

________________	________________	________________
Name of Participant	Date	Signature
________________	________________	________________
Name of Person taking consent	Date	Signature

Appendix 6: Study Sponsorship Letter

Bournemouth
University

To: HRA/NHS RESEARCH ETHICS COMMITTEE

Project Title: Exploring the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England

As Project Sponsor, Bournemouth University agrees to ensure:

- The research proposal respects the dignity, rights, safety and well-being of participants
- The research proposal is worthwhile and of high scientific quality
- Arrangements proposed for the research are consistent with the UK Policy Framework for Health and Social Care Research
- That organisations and individuals involved in the research have or will agree the division of responsibilities between them

Signature of authorised signatory on behalf of Bournemouth University:

Name:	Mrs Julie Northam
Role:	Head, Research Development & Support
Date:	26th May 2020

Melbury House,
1-3 Oxford Road, Bournemouth, Dorset
BH8 8ES
United Kingdom

VAT Reg. No. GB 332 2075 41

Appendix 7: Indemnity-Bournemouth University

TO WHOM IT MAY CONCERN 1st August 2019

Dear Sir/Madam

BOURNEMOUTH UNIVERSITY AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following covers are currently in place:

EMPLOYERS' LIABILITY

Certificate No.	Y016458QBE0119A/044
Period of Indemnity	1st August 2019 to 31st July 2020
Limit of Indemnity	£50,000,000 any one event unlimited in the aggregate
Includes	Indemnity to Principals
Cover provided by	QBE UK Limited and Excess Insurers

PUBLIC AND PRODUCTS LIABILITY

Certificate of Entry No.	UM044/99
Period of Indemnity	1st August 2019 to 31st July 2020
Includes	Indemnity to Principals
Limit of Indemnity	£50,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability

Cover provided by	U.M. Association Limited and Excess Cover Providers led by QBE UK Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Paul

Paul Cusition
For U.M. Association Limited

Appendix 8: NHS/HRA Ethics Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Caroline Ellis-Hill

Room R110 Royal London House

Email: approvals@hra.nhs.uk

HCRW.approvals@wales.nhs.uk

Christchurch Road

Bournemouth

BH1 3LT

05 October 2020
(Re-issued 08 October 2020)

Dear Dr Ellis-Hill

HRA and Health and Care

Study title:	**Exploring the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England**
IRAS project ID:	**282540**
Protocol number:	**1/2020**
REC reference:	**20/LO/0961**
Sponsor	**Bournemouth University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation.

The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **282540**. Please quote this on all correspondence.

Yours sincerely,

Natalie Wilson
Approvals Manager
Email: camberwellstgiles.rec@hra.nhs.uk

Copy to: *Mrs Julie Northam, Bournemouth University, Sponsor contact* **List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Study Poster]	1.0	01 July 2020
Copies of advertisement materials for research participants [Study Flyer]	1.0	01 July 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [BU Employer Liability and Public&Products Liability]		01 August 2019
GP/consultant information sheets or letters [GP Notification Letter]	1.0	21 September 2020
Interview schedules or topic guides for participants [Topic Guide for older people]	1.0	01 July 2020
Interview schedules or topic guides for participants [Topic Guide for Day Hospital Staff]	1.0	01 July 2020
IRAS Application Form [IRAS_Form_01102020]		01 October 2020
IRAS Application Form XML file [IRAS_Form_01102020]		01 October 2020
IRAS Checklist XML [Checklist_01102020]		01 October 2020
Letter from funder [Project Grant Agreement]	1.0	20 July 2018
Letter from sponsor [Letter from Sponsor]		26 May 2020
Letters of invitation to participant [Letter of invitation to older people]	1.0	01 July 2020
Letters of invitation to participant [Letter of Invitation to Day Hospital Staff]	1.0	01 July 2020
Organisation Information Document [Organisation Information Document]	2.0	22 July 2020
Other [Older People Support Service Leaflet]	1.0	21 September 2020
Other [Response to REC provisional opinion]	1.0	21 September 2020
Other [BU Professional Indemnity]		01 August 2019
Other [Data Management Plan]	1.0	01 July 2020
Participant consent form [Participant Consent Form for older people]	2.0	21 September 2020
Participant consent form [Participant Consent Form for Day Hospital Staff]	2.0	21 September 2020
Participant information sheet (PIS) [Participant Information Sheet for older people]	3.0	01 October 2020
Participant information sheet (PIS) [Participant Information Sheet for Day Hospital Staff]	2.0	21 September 2020
Referee’s report or other scientific critique report [Internal Review Report]		08 April 2020
Referee’s report or other scientific critique report [External Review Report]		14 May 2020

Research protocol or project proposal [Study Protocol]	2.0	21 September 2020
Schedule of Events or SoECAT [Final]	1	22 July 2020
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		17 June 2020
Summary CV for student [Student (Researcher) CV]	1.0	01 July 2020
Summary CV for supervisor (student research) [Supervisor (Caroline Ellis-Hill) CV]	1.0	17 June 2020
Summary CV for supervisor (student research) [Supervisor (Ann Hemingway) CV]	1.0	22 July 2020
Summary CV for supervisor (student research) [Academic_Supervisor_(Stefanos Mantzoukas)_CV]	1.0	23 July 2020
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of the Protocol]	1.0	01 July 2020

Appendix 9: InnovateDignity ESAB Ethics Approval Form

INNOVATE
DIGNITY

INNOVATEDI
Training the next generation
deliver innovations in dignifie
care systems for

Ethical Scrutiny and Advisory Board 26th November 2020

Project 6: Adam Nyende

First reader: Judith Dyson, Birmingham City University, UK

Second reader: Cathrine Moe, Nord University, Norway

Project title: Exploring the lived experience of control and well-being of older people living with frailty within the healthcare service provision in southern England

The major ethical issues in this project is data protection/data management and good practice for ethics**.**

- Participants who are potentially vulnerable. The researcher intends to interview frail older people, by definition, people with a great many physical and mental health related vulnerabilities and with the potential to have cognitive impairments. This group of participants may find the process arduous and may not be able to offer informed consent. The researcher has addressed this by providing accessible information, the intention to remind participants they can stop at any time, the provision of short breaks and the provision of accessible venues. Participants will be interviewed only once for this study and the researcher will assess the capacity of participants to consent.
- The potential for participant distress. The researcher has liaised closely with supervisors in considering/including sensitively worded questions. Information on sources of support is offered.
- There is the potential that participants could disclose information that suggests they are at risk from others or themselves. The researcher refers to the day hospital and university safeguarding policy and acknowledges. The researcher informs participants in the PIS that in the instance of disclosure of harm/potential harm confidentiality will be breached to protect the individual.
- Confidentiality is a risk and has been considered by storing participants personal data separate to research data and anonymising transcripts.
- The researcher will interview participants at a venue of their choice which may pose a risk to themselves. A lone worker policy will be abided to and the

researcher offers examples of how they will ensure their safety (e.g. informing people when they enter leave the interview).

Data management:

The research project has met the criteria according to the INNOVATEDIGNITY Template Horizon 2020 “DATA MANAGEMENT PLAN (DMP)”. See the following comments:

The purpose of the data collection is clearly stated (to explore issues related to the lived experience of control and well-being among frail older persons in Southern England). Also there is a clear relation between data collection (1:1 interviews, patient accounts/narratives, care staff accounts/narratives and field notes) and the objectives of the project.

The study is likely to generate up to 30 interviews, which will represent over 600 pages of transcripts. Data will be stored within the local IT system.

For the purpose of discoverability of the data the researcher will use QuDEx (Qualitative Data Exchange format) for qualitative data drawing on best practice guidance from the UK Data Archives and he will also use the Common European Research Information Format (CERF) where needed, from version 1.6 this offers specific support for recording metadata for datasets. The UK Data Service guidance will also be used.

The researcher has described the process of making the data openly accessible: The data is likely to be sensitive but can be shared within the consortium using agreed principles. There will be an embargo on publications for at least a year and if possible, three years (to be confirmed). Data will be openly accessible after this date and available via UK Data Archives.
The data can be shared among parties on the InnovateDignity project consortium but this will be subject to ethical approval and consent of research participants who will be informed at the entry to the study.
There is also a description on how to make data interoperable and how to increase data re-use.

We confirm that this project has complied with local requirements.

First Reader Judith Dyson	Second Reader Cathrine Fredriksen Moe Cathrine Fredriksen

Appendix 10: NHS/HRA Ethics Amendment Approval Letter

NHS
Health Research Authority

London - Camberwell St Giles Research Ethics Committee
Ground Floor
Temple Quay House
2 The Square
Bristol
BS1 6PN

Tel: 0207 104 8089

10 August 2021

Mr Adam Nyende

Room B322 Bournemouth House

Christchurch Road

Bournemouth

BH1 3LH

Dear Mr Nyende

Study title: **Exploring the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England**
REC reference: **20/LO/0961**
Protocol number: **1/2020**
Amendment number: **Amendment 1**
Amendment date: **1 July 2021**
IRAS project ID: **282540**

The above amendment was reviewed at the meeting of the Sub-Committee held via correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [NYENDE Adam_Ethics Amendment Tool]	1	01 July 2021
Participant consent form [Consent form (Older People)]	3	24 June 2021
Participant consent form [Consent form (Hospital Staff)]	3	24 June 2021
Participant information sheet (PIS) [Participant Information Sheet (Older People)]	4	24 June 2021
Participant information sheet (PIS) [Participant Information Sheet	3	24 June 2021
(Hospital Staff)]		
Research protocol or project proposal [Study Protocol]	3	24 June 2021

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

https://www.hra.nhs.uk/planning-andhttps://www.hra.nhs.uk/planning-and-improving-research/learning/improving-research/learning/

IRAS Project ID - 282540: Please quote this number on all correspondence

Yours sincerely

PP

Ms Susan Harrison Chair

E-mail: camberwellstgiles.rec@hra.nhs.uk

London - Camberwell St Giles Research Ethics Committee

Attendance at Sub-Committee of the REC meeting via Correspondence

Committee Members:

Name	*Profession*	*Present*	*Notes*
Ms Susan Harrison	Retired Health and Social Services Manager	Yes	
Dr Mark Tanner	Consultant Psychiatrist	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Jade Robinson	Approvals Administrator

Appendix 11: Interview schedule (Older people)

Topic Guide for Older People

- Introduction, welcome and demographics (gender and age)

- **Orientation to service utilisation**
    - I contacted you via the day hospital– what other services have you received recently?
    - Discussion of the services received to gain contextual information and focus
    - Prompts
        - Can you tell me more about that?
        - What was it like for you??
- **Orientation to the lived experience of control**
    - When using X service– how much control do/did you feel you have ….
    - Prompts
        - Can you tell me about a time when …
        - What did that feel like?
        - Can you tell me more about that…
        - And then what happened….
- **General lived experience of control**
    a. At the moment how much control do you feel you have in your life?
    b. Prompts
        - Can you tell me more about that…
        - What did that feel like?
        - And then what happened….
- **Hoped-for experience**
    - In an ideal world, what would services (or x service) look and feel like for you?

- **Ending**
    - Is there anything else you would like us to talk about today that we have not discussed?
    - Thank you so much for your valuable time.

Appendix 12: Interview schedule (Day Hospital staff)

Topic Guide for Day Hospital staff

- Introduction, welcome and demographics (gender and age)
- **Orientation to service provision**
    - I contacted you via the Day Hospital– what is your role and what services do you provide at the hospital?
    - Discussion of the services provided to gain contextual information and focus
    - Prompts
        - Can you tell me more about that?
        - What was it like for you?
- **Orientation to practice experience of control**
    - Feedback about frail older peoples experiences of control and well-being
    - What does this make you feel/think?
    - Prompts
        - Can you tell me about a time when …
        - What did that feel like?
        - Can you tell me more about that…
        - And then what happened….

    - Do you feel you could take on other issues in your service /your practice -if so how?
- **General experience of sharing control**
    - What do you see as the benefit of patients having more control over their lives and care?
    - When providing Y service– how much control do/did you feel that patients have/had…..?
    - What does this make you feel/think?
- **Hoped-for situation**
    - What are the barriers for you?
    - Do you feel you are addressing any of these issues in your service /your practice -if so how?
        c. Prompts
            - Can you tell me more about that…
            - What did that feel like?
            - And then what happened….
    - What are the opportunities for you?
- **Ending**
    - Is there anything else you would like us to talk about today that we have not discussed?
    - Thank you so much for your valuable time.

Appendix 13: Example of a transcript

Unique identifier: Participant 27 (027_O)
Date of the interview: 11/11/21
Place of the interview: Participant’s home
Interviewer Name: Adam Nyende
Interviewee details: Male, aged 82, and Married (Living with the wife). The interview was conducted in the wife’s presence.

Interviewer: Yeah, so right, and this is my timer to make sure it’s not too long, yeah. Urr, thanks a lot for your time. My name is Adam, and I’m a student at Bournemouth University. I would like to speak to you today about your healthcare experience and how you would like your care experience to be improved. But before I get to that point, could you please tell me more about yourself? Your name, your age, your marital status.

Participant: My name is *deleted*, I’m eighty-two, I’m married to *deleted*, we’ve been married to sixty-two years on the twenty-eight of November.

Interviewer: Right.

Participant: Urm, we lived a very active life until about ten years ago when I was diagnosed with Parkinson’s disease. Urm, whilst we were living in the Midlands, we lived in Solihull. Urm, it was in the early stages, and it really didn’t have any real effect on my urm standard of living, carried out everything that I normally did. Urm,

Interviewer: Please carry on, yeah.

Participant: Ten years ago, we decided to move to Bournemouth,

Interviewer: Right.

Participant: We live near one of our youngest daughters. So, when you look back on life, everything seems all… from a health point of view urm… life seemed to have changed about when we moved down here, I had a heart by-pass, and I was designated, designated as being a celiac and urm, our… I think I was, I think… from a health point of view it, it deteriorated, it started deteriorating about two years ago.

Interviewer: Right. You did mention that you had a very active life, right?

Participant: Yeah.

Interviewer: Could you please take me through what your life was like before you got diagnosed with Parkinson’s?

Participant: Well, I worked in the motor industry; I worked in the motor industry for forty years. I was managing director of a service company, Urm… responsible for service to the motor industry in Europe and North America, well, most of the world, and Urr has offices in the UK, Kentucky in the USA and Dusseldorf in Germany. So, we led a very active life urm, seven days a week.

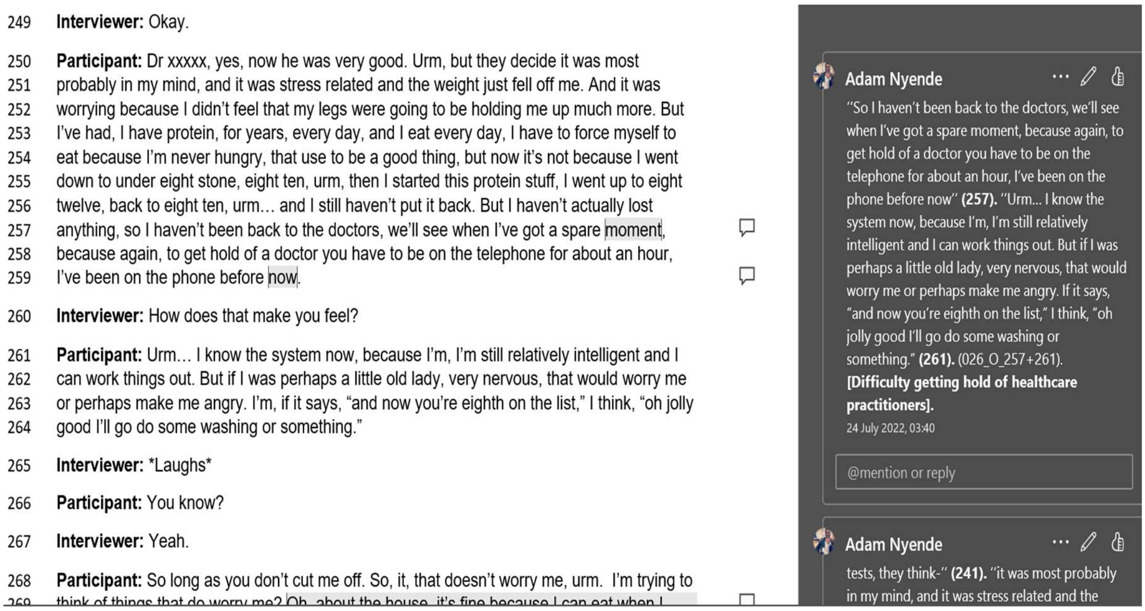
Interviewer: Anything more that you'd like to share about your history, your life growing up?

Participant: Urm… I, most of the activities that we came, that were… were urm, around the world, the work and urm... relaxation point of view most of it was, the only thing that it really had any interest in was sport and our gardening.

Interviewer: You did mention that urr, the Parkinson's condition was diagnosed and detected ten years ago, right?

Participant: June 24th

Appendix 14: Examples of line-by-line reading



Interviewer: Okay.

Participant: Dr xxxxx, yes, now he was very good. Urm, but they decide it was most probably in my mind, and it was stress related and the weight just fell off me. And it was worrying because I didn't feel that my legs were going to be holding me up much more. But I've had, I have protein, for years, every day, and I eat every day, I have to force myself to eat because I'm never hungry, that use to be a good thing, but now it's not because I went down to under eight stone, eight ten, urm, then I started this protein stuff, I went up to eight twelve, back to eight ten, urm… and I still haven't put it back. But I haven't actually lost anything, so I haven't been back to the doctors, we'll see when I've got a spare moment, because again, to get hold of a doctor you have to be on the telephone for about an hour, I've been on the phone before now.

Interviewer: How does that make you feel?

Participant: Urm… I know the system now, because I'm, I'm still relatively intelligent and I can work things out. But if I was perhaps a little old lady, very nervous, that would worry me or perhaps make me angry. I'm, if it says, "and now you're eighth on the list," I think, "oh jolly good I'll go do some washing or something."

Interviewer: *Laughs*

Participant: You know?

Interviewer: Yeah.

Participant: So long as you don't cut me off. So, it, that doesn't worry me, urm. I'm trying to think of things that do worry me? Oh, about the house, it's fine because I can eat when I

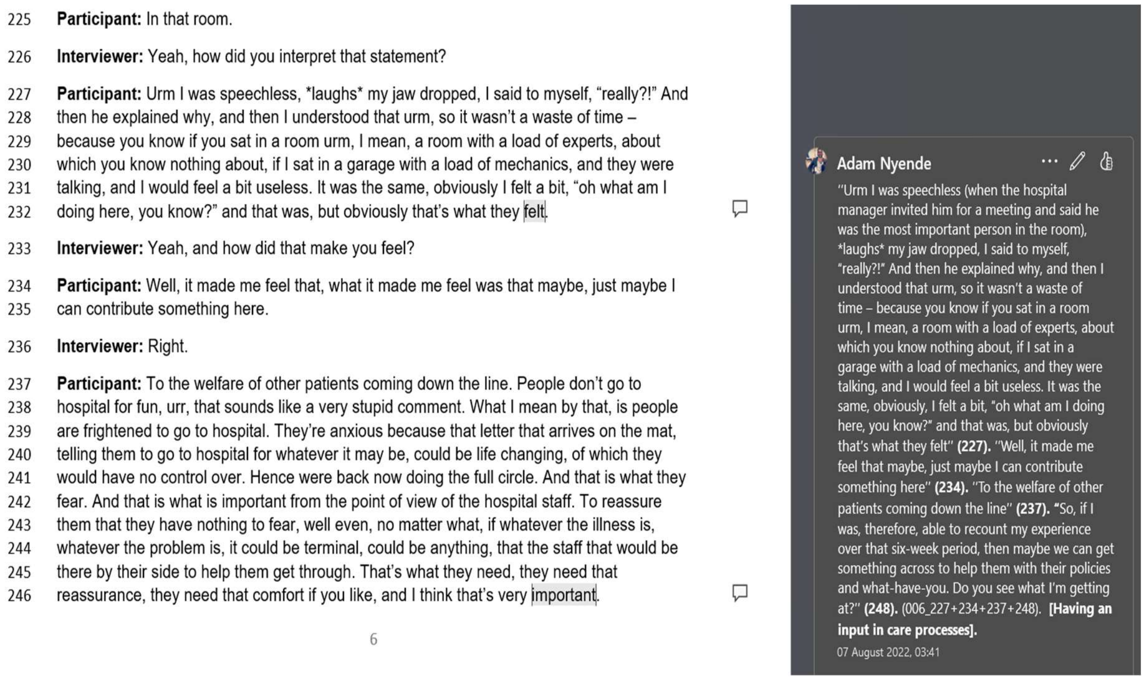
Adam Nyende

"So I haven't been back to the doctors, we'll see when I've got a spare moment, because again, to get hold of a doctor you have to be on the telephone for about an hour, I've been on the phone before now" **(257).** "Urm... I know the system now, because I'm, I'm still relatively intelligent and I can work things out. But if I was perhaps a little old lady, very nervous, that would worry me or perhaps make me angry. If it says, "and now you're eighth on the list," I think, "oh jolly good I'll go do some washing or something." **(261).** (026_O_257+261). **[Difficulty getting hold of healthcare practitioners].**

24 July 2022, 03:40

Adam Nyende

tests, they think-" **(241).** "it was most probably in my mind, and it was stress related and the



Participant: In that room.

Interviewer: Yeah, how did you interpret that statement?

Participant: Urm I was speechless, *laughs* my jaw dropped, I said to myself, "really?!" And then he explained why, and then I understood that urm, so it wasn't a waste of time – because you know if you sat in a room urm, I mean, a room with a load of experts, about which you know nothing about, if I sat in a garage with a load of mechanics, and they were talking, and I would feel a bit useless. It was the same, obviously I felt a bit, "oh what am I doing here, you know?" and that was, but obviously that's what they felt.

Interviewer: Yeah, and how did that make you feel?

Participant: Well, it made me feel that, what it made me feel was that maybe, just maybe I can contribute something here.

Interviewer: Right.

Participant: To the welfare of other patients coming down the line. People don't go to hospital for fun, urr, that sounds like a very stupid comment. What I mean by that, is people are frightened to go to hospital. They're anxious because that letter that arrives on the mat, telling them to go to hospital for whatever it may be, could be life changing, of which they would have no control over. Hence were back now doing the full circle. And that is what they fear. And that is what is important from the point of view of the hospital staff. To reassure them that they have nothing to fear, well even, no matter what, if whatever the illness is, whatever the problem is, it could be terminal, could be anything, that the staff that would be there by their side to help them get through. That's what they need, they need that reassurance, they need that comfort if you like, and I think that's very important.

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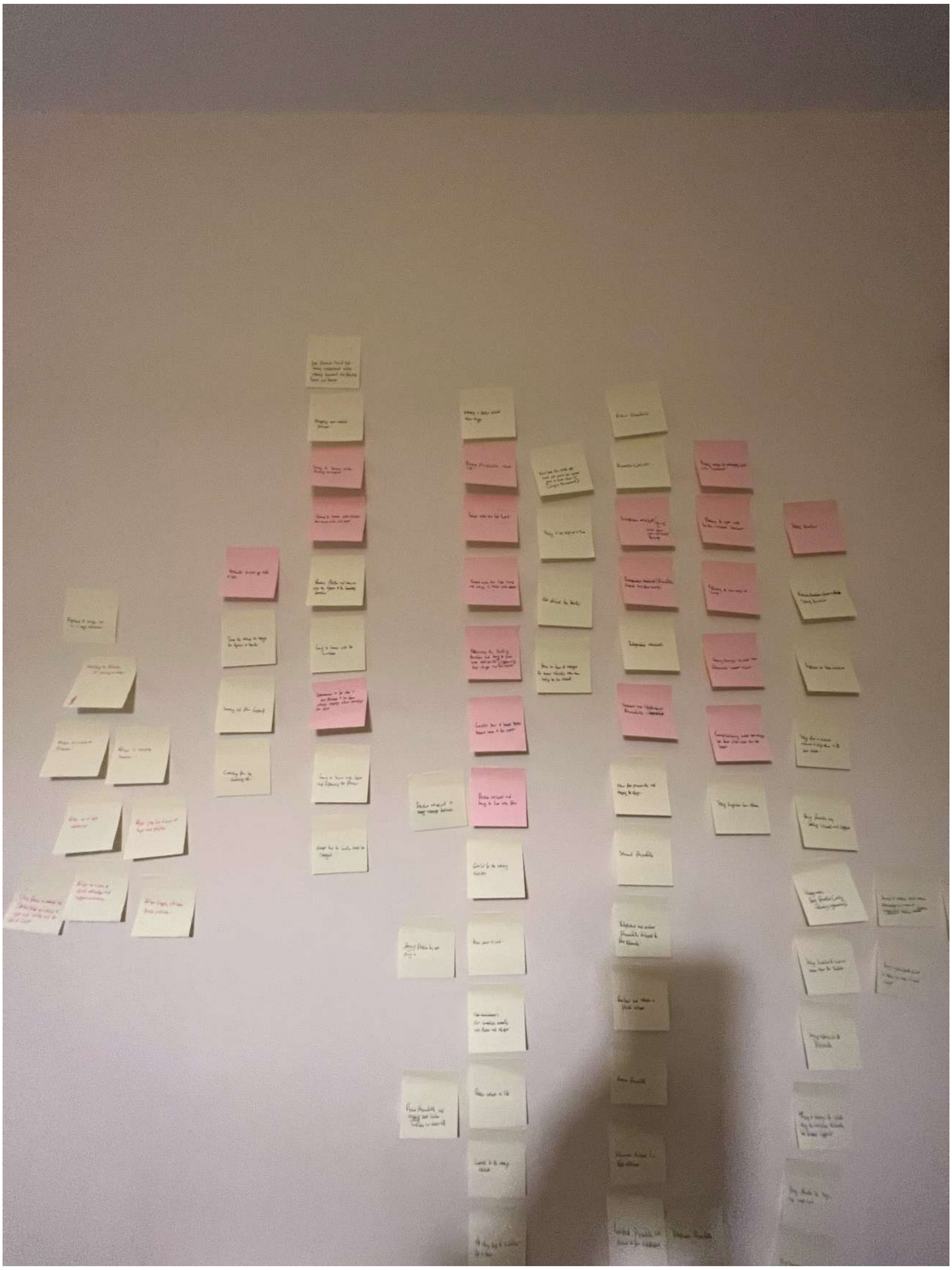
Adam Nyende

"Urm I was speechless (when the hospital manager invited him for a meeting and said he was the most important person in the room), *laughs* my jaw dropped, I said to myself, "really?!" And then he explained why, and then I understood that urm, so it wasn't a waste of time – because you know if you sat in a room urm, I mean, a room with a load of experts, about which you know nothing about, if I sat in a garage with a load of mechanics, and they were talking, and I would feel a bit useless. It was the same, obviously, I felt a bit, "oh what am I doing here, you know?" and that was, but obviously that's what they felt" **(227).** "Well, it made me feel that maybe, just maybe I can contribute something here" **(234).** "To the welfare of other patients coming down the line" **(237). "**So, if I was, therefore, able to recount my experience over that six-week period, then maybe we can get something across to help them with their policies and what-have-you. Do you see what I'm getting at?" **(248).** (006_227+234+237+248). **[Having an input in care processes].**

07 August 2022, 03:41

Appendix 15: Sample of manually cut transcript segments

Appendix 16: Process of developing the preliminary categories



Appendix 17: Scoping Review published paper

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A Sense of Control and Wellbeing in Older People Living with Frailty: A Scoping Review

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A Sense of Control and Wellbeing in Older People Living with Frailty: A Scoping Review

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ABSTRACT

A sense of control is important for supporting older people living with frailty to develop adaptive functioning to optimize wellbeing. This scoping review examined the literature on the sense of control and wellbeing in older people living with frailty within their everyday life and care service use. Nine databases were searched using the timeframe 2000 to 2021 to identify key ideas regarding control and wellbeing in older people with frailty. The review highlighted three major themes: a) Control as conveyed in bodily expressions and daily activities, b) Sense of control and influence of place of residence, and c) Control within health and social care relationships. Maintaining a sense of control is not only an internal feeling but is impacted by physical and social environments. Greater focus is needed on the nature of relationships between older people living with frailty and those who work alongside them, which support control and wellbeing.

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Sense of control; older people; wellbeing; frailty; scoping review; care

Introduction

As people age, they are gradually more likely to develop and live with complex co-morbidities linked to chronic diseases, illnesses, and injuries, resulting in a condition known as frailty (Buckinx et al., 2015; De Donder et al., 2019; Oliver et al., 2014). The British Geriatrics Society (BGS) defines frailty as; “*a distinctive health state related to the aging process in which multiple body systems gradually lose their in-built reserves”* (BGS, 2014, p. 6). Frailty is associated with cumulative deficits in multiple organ systems contributing to decreased bodily reserve and functional capacity in old age (Kojima, 2015; Nicholson et al., 2013; Turner & Clegg, 2014).

The impact of frailty in older people mainly manifests as physical decline experienced on two levels: a) the *individual body* and b) the *contextual body*. The individual body refers to the person’s body and its problems, such as ailments and injuries. The contextual body refers to the body and its limitations concerning the physical and social surroundings, such as being unable to independently

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perform daily living activities (Ekwall et al., 2012). Such deficits and limitations place a person at increased risk of adverse health outcomes, including admission to higher care levels, emergency hospitalization, prolonged hospital stay, and increased mortality (Andrew et al., 2012; Dent & Hoogendijk, 2014; González- Bautista et al., 2020; King et al., 2017). Consequently, older people living with frailty often report poor self-rated health and low levels of life satisfaction (Abu- Bader et al., 2003; Johannesen et al., 2004; King et al., 2017).

Perceived health in older people living with frailty is often linked to psychosocial factors, especially a sense of control (Dent & Hoogendijk, 2014; Elliot et al., 2018; Gale et al., 2014). Although there is no conclusive or all- inclusive definition of the concept of control, the literature highlights that the construct has been studied using different dimensions. The dimensions include perceived control, self-efficacy, personal mastery, locus of control, control beliefs, learned helplessness, and primary and secondary control (Skinner, 1996). In essence, these dimensions interrelate in creating an overall impact on individuals' ability to produce desired outcomes or a feeling that life changes are under one's mastery rather than life being directed by fate or uncontrolled external factors (Kempen et al., 2005; Lachman et al., 2011; Robinson & Lachman, 2017). Thus, a perceived sense of control is often translated into personal and sometimes social resources that individuals use to successfully manage their everyday life and environment and adapt to life changes such as old age and its associated challenges (Kempen et al., 2003).

A sense of control is important for individuals living with frailty because of the need to manage bodily changes and activity and social limitations to prevent deterioration as well as to maintain a sense of wellbeing (Kempen et al., 2003; Underwood et al., 2020; van Oppen et al., 2022). Frailty is associated with a loss of control in older people. Archibald et al. (2020) argue that frailty in older people is associated with diminished mobility and independence, which contributes to a loss of control over one's body and environment and affects their sense of identity and self-worth. In addition, a perceived lack of control negatively influences the risk and incidence of frailty in older people. The literature highlights that declining levels of control are associated with a greater likelihood of frailty (Dent & Hoogendijk, 2014; Elliot et al., 2018; Gale et al., 2014 Frank J. Infurna & Gerstorf, 2014).

In contrast, perceived control plays a buffering role against challenges contributing to old age frailty. For example, studies identified that perceived control has a moderating effect on the impact of low social-economic status and greater exposure to chronic stress on the development and progression of frailty in older people (Barbareschi et al., 2008; Dent & Hoogendijk, 2014; Mooney et al., 2018; Pudrovska et al., 2005).

Despite the bi-directional relationship between perceived control and frailty, the evidence is unclear as to whether the adverse health outcomes in the form of frailty precede the loss of control or the limited sense of control contributes to frailty. Regardless of the trajectory, however, the above findings make it clear that a loss of control is one of the primary losses experienced by older people living with frailty (Dent & Hoogendijk, 2014; King et al., 2017).

Evidence suggests that feelings of control progressively decrease as people grow older, irrespective of frailty status (Barbareschi et al., 2008; Krause, 2007; Ross & Mirowsky, 2002; Wolinsky et al., 2003). As a result, there is an increased emphasis on promoting a sense of control in old age to minimize the risk and impact on health outcomes (Hong et al., 2021; Kim, 2020; Skaff, 2007). This is because perceived control is considered a fundamental psychological aspect that improves coping and adaptive behaviors enabling older people to exploit available resources to cope with life stressors to maintain psychological wellbeing (Caplan & Schooler, 2007; Chou & Chi, 2001; Firth et al., 2008; Robinson & Lachman, 2017). Additionally, perceived cognitive control is associated with greater control of emotions, which is vital in improving the emotional wellbeing and cognitive performance in older people (Charles & Carstensen, 2010; Lachman, 2006; Stephanie A. Robinson & Lachman, 2018; Zahodne et al., 2015). Moreover, a sense of control is associated with adopting positive health behaviors such as adherence to treatment, good diet, and exercises which are vital in enhancing better health outcomes in old age (Barbareschi et al., 2008).

Evidence supports the linkage of perceived control with better mental and physical health outcomes, including lower disability levels, faster recovery of bodily functions, and lower mortality risks, particularly among older people experiencing a gradual decline in functioning (Assari, 2017; Bailis et al., 2001; Kempen et al., 2003, 2005; Popova, 2012; Turiano et al., 2014; Ward, 2013). Consequently, promoting a sense of control is considered an essential component of successful aging and research on older person care has emphasized a need to support and empower older people to take more control of their health and wellbeing (Infurna et al., 2013; Kunzmann et al., 2002; Lachman et al., 2009; Oliver et al., 2014; Turiano et al., 2014).

Despite this well-documented importance of a sense of control for older individuals, limited reviews focus on control in different categories of older people. Most reviews on the sense of control in old age have generally focused on older people. No scoping review explicitly targets the sense of control in older people with frailty. More importantly, such a lack of studies limits the development and maintenance of psychosocial resources and the potential to identify those factors that restrict control and increase frailty in older people, undermining their resilience and making them more vulnerable to infirmity and elevated risk of mortality (Claassens et al., 2014; Dent & Hoogendijk, 2014; Milte et al., 2015; Nicholson et al., 2012).

This review, therefore, aims: 1) to examine the extent, range, and nature of research activity into a sense of control and wellbeing in older people living with frailty within their everyday life and health and social care services use and 2) to identify research gaps in the existing literature to inform primary research on the topic area (Arksey & O’Malley, 2005). With these aims, the review set out the following question "*What is known about control and its relation to wellbeing in older people living with frailty within their everyday life and health and social care service use?"*. A scoping review was chosen for two reasons. Firstly, because of time constraints and the fact that the review aimed at identifying the available literature and the research gaps on the topic area rather than formulating practice recommendations (Munn et al., 2018). Secondly, scoping reviews are flexible yet rigorous and transparent processes. Rather than being guided by a highly focused research question that aims at searching for specific study designs, as is the case in systematic reviews, the scoping review method is guided by a requirement to identify all relevant literature regardless of the study design (Arksey & O'Malley, 2005).

Materials and methods

A scoping review was carried out following the five key stages of the Arksey and O'Malley (2005) framework: identifying the review question, identifying relevant studies, study selection, charting the data, and collating, summarizing, and reporting the results (Arksey & O'Malley, 2005). Furthermore, we incorporated Levac et al. (2010) recommendations to make the review robust and enhance its clarity and methodological rigor. Firstly, we used the components of the topic area, such as the Population, Concept and Context (PCC), to define the review question, search strategy and, subsequently, the inclusion and exclusion criteria. Secondly, we clarified the decision-making process regarding the study selection process to ensure transparency. Thirdly, the chosen charting approach was consistently applied across all the included papers. Finally, we applied qualitative thematic analysis to link the meaning of the results to the review purpose and the implication for future research. These recommendations enabled us to provide a sufficient methodological description of the review and analysis of the data to make it easy for the readers to understand how we arrived at the results (Levac et al., 2010).

The review included relevant original research articles published between 2000 and 2021. This timeline was chosen because we were interested in understanding how the notion of control has evolved over the years. Nine databases (PubMed, PsycINFO, Medline Complete, Web of Science, Social Care Online, Science Direct, Scopus, CINAHL Complete, and SocINDEX) were chosen to provide a comprehensive overview of the health, psychological and social literature. The search strategy included keywords, synonyms, and truncations, as summarized in Table A1. The search process was conducted iteratively from 15/10/2020 to 20/11/2021. The search strategy was continually refined after several iterations of the search, and the first author made decisions on refinement with guidance from the second and third authors (Levac et al., 2010). Finally, the key search terms were determined using the PCC considerations to guide the search for papers (Arksey & O'Malley, 2005; Levac et al., 2010).

The review included papers a) focusing on empirical research with older people aged 60 years and over and living with frailty and stakeholders involved in their care, b) focusing on control and/or its related concepts, and c) conducted in different care settings. The review also considered quantitative and qualitative empirical studies conducted in English in all parts of the world.

To ensure that the inclusion and exclusion criteria fit the scope of the review, we linked the review question to the review purpose by envisioning the intended outcomes of the review before it was undertaken. We debated the inclusion and exclusion criteria and agreed on the best and most feasible criteria to answer the review aims and objectives. Defining the scope involved balancing the need for breadth with feasibility, particularly time constraints and acknowledging the limitations linked to the limited scope and other methodological decisions (Levac et al., 2010).

The inclusion and exclusion criteria were used to select the studies that “represent the best fit with the research question” (Arksey & O’Malley, 2005, p. 15). After the title search, the abstracts were examined, and this process concluded with a full-text examination of the eligible papers to inform the charting process. The reference lists of the eligible papers were also reviewed, and some more papers that met the inclusion criteria were included. Endnote (2013) was used to organize and manage search records and for reference in the final scoping review report (Arksey & O’Malley, 2005). In addition, the study used the Preferred Reporting Items for Systematic Reviews and Meta- Analyses (PRISMA) flow diagram (Figure A1) to make the literature search visually accessible and easily read (Page et al., 2021).

The charted papers were manually analyzed using a qualitative thematic analysis framework by Braun and Clarke (2012). This framework has six key steps: Step 1: Becoming familiar with the data, Step 2: Generating initial codes, Step 3: Searching for themes, Step 4: Reviewing potential themes, Step 5: Defining and naming themes, and Step 6: Producing the report. The first author read and re-read the charted data in Microsoft Excel (Microsoft, 2022) to identify recurring points, similarities, and differences (codes) in line with the review question (Arksey & O’Malley, 2005). These codes were organized according to key issues by prioritizing certain aspects of the literature according to the review question and what was most noticeable during the review process (Arksey & O’Malley, 2005). This resulted in the identification of three overarching themes. The themes generated were decided through discussions between the authors. The first author analyzed and synthesized results and developed the first round of themes. The second and third authors provided feedback and a second perspective on the first author’s definition and interpretation of the themes.

Since a scoping review aims to map out the existing evidence to identify gaps and inform primary research and not to make clinical or policy recommendations, we did not undertake any methodological appraisal of the quality of the included studies (Grant & Booth, 2009).

Finally, the review was part of a doctoral project, and the first author worked with the second and third authors, who provided supervisory input on all stages of the review. The first author did the initial review. Consequently, the second and third authors provided feedback and modifications made by the first author based on the feedback. The review process was complete when we were all satisfied with the final results.

Results

The database search retrieved a total of 4,438 records, and a total of 34 papers were included in the review.

The majority of the papers were published in the Scandinavian countries (*n* = 12), the Netherlands (*n* = 7) and the USA (*n* = 5) and a small number in Australia (*n* = 2), Belgium (*n* = 1), Canada (*n* = 1), England (*n* = 1), Germany (*n* = 1), Hongkong (*n* = 1), Italy (*n* = 1), Mexico (*n* = 1), and Siri Lanka (*n* = 1). 77% of the papers were published between 2010 and 2020 (*n* = 26), and 24% were published between 2000 and 2008 (*n* = 8). In terms of the methodology, 56% of the papers were quantitative (questionnaires, *n* = 14, other methods, *n* = 5). In addition, 97% focused on capturing the views of older people living with frailty (*n* = 33), while 9% focused on carers' views (*n* = 3). The major outcome measures for the quantitative papers included different dimensions of control (locus of control, expected and desired control, multidimensional health locus of control, perceived autonomy, independence, self-efficacy, and mastery), domains of social, physical, and psychological wellbeing (autonomy, personal growth, mastery, positive relations, purpose in life, emotional balance, self-acceptance, chronic stress, depression and cognitive functioning), Quality of life (QoL) dimensions (life overall, health, social relationships and participation, freedom, home and neighborhood, financial circumstance, leisure, activities and religion), perceived health (physical health, functional disability, morbidity, long length of hospital stay, emergency rehospitalization, higher level of care needed on discharge, and mortality), Self-Management Abilities (SMA) (Cognitive abilities, active motivational abilities, and resource-combining abilities) and life satisfaction. There were only 13 qualitative papers with limited in-depth approaches. Six papers used content analysis, two followed the grounded theory and just one used phenomenology.

The results highlighted three themes: a) Control as conveyed in bodily expressions and daily activities, b) Sense of control and influence of place of residence, and c) Control within health and social care relationships. Table 2 provides an overview of all the included papers and their contributions to the themes.

Table A2 Overview of the included paper

Theme 1: Control as conveyed in bodily expressions and daily activities

Control in older people living with frailty is mainly expressed within the increasing limitations in their bodies and activities of daily living.

Control over the body

Bodily changes and pain limited control over the body and independence in older people living with frailty, as highlighted by Siriwardhana et al. (2019), who looked at the association between frailty and QoL domains, including independence and control over life. As a result, many older people living with frailty rely on the assistance of others to achieve even simple daily activities, for example, getting out of bed, which meant that they sometimes stayed in their beds or chairs for extended periods as they waited for assistance (Kwong et al., 2014). Such incidents are linked to physical and psychological stress and a lower sense of control, further exposing older people to greater severity of physical frailty (Mooney et al., 2018). Therefore, a sense of control was linked to individuals' perceived potential to manage their bodies and maintain self-care capacity.

When older people living with frailty engage in different self-care activities, such as exercises, managing their medication, and maintaining a good diet, they are more able to manage the limitations brought about by their bodies and the associated symptoms (Claassens et al., 2014; Niesten et al., 2012). Even in cases where their engagement with self- care activities was unrelated to the caring needs emerging from their frail condition, self-care activities provided and reinforced a perception of control and better QoL (Kwong et al., 2014; Milte et al., 2015). For example, by adopting a good oral hygiene schedule, older people living with frailty felt that they retained some control over their physical body and maintained a better sense of wellbeing (Niesten et al., 2012).

Consequently, the review has led us to understand that the levels of control of older individuals living with frailty have external manifestations and bodily expressions. If older individuals perceive they have or retain control of certain aspects of their body, this can compensate for parts of their body they do not have control over due to frailty. This perceived sense of control of parts of their body can consequently create feelings of wellbeing despite their frailty.

Control over activities of daily life

The review found that a sense of control in older people living with frailty impacted activities of daily living (Abu-Bader et al., 2003; Ekdahl et al., 2010; Hedman et al., 2019; Janlöv et al., 2006; Lambotte et al., 2019; Strohbuecker et al., 2011). Johannesen et al. (2004) examined the association between measures such as continuity and self-determination with everyday life satisfaction among older people living with frailty. Results indicated that continuing daily activities is positively associated with life satisfaction. These individuals feel in control whenever they have choices over everyday life aspects, such as whether to do certain things on their own and maintaining regular routines in everyday life such as gardening, cleaning, preparing meals and engaging in community activities (Andersson et al., 2008; Claassens et al., 2014; Ebrahimi et al., 2013; Ekwall et al., 2012; Falk et al., 2011; Janlöv et al., 2006; Kristensson et al., 2010; Portegijs et al., 2016; Thorson & Davis, 2000). Engaging in meaningful activities of daily living enhances several control and wellbeing outcomes in older people living with frailty, such as a sense of identity, independence, environmental mastery, and reduced risk of adverse health outcomes, including hospitalization (Andrew et al., 2012; Dent & Hoogendijk, 2014; Ebrahimi et al., 2013; Ekwall et al., 2012; Gale et al., 2014; González-Bautista et al., 2020; Hedman et al., 2019; Siriwardhana et al., 2019). The literature identifies at least three preconditions for older individuals living with frailty to maintain greater control over their daily activities. Firstly, by remaining at home or in a familiar environment where they feel not only safe and supported by familiar care providers but also stay connected with family, friends, and other members of society that they value to avoid social isolation and loneliness (Andersson et al., 2008; Broese van Groenou et al., 2016; Ebrahimi et al., 2013). Secondly, a range of self-management techniques can strengthen older people's cognitive and behavioral capabilities to manage their lives, improve their wellbeing and prepare for future age and health-related challenges. Several quantitative studies analyzed the relationship between Self- Management Abilities (SMA) and subjective wellbeing, QoL and self-rated health. They found that SMA is vital in supporting older people living with frailty to take the initiative in managing aspects of daily lives and maintaining various multi-functional resources significant in dealing with different age-related declines (Cramm et al., 2014; Frieswijk et al., 2006; Schuurmans et al., 2005; Vestjens et al., 2020). Thirdly, having easy access to practical aids such as vision and mobility aids coupled with supportive architecture such as furniture raisers to get out of bed or reach kitchen cabinets easily made a significant difference to the sense of control among older people living with frailty (Claassens et al., 2014).

In summary, the literature highlights that older people living with frailty maintain greater levels of control when they maintain normal routines and retain choices in simple daily activities.

Theme 2: Sense of control and influence of place of residence

This theme highlights the differences in the levels and experiences of control and wellbeing among older people living with frailty in the community and during their transition to nursing homes.

Living at home

As highlighted above, living at home was associated with independence and a higher sense of control. Grain (2001) compared the sense of control and life satisfaction between homebound older people and nursing home residents and found that they expressed higher perceived control than their nursing home counterparts. This is because of their engagement in everyday activities where they felt that they were not a burden to other people, thus enhancing their sense of continuity, self-determination and good health (Ebrahimi et al., 2013; Grain, 2001; Johannesen et al., 2004). Moreover, living at home allowed for seamless integration of their new caring needs, the caregiving process, and the familiarity with the environment, ergo creating a sense of “homeness” and a notion of continuity which are crucial in enhancing older people’s sense of wellbeing (Andersson et al., 2008). Consequently, older people living with frailty at home feel safer, more engaged, and have a greater sense of continuity, increasing their sense of control and wellbeing.

Despite the preference to stay at home, some older people living with frailty reported that trying too hard to remain independent sometimes created a heavy burden for themselves, thereby perceiving excessive control as harmful to their health and overall wellbeing (Claassens et al., 2014). In addition, the physical and cognitive limitations arising from illness or frailty impacted individuals’ capacity to participate in decision-making processes. In such situations, retaining a sense of control became a burden rather than a contributor to wellbeing, compelling older people to surrender some or all of their decision-making power and control to significant others, such as professional caregivers and/or family members (Andersson et al., 2008; Bilotta et al., 2010; Claassens et al., 2014; Ekdahl et al., 2010; Lambotte et al., 2019).

However, in those cases where older individuals preferred to have their care decisions made by others, they wished to be informed and listened to by their care providers. This open communication minimized the possibility of the older person interpreting that care providers were taking the care responsibility away from them and anticipated as they were handing it over willingly (Ekwall et al., 2012). Furthermore, willful handing over of control to family members required that the older individual living with frailty did not anticipate this to be a burden for the family member; otherwise, this negatively impacted their wellbeing (Janlöv et al., 2006).

In summary, living at home enhanced a sense of safety, independence, and continuity among older people living with frailty. Although age and disease- related decline sometimes compelled them to surrender their control, willfully relinquishing control was paradoxically considered one way of exercising control as long as the person was informed and listened to by their care providers.

Control and relocation away from own home

In those cases where older people living with frailty had no option but to relocate from their home to a nursing home or even from one nursing home to another, this was often a stressful event as relocation aspects altered their normal routines (Falk et al., 2011). Hence, these routine alterations in the new living environments created outcomes including uncertainty, confusion, and abandonment, thereby imposing further limitations on older people’s sense of control and creating adverse health effects, including mortality (Thorson & Davis, 2000). In nursing homes, giving up usual activities and routines and depending on others for participation in everyday habits and community life created a sense of passivity that was anticipated as a loss of control among older people living with frailty (Grain, 2001; Johannesen et al., 2004; Kwong et al., 2014; Sandgren et al., 2020; Strohbuecker et al., 2011). Older individuals living with frailty were able to ameliorate this sense of loss of control by having a say in their relocation, undergoing a pre-relocation preparation, and maintaining some of their habits, e.g., moving to the same side of the new buildings as the previous building (Falk et al., 2011; Thorson & Davis, 2000).

Both formal and informal care providers were crucial in developing or retaining degrees of control of older people living with frailty during and after their relocation. For example, formal caring staff, such as nurses, can promote the participation of older people in their clinical assessment and care planning, acknowledging older people's choices and respecting their privacy and dignity, which enhanced their sense of control (Hedman et al., 2019). Similarly, informal carers supported older people in nursing homes to attend social gatherings, engage in exercises and supervised their formal care, thereby empowering them to maintain control (Kwong et al., 2014; Wallerstedt et al., 2018). However, nursing home staff shortages and a lack of expertise in dealing with older people living with frailty may affect the approaches above (Kwong et al., 2014). This is particularly the case when nurses make decisions for older people without consulting them about their wishes or complaints, intensifying their loss of control (Strohbuecker et al., 2011).

In summary, the relocation of older people living with frailty to institutionalized care can limit their sense of control, particularly when this transition is accompanied by sudden changes in older people's routines. Furthermore, staff shortages or lack of expertise in supporting older people living with frailty may lead to formal carers making and imposing decisions, intensifying their loss of control in nursing homes. In contrast, the involvement of older people living with frailty in decisions regarding their relocation and care planning, as well as the perceived support from their loved ones, can empower them to maintain degrees of control in institutional care.

Theme 3: Control within health and social care relationships

A sense of control in older people living with frailty is linked to the nature of the care relationships and the power dynamics within the health and social care systems.

Role of trusting relationships

The reviewed literature identified that developing a trusting relationship between older people living with frailty and formal/informal carers is pivotal in enhancing older people's sense of control. The starting point for creating such a relationship can be the display of humor and empathy in caring interactions using simple gestures such as chatting, hugging and holding hands (Claassens et al., 2014; Hedman et al., 2019). This can create a sense of support and joy for older people living with frailty and further develop their communication, cooperation and a natural togetherness with their carers, leading to more caring and individualistic relationships and the perception of being a member of the caring team (Claassens et al., 2014; Hedman et al., 2019; Wallerstedt et al., 2018).

Consequently, a trusting, caring relationship enables an environment where care aspects such as information sharing and joint decision-making thrive, facilitating key control dimensions such as choice, autonomy and participation (Ekdahl et al., 2010; Hedman et al., 2019). In addition, this type of relationship further develops mutual respect and recognition of individuality. This is important in recognizing the individual's unique experiences and care needs and/or wishes, which is vital in facilitating a sense of balance and normality and creating a greater sense of control for older individuals living with frailty (Claassens et al., 2014; Lambotte et al., 2019; Strohbuecker et al., 2011; Vestjens et al., 2020). Moreover, a thriving interprofessional working relationship between care providers ensures that care needs are sufficiently met and creates a feeling of security for older individuals (Claassens et al., 2014; Hedman et al., 2019). Finally, within the context of informal care, a trustful relationship enhances the notion of care reciprocity between older individuals and their informal carers. This creates the perception that older people living with frailty are not only resource takers, further intensifying their sense of control and usefulness (Ebrahimi et al., 2013; Janlöv et al., 2006; Lambotte et al., 2019).

In summary, empathetic, cooperative and reciprocal relationships between older people living with frailty and care providers, and good interprofessional relationships among care providers can enhance older people's independence in care, a sense of togetherness, and perceived control.

Sense of control and power relationships

The reviewed literature shows that the depersonalization of the care process can create a perceived power imbalance between older individuals living with frailty and professional care staff. As a result, some care staff may not discuss the care options or plans with older individuals living with frailty, mainly disregarding the need for information sharing or overruling older people's views if expressed (Ekdahl et al., 2010; Ekwall et al., 2012; Falk et al., 2011; Kristensson et al., 2010). For example, some older people living with frailty felt they lacked information on different care aspects, such as the type of help they could claim, due to the reluctance of home help officers to share such details willingly (Janlöv et al., 2006). Such power imbalances can intensify older individuals' feelings of powerlessness, making them unable to ask questions or query decisions and compelling them to do as they are told (Andersson et al., 2008; Ekwall et al., 2012).

The bureaucratic tendencies and the pre-determined, rigid, and unresponsive functioning of hospitals and other care organizations can make older individuals living with frailty feel powerless (Ekdahl et al., 2010; Janlöv et al., 2006; Kristensson et al., 2010). In addition, they often struggle with gatekeepers of such care organizations, especially when waiting for key decisions such as relocation or discharge, creating feelings of uncertainty (Kristensson et al., 2010). Moreover, some care organizations pay more attention to specific tasks and less to a comprehensive understanding of the person, which is often disempowering to older people living with frailty (Hedman et al., 2019; Kristensson et al., 2010). This limits older peoples' sense of control and potential to adjust to their care environment and situation.

In summary, the organizational structures of care organizations and the existing power imbalances between care professionals and older people living with frailty contribute to feelings of uncertainty, powerlessness and a limited sense of control in older people living with frailty.

Discussion

This scoping review examines and summarizes the literature on a sense of control and wellbeing in older people living with frailty within their everyday life and health and social care services. There is a small but growing literature in this area, with most work being carried out in Scandinavian countries. Drawing on perspectives of older people living with frailty and their caregivers in different care settings, the review generated three themes a) *Control as conveyed in bodily expressions and daily activities*; b) *Sense of control and influence of place of residence*; and c) *Control within health and social care relationships.*

There is clear quantitative and qualitative evidence demonstrating the relationship between the body, sense of control and sense of wellbeing for people living with frailty. The greater the limitation in bodily ability, the greater the challenge to a sense of control and wellbeing. These findings align with other studies that have shown that poor health creates biological disruptions in the body that exacerbate physical declines and contribute to the loss of functional abilities and ill-being in older people (Bhullar et al., 2010; Clarke & Korotchenko, 2011; Clarke et al., 2008; Satariano et al., 2010). Also, the findings align with a broader change in the sense of identity noted previously in older people. Older people experience body changes, including unintentional weight loss and slowing down, which affect their sense of identity (Alibhai et al., 2005; Chapman, 2011; Martin & Twigg, 2018; Thomas, 2005). Among others, the first theme highlights a disproportionate emphasis on biomedical aspects of the body, even though internal feelings of control can significantly compensate for the physical decline. Martin and Twigg (2018) argue that focusing on the biomedical aspects of the body alone is 'reductionist and "objectifying," and more attention should be placed on the 'embodied experiences of everyday life of older people (p. 3). This perspective is often linked to the concept of subjective aging, where some older people feel younger than their biological age and physical appearance, which is associated with resilience and better health outcomes in old age (Cleaver & Muller, 2002; Kleinspehn-Ammerlahn et al., 2008; Kornadt et al., 2018).

Another key aspect of the review is the importance of self-management and a sense of control. This is particularly important for people living with frailty, as deterioration can be slowed by engaging in activities and exercise (Angulo et al., 2020; Silva et al., 2017; Theou et al., 2011). This finding concurs with other studies exploring SMA's benefits to older people's wellbeing (Clarke et al., 2020; Cramm & Nieboer, 2015; Cramm et al., 2012; Steverink et al., 2005). The overriding message from these studies is that older people with health challenges that impede their participation in everyday activities can benefit from taking initiatives such as engaging in physical exercises. Clarke et al. (2020) accentuate that exercises are vital to older people because they enable them to maintain health and physical functionality to continue participating in everyday activities. Another study indicates that SMA among older people can play a preventative role, especially when dealing with long-term cognitive decline (Cramm & Nieboer, 2022). However, some research has extended the discussion on the benefits of SMA beyond physiological aspects and highlighted the social benefits of SMA to older people, particularly in reducing loneliness (Nieboer et al., 2020). One way to enhance SMA is through promoting health literacy and ensuring high-quality patient-professional relationships (Cramm & Nieboer, 2015; Geboers et al., 2016). Generally, most of the available work on SMA in older people is mainly quantitative, focusing much on measurable outcomes. It would be interesting to find out what older people feel about SMA in their everyday life.

An important finding from the review is that the physical and social environment mediates a sense of control. Theme two suggests that older people living with frailty prefer to stay in their homes for as long as possible. This is supported by the wider literature on older people in general (Bárrios et al., 2020; Stones & Gullifer, 2016). This highlights how the sense of control and wellbeing is not only based within the individual but are relational. Theme two highlights the detrimental impact of environmental change and the potential lack of control over this change. These findings align with other studies that report diminished autonomy over everyday decisions when older people transition to nursing homes (Reimer & Keller, 2009; Wikström & Emilsson, 2014). However, some studies have reported that in some cases, older people in nursing homes can exercise free will on different aspects, such as bedtime and privacy, depending on the nurses' flexibility, positive attitude, and respect for older people's needs (Tuominen et al., 2016). In both cases, feeling in control over the environment seems to have more to do with how the environment makes people feel than the environment itself. Todres et al. (2009) concur that feeling human is closely associated not only with the familiarity of the physical environment but primarily with the sense of comfort, security, and unreflective ease it exudes, and the lack of such attributes can lead an individual to feel like a stranger and the environment unhomely. The reviewed literature has revealed the challenges that older people living with frailty encounter during their relocation to nursing homes and from one nursing home to another and the ideals of good relocation care practices. However, these aspects have been explored mainly using quantitative approaches, and gerontological research and practice would benefit from understanding the lived experiences of relocations among older people.

Theme three suggests that a sense of control in older people living with frailty is supported through trusted relationships at different care levels. This implies that people are not just individuals, as seen in the medical model, but they live within networked relationships of meaning throughout their lives, and it is this meaning that should be the currency of care (Todres et al., 2007). Trusting relationships based on respect, empathy, and compassion can create a sense of security and togetherness in care processes, increasing care satisfaction (Heggestad et al., 2015; Sung & Dunkle, 2009).

These findings are consistent with Dinç and Gastmans (2013), who argue that trust is vital in building relationships between nurses and patients and that trusting relationships form the cornerstone of caring practices. However, this relationship is sometimes missing in care processes (Johnsson et al., 2019). The review has highlighted the role of formal and informal care providers in facilitating or obstructing a sense of control in older people living with frailty. However, few studies focus on care providers' perspectives on control and wellbeing in older people with frailty. The review was only able to locate three studies by Hedman et al. (2019), Wallerstedt et al. (2018), and Broese van Groenou et al. (2016), which focused on the perspectives of formal and informal care providers. Considering caregivers' critical role in facilitating a sense of control and wellbeing in older people, conducting more studies that capture their perspectives is essential.

Furthermore, this review highlights that trusting caring relationships are sometimes challenged by organizational systems and service user vulnerability. This often manifests in power imbalances at the care provider and organizational levels. For example, care providers are perceived as experts who use their professional knowledge and competence to make care decisions, sometimes without the involvement of the older person, which culminates in a diminished sense of control for the older individual (D'Avanzo et al., 2017). Similarly, care organizational structures can support existing power imbalances between care professionals and older people living with frailty, creating conditions for delimiting the sense of control. This occurs where care interactions are dominated by a "system" discourse into which the person either fits or does not, with no room for other interpretations or discourses other than that of the professionals (Galvin & Todres, 2013).

Limitations of the review

This review was carried out as part of a PhD study which meant that the main author carried out most of the work rather than two or more researchers conducting and cross-checking all decisions in detail. However, all decisions were discussed and checked with the supervisory team in regular supervisory sessions, and any issues were resolved by consulting the second and third authors. In addition, in the search process, we only used key terms and other search components, such as subject headings, were not considered. Similarly, the first level of screening considered titles and not titles and abstracts. Therefore, relevant articles may have been missed. Furthermore, to strike a balance between feasibility in terms of time and the ability to answer the review question or achieve the review purpose, we decided to limit the search to only peer-reviewed primary research. Thus, some potentially relevant literature may have been left out from other sources, such as review articles, websites, blogs, research protocols, reports, conference proceedings, dissertations/theses, editorials, and commentaries which formed part of the exclusions. Finally, as this was a scoping review, there was no assessment of the methodological quality of the included papers. Therefore, it is possible that some of the included papers may not be of the highest quality or methodological rigor.

Conclusion

A sense of control in older people living with frailty is increasingly acknowledged as an important care and policy issue. This review shows that there is clear quantitative and qualitative evidence to demonstrate the importance of the sense of control in managing the development of frailty and the active maintenance of ability leading to a sense of wellbeing. Furthermore, this scoping review highlights that the sense of control is not solely an internally regulated feeling but is highly dependent and inextricably linked to the physical and social environments and the meanings held within these environments. However, most studies have been quantitative. This review highlights the need for more qualitative studies to explore and gain understanding from older people living with frailty and those working alongside them to understand these relationships and their meanings.

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Appendix 1:

Table A1. Final search terms, synonyms, and truncations.

Component	Synonym
Population (P): ● Older people living with frailty	*frailty'"OR""frail elderly""OR""frail older people""OR""frail older persons"*
Concept (C) ● Sense of control ● Well-being	*AND* *'"Sense of control OR""Perceived control"'OR "Primary control" OR "Secondary control" OR "Experience of control'"OR 'Sense of efficacy' OR Control OR""Locus of control""OR"'Personal control"OR"Control"OR "Personal efficacy" OR "Self- determination" OR "independence" OR "autonomy" OR "choice" OR "self- management"* *"'wellbeing''or''well-being''or''well being'"*
Context (C) ● Health or Social Care	*AND* *(Hospital OR Home OR Community OR "Care home" OR "Nursing home" OR "Municipal")*

setting

Table A2. The table below provides an overview of the included papers.

							Contribution to the themes		
							1-Body/ADL*(note) 2-Residence 3-H&SC relationships		
No	Author(s)	Year	Country	Study design and sample	Setting	Control and/or wellbeing construct (s) measured/investigated	Theme 1	Theme 2	Theme 3
1.	Abu-Bader et al.	Abu-Bader et al. (2003)	USA	● Quantitative (structured interviews) ● 99 frail older people aged 60+	Community	● Relationship between life satisfaction and physical health, emotional balance, social support, and locus of control.	X		
2.	Andersson et al.	Andersson et al. (2008)	Sweden	● Qualitative (narrative approach) ● 17 older people having a life-threatening disease and/or receiving palliative care and aged 75+	Community	● Aspects of a good life in the last phase of life.	X	X	X
3.	Andrew et al.	Andrew et al. (2012)	Canada	● Quantitative (questionnaire) ● 5,703 frail older people aged 70+	Community	● Psychological wellbeing focusing on the relationship between wellbeing, frailty and mortality.	X		
4.	Bilotta et al.	Bilotta et al. (2010)	Italy	● Quantitative (questionnaire) ● 239 frail older people aged 65+	Community	● Relationship between frailty and Quality of Life (QoL).		X	
5.	Broese van Groenou et al.	Broese van Groenou et al. (2016)	Netherlands	● Quantitative (interviews) ● 74 frail older people aged 65+, 94 informal caregivers, and 102 formal caregivers	Community	● Mixed care networks and their impact on activities of daily living level, memory problems, social network, perceived control of care and levels of mastery.	X		
6.	Claassens et al.	Claassens et al. (2014)	Netherlands	● Qualitative (grounded theory) ● 32 frail older people aged 65+	Community	● Perceived internal and external factors that constitute perceived control over healthcare.	X	X	X
7.	Cramm et al.	Cramm et al. (2014)	Netherlands	● Quantitative (questionnaire) ● 869 frail older adults aged 70+	Community	● Relationship of Self-Management Abilities (SMA) and frailty to perceived poor health.	X		
8.	Dent et al.	Dent and Hoogendijk (2014)	Australia	● Quantitative (prospective, observational study) ● 172 frail older people aged 70+	Hospital	● Association between psychosocial factors and frailty and the impact of psychosocial factors on the association between frailty and adverse outcomes.	X		
9.	Ebrahimi et al.	Ebrahimi et al. (2013)	Sweden	● Qualitative (content analysis) ● 22 frail older adults aged 65+	Community	● Influences on subjective experiences of good health.	X	X	X

(*Continued*)

Table A2. (Continued).

10.	Ekdahl et al.	Ekdahl et al. (2010)	Sweden	• Qualitative (content analysis) • 15 frail elderly patients aged 75+	Hospital	• Preferences for participation in medical decision-making during hospitalization.	X		X	X
11.	Ekwall et al.	Ekwall et al. (2012)	Sweden	• Qualitative (interviews/content analysis) • 14 older people in the acute care process (5 men and 9 women) aged 70+	(Acute) Hospital	• Experiences of physical decline and strategies for adapting to physical decline (compensating/controlling and accepting/ resignation).	X		X	X
12.	Falk et al.	Falk et al. (2011)	Sweden	• Mixed methods • 74 were inter-institutionally relocated (movers), while 81 served as an equivalent reference group (non-movers) 155 frail older persons	Residential care	• Effects and experiences of inter-institutional relocation on QoL, wellbeing, and perceived personal centeredness.	X		X	X
13.	Frieswijk et al.	Frieswijk et al. (2006)	Netherlands	• Quantitative (questionnaire) • 193 slightly to moderately frail older people aged 65+	Community	• Impact of increasing SMA (bibliotherapy) on mastery and wellbeing.	X			
14.	Gale et al.	Gale et al. (2014)	England	• Quantitative (questionnaire) • 2557 not frail, pre-frail and frail older men and women aged 60+	Community	• Prospective relationship between psychological wellbeing and incidence of physical frailty.	X			
15.	González-Bautista et al.	González-Bautista et al. (2020)	Mexico	• Quantitative (survey questionnaire) • 1,519 frail older adults aged 60+	Community	• Longitudinal association between Social Determinants of Health (SDH) and frailty status with all-cause mortality.	X			
16.	Grain, Madeleine	Grain (2001)	USA	• Quantitative (questionnaire) • 37 frail nursing home residents and 37 home-bound frail older people (both aged 60+)	Home-bound and Nursing home	• Comparison between a sense of control and life satisfaction between nursing home residents and home-bound older people.			X	
17.	Hedman et al.	Hedman et al. (2019)	Sweden	• Qualitative (descriptive phenomenology) • 13 registered nurses	Nursing home	• Experience of caring for older people in nursing homes to promote autonomy and participation.	X		X	X
18.	Janlöv et al.	Janlöv et al. (2006)	Sweden	• Qualitative (content analysis) • 28 frail home help recipients aged 75 +	Community	• Experience of participation in and influence on decisions about public home help/care.	X		X	X
19.	Johannesen et al.	Johannesen et al. (2004)	Denmark	• Quantitative (interviews) • 187 frail men and women aged 85+	Community	• Association between social relation, continuity, self-determination, and use of own resources with everyday life satisfaction.	X		X	

(*Continued*)

Table A2. (Continued).

20.	King et al.	King et al. (2017)	USA	• Quantitative (structured questionnaire) • 4,162 frail older people aged 65 to 105 years	Community	• Association between a newly developed cumulative laboratory-based frailty index (FI) and intrinsic and extrinsic characteristics.	X			
21.	Kristensson et al.	Kristensson et al. (2010)	Sweden	• Qualitative design (open-ended interviews) • 14 frail older adults aged 70+	Hospital	• Experience of receiving health care and/or social services.	X			X
22.	Kwong et al.	Kwong et al. (2014)	Hong Kong	• Qualitative (content analysis) (FGDs) • 24 frail elderly aged 65+	Nursing home	• Perception of quality of life in nursing homes.	X		X	
23.	Lambotte et al.	Lambotte et al. (2019)	Belgium	• Qualitative (in-depth interviews) • 65 frail older adults aged 60+	Community	• Experience of relational aspects of mastery and caregivers' role in maintaining mastery over the care process.	X		X	X
24.	Milte et al.	Milte et al. (2015)	Australia	• Randomised Controlled Trial (RCT) • 136 frail older adults (70 usual care/ control group and 66 specialized care).	Hospital	• Influence of health locus of control on physical function, quality of life, depression, and satisfaction with care transition.	X			
25.	Mooney et al.	Mooney et al. (2018)	USA	• Quantitative (questionnaire) • Cross-sectional sample included 5,250 respondents, and in the longitudinal sample, 2,013 respondents who were all frail and aged 65+	Community	• Effect of chronic stress and socioeconomic status (SES) on baseline frailty and change in frailty status over 4 years. • Extent to which perceived control mediates or moderates the effects of chronic stress.	X			
26.	Niesten et al.	Nicholson et al. (2012)	Netherlands	• Qualitative (open-ended interviews) • 38 frail older dentulous people aged 65+	Day-care centers and Assisted-living homes	• The impact of natural teeth on the QoL.	X			
27.	Portegijs et al.	Portegijs et al. (2016)	Finland	• Quantitative (longitudinal analyses) • 753 frail older people aged 75 to 90 years	Community	• Relationship between frailty, life-space mobility and perceived autonomy in participation outdoors.	X			
28.	Sandgren et al.	Sandgren et al. (2020)	Sweden	• Quantitative • 78 frail older persons aged 65+ (questionnaire)	Nursing home	• QoL among different gender and age groups in nursing homes.			X	

(*Continued*)

Table A2. (Continued).

29.	Schuurmans et al.	Schuurmans et al. (2005)	Netherlands	• Quantitative (questionnaire) • Frail older individuals (Study 1 sample *n* = 275 aged 64+), study 2 sample *n* = 1338 aged 65+)	Community	• Relationship between SMA, perceived health, subjective wellbeing, general self-efficacy and mastery.	X		
30.	Siriwardhana et al.	Siriwardhana et al. (2019)	Sri Lanka	• Quantitative (questionnaire) • 746 frail older adults aged 60+	Community	• Association of frailty with overall and domain-specific QoL.	X		
31.	Strohbuecker et al.	Strohbuecker et al. (2011)	Germany	• Qualitative (grounded theory) • 9 residents suffering from chronic disease or frailty and aged 70+	Nursing home	• Palliative care needs of nursing home residents	X	X	X
32.	Thorson, James A. and Davis, Ruth Ellen	Thorson and Davis (2000)	USA	• Quantitative (longitudinal) • 269 older individuals with an average age of 79.8 years	Nursing home	• Impact of institutional relocation on mortality and morbidity.	X	X	
33.	Vestjens et al.	Vestjens et al. (2020)	Netherlands	• Quantitative (questionnaire) • 588 frail older people aged 75+	Community	• Relationship between SMA, productive patient-professional interactions and wellbeing.	X		
34.	Wallerstedt et al.	Wallerstedt et al. (2018)	Sweden	• Qualitative (content analysis) • 40 next of kin for frail older people	Nursing home	• Next of kin experiences of participating in care of older people in nursing homes.		X	X

1-Body/ADL = Control as conveyed in bodily expressions and daily activities; 2- Residence = Sense of control and influence of place of residence; 3- H&SC relationships= Control within health and social care relationships.

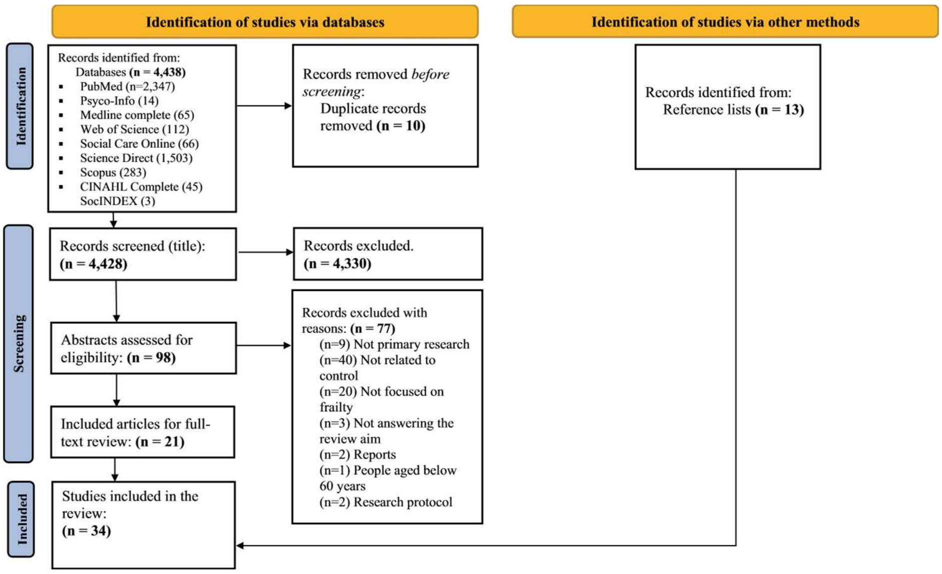

Figure A1. PRISMA flow diagram summarizing the phases of the literature search.

Appendix 18: Study Protocol

Exploring the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England

SHORT STUDY TITLE / ACRONYM:

CONtrol: Sense of control in frail older persons

- **This protocol has regard for the HRA guidance and order of content;**

IRAS Project ID: 282540

Sponsor: Bournemouth University

STUDY TITLE. Exploring the lived experience of control and wellbeing of older persons diagnosed with frailty within the care service provision in southern England

SHORT STUDY TITLE. CONtrol: Supporting a sense of control in frail older persons

PROTOCOL VERSION: 3.0 24th June 2021

RESEARCH REFERENCE NUMBERS

IRAS Number: 282540

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Researcher agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirements.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor.

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest, accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature:	Date:
....	24/06/2021
Name (please print):	
Mrs JULIE NORTHAM	
Position:	
Head, Research Development & Support ………..	

Researcher:

Signature:	Date:
Adam Nyende	24/06/2021

LIST of CONTENTS

KEY STUDY CONTACTS

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Funder(s)	European Commission [Horizon 2020]-Marie Skłodowska-Curie Research Actions (INNOVATEDIGNITY Project)
Key Protocol Contributors	Dr. Caroline Ellis-Hill-Bournemouth University (United Kingdom) Dr. Stefanos Mantzoukas-University of Ioannina (Greece)

STUDY SUMMARY

Study Title	Exploring the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England.
Internal ref. no. (or short title)	CONtrol: Supporting a sense of control in frail older persons
Study Design	Qualitative (Phenomenological) Study
Study Participants	▪ Older people diagnosed with frailty and receiving care at the Day Hospital. ▪ Day Hospital staff working with frail older people, including nurses, doctors, physiotherapists, occupational therapists and therapy assistants.
Planned Size of Sample Phase 1	▪ Interviews with up to 20 frail older people
Phase 2	▪ Interviews with up to 10 Hospital staff
Planned Study Period	36 months
Research Question	What is the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England?

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIAL SUPPORT GIVEN**
European Commission [Horizon 2020]-Marie Skłodowska-Curie Research Actions (INNOVATEDIGNITY Project)	▪ Annual Salary = £37,384, Mobility allowances = £4,907 per annum and Family allowances = £4,089 per annum ▪ Supervisory Support- Dr. Stefanos Mantzoukas- University of Ioannina (Greece) ▪ Secondment Training to the Royal College of Nursing-UK ▪ Access to research training and development opportunities
Bournemouth University	▪ Supervisory Support-Dr Caroline Ellis-Hill and Professor Ann Hemingway ▪ Office Space ▪ Access to Continuing Professional Development (CPD) ▪ Access to Graduate School and Postgraduate Research Training and Development

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITTEES/GROUPS & INDIVIDUALS

Study Supervision Group

This study is part of a Doctoral research project undertaken at Bournemouth University by the researcher and as such is supported by an academic supervisory team.

This study is part of a wider EU funded project entitled the INNOVATEDIGNITY project which provides a shared research and training agenda to educate the next generation of interdisciplinary care researchers and leaders across Europe. The project is a response to the global need to provide sustainable and dignified care for older people at home and in residential, municipal and hospital settings. The project has fifteen (15) research themes studied by fifteen (15) Early Stage Researchers (ESRs) under a consortium of nine (9) institutions of higher education and supported by non-academic partner organisations in the countries of Denmark, England, Greece, Norway and Sweden.

The wider network focuses in detail at how older people currently experience care, how they can be supported to live well and how technology, gender, and institutional factors can impact experiences of dignity and well-being. As well, the Project studies new ways of engaging with older people to examine new kinds of care delivery in response to the growing lack of sustainability in older person care and evidence of current care failings. The current study is theme six (6) of the project and based at Bournemouth University, England. The academic supervisory team is made up of;

Dr. Caroline Ellis-Hill- Bournemouth University (England)

Professor Ann Hemingway- Bournemouth University (England)

Dr. Stefanos Mantzoukas- University of Ioannina (Greece)

KEYWORDS

Frailty

Older persons

Lifeworld

Control

Care

Wellbeing

STUDY FLOW CHART

Data Collection Planning Phase (2 months)

- Re-visit the data collection plan with the RBCH R&D Department
- Conduct a pilot study (pre-test) with one older person and one staff member
- Recruit potential participants

Phase 1: Data collection with frail older persons (7 months)

- Set up appointments with the potential participants (frail older people)
- Discuss the details of the Participant Information Sheet
- Sign Consent/agreement forms
- Conduct individual face to face or online (Skype/Zoom or Microsoft Teams) or telephone semi-structured interviews with up to twenty (20) frail older people
- Audio-record the interviews
- Take field notes in a journal

Phase 2: Data Collection with Hospital Staff (3 months)

- Set up appointments with the potential participants (hospital staff)
- Discuss the details of the Participant Information Sheet
- Sign Consent/agreement forms
- Conduct individual face-to-face or online (Skype/Zoom or Microsoft Teams) or telephone semi-structured interviews with up to ten (10) Hospital Staff
- Audio-record the interviews
- Take field notes in a journal

Data Analysis and Dissemination of the Final Report (12 months)

- Analyse the transcripts and field notes following the approach set out by van Manen (1997)
- Review up to date studies that might be relevant to the emerging data/findings
- Submit the final report and disseminate project findings

STUDY PROTOCOL

Exploring the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England

1. BACKGROUND

This section will present an overview of the conceptualisation and prevalence of frailty in old age in the United Kingdom and the need to focus on older people's meaning of a sense of control as a way of ensuring a more humanising care approach for older persons diagnosed with frailty.

Older people make up the biggest number of users of health and social care services in the United Kingdom, and many of them have been diagnosed with frailty (Turner and Clegg 2014). The British Geriatrics Association (BGA) defines frailty as;

> '*a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves'* (BGS 2014).

Frailty is usually characterised by decreased bodily reserve and functional capacity coupled with increased exposure to negative health outcomes as a result of cumulative deficits in multiple organ systems (Nicholson et al. 2013; Turner and Clegg 2014; Kojima 2015).

Although not all old people are frail, research from the UK indicates that 10 per cent of persons aged 65 years and over live with frailty, and this number is increasing to 65 per cent in people aged over 85 (Clegg et al. 2013; BGS 2014). Furthermore, despite the inconsistency in the prevalence of frailty- partly attributed to the highly heterogeneous nature of the older population and a lack of consensus on the operational definition and diagnostic criteria for frailty, evidence suggests that the emergence of frailty is linked to the onset of old age which is usually associated with reduced functional capacity and increased risks to diseases and disabilities (Song et al. 2010; Nicholson et al. 2013; Turner and Clegg 2014; Kojima 2015).

The condition of frailty in old age is now described as a long-term health-related status whose onset is typified by incidences such as falls, a recent decline in mobility, delirium or confusion, sudden change incontinence, and a sensitivity to medication (BGS 2014; Turner and Clegg 2014). Similarly, most of the frail older people have some form of physical and/or mental health limitation including visual, hearing and cognitive impairments, are often prescribed multiple medications, and may normally be subjected to delayed discharge from hospitals (Turner and Clegg 2014). Moreover, older people with frailty are susceptible to erratic health status changes triggered by minor events such as new medication and minor infections (Clegg et al., 2013). Consequently, frail older people stand a long term risk of disability, hospital/care or nursing home admission, increased care dependency, and mortality (Fried et al. 2001; Clegg et al. 2013; Kojima 2015).

While frailty is not always apparent and is occasionally overlooked, particularly in clinical assessments which are based on medical sub-specialities and single organ diseases (Turner and Clegg 2014), there seems to be some consensus within the literature on the models within which frailty can be situated and understood. Emerging evidence suggests that there are broadly two models of frailty i.e. the Phenotype model and the Cumulative Deficit Model (Clegg et al. 2013; Turner 2014).

The phenotype model highlights a set of five patient variables or characteristics which, if present, can predict poor outcomes relating to frailty. These characteristics include 'unintentional weight loss', 'reduced muscle/weak grip strength', 'self-reported exhaustion', 'reduced/slow gait speed', and 'low energy expenditure' (Clegg et al. 2013; Turner 2014). This model highlights that individuals' frailty levels can be determined depending on the number of characteristics they display. For instance, individuals with three or more of the five variables are considered to be frail, those with one or two variables as pre-frail, while those with no variables as not frail or robust older people (Fried et al. 2001).

The Cumulative Deficit Model, on the other hand, uses 'symptoms' (such as low mood and loss of hearing), 'signs' (such as tremor), 'diseases', and 'disabilities'- collectively termed as deficits, to define frailty. According to this model, ageing comes with an accumulation of deficits and people become frail due to the cumulative effect of individual deficits which are combined into an individual's 'frailty index' (Rockwood et al. 2005). Consequently, the frailty index represents the proportion of the potential deficits present in an individual and reflects the likelihood that frailty is present (Rockwood and Mitnitski 2007).

Frailty can be diagnosed in many ways including using validated tools such as the 'Gait Speed Test', 'PRISMA-7 questionnaire', 'Timed Up and Go Test' (TUGT) and the 'Edmonton Frail Scale' (Turner and Clegg 2014). Furthermore, in the UK, there has been a recent adoption of a new assessment tool within the NHS for identifying the degree of frailty within people aged 65 and over termed as the Electronic Frailty Index (eFI). This electronic tool is used by many General Practices to identify older people who might be living with varying levels of frailty by basing on the individual's 'cumulative deficits' and their primary electronic health care data. The tool is based on an overall score of 36 points to indicate the sum of deficits present in a person-with a higher score pointing to a higher degree of severity in frailty and increasing vulnerability to adverse outcomes (NHS-England 2017).

As the population of older people in the UK continues to grow, there is an increasing focus on how their care needs will be met to support their dignity and wellbeing within the current care context (Ward et al. 2012). With most of the older people grappling with frailty and its related challenges including long term care needs (Clegg et al. 2013; BGS 2014), it seems relevant to focus on them to improve their care services, quality of life and wellbeing. Central to this is the need to understand frail older people's lives as experientially lived in order to enhance a more humanising approach in a health care system that is dominated largely by *"the rules of modern science"* (Dahlberg 2011, p.19).

Although there have been significant improvements within the healthcare systems, particularly due to medical innovations, the current healthcare approach is still dominated by the medical model, which emphasises the measurable and biomedical aspects of individuals (Dahlberg 2011) and the *"sometimes-necessary technological and specialised focus"* (Todres et al. 2009, p.68). Consequently, people's thoughts, feelings, wishes, intentions, and other aspects of their existence that are not easy to measure are sometimes ignored, thus resulting in less personal and dehumanising care regimes (Dahlberg 2011; Galvin and Todres 2013).

Furthermore, in highly technical care contexts, there can be generally depersonalising situations, such as limited communication between professionals and individuals requiring care. In many healthcare facilities, care is made up of machinery that often consumes the attention of healthcare providers, who end up caring for the machines rather than the people who are connected to these machines. The impact of technology is also seen in the wider focus of healthcare professionals on technological discourses such as numbers and outcomes, making it easy to lose track of the human being and/or their basic emotional needs. Although this may not be entirely the fault of care professionals, such a care system can create an environment of loneliness and distrust on the part of the person requiring care due to limited opportunities for human contact (Todres et al. 2000). This generates *"the dilemma of others knowing how I am but not who I am"* which is often disempowering and deprives individuals requiring the care of their right to collaborative participation in the care process (Todres et al. 2000, p.279).

Therefore, for care systems to be more humanising, there is a need to re-think the approach and focus more on those (taken for granted) care aspects that make people feel more human (Galvin and Todres 2013). There is a need for an approach that focuses attention on the full context of an individual's identity and historical narrative (Frank 2013) to better understand their human experiential world. Given that, Todres et al. (2007) argue for a 'lifeworld approach' as a philosophical foundation which can provide values and general ideas on how healthcare practice can be more humanising particularly in providing a more holistic perspective on being human. According to them, this approach highlights a model where healthcare systems are designed around the concerns, experiences and the world around those at the receiving end of care.

A sense of control has become one of the most important aspects of health and social care practice, particularly in the context of old age (Angus and Reeve 2006; Kristensson et al. 2012; Claassens et al. 2014). In the UK, for example, the theme of control in health and social care has been linked to ideas of 'personalised care' (NHS England, 2019) and 'dignity in care' (SCIE, 2020).

Control as a term is increasingly being used in health and social care to describe a process where service users make choices and have the potential to take action in their lives, including their care, environment, identities and personal relationships (Claassens et al. 2014; Pirhonen and Pietilä 2016). It is therefore important for empirical research to focus on a deeper understanding of the experience of control in health and social care, particularly among frail older people who are often considered weak and in "*need of significant care and support*" and yet they actively resist the label of 'frailty' (WHO 2004, p.26; Nicholson et al. 2013).

Claassens et al. (2014) propose a model of perceived control to assist in conceptualising the term control in frail older people. They argue that perceived control "*reflects the feeling or belief that health care is under control arising from multiple constituting factors*" (p.167). They further highlight that perceived control in individuals is highly dependent on several internal and external factors that constitute control, and these factors reinforce each other. The internal factors include 'self-confidence in organising professional and/or informal care', and 'self-confidence in health management in the home setting', while the external factors include 'perceived support from people in the social network', 'perceived support from health care professionals and organisations' as well as the 'perceived support from (health care) infrastructure and services' (Claassens et al. 2014).

There is a realisation that enhancing the sense of control for users of health and social care services can improve participation and a sense of dignity for service users (Age Cymru 2019). For example, Nicholson et al. (2013) argue that frail older people use adaptive coping strategies such as creating social connections to enhance self-care, maintain social roles and also assume new roles. Moreover, providing good information to service users about their health and factoring their concerns in care decisions can also enhance their participation in care and control over healthcare decisions (Bastiaens et al. 2007).

Despite the importance of control, particularly in understanding how people remain in charge of their lives, very little research has been conducted to gain a deeper understanding of how frail older people experience control in their care and lives and how this impacts their overall well-being. Previous research on frail older people has tended to focus on general aspects of frailty experiences, such as the experience of living and dying with frailty in old age (Nicholson et al. 2012; Nicholson et al. 2013), experiences with and perceptions of health (Ebrahimi et al. 2012), perceptions on the quality of life (Hjaltadóttir and Gústafsdóttir 2007; Puts et al. 2007), caregiving processes (Kita and Ito 2013) and care providers' perspectives on managing frailty (Wallin et al. 2008).

To close this gap, the study proposes to use a lifeworld approach to elicit the perspectives of frail older people by focusing on their lived experience and the meaning of control to understand how they remain in charge of their lives and care within the context of being frail.

The study will explore ways in which frail older people experience control, how control is shared with their care providers, how their sense of control is related to their experiences of care, dignity and well-being, and how their sense of control can be enhanced to support their well-being.

Consequently, the proposed study will make an important contribution to understanding how health and social care practice can enhance or undermine the way frail older people experience control over their lives and care in order to contribute to the design and delivery of appropriate humanising care practices.

2. RATIONALE

Aim of the study

The aim of this study is to gain a deeper understanding of the meaning of control and well-being for older people diagnosed with frailty and how health and social care services affect this experience.

Research Question: What is the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England?

3. THEORETICAL FRAMEWORK

This study will be guided by the lifeworld theory and a phenomenological approach that are interested in looking at people's lived (subjective) experiences. The lifeworld approach can be traced back to the works of Edmund Husserl (1970), who originally referred to the lifeworld as the spatial-temporal world of things around people that they may not even notice and thus take for granted. Therefore, the lifeworld, as applied to human beings, can be seen as the *“humanly qualitative nature of the world we live in”* and often take for granted (Todres et al. 2007, p.55).

This theory will aid the researcher in obtaining the depth and detail of the everyday life of the participants as experientially lived. The study will draw on the dimensions of the lifeworld such as temporality, spatiality, mood, embodiment, and inter-subjectivity as basic principles upon which the researcher will explore and describe the participants' lifeworld- the experiential stream of happenings to human beings in everyday moments (Biley and Galvin 2007).

Todres et al. (2007) link the concept of lifeworld to health care research and practice by suggesting practical ways in which the theory can be used to support humanising care practices. They argue that *“how we live in relation to time, space, body, others and mood is fundamental to describing the holistic context in which being human makes sense”* which in turn can be very useful in gaining a fuller understanding of the person at the receiving end of healthcare (Todres et al. 2007, p. 60). This is even more significant within the context of the current healthcare regimes, which are characterised by the increasing use of technology and specialisation, which all impact the relational aspects of care and sometimes contribute to dehumanising healthcare practices.

Therefore, in their bid to propose a philosophical foundation for a more humanising care approach, Todres et al. (2007) provide a synthesis of the scope and value of lifeworld-led care. In doing so, they advance a value framework to guide and provide a basis for humanising care and qualitative research within healthcare systems (Todres et al. 2009). This framework is based on the core value of humanising care, and it paves the way for ‘lifeworld-led care’, which is based on the perspectives and qualitative experiences of people as well as the lifeworld dimensions which can all be applied through qualitative research methodologies such as phenomenology and narrative inquiry (Todres et al. 2007; Todres et al. 2009).

Consequently, the present study will be guided by the ideals of the lifeworld theory and the care humanising framework in applying a hermeneutic phenomenological approach to explore the lived experiences of control and well-being for older people diagnosed with frailty.

4. RESEARCH QUESTION/OBJECTIVES

What is the lived experience of control and well-being of older persons diagnosed with frailty within the care service provision in southern England?

4.1. Research Objectives

i. To explore the lived experience of control and well-being of older persons diagnosed with frailty within their life and care service use.
ii. To explore what frail older people perceive may increase their experience of control and well-being in their care environments.
iii. To explore how the lived experience of control relates to frail older peoples' experiences of care, dignity and well-being.
iv. To examine the experiences of care providers in sharing control with people diagnosed with frailty.
v. To identify how care services for frail older persons can be enhanced to support personal control and well-being.

4.2. Outcome

i. The proposed project will provide an in-depth understanding of a) how frail older people understand and experience control in their lives and care b) how their experiences can be used to shape and enhance care design and delivery and c) how professional care providers can integrate into care practice principles that enhance service users' sense of control and wellbeing. Many of the research projects within health and social care are focused on the perspectives of care professionals. This study will, therefore, provide an understanding of the lived experiences of those at the receiving end of care.
ii. The research project will also contribute to an understanding of how the lifeworld approach can be used in health and social care practices to enhance the dignity and well-being of service users. This approach emphasises the humanising aspects of care and therefore, the project results will go a long way in highlighting the applicability of the approach in enhancing humanising care practices.

5. STUDY DESIGN AND METHODS OF DATA COLLECTION AND DATA ANALYSIS

5.1. Study design

The proposed study will follow a qualitative research design as guided by an interpretivist ontology and epistemology. This design has been largely informed by the researcher's overall goal of seeking to "*contextualize, understand and interpret" frail* older people’s experiences of control and wellbeing within care systems (Szyjka 2012, p.2). The qualitative methodology will aid the researcher in obtaining a deeper understanding and interpretation of the phenomenon (sense of control) from the perspective of the people involved (frail older people and Hospital staff) as experienced in their everyday life (Glesne 2016).

In line with the aim of elucidating first-person experiences of the phenomena and an appreciation that reality is better understood when *“seen through the eyes”* of the people experiencing it (Matua 2015, p.31), the study will be guided by the hermeneutic phenomenological approach as described by Heidegger and van Manen in what Vivilaki and Johnson (2008) describe as a dual philosophical and methodological research journey.

From a philosophical standpoint, this approach has been chosen because of its inherent connection to the lifeworld theory, its emphasis on human experiences (Polit and Beck 2009) and what Heidegger 1962 termed in his work as ‘being and time’ (Heidegger 2010). According to the latter, analysis is focused on how people understand and interpret themselves in the (often ignored and taken for granted) world in which they find themselves and the representation of the unity between individuals and their world. Moreover, Heidegger’s ideas are premised on the notion that lived experiences are inherently an interpretive process and that hermeneutics is a core feature of human existence (Polit and Beck 2009).

From a methodological perspective, the approach has been chosen to guide the data collection and analysis processes because of the opportunity it offers to search for similarities in people’s lived experiences and also capture the meanings and understandings of those experiences by interpreting the research data (Cashin et al. 2008; Gadamer 1975/2006). Therefore, individual semi-structured interviews will be used as the data collection method to obtain *“descriptions of the lifeworld of the participants and interpret the meaning of the described phenomena”* (Kvale and Brinkmann 2008, p.3).

Accordingly, the study planning, data collection and analysis will follow van Manen's (1990, p31) human science research steps, including:

i. Turning to the nature of lived experience: The step involved the researcher identifying the phenomenon of interest, which is the experience of control and well-being for frail older people, which was translated into a research question.
ii. Investigating experience as we live it: This step will involve studying the phenomenon by interviewing frail older people and their professional care providers (Hospital staff) using interviews as a method of investigation.
iii. Reflecting on the essential themes which characterise the phenomenon: This step will include the researcher identifying the essential themes that are typical to the phenomenon through reflecting on the participant's meaning of their experiences.
iv. Describing the phenomenon in the art of writing and rewriting: At this stage, the researcher will engage in the process of writing and rewriting the text to present the thoughts, feelings and attitudes of the research participants.

v. Maintaining a strong and orientated relation to the phenomenon: This stage invites the researcher to remain oriented to the phenomenon under study and this will be done by striving to stay focused on the research question.
vi. Balancing the research context by considering the parts and the whole: The researcher will strive to constantly link the separate parts of the study and text to ensure a clear focus on the phenomenon under study.

Overall, the data collection process will include conducting individual semi-structured interviews with up to 20 frail older people and up to 10 Hospital staff in two phases across a period of 12 months.

5.2. Sampling and recruitment of study participants

The participants will be identified and selected using a purposeful sampling technique. All the participants will be recruited through the nominated manager at the Day Hospital, who will act as the gatekeeper. The study aims to recruit participants following the inclusion and exclusion criteria summarised in the table below. For details on the sampling and recruitment strategy, see section 7, 'Sample and Recruitment.'

Phase/Eligibility criteria.	**Inclusion Criteria**	**Exclusion Criteria**
Phase One (Older people)	f) Older people (aged 65 years and over) g) Individuals diagnosed with frailty and receiving (part of their) care services at the Day Hospital h) Capacity to give informed consent i) Ability to use the English language j) Judgement by the clinical staff and/or nominated manager that the potential participant can take part in an in-depth interview	d) Inability to communicate in English e) Acutely medically unwell individuals
Phase Two (Hospital Staff)	e) Staff working routinely with frail older people at the Day Hospital f) Full-time and Part-time employment g) Minimum of six (6) months of work experience with frail older people h) Capacity to give free and fully informed consent	b) Staff who do not have routine direct contact with patients' care such as the senior managers

5.3. Data Collection Methods and Processes

Individual face-to-face or online (Skype/Zoom or Microsoft Teams) or telephone semi-structured interviews will be adopted as the major data collection method with the participants (frail older people and Hospital staff) who have experienced the phenomena of interest (Creswell 2007). In this form of interview, the researcher will strive to gain entrance into the participants' lifeworld to better understand their lived experiences but without leading the discussion (Polit and Beck 2009). Phenomenological interviews are open, and the researcher will aim to facilitate (guide) participants to provide rich descriptions of the phenomena under study using their own experiences and everyday life examples (Holloway and Galvin 2016). However, the interviews will follow a 'conversational flow' which will be divided into activities such as asking a question, negotiating for meaning between the participant and the researcher, understanding the participant's concrete description, the researcher's interpretation of the descriptions, and the participant's validation and evaluation of their descriptions [coda] (Brinkmann 2013).

This form of interview will enable the researcher to obtain rich data through probing and expanding the participants' responses (Rubin and Rubin 2005).

i. Before the onset of data collection, the researcher will engage in the process of negotiating and establishing relationships (rapport) with the participants. This will be done in a variety of ways, including reminding potential participants that the researcher is independent of any service providers and will not feedback any individual responses to them; expressing interest in participants' concerns, accommodating routines; expressing humility; expressing interest in participants' conversations before and after the interview (Devers and Frankel 2000). All of these will be considered during the entire data collection process.
ii. The researcher will begin the data collection with a greeting/introductory remark, and this will be followed up with questions on the participants' demographic data, such as age and gender.
iii. The interviews will be based on a range of up to six (6) key topics to answer the research question. These topics will be contained in topic guides.
iv. Generally, the interviews will commence with an opening statement such as 'Tell me about your experience of' and follow up with probes such as 'Can you tell me more about that?'; 'What was it like for you?'; 'Can you give me an example' based on emerging information as a way of encouraging participants to reflect on the meaning of their responses.
v. Throughout the interviews, the researcher will remain attentive and open to what is being said, paying attention to silences, and interpreting the meaning.
vi. Crucially, the researcher will observe the verbal and nonverbal behaviours of the participants, their environment, and the manner of response, which will be recorded in a field journal after each interview.
vii. The researcher will then end with a closing question to provide an opportunity for the participant to give any additional information or comments.
viii. After completing the interviews, the researcher will thank the participants for their valuable time.

5.3.1. Phase one (1):

The first phase of the data collection process will include one-to-one interviews with up to twenty (20) frail older people. As discussed under section 7.3.2, the identification and recruitment of participants will be carried out with the support of the nominated manager.

All the interviews will be conducted by the researcher using a topic guide (Appendix 7) at the participants' homes /community or at Day Hospital, whichever is more convenient for the person. The researcher will discuss with the nominated manager on the availability of a safe, private, and comfortable space where interviews can be conducted with those participants who will decide to have the interviews at the hospital. The researcher will cover the transport costs for those participants who will opt to have face to face interviews at the Day Hospital. The interviews are expected to last no longer than 60-90 minutes, and there will be opportunities for short breaks between the interviews. Additionally, with the permission of the participants, all the interviews will be audio recorded to ensure data completeness and that no valuable information is lost during the interview process. The anticipated time scale for this phase is 7 months.

5.3.2. Phase Two (2):

The second phase of the data collection process will entail one-to-one interviews with up to ten (10) Staff at the Day Hospital. As detailed in section 7.3.3, the researcher will identify and recruit the participants in this phase with the support of the nominated manager.

All the interviews at this phase will be conducted by the researcher at the Day Hospital unless the participants choose a different venue. The interviews will be conducted using a topic guide (Appendix 8) and are expected to last no longer than 60 minutes. As well, all the interviews will be audio recorded (with permission from the participants) to ensure data completeness and that no valuable information is lost during the interview processes. The intention to involve the Hospital staff in the study will be declared at the beginning of the study. The anticipated time scale for this phase is 3 months.

All the study interviews will be transcribed verbatim immediately after each interview, and the researcher will ensure that each interview transcription has the appropriate labelling. Each transcript will contain essential features in line with the recommendations of the UK Data Service (2020) in order to enhance the sharing and reuse potential of the study data. These include ''a unique identifier (a name or number); a uniform and consistent layout throughout a research project or data collection; a document header or cover sheet with interview or event details such as date, place, interviewer name and interviewee details; speaker tags to indicate the question/answer sequence or turn-taking in a conversation; line breaks between turn-takes; numbered pages; and pseudonyms to anonymise personal identifying information''.

5.4. Data analysis

The analysis of the data will be carried out after the data collection and interview transcription has been concluded and this will be done by the researcher with the support of the research supervisory team.

Data analysis will be done following van Manen's (1997) data analysis approach, which is aimed at offering interpretation and generating meaning from the research data.

i. The researcher will begin the data analysis process by organising the data through reading and re-reading the transcripts and field notes and then breaking the data into categories, units or themes. This stage will be aided by using the Nvivo software, particularly to organise the data.
ii. The researcher will then embark on the process of analysing the themes to identify both the essential and incidental themes emerging from the data with respect to the experience of control and well-being.
iii. The researcher will then engage in the process of reflecting on the essential themes that characterise the phenomenon to make explicit and clarify the structure of the essence (meaning) of the phenomena within a given context.
iv. In the process of reflecting on the themes, the researcher will be guided by the dimensions of the lifeworld, i.e. temporality, spatiality, intersubjectivity, embodiment and mood.
v. After mapping out the experiential themes or structures that make up the lived experience, the researcher will describe the phenomenon through reading and re-writing (theorising) the text while making sure that he makes explicit and remains sensitive to the feelings, thoughts, and attitudes of the participants. The researcher will also refer to the reflective journal he will keep throughout the research project. At this stage, the researcher will also make sure that he relates the emerging findings to the available literature to identify any areas of convergence and divergence.
vi. All these steps will be conducted while remaining orientated to the research (phenomenon) question and context.

The project supervisors will support the analysis by playing a validation role to the researcher's interpretation of themes and to critically discuss if the chosen data categories make sense by providing another (critical) layer of interpretation and discussion.

6. STUDY SETTING

6.1. Recruitment Site

The study participants will be recruited from the University Hospitals Dorset NHS Foundation Trust. The Day Hospital provides a range of services for older people including assessment, treatment and rehabilitation which are aimed at maximising their health and independence, assisting primary and social care services with treatment and management of people with complex conditions that are associated with age as well as avoiding hospital admissions, and facilitating early supported discharge.

In terms of the health care providers, the Day Hospital has a range of specialists including occupational therapists, physiotherapists, and nurses specialising in the older person and multi-pathological conditions as well as older person consultants. These professionals provide services including Community Falls team reviews and treatment planning, Memory Clinics, MDT assessments and rehabilitation programmes, Balance groups, Cardiovascular service for Stroke patients, Parkinson's groups, FES Clinic, Functional Electrical Stimulation, Vestibular Interventions Clinic and Ear Irrigation (RBCH 2020).

The XXX Day Hospital has therefore been selected as the recruitment setting because of its extensive focus on managing older people's health-related challenges including frailty within parts of southern England. It is hoped that the insights and perspectives of both the patients and their professional care providers will be very valuable in answering the research question.

6.2. Access to site

Initial contact has been established with the XXX Day Hospital through one of the Staff - Ms Lisa Pigott who is a Clinical Lead at the Hospital.

7. SAMPLE AND RECRUITMENT

As highlighted in section 5.2 above, the study will employ a purposeful sampling technique to identify and recruit participants across the two data collection phases. The following section details the sampling and recruitment decisions and their justification.

7.1 Eligibility criteria

As already highlighted, the researcher will recruit participants using the following inclusion and exclusion criteria.

7.1.1. Phase one inclusion criteria (frail older people)

The pre-selected inclusion criteria for this category of participants include older people (aged 65 years and over); individuals diagnosed with frailty and receiving (part of their) care services at the Day Hospital; the capacity to give free and fully informed consent; ability to use the English language, as well as judgement by the clinical staff and/or nominated manager that the potential participant can take part in an in-depth interview.

7.1.2. Phase one exclusion criteria

The exclusion criteria, on the other hand, will include people who cannot communicate in English and individuals who are acutely medically unwell.

7.1.3. Phase two inclusion criteria (Hospital staff)

The study will include staff that routinely work with frail older people at the Day Hospital, including nurses (registered and unregistered), doctors, physiotherapists, occupational therapists and therapy assistants who can give free and fully informed consent. Furthermore, the study will include both part-time and full-time staff with a minimum of six months of work experience with frail older people. The six months and above experience will provide a solid base for participants to draw deep insights to answer the research question.

7.1.4. Phase two exclusion criteria

The second phase of the study will, on the other hand, exclude all staff who do not have routine direct contact with patients' care, for example, the senior managers.

7.2. Sampling

7.2.1. Sample size

The study will recruit up to 20 frail older people and up to 10 Hospital staff. The number of participants will be considered adequate at a point where a clearer understanding of the lived experiences will not be achieved through further discussions with (additional) research participants (Laverty 2003).

7.2.2. Sampling Technique

The participants will be identified and selected using a purposeful sampling technique. Purposeful sampling is ideal for the research question and the chosen approach as it will allow the researcher, based on pre-determined common criteria, to seek and select participants that have a unique or important perspective on the phenomenon under study and can provide rich information (Patton 2002; Robinson 2014).

7.3 Recruitment

7.3.1 Sample identification

As highlighted in section 6, the recruitment setting will be XXX Day Hospital. The initial access to the site was gained by the researcher by contacting the RBCH Research and Development (R&D) Department to initiate the local NHS R&D capability and capacity confirmation.

Therefore, once ethical approval has been obtained from all the relevant Research Ethics Committees, the researcher will again contact the RBCH Research and Development (R&D) department to obtain a 'Letter of Access', which will legally allow him to access the recruitment site. In terms of recruiting study participants, the researcher will be guided by the principles of the Good Clinical Practice and the local site Standard Operating Procedures (SOPs). Accordingly, at the time of recruitment, the researcher will approach and have a discussion with the nominated manager (a research nurse or consultant) regarding the inclusion and exclusion criteria and request the nominated manager to identify and bring him into contact with the potential participants that meet the study inclusion criteria.

7.3.1.1 Frail older people

The potential participants will be identified by the nominated manager at the Day Hospital, who will then inform the researcher. The researcher will discuss the inclusion and exclusion criteria with the nominated manager and ask them to go through the patients' medical records and other identifiable data to identify all those that meet the criteria. Importantly, the researcher will collaborate with the nominated manager to identify participants that fall into the COVID-19 high-risk category and then exclude them based on that assessment.

The nominated manager will then contact the eligible patients either through email or telephone and give them an invitation letter via post or email and ask them if they would be interested in finding out more about the study. Alternatively, invitation flyers will be handed out to the patients by the clinical team as part of their treatment packs.

At this stage, the researcher will request the gatekeepers to take verbal permission from potential participants (once screened) to give their contact numbers to the researcher so he can contact them to expedite recruitment.

The researcher will then share the Participant Information Sheets (Appendix 1) and the Participant Consent Forms (Appendix 3) and also discuss the details of the study with the eligible and interested individuals.

In deciding to go through the nominated manager (gatekeepers) to identify the potential participants, the researcher has weighed up the potential risks associated with this decision, particularly the possibility of some patients feeling obliged to participate in the study due to the perceived power that clinicians (gatekeepers) may have over them. To minimise such risks, the researcher will brief the gatekeepers that while it is valuable to him for participants to take part in the study, it is a voluntary endeavour. Furthermore, the researcher will discuss the potential participants' participation without the presence of the gatekeeper(s). Here, the researcher will emphasise that taking part in the study is completely voluntary and that the participant can opt-out without any consequences and that the gatekeepers (nominated manager and/or clinical care team) will not know of their decision (Ritchie et al. 2013). Additionally, the possibility of having interviews in participants' homes/community away from the hospital will minimise the possibility of participants feeling pressured to take part in the study.

Furthermore, to avoid selection bias, particularly towards participants who are considered difficult by the clinical care team, the researcher will inform the clinical care team that he is interested in people's experiences in life and not necessarily to judge their services and that the data will not be identified back to the care team. The researcher is interested in hearing about the difficulties that people go through and to understand people's experiences. Therefore, the research is not about judging the service as such rather about exploring what something feels like for somebody. There might be people that the care team finds difficult to work with and it would be interesting for the researcher to talk to them not to judge the care services but to understand what it feels like for them.

7.3.1.2 Day Hospital staff

As far as the recruitment for the second phase is concerned, the researcher is planning to go to staff meeting(s) at the Day Hospital where he will introduce the study details to the staff that routinely work with frail older people including the nurses (registered and unregistered), doctors, physiotherapists, occupational therapists and therapy assistants and also provide them with invitation flyers to request their participation in the study. Alternatively, the researcher will request the nominated manager to share an invitation email with information sheets to all eligible staff who might be interested in taking part in the study. The invitation email and/or flyer will then signpost interested individuals to the researcher who then will follow up directly with all those who will have expressed interest to discuss the details of the study including the Participant Information Sheets (Appendix 2) and the Participant Consent forms (Appendix 4).

In addition to the above strategies, the researcher will use a study poster with key study details to invite potential participants. The poster will be displayed at the Day Hospital reception or notice board (with permission from the site) where it can be easily read by both the older people and the staff.

The recruitment setting is therefore, a very important aspect of the study and the researcher will ensure that he sets and maintains a good working relationship with the recruitment site through open communication (with data protection rules), complying with the research protocol and the local Standard

Operating Procedures (SOPs) as well ensuring the safety and wellbeing of all the parties involved in the study, particularly the participants.

In order to deal with the possibility of having more participants than the researcher needs for the study, the researcher will ensure that he starts by working with a small number of people at a time, for example, five to ten persons and stop for a bit before starting again.

Finally, the researcher has also applied for NIHR portfolio support and if agreed, he will take advantage of the NIHR study support services to support the study delivery in terms of timelines, recruitment targets and performance.

7.3.2 Consent

In obtaining consent from the study participants, the researcher will be guided by the principles of Good Clinical Practice (GCP) on informed consent. Informed consent is;

> "*a process by which a subject voluntarily confirms his/her willingness to participate in a particular trial (research) after having been informed of all aspects of the trial (research) that are relevant to the subject's decision to participate. Informed consent is documented by means of a written, signed and dated informed consent form"* (HRA 2020).

Informed consent is integral to respect for persons, and therefore, potential participants must understand all aspects of the proposed research before they agree to participate in the study to minimise potential risks and inconveniences. It is a vital aspect because participation in any research is typically selfless, and therefore, it is only based on participants' free, full and informed consent that researchers are entitled to include them.

Accordingly, a detailed discussion about the study will be carried out with the potential participants and a written confirmation will be obtained by the researcher before participants are engaged in any research activity.

Before the researcher approaches the participants to discuss and obtain informed consent, they will have to be identified in line with the procedures discussed under section 7.3 above. Accordingly, it is the nominated manager at the hospital, and not the researcher, who will have access to the participants' medical records and/or their personal identification data for purposes of identifying the eligible participants. Therefore, if participants' contact details are needed, these will only be passed on to the researcher at the point that each participant has expressed interest in the study and willingness to be contacted by the researcher.

Once the potential participants have expressed interest in the study, the researcher will approach/contact them to discuss the details of the study, including the participant information sheets and consent forms. In preparation for this stage, some of the aspects considered include the capacity of the potential participants to consent, the nature of information about the study that will be provided to the potential participants, the time potential participants will be allowed to absorb and understand the information provided to them, voluntariness on the part of the participants, the right to withdraw from the study, and recording of the consent.

The process of obtaining consent will begin with the researcher providing participants with all the necessary information about the study including the topic, objectives, research question and methods and details on how their data and privacy will be handled (through the Participant Information Sheets). This

information will also explain the selection and inclusion criteria, why those participants have been selected to take part in the study as well as any potential benefits and harm associated with the study.
Additionally, all participants will be provided with details on their right to withdraw from the study at any time without giving any reason. They will be reassured that their withdrawal from the study/interview will not impact their ongoing care. The participants will not be required to give any reason for withdrawing from the study should they choose to. However, if participants volunteer their reasons for withdrawing, these will be documented in the field journal.

It is important to highlight that the study will involve both the frail older people and their professional care providers, and this might also put the frail older people in a vulnerable position in relation to the professional care providers because they are dependent on the support and care they receive from these staff. The researcher will, therefore, ensure that further explanation of the study and consent is undertaken to reassure the older people that their care will not be compromised due to their participation in the study.

All this information will be provided both orally and in writing. The written information will be contained in printed documents (participant information sheets and consent forms) which have been approved by the relevant Research Ethics Committees (RECs) and in the correct version. As well, all the study documents will be written in clear language and appropriate font size. The Health Research Authority (HRA) recommends the use of a font size of 16 for research documents shared with older people.

If, after providing all this information, the participants express willingness to take part in the study, the researcher will request them to sign the consent forms to state that they fully understand the purpose of the study and that they are willing to participate. The consent forms will be signed and dated by both the participant and the researcher on the day of the interview. The participants will also be requested to initial each item of the consent form as a confirmation that they have agreed to each one of them and to demonstrate that each item was completed by the participant and not any other person. The consent form will be checked again at the start of the interview to ensure that it is correctly completed.

As an incentive and token of appreciation for taking part in the study, the researcher will provide refreshments such as tea and biscuits for the recruited staff. Additionally, the staff will be provided with an Amazon cash voucher of £10 to show appreciation if they take part in the study in their own time.

7.3.3 Anonymity

Confidentiality and anonymity are crucial aspects of research. The entire research process will be conducted in a manner that upholds the anonymity principle in line with the UK General Data Protection Regulation-GDPR (2018).

At the participant identification stage, care will be taken to ensure that sample participants are identified and initially approached by the nominated manager, who has access to the participants' medical records and personal identifiable data. Therefore, participants' contact details, including telephone numbers/email addresses and other identifiable data will only be passed on to the researcher at the point when the participant has expressed interest in the study and willingness to be contacted by the researcher.

Additionally, care will be taken to ensure that the identity of the study participants is not disclosed to anyone except for safeguarding concerns, and these will be discussed with the potential participants. Also, the participant's address/postcode may be held in an envelope by a researcher's colleague (buddy) who has an appropriate professional background as a safety measure for lone working, but this information will be destroyed immediately after each data collection visit.

Furthermore, anonymity will also be ensured by using pseudonyms in the place of the participants' names. For the hospital staff that can be easily identified due to their job roles, the researcher will ensure that he uses general terms such as 'nursing staff' or 'therapy staff' or Participant A, B, C, etc., alongside any quotes when referring to hospital staff to make it appear more generic but still enable the reader to understand the participant's background. Additionally, the researcher will consider changing some of the contexts of the responses but without changing the meaning of the quotes. Similarly, the researcher will consider using data reduction by taking out potentially identifying information from the participants' responses.

Moreover, the researcher will ensure that there is minimal personal data used in the study. The only personal identifiable data that will be used include participants' names and signatures (on the consent forms), telephone contacts and/or email addresses for contacting participants, as well postcodes (personal addresses) for participants who will choose to be interviewed from their homes. The signed paper copies of the consent forms will be stored in a private locked drawer (cabinet) at the researcher's office after the interviews before being transferred (scanned) into electronic format as soon as possible and stored on a Bournemouth University secure H-drive. The paper copies will then be securely destroyed five years after the study.

The data collected will also be securely stored to avoid any unauthorised access that might compromise the confidentiality of the information obtained. The field notes, as well as the original audio recordings, will be held securely and stored in a private, locked drawer (cabinet) at the researcher's office and transferred to electronic files (transcriptions) as soon as possible. The transcripts will then be stored on the Bournemouth University password protected H-drive in a separate folder and the original audio-recordings securely deleted at the end of the study. The access of the anonymised data will also be restricted during the study and only accessed by the researcher and the supervisory team. Regarding online interviewing, the video recordings from the interviews will be treated in the same way as any other study data when it comes to confidentiality. In other words, all the audio and video recordings will be stored in a BU- password secured laptop and deleted immediately after data transcription. Importantly, participants will decide at the beginning of each interview whether they wish to have the video of the interview recorded or just the audio.

Finally, the research results will also be presented and published in an anonymised form so that no data can be traced to the participant. All identifiable personal data such as participants' names, roles and location will not appear anywhere in the study report or other forms of dissemination. Instead, all the participants will be assigned pseudonyms as a way of preserving their anonymity. As well, some aspects of the participants' narratives may be changed but without affecting the sense of the account to preserve anonymity. The identity of the data collection setting will also not appear anywhere in the published results. Instead, it will be replaced with the ‘Day Hospital in southern England’ tag as a way of protecting their anonymity.

Importantly, all the information obtained from participants will not be used for purposes other than that outlined in the Participant Information Sheets.

8. ETHICAL AND REGULATORY CONSIDERATIONS

8.1. InnovateDignity Project Ethical and Regulatory Considerations

Along with the Bournemouth University and the Health Research Authority's ethical considerations, this research project will be guided by the InnovateDignity project's ethical and regulatory considerations. The following are the ethical considerations unique to the InnovateDignity project.

1. The project requires that all research activities comply with the Declaration of Helsinki, follow good practice guidance (EU Reg. no. 536/2014), and adhere to the Charter of Fundamental Rights of the European Union, 2000/C 364/01.
2. The project further requires that all activities with human participants be subjected to formal ethical approval, including dissemination using publications. A copy of the project's ethical approval will be kept public once it is obtained and this will contain participant information sheets and consent forms kept on file and submitted to the Research Executive Agency of the European Commission on request. It will also include copies of opinions/approvals by ethics committees and/or competent authorities of the country in which the research will be conducted (United Kingdom), which will be kept on file and submitted to the Research Executive Agency of the European Commission on request.
3. The research plans and actions will also undergo additional independent scrutiny by the INNOVATEDIGNITY Ethical Scrutiny & Advisory Board (ESAB). Although the study protocol will initially go through the HRA and BU ethical scrutiny committees, the ESAB will add a layer of independent scrutiny. The ESAB will offer another independent scrutiny of all supporting documentation for the study’s ethical process, for example, the Participant Information Sheets, Consent forms, Data Storage Plans, measures taken to ensure confidentiality and anonymity etc. The ESAB will draw on guidance from the UK Department of Health Research Governance Framework for Health and Social Care.
4. The researcher is also required to follow the InnovateDignity project Data Management Plan. Accordingly, anonymised data will be made easily accessible to other researchers after the study by depositing it in the ‘UK Data Archive’. However, there will be an embargo of up to 3 years on publications immediately after the study, after which data will be made

available and accessible via the UK Data Archive. More details are highlighted in section 8.9.

The rest of the considerations are consistent with the requirements of the UK Policy Framework for Health and Social Care Research and the Bournemouth University Code of Good Research Practice, which have been harmonised in the following sections.

8.2. Assessment and Management of Risk

The vulnerabilities of older people are not always obvious and therefore, researchers should ensure that the well-being of all participants is protected, and this should include both physical and emotional wellbeing. The Declaration of Helsinki (1964) highlights that the well-being of research participants must take precedence over the interests of society and science.

The researcher is aware that any research might cause distress and, in some cases, harm. In this study, the potential causes of harm or distress to the participants might include the nature of questions, the setting/timing of the interviews/research and the attitude of the researcher. It is difficult to know how people may react to seemingly simple questions which may be sensitive, emotional or have personal meanings for that person, thus creating anxiety or upset and necessitating support. Additionally, as the overall research aim is to seek a deeper understanding of the lived experiences of frail older people, there is a possibility or even likelihood that sensitive topics might arise as participants describe their life experiences because how much they disclose during the interviews will be entirely up to each participant.

Furthermore, the research poses risks to the safety and emotional well-being of the researcher. The possibility of lone working carries potential safety risks, including physical and emotional harm from some participants, their family members and pets, as well as people from their community, particularly for participants who are living in violent communities and neighbourhoods.

Therefore, the researcher will ensure that safeguards are put in place to protect the welfare and safety of participants and the researcher. In addition to the Bournemouth University Lone Working Policy, the researcher will adopt the NHS Lone Working Policy, as well as the NHS Safeguarding of Adults Policy, to protect the welfare and safety of the participants and the researcher.

For example, participants will be reminded at the beginning of the interview that they can stop the interview at any time or choose not to answer any specific question posed to them during the interview. Furthermore, if a participant becomes distressed at any point during the interview, the researcher will pause the interview and ascertain if they wish to stop or continue after a break or completely end the interview, in which case the researcher will take adequate care to ensure that the participant is safe to leave and that a carer is available if needed. The researcher would then phone them the following day to make sure they are doing alright and to find out from them if they are happy to be referred to the Day Hospital for extra support in case there are any ongoing concerns. The researcher will draw on his professional social work knowledge and experience of working with older people to make sure that he is sensitive to the subtle signs of distress.

Importantly, the researcher will provide participants with brief, appropriate leaflets and information to signpost them to the available support services including details on the **Patient Advisory Liaison Service (PALS)** [https://www.nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service/], the **local AgeUK** “Relieving Loneliness: Community Connections” services [https://www.ageuk.org.uk/bournemouthpooleeastdorset/our-services/visiting-and-befriending/] and the **Silver Line** [https://www.thesilverline.org.uk/what-we-do/]. Also, the researcher will print out copies of the webpages/leaflets of the above-mentioned organisations and take them with him. A draft leaflet has been submitted for REC approval.

Additionally, an agreed strategy is in place to support the researcher, as the emotional well-being of the researcher is seen as very important. The first level of support would be the researcher talking to one of his colleagues at the University, being careful not to disclose participants’ personal details. If the researcher remains distressed, he will share this with his supervisors and seek support from them. If further support is needed the University counselling service will be able to provide this.

Furthermore, the participants will be informed that for safeguarding reasons, the researcher has a duty to disclose any information from the interview that he thinks has the potential to cause immediate self-harm to the participant or harm to other people. This safeguarding responsibility has been mentioned in the participant information sheets so that the participant can decide whether or not to talk about certain aspects during the interview.

The Hospital staff will also be informed in the participant information sheets that if they raise any issues of concern about practice or safeguarding, such as potential criminal offence, including professional malpractice or anything that has the potential to cause immediate self-harm or harm to other people, then the researcher would have to raise the issues to the relevant authorities. The researcher would speak with the supervisory team in the first instance. Then, if necessary, talk to the Trust Research Co-ordinator and finally follow the Trust's Escalating Concerns Policy when required. The safety and welfare of the participant and the staff member would be protected by remaining anonymous while discussing the case with supervisors and the Trust Research Co-ordinator, through keeping the participant informed as much as they wished about the process and if the case went forward, the researcher expects that the safety and welfare of the participant and staff member would be covered under the Trust’s Escalating Concerns Policy.

8.3. Research Ethics Committee (REC) and other Regulatory review & reports

Before the study, a favourable opinion will be sought from the HRA’s Research Ethics Service and approval from the Health Research Authority [HRA] (NHS) and Bournemouth University’s Science, Technology & Health Research Ethics

Panel (REP). These ethics committees will give an opinion and approve the study protocol and the relevant documents, including the Participant Information Sheets and Consent forms.

8.3.1. For NHS REC reviewed research

- For purposes of this study, all the substantial amendments that require review by the NHS REC will not be implemented until that review is in place and other mechanisms are in place to implement amendments at the study site.
- Furthermore, the researcher will produce the annual reports as required. An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.
- The researcher will notify the REC of the end of the study. However, if the study is ended prematurely, the researcher will notify the REC, including the reasons for the premature termination.
- Within one year after the end of the study, the researcher will submit a final report with the results, including any publications/abstracts, to the REC.
- All correspondence with the REC will be retained by the researcher.

8.3.2. Regulatory Review & Compliance

Before recruiting participants for the study, the researcher will ensure that appropriate approvals from the Research and Development Department of the University Hospitals Dorset NHS Foundation Trust are in place and also comply with the relevant guidance.

For any amendment to the study, the researcher, in agreement with the sponsor will submit information to the Health Research Authority for it to issue an approval for amendment. The researcher will work with the Research and Development Department of the University Hospitals Dorset NHS Foundation Trust so they can put the necessary arrangements in place to implement the amendment to confirm their support for the study as amended.

8.3.3. Amendments

In circumstances where substantial amendments to the REC application or supporting documents are required, the researcher will, through the sponsor, submit a valid notice of the amendment to the REC for consideration.

If applicable, other specialist review bodies (e.g. Confidentiality Advisory Group (CAG) will also be notified about substantial amendments in case the amendment affects their opinion of the study.

Furthermore, amendments will also be notified to the National Coordinating Function of England (where the lead NHS R&D office is based) and also communicated to the Research and Development Department of the University Hospitals Dorset NHS Foundation Trust to assess whether the amendment (s) affect (s) the site's capacity and capability.

The changes to the study and its conduct will be explained to the participants already recruited into the study and ensure that they fully understand the new information. If they are still willing to continue with the study once they are aware of and understand the new information, they will be re-consented using the updated consent form.

In deciding to amend the protocol or the supporting documents, the researcher will work with the supervisory team and the sponsor to determine if the decision to amend the protocol is necessary and whether the amendment is substantial or non-substantial in line with the HRA guidelines on the categorisation of amendments. Therefore, the Clinical Governance Advisor will be responsible for the decision to amend the protocol and for deciding whether an amendment is substantial or non-substantial.

All the substantive changes will be communicated to relevant stakeholders (e.g., REC, R&D, regulatory agencies) through email.

All the amendment history will be documented and tracked using the Amendment History Sheet (Appendix 6).

8.4. Peer Review

This study is part of the Doctoral Research Degree at Bournemouth University and will undergo high-quality peer review on an ongoing basis from experienced academic teams within and outside the University.

1) The first step involved the researcher working with two experienced academic supervisors, one based at Bournemouth University and the other at the University of Ioannina (Greece). The researcher worked with the supervisors through weekly meetings where they provided valuable feedback and supported the researcher in refining his initial research ideas and aligning them with the overall InnovateDignity Project themes.
2) In addition to the ongoing weekly supervisory meetings, the researcher will also attend key milestone review meetings to monitor the progress of the study, as indicated below.
    a) **Probationary Review:** Probationary Review took place on the 1st of April 2020 between the researcher, the main supervisor and two independent academic members of the Faculty of Health and Social Sciences. The researcher received feedback on his proposal and was recommended to progress to the next phase of the research project i.e. to develop a research protocol. The researcher was issued with a probationary review outcome report detailing the examiners' comments and key recommendations.
    b) **External Review:** The research protocol was reviewed by an experienced academic outside Bournemouth University who provided independent, expert and proportionate peer review. This was also a requirement for obtaining the Bournemouth University study Sponsorship. An external peer review report was provided by the reviewer.
    c) **Annual Reviews** (Re-enrolment reviews): The research project will be subjected to annual reviews, which will take place no later than 1st June each year. The annual reviews will provide an opportunity to record key achievements to date, confirm satisfactory and timely progress against milestones, confirm regular engagements with the supervisory team, review

ethics, health and safety risk assessment, and research and personal development needs, as well as provide an opportunity to discuss any difficulties that would have arisen.

d) **Major Review-** In addition to annual reviews, the study will be subjected to a Major Review. Here, the researcher will have a discussion with an independent academic panel to assess the quality and timeliness of the work to date, confirm that the scope of the research project will fulfil the requirements of a PhD award and confirm the researcher's capability to complete the research in a satisfactory and timely manner. Undertaking the Major Review will allow the researcher to bring together the research activities and outputs they have undertaken since enrolment, have someone from outside their supervision team review and offer constructive feedback, defend the approach to their research so far, and practice for the final viva voce. The major review is expected to be completed by the 4th of May 2021.

8.5. Patient and Public Involvement

The PPI was conducted with the support of the BU PIER team who assisted the researcher in recruiting three experts (aged 65, 70 and 80 years) to provide input on various aspects of the study. The following is a summary of what the researcher learnt from the experts.

- The proposed study is very important because, so often, the care of older people is looked at from the point of view of the carer(s) rather than what the older person would like or need.
- Additionally, a sense of control is a good subject for investigation because there is a degree of loss of control for people within the care system where it is alleged that they have lost their independence and have to depend on others, particularly in care/nursing homes.
- The study benefits older people because it would give them a feeling that their voice is being listened to and make them feel that they do count.
- Taking part in this study would also give frail older people a feeling of usefulness, and from their well-being point of view, it would boost their morale.
- In terms of the costs associated with the study, frail older people are most likely going to get tired during the interviews, and they would, therefore, need to be treated gently. This could involve both physical and mental tiredness due to concentrating- something they may not be used to. Furthermore, if they are in a hospital setting, it is assumed that they are there because they are sick and that they need a lot of care. So, it would require the researcher to be very sensitive to how they are. It is possible that some older people, particularly in the hospital setting, might well find themselves falling asleep when the researcher is talking to them, and that would signal that they have had enough and need a break.
- One expert suggested that it would also be important to understand how care is experienced from different angles, i.e. from those who are frail and need care at home, in a nursing home environment and in a rest home environment. However, although this suggestion is interesting, it is beyond the scope of the current study.

- The font size of the participant information sheet is small, which could be enlarged in the final version, bearing in mind that the people who will read this information are old and might not have good eyesight.
- Some parts of the Participant Information Sheet were a little wordy, particularly the section on the ‘purpose of the study’, and the experts suggested that it would be great to try and press them down a little bit using everyday language to make it less wordy.
- Furthermore, the experts noted that although some sections in the Participant Information Sheets might sound complicated and may perhaps not easily make meaning to some people, they need to be said (maintained), particularly the section on how ‘information will be managed’ (data protection).
- In terms of supporting participants to take part in the study, the researcher was advised that he would need a great deal of patience, and this could include thinking of different ways of saying something in case participants seem not to understand what he is saying.
- There is a need to be gentle because older people respond to gentleness and kindness. This includes being patient and not hurrying participants. They need time to process what the researcher is saying in order to be able to respond.
- Additionally, older people are more likely to respond to invitations to participate in research studies when study documents are printed out and given/sent out to them in hard copy rather than through email.

In light of the above input/ideas, the researcher has decided;

- To increase the font size of the study documents, simplify the wording, and remove repetitions in the documents. Particularly, the researcher has reduced the words under the section on the ‘purpose of the study’ in the participant information sheet using simpler statements.
- To maintain the wording under the section on data protection of the participant information sheet.
- That he will be very observant of the participants’ body language and pay great attention to how they respond to have a heightened awareness if they are getting tired and pause for a break.
- To allocate more data collection time to older people since the interviews might take longer due to the anticipated breaks during the interviews.
- That all the study documents will be printed and then sent over to the potential participants as a way of increasing the study response rate and supporting older people to take part in the study.

8.6. Protocol Compliance

Care will be taken to ensure compliance with the protocol, and any accidental protocol deviations will be adequately documented on the relevant forms and reported by the researcher to the supervisory team immediately. The sponsor will be informed of any deviation.

8.7. Data Protection and Patient Confidentiality

The researcher will comply with the requirements of the Data Protection Act (2018) of Great Britain with regard to the collection, storage, processing and disclosure of personal information and will uphold the Act’s core principles.

The researcher will be the custodian of the data generated from the study and will ensure that all the information obtained from the research is not used for any purpose other than that outlined in the Participant Information Sheet. Additionally, care will be taken to ensure that the identity of the participants is not disclosed to anyone except for safeguarding or lone working safety reasons. The name of the hospital, the participants' names and job roles will not appear anywhere in the transcripts or the written report/publications. Instead, the participants will be assigned name tags, such as Participant 1 or Professional 1, etc., as a way of protecting their anonymity. The identity of the Day Hospital will be replaced with the 'Day Hospital in southern England' tag as a way of protecting their anonymity.

Furthermore, the data collected will be securely stored to avoid any unauthorised access that might compromise the confidentiality of the information obtained. The data generated from the study will only be accessed by the researcher and his academic supervisors during the study, and in this case, the data will be transmitted in an anonymised and encrypted form with a password. However, in instances where the participant mentions something during the research that makes Bournemouth University or the researcher worried about a safeguarding or whistleblowing issue, including malpractice and harm to self and others, then the Hospital and/or University's 'Whistleblowing" (Disclosure in the Public Interest) Policy and Procedures will be followed, and the relevant authorities will be informed for such concerns/breaches to be investigated and addressed in the public interest. This will be the only exception to anonymity and confidentiality in this study.

The data generated from the study will be analysed by the researcher himself with guidance from the academic supervisors, and this will be done at Bournemouth University, where the researcher is currently pursuing his doctoral studies.

The original audio recordings will be stored in a secure, private, locked drawer (cabinet) at Bournemouth University and transferred (scanned) into electronic format (typed transcriptions) as soon as possible and stored on a Bournemouth University secure H-drive in a separate folder. The original audio recordings will then be securely deleted at the end of the study. The signed paper copies of the consent forms will be stored in a private locked drawer (cabinet) at the researcher's office after the interviews before being transferred (scanned) into electronic format as soon as possible and stored on a Bournemouth University secure H-drive. The paper copies will then be securely destroyed five years after the study.

Finally, the researcher will ensure that minimal personal data is used in the study and that the personal data retention periods are kept to an absolute minimum. Therefore, upon graduation, the personal data will be stored/accessed for one (1) year, while the electronic consent forms will be stored for five (5) years for audit purposes, after which they will be securely destroyed, and any electronic files overwritten and deleted.

8.8. Indemnity

The study is being sponsored by Bournemouth University. Bournemouth University holds Public Liability insurance to cover the legal liability of the University as a Research Sponsor in the eventuality of harm to a research participant arising from the management of the research by the University. This does not in any way affect an NHS Trust's responsibility for any clinical negligence on the part of its staff (including the Trust's responsibility for Bournemouth University employees acting in connection with their NHS honorary appointments).

Furthermore, Bournemouth University holds Professional Indemnity insurance to cover the legal liability of the University as Research Sponsor and/or as the employer of staff engaged in the research for harm to participants arising from the design of the research, where the research protocol was designed by the University.

Additionally, Bournemouth University's Public Liability and Professional Indemnity insurance policies provide an indemnity to its employees for their potential liability for harm to participants during the conduct of the research. This does not in any way affect an NHS Trust's responsibility for any clinical negligence on the part of its staff (including the Trust's responsibility for Bournemouth University employees acting in connection with their NHS honorary appointments).

8.9. Access to the final study dataset

Once the study has ended, the researcher will ensure that the Data is made accessible to other researchers in line with the provisions of the InnovateDignity Project Data Management Plan and the Bournemouth University Research Data Policy.

The InnovateDignity Project requires that the researcher makes the data from the project 'FAIR', i.e. findable (including provisions for meta-data), openly accessible, interoperable and increasing data re-use (through clarifying licenses). Accordingly, it is a requirement from the project funder that the anonymised data from the project is deposited in the 'UK Data Archive' in Qualibank, for example, and QuDEX as a way of ensuring that the data are easily accessible to other researchers in the specific field of study and/or social scientists in related fields such as health care and policy research. However, there will be an embargo of up to 3 years on publications, after which data will be available and accessible via the UK Data Archive.

The data will be secured in line with the UK Data Archive policies, and at the end of the project and the three-year embargo, researchers seeking access to the data will have to go through the UK Data Service access processes.

Therefore, since the project funder requirements will result in data being deposited in an alternative repository other than that of Bournemouth University, the researcher will ensure that sufficient metadata relating to the research data is registered with the Bournemouth University's data repository- Bournemouth Online Research Data Repository (BORDaR) to enable other researchers to understand the nature of the research to which it relates; identify the re-use potential; know how to access the data and any key project documentation (e.g. protocols) required for the same purposes in line with the Bournemouth University Research Data Policy. A detailed Data Management Plan has been prepared for this study.

9. DISSEMINATION POLICY

9.1. Dissemination Policy

The data arising from the study will be jointly owned by Bournemouth University and the European Commission under the INNOVATEDIGNITY Project. On completion of the study, the data will be analysed and a final full study report prepared in the form of a doctoral thesis.

The thesis will be submitted to Bournemouth University and once approved, it will be deposited into the library and the University online repository known as the Bournemouth University Research Online (BURO).

The researcher will act as the lead author on any publications arising from the study data. The supervisory team will review any publications before they are submitted or sent for peer review.

All publications and dissemination of the results including the final study report, promotional materials such as brochures, leaflets, posters and presentations will acknowledge the European Commission as the funder of the research project. Accordingly, part of the acknowledgement section will bear the European emblem and include the following statement to indicate that the project was undertaken with the financial support provided by the European Community: *"This project has received funding from the European Union's Horizon 2020 research and innovation Programme under the Marie Skłodowska-Curie Grant Agreement No 813928".*

Furthermore, the researcher will ensure that all the publications, publicity and dissemination materials in whatever form or by whatever medium specify that the content reflects only the author's (researcher) views and that the European Commission is not liable for any use that may be made of the information contained in such publicity.

The researcher plans to share the final results with the study participants, and this will be in the form of a summary report both in soft (through email) and hard copy. The Hospital management together with the study participants will be asked if they would like to be provided with an accessible summary of findings. Additionally, participants are welcome to request for the full study report from the researcher and this information would be availed after the final study report (thesis) has been compiled, submitted and approved by Bournemouth University.

The researcher will also make use of the InnovateDignity project official social media platforms such as Twitter to disseminate the results and outcomes of the study. Additionally, the researcher will also look to share the research results at different national and international conferences.

Finally, the researcher will, together with other InnovateDignity Project Early Stage Researchers (ESRs), organise a final inter-sectoral conference where the project results and outcomes will be shared with different stakeholders including older people. This conference is expected to take place within the project grant period.

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11. APPENDICES

Appendix 1: Participant Information Sheet (Older people)

Bournemouth
University

IRAS Version: 4.0
IRAS ID: 282540
Date: 24/06/2021

Participant Information Sheet (Older people)

1. Welcome and Introduction

Hullo, my name is Adam Nyende, and I am a research student at Bournemouth University.

I have learnt that it is easy to lose the feeling of control when you are an older person. In this study, I would like to find out more about your experiences. This will involve my coming to talk to you at home, or, if you wish, in another agreed place. However, if it is not possible to meet face to face, then the use of Skype/Zoom/Microsoft Teams or telephone will be considered. We would talk for up to 1 to 1 ½ hours and explore your experiences and views about your sense of control and wellbeing. It is up to you to decide whether or not to take part in the study.

Below you will find out more about this research project.

2. The title of the research project

An exploration of a sense of control and wellbeing in the lives of older people.

3. Invitation to take part

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

4. Who is organising/funding the research?

This research is being organised by Bournemouth University and funded by the European Commission under the Horizon 2020 (Marie Skłodowska-Curie Research Actions).

5. What is the purpose of the project?

The purpose of the study is to explore the experiences of control and wellbeing of older persons and to try and improve the care services for these people. Some research studies have shown that older people sometimes have a sense that they have less control in their lives and so the researcher would like to see how this impacts on care services and how these services can be developed to support them better. The research is undertaken as part of doctoral degree requirements.

6. Why have I been chosen?

You have been contacted to take part as you have been assessed and treated as a patient at XXX Hospital where you currently receive (part of) your care services and you are aged 65 years or over. Your age and personal experiences position you to provide valuable insights on the research topic. This study intends to recruit up to 20 (twenty) older people.

7. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. We want you to understand what taking part involves before you decide on whether to take part.

If you or any family member have an on-going relationship with Bournemouth University e.g. as a member of staff, as a student or other service user, your decision to take part (or continue in the study) will not affect this relationship in any way.

Additionally, no element of your ongoing care at the Day Hospital will be impacted whether you take part or not.

8. What will I have to do if I take part?

If you agree to take part in the study, it would be expected from you to take part in a face to face interview with the researcher which is expected to last for no longer than 1 to 1 ½ hours to explore your experiences and views about your sense of control and how this has impacted your wellbeing. However, if it is not possible to meet face to face, then the use of Skype/Zoom/Microsoft Teams or telephone will be considered. There will be opportunities for short breaks in between the interview.

The interview will involve talking about what you feel about how much control you have got in your life, how care services affect this, and how they could be improved.

Generally, the questions will focus on your personal experiences and perceptions. If you feel uncomfortable about answering any questions, you do not need to answer them.

9. Where will this take place?

The interview will be conducted either at your home or in a private space at the Day Hospital, and this will be agreed in advance between you and the researcher. However, there is the flexibility to have the interview in another appropriate and mutually agreed venue. In case you decide to have the interview at the Day Hospital and require transport to get there, the researcher will cover the transport costs.

10. What measures are in place to protect against coronavirus?

The researcher will ensure that safeguarding measures such as hand washing, social/physical distancing and wearing facial coverings are in place to protect against coronavirus during the interviews.

11. Will I be recorded, and how will the recorded media be used?

The interview will be recorded using an audio-recorder. This is to make sure that the researcher does not miss any of your responses. People often say very helpful things in these discussions, and the researcher may not write fast enough to get them all down. Consequently, the researcher will transcribe the original recording into text.

The researcher will then analyse what you have said and some things that you say might be in the research report, conference presentations, journal publications and project official social media accounts but nobody will know who you are.

The original recordings will be held securely and stored in a private, locked drawer at the researcher's office and transferred to electronic files (transcribed text) as soon as possible. The electronic files will then be stored on a Bournemouth University password-protected computer and the original audio recordings securely deleted.

12. When will I have the opportunity to discuss my participation?

You will have the opportunity to discuss your participation before the start of the interview. You will be given a minimum of 24 hours to consider taking part in the study and also contact the researcher with any questions and/or concerns. At this stage, you will have the opportunity to raise any issues and concerns regarding your participation. Please note that you are also welcome to discuss any issues regarding your participation with the researcher at any stage of the study.

13. Can I change my mind about taking part?

Yes, you can stop taking part in the study activities at any time and without giving a reason. Your taking part in this study is voluntary, and if you choose to stop taking part in the study, it will not affect your ongoing care in any way.

14. If I change my mind, what happens to my information?

After you decide to withdraw from the study, the researcher will not collect any further information from or about you. As regards information already collected before this point, you will not be able to change or withdraw it once it has been included in the data analysis because nobody will know who you are. As personal details will have been removed the researcher will be unable to identify which information is yours. The researcher needs to manage your information in specific ways in order for the research to be reliable.

Further explanation about this is in the Personal Information section below.

15. What are the advantages and possible disadvantages or risks of taking part?

Whilst there are no immediate benefits to you taking part in the project, it is hoped that this work will provide you with an opportunity to share your feelings and experiences and how these can contribute to improving caring services.

Whilst the researcher does not anticipate any risks to you in taking part in this study, it is possible that some of your responses could generate some form of stress since the entire interview will be about understanding your present and past life experiences. You may, therefore, find talking about parts of your experience stressful or upsetting.

However, if this happens, you can choose not to talk about these parts of your experience or stop the interview at any time without giving a reason and the researcher will check that you are ok. If you have any ongoing issues the researcher will signpost you to further support.

16. What type of information do I need to provide and why is the collection of this information important?

This study seeks to obtain information related to your personal experiences, opinions and views relating to control and wellbeing in your life and how you get your care at the Day Hospital.

The information you will provide is important as your experiences, whilst unique, may share common patterns with others living in similar situations and contexts. Therefore, they will provide greater understandings as to appropriately support these individuals in enhancing their quality of life and improving their sense of wellbeing.

To achieve this, the researcher will need to use information from you and your medical records for this research project.

The personal information will include your;

- Initials
- Name
- Signature
- Age
- Gender
- Contact details
- Postcode

This information will be used to do the research or to check your records to make sure that the research is being done properly.

17. How will my information be managed?

Bournemouth University (BU) is the organisation with the overall responsibility for this study and the Data Controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university.

Undertaking this research study involves collecting and/or generating information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control use of information about identifiable individuals, but do not apply to anonymous research data: "anonymous" means that we have either removed or not collected any pieces of data or links to other data which identify a specific person as the subject or source of a research result.

BU's Research Participant Privacy Notice sets out more information about how we fulfil our responsibilities as a data controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information.

Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet. To protect your rights in relation to your personal information, the researcher will use as minimal identifiable information as possible and control access to that information as described below.

a) Publication

You will not be able to be identified in any external reports or publications about the research. People who do not need to know who you are will not be able to see your name or contact details. Otherwise, your information will only be included in these materials in an anonymous form, i.e. you will not be identifiable and your data will have a code number instead.

Once we have finished the study, we will keep some of the data so we can check the results. The researcher will write the research reports in a way that no-one can work out that you took part in the study.

The research results will be published in the form of a research report (thesis), journal articles, conference papers and social media blogs and this will take place after the data collection and analysis stages.

b) Security and access controls

All the information collected about you will be kept safe and secure. The information will be held in hard copy in a secure location and on a BU password-protected secure network where held electronically.

Personal information which has not been anonymised will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified in the Privacy Notice. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations.

c) Further use of your information

The information collected about you may be used in an anonymous form to support other research publications in the future and access to it in this form will not be restricted. It will not be possible for you to be identified from this data. To enable this use, anonymised data will be added to the ‘UK Data Archive’: an online Research Data Repository where all the project data will be centrally stored and accessible to the public after the study.

d) Keeping your information if you withdraw from the study

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have if this has on-going relevance or value to the study or once this information has been included in the data analysis. This may include your personal identifiable information. This is because we need to manage your information in specific ways in order for the research to be reliable. However, if you have concerns about how this will affect you personally, you can raise these with the researcher when you withdraw from the study.

You can find out more about how we use your personal information, your rights in relation to your data and how to raise queries or complaints;

- by asking the researcher
- by contacting James Stevens, our Chief Data Officer at **dpo@bournemouth.ac.uk** or **01202 962472.**
- in the HRA data protection and patient information governance section.
- in the BU Research Participant Privacy Notice

e) Retention of research data

Project governance documentation, including copies of **signed participant consent forms:**

We keep this documentation for five (5) years after completion of the research, so that we have records of how we conducted the research and who took part. The only personal information in this documentation will be your name and signature, and we will not be able to link this to any anonymised research results. The consent forms will be transferred onto the Bournemouth University's electronic hard drive/secure server while the paper copies will be held securely and stored in a private, locked drawer (cabinet) at the researcher's office.

18. Research results:

As described above, during the course of the study information collected about you as an individual will be anonymised (nobody will know who you are). This means that your personal information will not be held in identifiable form after the research activities have been completed.

You can find more specific information about retention periods for personal information in our Privacy Notice.

We shall deposit the anonymised research data in an online research data repository after the study so that it can be used for other research purposes as described in Section 17*c* above.

19. Who will have access to the information that I provide?

Before the end of the research project, the information provided during the interview will only be accessed by the researcher and in some cases the research supervisory team during data analysis. The only exception is in instances where something is mentioned during the interview that has the potential to cause immediate harm to you or other people. In such cases, the university and/or Hospital's safeguarding procedures will be followed and the relevant people will be informed for safeguarding reasons. This will be the only exception to anonymity and confidentiality in this study.

20. How can I find out about the results of the study?

The researcher will be happy to provide you with a summary of the approved research results through post or email and can provide a soft copy of a full research report through email.

21. Contact for further information about the research

	If you have any questions or would like further information, please contact **Adam Nyende** who is the **researcher** for this study. Email:anyende@bournemouth.ac.uk **or** Telephone: 07466-409939.

22. What if there is a problem?

The Patient Advisory Liaison Service (PALS) is a confidential NHS service that can provide you with support for any complaints or queries you may have regarding the care you receive as an NHS patient. PALS are unable to provide information about this research study.

If you wish to contact the PALS teams please telephone**:** **01202 704886** or email: pals@rbch.nhs.uk.

If you wish to complain about any aspect of this study, you should contact **Professor Vanora Hundley,** Deputy Dean - Research and Professional Practice Bournemouth University-by email: **researchgovernance@bournemouth.ac.uk** or telephone: **01202 965206.**

23. Finally

If you decide to take part, you will be given a copy of the information sheet and a signed participant consent form to keep.

Thank you for considering taking part in this research project.

Appendix 2: Participant Information Sheet (Day Hospital Staff)

IRAS Version: **3.0**
IRAS ID: **282540**
Date: **24/06/2021**

Participant Information Sheet (Day Hospital Staff)

1. The title of the research project

Exploring the lived experience of control and wellbeing of older persons diagnosed with frailty within the care service provision in southern England.

2. Invitation to take part

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

3. Who is organising/funding the research?

This research is being organised by Bournemouth University and funded by the European Commission under the Horizon 2020 (Marie Skłodowska-Curie Research Actions). In this information sheet, we", "our" and "us" refers to Bournemouth University (BU).

4. What is the purpose of the project?

The purpose of the study is to explore the experiences of control and wellbeing of older persons and to try and improve the care services for these people. The research is undertaken as part of doctoral degree requirements.

5. Why have I been invited?

You have been contacted because of your professional experience of working with frail older people at the XXX Day Hospital. Your professional knowledge, skills and experiences ideally position you in providing valuable insights on the research topic. This study intends to recruit up to ten (10) staff who have worked with frail older people for more than 6 months**.**

6. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a participant consent form. We want you to understand what participation involves before you make a decision on whether to participate.

If you or any family member have an on-going relationship with Bournemouth University or the research team, e.g. as a member of staff, as student or other service user, your decision on whether to take part (or continue to take part) will not affect this relationship in any way. Additionally, no element of your legal rights will be impacted whether you participate or not.

Furthermore, the researcher will provide refreshments such as tea and biscuits during the interview. Additionally, you will be provided with an Amazon cash voucher of £10 as a token of appreciation if you take part in the study in your own time.

7. What would taking part involve?

You will be asked to take part in a face to face interview with the researcher which is expected to last for no longer than one hour to explore your experiences, perceptions and opinions regarding sharing control with older people diagnosed with frailty and on how the care for frail older persons can be enhanced to support personal control and wellbeing. However, if it is not possible to meet face to face, then the use of Skype/Zoom/Microsoft Teams or telephone will be considered.

We shall be talking about your perception and experience of sharing control with frail older people and how this could be improved.

Generally, the questions will focus on your professional experiences and perceptions. However, if you feel uncomfortable about answering any question, you do not need to answer it.

8. Where will the interview take place?

The interview will be conducted at the XXX Day Hospital by the researcher. However, there is the flexibility to have the interview in another appropriate and mutually agreed venue.

9. Will I be recorded, and how will the recorded media be used?

The interview will be audio-recorded. This is to make sure that I do not miss any of your responses. People often say very helpful things in these discussions, and I may not write fast enough to get them all down. However, the

audio recordings of your activities made during this research will be used only for analysis and the transcription of the recording(s) for illustration in the research report, conference presentations and other research outputs. No one outside the project will be allowed access to the original recordings.
The original recordings will be held securely and stored in a private, locked drawer at my office and transferred to electronic files (transcripts) as soon as possible. The electronic files will then be stored on a Bournemouth University password protected H-drive and the original audio recordings securely deleted.

10. When will I have the opportunity to discuss my participation?

You will have the opportunity to discuss your participation before the commencement of any interview process. You will be given a minimum of 24 hours to consider taking part in the study and also contact the researcher with any questions and/or concerns. At this stage, you will have the opportunity to raise any issues and concerns regarding your participation. Please note that you are also welcome to discuss any issues regarding your participation at any stage of the study.

11. Can I change my mind about taking part?

Yes, you can stop participating in the study activities at any time and without giving a reason. Your participation in this study is totally voluntary and there will be no consequences as a result of your termination of participation from the study.

12. If I change my mind, what happens to my information?

After you decide to withdraw from the study, we will not collect any further information from or about you. As regards information we have already collected before this point, you will not be able to change or withdraw it once it has been included in the data analysis as it will be anonymous. As personal details will have been removed we will be unable to identify which information is yours. We need to manage your information in specific ways in order for the research to be reliable.
Further explanation about this is in the Personal Information section below.

13. What are the advantages and possible disadvantages or risks of taking part?

Whilst there are no immediate benefits to you participating in the project, it is hoped that this research will allow you the opportunity to reflect on your professional work and also contribute to improving care service provision for frail older people.

Whilst we do not anticipate any risks to you in taking part in this study, it is possible that some of your responses could generate some form of stress since the entire interview will revolve around understanding your professional experience. You may, therefore, find talking about parts of your experience stressful or upsetting.

If this happens, you can choose not to talk about these parts of your experience or stop the interview at any time without giving a reason.

14. What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?

This study seeks to obtain information related to your professional experiences, opinions and viewpoints. With the increasing number of frail older people in our communities, a more specific focus on understanding their quality of life and care is required to improve their wellbeing.

Therefore, it is crucial to gain the views/perspectives of their professional care providers on how the care service provision can be improved. Consequently, the information you will provide in the form of your professional experiences will be very valuable in achieving the study objectives.

To achieve this, we will need to use information from you for this research project.

The personal information will include your;

- Initials
- Name
- Signature
- Gender
- Contact details
- Postcode

People will use this information to do the research and to make sure that the research is being done properly.

15. How will my information be managed?

Bournemouth University (BU) is the organisation with overall responsibility for this study and the Data Controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university.

Undertaking this research study involves collecting and/or generating information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control use of information about identifiable individuals, but do not apply to anonymous research data: "anonymous" means that we have either removed or not collected any pieces of data or links to other data which identify a specific person as the subject or source of a research result.

BU's Research Participant Privacy Notice sets out more information about how we fulfil our responsibilities as a data controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information.

Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet. To safeguard your rights in relation to your personal information, we will use the minimum personally-identifiable information possible and control access to that data as described below.

a) Publication

You will not be able to be identified in any external reports or publications about the research. People who do not need to know who you are will not be able to see your name or contact details. Otherwise, your information will only be included in these materials in an anonymous form, i.e. you will not be identifiable and your data will have a code number instead.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

The research results will be published in the form of a journal article, thesis and conference papers and this will take place after the data collection and analysis stages.

b) Security and access controls

We will keep all information about you safe and secure. BU will hold the information we collect about you in hard copy in a secure location and on a BU password-protected secure network where held electronically.

Personal information which has not been anonymised will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified in the Privacy Notice. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations.

c) Further use of your information

The information collected about you may be used in an anonymous form to support other research projects in the future and access to it in this form will not be restricted. It will not be possible for you to be identified from this data. To enable this use, anonymised data will be added to the 'UK Data Archive' an online Research Data Repository where all the project data will be centrally stored and accessible to the public after the study.

d) Keeping your information if you withdraw from the study

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have if this has on-going relevance or value to the study or once this information has been included in the data analysis. This may include your personal identifiable information. This is because we need to manage your information in specific ways in order for the research to be reliable. However, if you have concerns about how this will affect you personally, you can raise these with the research team when you withdraw from the study.

You can find out more about how we use your personal information, your rights in relation to your data and how to raise queries or complaints;

- by asking the researcher
- by contacting James Stevens, our Chief Data Officer at **dpo@bournemouth.ac.uk** or **01202 962472.**
- in the HRA data protection and patient information governance section
- in the BU Research Participant Privacy Notice

e) Retention of research data

Project governance documentation, including copies of **signed participant consent forms:**

We keep this documentation for five (5) years after completion of the research, so that we have records of how we conducted the research and who took part. The only personal information in this documentation will be your name and signature, and we will not be able to link this to any anonymised research results.

16. Research results:

As described above, during the course of the study we will anonymise the information we have collected about you as an individual. This means that we will not hold your personal information in identifiable form after we have completed the research activities.

You can find more specific information about retention periods for personal information in our Privacy Notice.

We shall deposit the anonymised research data in an online research data repository after the study so that it can be used for other research as described in Section C above.

17. Who will have access to the information that I provide?

Before the end of the research project, the information provided during the interview will only be accessed by the researcher and in some cases the research supervisory team during data analysis. Additionally, the data you provide will not be used for your assessments/appraisal and you will not be vulnerable to your supervisors and/or managers.

The only exception is in instances where something is mentioned during the interview that raises issues of concern about practice such as potential criminal offence including professional malpractice or has the potential to cause immediate harm to you or other people.

In such cases, the University and/or Hospital's safeguarding procedures will be followed and the relevant people will be informed for safeguarding reasons. This will be the only exception to anonymity and confidentiality in this study.

18. How can I find out about the results of the study?

The researcher will be happy to provide you with a summary of the approved research findings and can also provide a full research report via email.

19. Contact for further information

If you have any questions or would like further information, please contact **Adam Nyende** who is the researcher for this study.

Email: anyende@bournemouth.ac.uk **or** telephone: **07466-409939.**

20. What if there is a problem?

If you wish to complain about any aspect of this study, you should contact **Professor Vanora Hundley,** Deputy Dean - Research and Professional Practice Bournemouth University-by email: researchgovernance@bournemouth.ac.uk or telephone: **01202 965206.**

21. Finally

If you decide to take part, you will be given a copy of the information sheet and a signed participant consent form to keep.

Thank you for considering taking part in this research project.

Appendix 3: Participant Consent form (Older people)

IRAS Version: **3.0**
IRAS ID: **282540**
Date: **24/06/2021**

Participant Identification Number for this study:

CONSENT FORM-Older People

Title of Project: An exploration of a sense of control and wellbeing in the lives of older people.

Name of Researcher: **ADAM NYENDE**

Please initial box

1. I confirm that I have read the information sheet dated **24 June 2021** (Version **4.0**) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I confirm that I have been given access to the BU Research Participant Privacy Notice which sets out how my personal information will be collected and used (https://www1.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy). ☐

3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time or decline ☐

to answer any particular question(s) without giving any reason, and without my medical care or legal rights being affected.

4. I understand and consent to the following activities;

- Having either a face to face, online (Skype/Zoom or Microsoft Teams) or telephone interview with the researcher
- Being audio recorded during the interview ☐
- My words will be quoted in publications, reports, web pages and other research outputs without using my real name.

5. I understand that, if I withdraw from the study, I will also be able to withdraw my data from further use in the study except where my data has been anonymised (as I cannot be identified) or already incorporated in the analysis. ☐

6. I understand that my data may be included in an anonymised form within a dataset to be archived at 'UK Data Archive' online Research Data Repository. ☐

7. I understand that relevant sections of my medical notes may be looked at by individuals from XXX Day Hospital and Bournemouth University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

8. I understand that the information collected about me will be used to support future research publications, reports or ☐

presentations, and may be shared anonymously with other researchers.

9. I understand that the information held and maintained by XXX Day Hospital about me may be used to help contact me or to provide information about my health status. ☐

10. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 4: Participant Consent form (Day Hospital Staff)

IRAS Version: **3.0**
IRAS ID: **282540**
Date: **24/06/2021**

Participant Identification Number for this study:

CONSENT FORM-Day Hospital Staff

Title of Project: **Exploring the lived experience of control and wellbeing of older persons diagnosed with frailty within the care service provision in southern England**

Name of Researcher: **ADAM NYENDE**

Please initial

box

1. I confirm that I have read the information sheet dated **24 June 2021** (Version **3.0**) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I confirm that I have been given access to the BU Research Participant Privacy Notice which sets out how my personal data will be collected and used (https://www1.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy). ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time or decline to answer any particular question(s) without giving any reason, and without my legal rights being affected. ☐

4. I understand and consent to the following activities;

☐

- Having either a face to face, online (Skype/Zoom or Microsoft Teams) or telephone interview with the researcher
- Being audio recorded during the interview
- My words will be quoted in publications, reports, web pages and other research outputs without using my real name.

5. I understand that, if I withdraw from the study, I will also be able to withdraw my data from further use in the study except where my data has been anonymised (as I cannot be identified) or it will be harmful to the project to have my data removed. ☐

6. I understand that my data may be included in an anonymised form within a dataset to be archived at 'UK Data Archive' online Research Data Repository. ☐

7. I understand that the information collected about me will be used to support future research publications, reports or presentations, and may be shared anonymously with other researchers. ☐

8. I understand that the information held and maintained by XXX Day Hospital about me may be used to help contact me. ☐

9. I agree to take part in the above study.

________________	________________	________________	
Name of Participant	Date	Signature	☐
________________	________________	________________	
Name of Person taking consent	Date	Signature	

Appendix 5: Schedule of Procedures

Procedures	**Timelines**		
	Jan-Feb (2021)	**Mar-Sept (2021)**	**Sept-Dec (2021)**
Study pre-test and participant recruitment	**x**		
Obtaining informed consent from older people		**x**	
Interviews with older people		**x**	
Obtaining informed consent from the Hospital staff			**x**
Interviews with the Hospital staff			**x**

Appendix 6: Protocol Amendment History Sheet

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made
1.	3.0	24 June 2021	Adam Nyende	1) The official name of the NHS participating organisation has been updated. 2) Included online and telephone interviewing as options in case it is not possible to have to face to face interviews. 3) The option of covering the participants’ (older people) transport costs for those who will opt to have face to face interviews at the Day Hospital and require transport to get there has been included. 4) Changes have been to the study protocol, participant information sheets and consent forms.

Appendix 7: Topic Guide for Older people

- Introduction, welcome and demographics (gender and age)

- **Orientation to service utilisation**
    - I contacted you via the day hospital– what other services have you received recently?
    - Discussion of the services received to gain contextual information and focus
    - Prompts
        - Can you tell me more about that?
        - What was it like for you??
- **Orientation to the lived experience of control**
    - When using X service– how much control do/did you feel you have ….
    - Prompts
        - Can you tell me about a time when …
        - What did that feel like?
        - Can you tell me more about that…
        - And then what happened….
- **General lived experience of control**
    - d. At the moment how much control do you feel you have in your life?
    - e. Prompts
        - Can you tell me more about that…
        - What did that feel like?
        - And then what happened….
- **Hoped-for experience**
    - In an ideal world, what would services (or x service) look and feel like for you?

- **Ending**
    - Is there anything else you would like us to talk about today that we have not discussed?
    - Thank you so much for your valuable time.

Appendix 8: Topic Guide for Day Hospital staff

- Introduction, welcome and demographics (gender and age)

- **Orientation to service provision**
    - I contacted you via the xxxx Day Hospital– what is your role and what services do you provide at the hospital?
    - Discussion of the services provided to gain contextual information and focus
    - Prompts
        - Can you tell me more about that?
        - What was it like for you?
- **Orientation to practice experience of control**
    - Feedback about frail older peoples experiences of control and wellbeing
    - What does this make you feel/think?
    - Prompts
        - Can you tell me about a time when …
        - What did that feel like?
        - Can you tell me more about that…
        - And then what happened….

    - Do you feel you could take on other issues in your service /your practice -if so how?

- **General experience of sharing control**
    - What do you see as the benefit of patients having more control over their lives and care?
    - When providing Y service– how much control do/did you feel that patients have/had…..?
    - What does this make you feel/think?

- **Hoped-for situation**
    - What are the barriers for you?
    - Do you feel you are addressing any of these issues in your service /your practice -if so how?
        f. Prompts
            - Can you tell me more about that…
            - What did that feel like?
            - And then what happened….
    - What are the opportunities for you?
- **Ending**
    - Is there anything else you would like us to talk about today that we have not discussed?
    - Thank you so much for your valuable time.