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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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Introduction

As people age, they are gradually more likely to develop and live with complex comorbidities 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 (2018) 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 Sri 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 unhomey. 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 (Heggstad 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):	<i>frailty"OR""frail elderly""OR""frail older people""OR""frail older persons"</i>
<ul style="list-style-type: none"> Older people living with frailty 	
Concept (C)	AND
<ul style="list-style-type: none"> Sense of control Well-being 	<i>"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"</i>
Context (C)	AND
<ul style="list-style-type: none"> Health or Social Care setting 	<i>(Hospital OR Home OR Community OR "Care home" OR "Nursing home" OR "Municipal")</i>



Table A2. The table below provides an overview of the included papers.

No	Author(s)	Year	Country	Study design and sample	Setting	Control and/or wellbeing construct (s) measured/investigated	Contribution to the themes		
							Theme 1	Theme 2	Theme 3
							1-Body/ADL*(note)	2-Residence	3-H&SC relationships
1.	Abu-Bader et al.	2003	USA	<ul style="list-style-type: none"> Quantitative (structured interviews) 99 frail older people aged 60+ 	Community	<ul style="list-style-type: none"> Relationship between life satisfaction and physical health, emotional balance, social support, and locus of control. 	X		
2.	Andersson et al.	2008	Sweden	<ul style="list-style-type: none"> Qualitative (narrative approach) 17 older people having a life-threatening disease and/or receiving palliative care and aged 75+ 	Community	<ul style="list-style-type: none"> Aspects of a good life in the last phase of life. 	X	X	X
3.	Andrew et al.	2012	Canada	<ul style="list-style-type: none"> Quantitative (questionnaire) 5,703 frail older people aged 70+ 	Community	<ul style="list-style-type: none"> Psychological wellbeing focusing on the relationship between wellbeing, frailty and mortality. 	X		
4.	Bilotta et al.	2010	Italy	<ul style="list-style-type: none"> Quantitative (questionnaire) 239 frail older people aged 65+ 	Community	<ul style="list-style-type: none"> Relationship between frailty and Quality of Life (QoL). 		X	
5.	Broese van Groenou et al.	2016	Netherlands	<ul style="list-style-type: none"> Quantitative (interviews) 74 frail older people aged 65+, 94 informal caregivers, and 102 formal caregivers 	Community	<ul style="list-style-type: none"> 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.	2014	Netherlands	<ul style="list-style-type: none"> Qualitative (grounded theory) 32 frail older people aged 65+ 	Community	<ul style="list-style-type: none"> Perceived internal and external factors that constitute perceived control over healthcare. 	X	X	X
7.	Cramm et al.	2014	Netherlands	<ul style="list-style-type: none"> Quantitative (questionnaire) 869 frail older adults aged 70+ 	Community	<ul style="list-style-type: none"> Relationship of Self-Management Abilities (SMA) and frailty to perceived poor health. 	X		
8.	Dent et al.	2014	Australia	<ul style="list-style-type: none"> Quantitative (prospective, observational study) 172 frail older people aged 70+ 	Hospital	<ul style="list-style-type: none"> 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.	2013	Sweden	<ul style="list-style-type: none"> Qualitative (content analysis) 22 frail older adults aged 65+ 	Community	<ul style="list-style-type: none"> Influences on subjective experiences of good health. 	X	X	X

(Continued)

Table A2. (Continued).

10.	Ekdahl et al.	Ekdahl et al. (2010)	Sweden	<ul style="list-style-type: none"> Qualitative (content analysis) 15 frail elderly patients aged 75+ 	Hospital	<ul style="list-style-type: none"> Preferences for participation in medical decision-making during hospitalization. 	X	X	X
11.	Ekwall et al.	Ekwall et al. (2012)	Sweden	<ul style="list-style-type: none"> Qualitative (interviews/content analysis) 14 older people in the acute care process (5 men and 9 women) aged 70+ 	(Acute) Hospital	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Mixed methods 74 were inter-institutionally relocated (movers), while 81 served as an equivalent reference group (non-movers) 	Residential care	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 155 frail older persons Quantitative (questionnaire) 193 slightly to moderately frail older people aged 65+ 	Community	<ul style="list-style-type: none"> Impact of increasing SMA (bibliotherapy) on mastery and wellbeing. 	X		
14.	Gale et al.	Gale et al. (2014)	England	<ul style="list-style-type: none"> Quantitative (questionnaire) 2557 not frail, pre-frail and frail older men and women aged 60+ 	Community	<ul style="list-style-type: none"> Prospective relationship between psychological wellbeing and incidence of physical frailty. 	X		
15.	González-Bautista et al.	González-Bautista et al. (2020)	Mexico	<ul style="list-style-type: none"> Quantitative (survey questionnaire) 1,519 frail older adults aged 60+ 	Community	<ul style="list-style-type: none"> Longitudinal association between Social Determinants of Health (SDH) and frailty status with all-cause mortality. 	X		
16.	Grain, Madeleine	Grain (2001)	USA	<ul style="list-style-type: none"> Quantitative (questionnaire) 37 frail nursing home residents and 37 home-bound frail older people (both aged 60+) 	Home-bound and Nursing home	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Qualitative (descriptive phenomenology) 13 registered nurses 	Nursing home	<ul style="list-style-type: none"> Experience of caring for older people in nursing homes to promote autonomy and participation. 	X	X	X
18.	Janiöv et al.	Janiöv et al. (2006)	Sweden	<ul style="list-style-type: none"> Qualitative (content analysis) 28 frail home help recipients aged 75+ 	Community	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Quantitative (interviews) 187 frail men and women aged 85+ 	Community	<ul style="list-style-type: none"> Association between social relation, continuity, self-determination, and use of own resources with everyday life satisfaction. 	X	X	X

(Continued)



Table A2. (Continued).

20.	King et al.	King et al. (2017)	USA	<ul style="list-style-type: none"> Quantitative questionnaire 4,162 frail older people aged 65 to 105 years 	(structured)	Community	<ul style="list-style-type: none"> Association between a newly developed cumulative laboratory-based frailty index (FI) and intrinsic and extrinsic characteristics. Experience of receiving health care and/or social services. 	X
21.	Kristensson et al.	Kristensson et al. (2010)	Sweden	<ul style="list-style-type: none"> Qualitative design (open-ended interviews) 14 frail older adults aged 70+ 	(open-ended)	Hospital	<ul style="list-style-type: none"> Perception of quality of life in nursing homes. Experience of relational aspects of mastery and caregivers' role in maintaining mastery over the care process. 	X
22.	Kwong et al.	Kwong et al. (2014)	Hong Kong	<ul style="list-style-type: none"> Qualitative (content analysis) (FGDs) 24 frail elderly aged 65+ 		Nursing home	<ul style="list-style-type: none"> Perception of quality of life in nursing homes. 	X
23.	Lambotte et al.	Lambotte et al. (2019)	Belgium	<ul style="list-style-type: none"> Qualitative (in-depth interviews) 65 frail older adults aged 60+ 		Community	<ul style="list-style-type: none"> Experience of relational aspects of mastery and caregivers' role in maintaining mastery over the care process. 	X
24.	Milte et al.	Milte et al. (2015)	Australia	<ul style="list-style-type: none"> Randomised Controlled Trial (RCT) 136 frail older adults (70 usual care/control group and 66 specialized care). 		Hospital	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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.	Nielsen et al.	Nicholson et al. (2012)	Netherlands	<ul style="list-style-type: none"> Qualitative (open-ended interviews) 38 frail older dentulous people aged 65+ 		Day-care centers and Assisted-living homes	<ul style="list-style-type: none"> The impact of natural teeth on the QoL. 	X
27.	Portegijs et al.	Portegijs et al. (2016)	Finland	<ul style="list-style-type: none"> Quantitative (longitudinal analyses) 753 frail older people aged 75 to 90 years 		Community	<ul style="list-style-type: none"> Relationship between frailty, life-space mobility and perceived autonomy in participation outdoors. 	X
28.	Sandgren et al.	Sandgren et al. (2020)	Sweden	<ul style="list-style-type: none"> Quantitative 78 frail older persons aged 65+ (questionnaire) 		Nursing home	<ul style="list-style-type: none"> QoL among different gender and age groups in nursing homes. 	X

(Continued)

Table A2. (Continued).

29.	Schuurmans et al. (2005)	Netherlands	<ul style="list-style-type: none"> Quantitative (questionnaire) Frail older individuals (Study 1 sample $n = 275$ aged 64+), study 2 sample $n = 1338$ aged 65+) 	Community	<ul style="list-style-type: none"> Relationship between SMA, perceived health, subjective wellbeing, general self-efficacy and mastery. 	X
30.	Siriwardhana et al. (2019)	Sri Lanka	<ul style="list-style-type: none"> Quantitative (questionnaire) 746 frail older adults aged 60+ 	Community	<ul style="list-style-type: none"> Association of frailty with overall and domain-specific QoL. 	X
31.	Strohbecker et al. (2011)	Germany	<ul style="list-style-type: none"> Qualitative (grounded theory) 9 residents suffering from chronic disease or frailty and aged 70+ 	Nursing home	<ul style="list-style-type: none"> Palliative care needs of nursing home residents 	X X
32.	Thorson, James A. and Davis, Ruth Ellen (2000)	USA	<ul style="list-style-type: none"> Quantitative (longitudinal) 269 older individuals with an average age of 79.8 years 	Nursing home	<ul style="list-style-type: none"> Impact of institutional relocation on mortality and morbidity. 	X X
33.	Vestjens et al. (2020)	Netherlands	<ul style="list-style-type: none"> Quantitative (questionnaire) 588 frail older people aged 75+ 	Community	<ul style="list-style-type: none"> Relationship between SMA, productive patient-professional interactions and wellbeing. 	X
34.	Wallerstedt et al. (2018)	Sweden	<ul style="list-style-type: none"> Qualitative (content analysis) 40 next of kin for frail older people 	Nursing home	<ul style="list-style-type: none"> 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.

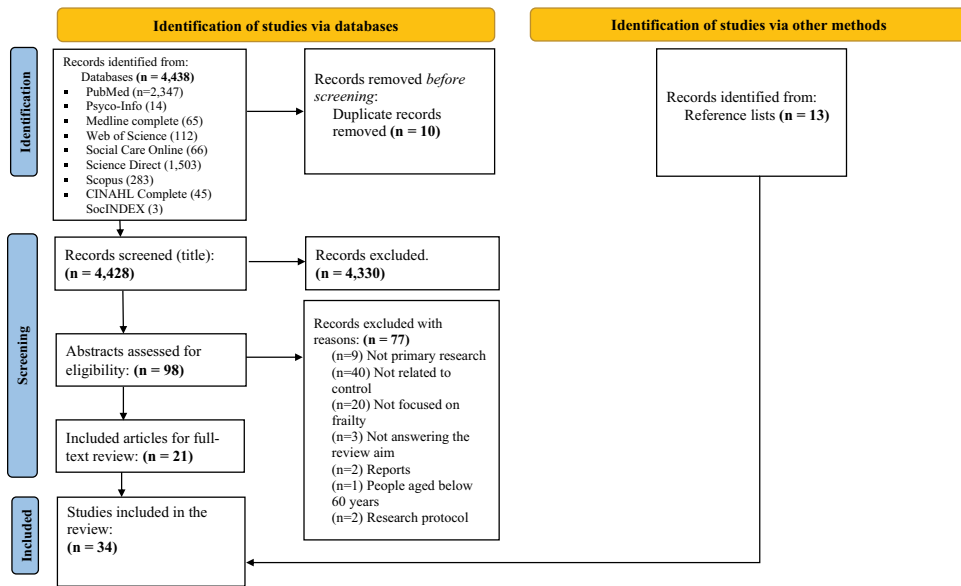


Figure A1. PRISMA flow diagram summarizing the phases of the literature search.