

**A Critical Realist
Evaluation of End of Life
Care in Care Homes**

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Abstract – Adam Spacey

A Critical Realist Evaluation of End of Life Care in Care Homes

Numbers of advance care plans and unnecessary admissions to hospital at the end of life are outcomes commonly used to determine the quality of end of life care in UK care homes. However, there is currently a sparsity of research systematically exploring the underlying processes behind these outcomes. This gap in knowledge has limited the effectiveness of interventions designed to improve end of life care in care homes. The study aim was therefore to inform the design and development of interventions capable of supporting the delivery of high-quality end-of-life care in UK care homes.

A two-phased study design utilising Critical Realist Evaluation was used to address this gap in knowledge and achieve the study aim. Qualitative data was collected (using focus groups and semi-structured interviews) from three care homes in the South West of England from participants comprising of registered nurses, non-registered care home staff and bereaved relatives.

Findings highlighted variable quality of advance care planning discussions in care homes. It was found that the current educational focus on gathering information, combined with some care home staff's emotional reluctance to discuss death and dying, and a taboo culture within the commercial sector associated with death and dying impacted on the quality of advance care planning discussions. Moreover, findings identified several underlying factors which may contribute to unnecessary admissions to hospital at the end of life from care homes. It was apparent that some care home staff's emotional attachments to residents, a sparsity of support during out of hours shifts, and a lack of interventional support could contribute to the likelihood of unnecessary admissions at the end of life. This situation was further influenced by relatives. Some relatives' difficulties accepting a different identity when their caring role ceases and then when

bereaved was found lead to conflict and relatives wanting to prolong their loved one's life.

The findings were used to develop intervention theories which provide recommendations for practice accounting for the diverse social, economic and organisational contexts of care homes in their design. These intervention theories provide the foundational components and rationale for the development of an evidence based multicomponent end of life care intervention; however, the development and evaluation of this intervention requires further research.

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Author's declaration

Please note the following parts of this thesis have been presented elsewhere:

The systematic review presented in chapter two: Spacey, A., Scammell, J., Board, M. and Porter, S., 2018. End-of-life care in UK care homes: a systematic review of the literature. *Journal of Research in nursing*. 0 (0) 1–21.

The systematic critical review presented in chapter three, and aspects of the methodology presented in chapter four: Spacey A., Scammell, J., Board, M. and Porter, S., 2019. Systematic critical realist review of interventions designed to improve end-of-life care in care homes. *Nurs Health Sci*. 1–12.

1 Introduction

1.1 Overview

This introductory chapter sets the foundations for the study. Firstly, the author's research journey is presented which outlines how the author's background has influenced the research process. To further set the background the introductory chapter explains the key concepts of end of life care (EoLC), it then goes onto to highlight how demographical changes and policy drivers in the UK have led to an increase in demand for EoLC in care homes.

Lastly, current research in the field is discussed which highlights persisting problems in the provision of EoLC in relation to the application of person-centred EoLC and unnecessary admissions to hospital from care homes at the EoL. However, at the commencement of the study, there was an absence of a comprehensive overview of the current standard of EoLC across the UK care home sector. Thus, the chapter concludes by providing a rationale for a comprehensive overview of EoLC in UK care homes, which is presented in the form of a systematic literature review in chapter two of this thesis.

1.2 Author's Background

My professional background as a Diagnostic Radiographer had led to me being around older patients supporting them through the process of having an X-ray. This experience of caring for and interacting with older people on a daily basis gave me an interest and passion for the welfare of older people. It was also around this time that I sadly experienced the death of my grandfather in a care home. I worked near to the home where my grandfather was staying so I was able to visit him frequently which led to me observing and taking an interest in the care that the staff provided. Despite me and my family being overall satisfied with the EoLC my grandfather received, his death did come as a bit of a shock to us as the care home staff rarely spoke to me or my family about death and dying until the very end. So, when the time come to say goodbye we were not as emotionally prepared as we could have been.

This personal experience helped me realise how you only get one chance at a 'good' death, and despite not being ready for the death of my grandfather we had the time to say goodbye and we were content that he was comfortable towards the end of his life. However, despite overall feeling that he had a 'good' death my professional experience and interest in the care of older people left me with questions about EoLC in care homes: could our experience of EoLC be improved? Why did the care home staff not prepare us for his death earlier? How do the experiences of others compare to my own?

I was therefore very excited when the opportunity to explore EoLC in care homes came up as part of a full time PhD studentship. From my own personal experience, I knew the impact that EoLC could have not only to people at the end of their lives, but their loved ones too. Thus, although taking the PhD opportunity meant I had to give up my full-time job as a Diagnostic Radiographer I was excited to utilise my interest in the care of older people to make a positive difference.

I remember telling my colleagues at the time who asked me "why are you doing that...? It will be sad and depressing". However, throughout my three years of studying EoLC in care homes, I have found it is the opposite of depressing and is in fact a rewarding and inspiring area. Everyone will be exposed death in some way at some point in their life, so having an opportunity to understand more about that experience, and to potentially improve and enhance it for people is something that I have never taken for granted, and something which has provided me with inspiration and motivation throughout this project. I have never once felt depressed, but only enthused to learn more.

Despite my personal experience of EoLC I was aware I was lacking a professional understanding of EoLC. At the time I believed this lack of professional experience was a weakness. However, throughout the duration of this research, I have found that this lack of prior professional experience was actually an advantage. Although it has made the process of learning about EoLC care homes more difficult, it has allowed me to understand and approach the perspectives and

views of participants more objectively reducing the chances of professional influences and conflicts.

1.3 Background to the Study

1.3.1 What is end of life care?

Death is part of life; everyone will experience death and almost all will experience losing someone close to them. Most people believe that death will occur suddenly, which is true for some, but for the majority dying is a process which can vary in length from days, weeks and to even years of decline (Hughes-Hallett et al. 2011; Lunney et al. 2003). EoLC is the term given for care provided to people who are approaching the last years, months or days of their life (Fisher et al. 2000; Marie Curie 2019). Regardless of the setting, EoLC involves physical, emotional, social and spiritual care for patients and their relatives and friends to control their symptoms so the person can be as comfortable and live as well as possible until they die (National Health Service (NHS) 2018). The focus of EoLC is on caring, supporting and comforting over curing (Fisher et al. 2000; Gaertner et al. 2017; NHS 2018).

The National Institute for Health and Care Excellence (NICE) has developed guidance on the care for dying adults. The guidance covers how to manage common symptoms and maintain dignity and respect for people who are dying and supporting their relatives through the process (NICE 2015). In order to meet these needs and maintain dignity EoLC is individualised and centred on the person who is dying, giving them control over their own care and any decisions made (NHS England 2016). Thus, the people providing EoLC need to plan, gather and record information about a person's wishes and preferences and take them into account in order to provide the best care possible for that person (Cloninger 2011). Advance care plans are used to gather and record information on residents' preferences and choices such as resuscitation wishes, funeral arrangements and preferred place of death (advance care planning is explored in greater detail in section 1.3.4) (Thomas and Lobo 2010; Froggatt et al. 2009).

Therefore, although EoLC generally has common components such as symptom management, each of these components needs to be tailored to an individual's needs and wishes (NHS England 2016). For example, symptom management consists of managing an individual's symptoms as they approach the EoL. However, a person's symptoms will depend on the individual themselves, the illness they are dying from, and their preferences and wishes. For instance, pain management is an important aspect of EoLC given that most people experience pain during the end of their lives (NICE 2015). However, pain can be emotional, physical, spiritual or social; therefore, how an individual's pain is managed can vary from the use of medication to providing emotional support (Thomas and Lobo 2010). Consequently, developing a holistic approach and providing care beyond symptom control and management is a necessary part of high-quality EoLC (NCPC 2006; Fisher et al. 2000).

1.3.2 Holistic care

Emotional and social support are important facets of holistic care and involve listening to the person who is dying and talking to them about how they feel in a non-judgmental way (Marie Curie 2019). It has been reported that activities such as listening to music, looking at old photos or sharing stories can help the person open up and feel more at ease talking about their situation (McConnell et al. 2016; McGill 2018). Additionally, taking the time to get to know the person, understanding their individual circumstances and developing a relationship has been found to help the provision of emotional and social support (Shimoinaba et al. 2014). This support is essential as although some people accept death and express feelings of relief, commonly people can feel helpless, anxious, lonely and fearful as they approach the end of their lives (Orzeck 2016). These feelings can lead to emotional and/or psychological distress which is when a person becomes overwhelmed by their emotions (Marie Curie 2019).

Spirituality is also an important part of providing holistic care and refers to thoughts and feelings about a person's being and purpose, which is based on a person's philosophical beliefs. Whilst, a person's religion and their particular

beliefs may be an important part of their spirituality, a person can be spiritual without being religious (Marie Curie 2019). Emotional and spiritual pain may occur during EoLC, where some people experience painful feelings such as anxiety, regret and fear (RCN 2015), which can often occur when a person has lost meaning and purpose in life (Marie Curie 2019). It has been reported that social support is important in maintaining the meaningfulness of life during EoLC (Dobrikova et al. 2016).

This emotional, social and spiritual support also extends to family members and friends of those who are dying. EoLC incorporates significant others such as relatives and friends, for example, including them in decisions made throughout the EoLC process (Fisher et al. 2000; NCPC 2006). As well as being included in decisions, EoLC involves providing bereavement support to relatives following the death of their loved one. Bereavement support is considered an extension of EoLC and can continue for as long as it takes or is required (Aoun et al. 2017). Bereavement support consists of providing support for bereaved people which can consist of friendly conversations, support, and giving time to reflect. Common forms of bereavement support include care home staff attending the funerals of residents and keeping in contact with the bereaved following death to provide support and comfort (Aoun et al. 2017). The bereavement period will vary in length depending on individual needs, as some bereaved relatives may require differing amounts of support following their bereavement (Germain et al. 2016). Therefore, as well as caring for the person who is experiencing death, it is important to provide comfort and support to those close to the person who is dying (NCPC 2006; Fisher et al. 2000).

However, meeting a person's physical and medical needs is still important as part of a holistic approach to care. For example, enabling a person to die in comfort and pain free will often require their physical and medical symptoms to be managed through the use of medications (NICE 2015). Nonetheless, this approach must align with the person wishes and preferences as some may prefer spiritual and emotional methods of support rather than medications (Marie Curie 2019).

Based on the information in this section, EoLC can be described as a non-curative intervention to support and comfort individuals and their families with a progressive chronic illness from which they are dying (Fisher et al. 2000; NCPC 2006). To further aid clarity, table 1 presents two commonly used and established definitions of EoLC.

Table 1 Definitions of end of life care

Source	Definition
Fisher et al. (2000)	<i>“End of life care for older adults encompasses an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement”</i>
National Council for Palliative Care (NCPC) (2006)	<i>“...helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.”</i>

1.3.3 End of life care in care homes and the resident population

In accordance with UK law care homes are defined as establishments which provide accommodation along with nursing and personal care for residents who are ill, disabled or who have a mental disorder (UK Care Standards Act 2000). Under this act, care homes are categorised as either ‘residential homes’ which have no on-site registered nursing and ‘nursing homes’ which provide nursing care through on-site registered nurses (see table 2). The UK care home

workforce is made up of care assistants (76%) and registered nursing staff (12%); the remaining workforce is made up of ancillary staff such as housekeeping and administrative staff (Griffiths et al. 2019). Although registered nurses still provide personalised care, care assistants work most closely with the nursing home residents providing everyday care including discussions with residents, while supervised by registered nurses (Leaman 2011).

However, care home staff do not provide EoLC alone. EoLC is provided by a multidisciplinary team who work closely with care home staff (NHS 2018; National Palliative and End of Life Care Partnership 2015). For example, residents on EoLC should be visited by General Practitioners (GPs) who can prescribe anticipatory medication and provide guidance for care home staff (Handley et al. 2014). As well as GPs, hospital professionals and ambulance staff also work closely with care home staff providing guidance and any medication or treatment to residents. Hospice staff, Physiotherapists, Social Workers, Occupational Therapists also each have a role in the care of residents and frequently communicate with care home staff (National Palliative and End of Life Care Partnership 2015). Furthermore, given the absence of on-site registered nurses in residential homes, their staff rely on district nurses to provide medical care, for example, to administer pain relief medications (Handley et al. 2014; Davies et al. 2011).

Table 2 Terminology: Nursing and residential homes

Residential homes	Settings which offer support in the form of care throughout the day and night, staff can help with meal times, washing, dressing and using the toilet. Residential homes rely on district nurses for registered nursing care.
Nursing homes	Settings which offer the same care residential homes, however, nursing homes have the addition of 24-hour care from registered nurses.

The collective term 'care home' is used when referring to both nursing and residential homes. When specifically referring to residential homes or nursing homes the individual term is used (i.e. nursing or residential home)

Almost 95% of care home beds are provided by the independent private sector (Competition and Markets Authority 2017). In 1984 most care home places for the older population (over 65 years old) were run and funded by local authority services (137,200 which represented 55%). However, by 2014, the number of private sector places had reached 200,200, which represents 74% of care homes places for the older population. The rise in private sector care homes was echoed by a fall in the number of care homes owned by the local authority, which in 2014 equated to only 21,700 (8% of care home places) (Laing and Buisson 2015). Although local authorities have important statutory duties, 90% of care and support is provided by 19,000 independent care homes ranging from corporate chains to family-run care home businesses (Competition and Markets Authority 2017).

Approximately 416,000 people live in care homes, equating to roughly 4% of the UK population aged 65 and over and 16% of the population aged 85 and over (Laing and Buisson 2015; Competition and Markets Authority 2017). Whilst a number of countries are facing challenges related to the ageing population due to longer life expectancies, it is particularly acute in the UK (Institute for Public Policy Research 2018; Bone et al. 2018). In 2016, there was approximately 11.8 million people aged 65 years and over in the UK, and this is predicted to increase by a further 8.6 million by 2066 (ONS 2018). Moreover, the population percentage of those aged 85 years and over in the UK was 1.6 million in 2016 and is predicted to double to 3.2 million by 2041 (ONS 2016). Furthermore, the South of England where this study is based, has a higher than average population of people over 65 years old, and projections predict that this population will grow by 50% over the next 25 years (ONS 2017a). Moreover, similar trends in the ageing population have been reported across the UK (ONS 2014), and it has been

forecast that the deaths each year in England and Wales will increase from 501,424 in 2014 to 635,814 in 2040 (Bone et al. 2018).

Age is synonymous with progressive chronic illnesses (World Health Organisation 2011). The likelihood of someone developing Alzheimer's disease doubles every five years over the age of 65 (Alzheimer's Society 2016), similar outcomes are seen with other long-term conditions such as heart disease (American Heart Association 2015). Additionally, half of all people in the UK aged over 85 are predicted to be living with frailty and this is expected to only rise (Turner and Clegg 2014). Moreover, more people are now living with multiple chronic conditions (multiple comorbidities), such as Alzheimer's and frailty (Kingston et al. 2018). By the age of 65, most people will have at least one long-term condition and by the age of 75 most will have at least two (The King's Fund 2018).

Although long-term conditions are not necessarily associated with death and EoLC most older people dying in care homes have a long-term condition and often multiple comorbidities (Kingston et al. 2018; Julien and Jose-Luis 2011). Research has shown that these long-term conditions and especially multiple morbidities require complex symptom management (Schiltz et al. 2018; Murray et al. 2005) and close care posing difficulties for care home staff (Barclay et al. 2014).

In addition to care home staff having to deliver EoLC to an older population, research suggests that the number of residents dying in care homes is set to increase (Bone et al. 2018). The latest mortality data has shown 525,048 deaths were registered in 2016 in England and Wales (ONS 2017b). Most of these deaths occurred in hospital (46.9%), while 23.5% of deaths occurred in people's own home, and 21.8% of deaths occurred in care homes and 5.7% in hospices. However, as this introductory chapter outlines (in the following sections) as a result of policy drivers and peoples' preferences for place of death, since 2004 deaths in care homes have increased by 5.3% and hospital deaths have

decreased by 11% (ONS 2018). Recent forecasts predict that if current trends continue, the numbers of deaths in care homes will increase by 108.1% making care homes the most common place of death in the UK by 2040 (Bone et al. 2018). Therefore, care home staff not only have to deliver EoLC for an increasing number of residents, but for residents with complex conditions and multiple comorbidities.

1.3.4 Policy drivers and peoples' preferences for place of death

In response to demographical changes, EoLC has become a political priority in many developed countries (UN 2017; Froggatt et al. 2017a). Specifically, over the past decade UK policy has focused on improving the quality of care delivered at the EoL, and on reducing its overall cost (DH 2008; DH 2014; The NHS long term plan 2019). Despite the plethora of different policies over the decades, the focus to enable more people to receive high-quality EoLC and to die in their preferred location has remained consistent (The NHS long term plan 2019; DH 2014). Prior to 2008, the NHS EoLC programme was set up by the UK government to improve patient choice at the end of life, including enabling greater numbers of people to die in their place of choice (DH 2006). A number of guidance tools and incentives resulted from the programme such as the introductory guide to EoLC in care homes (NCPC 2006). The 2006 guide for care homes aimed to support and guide care home staff to reduce the number of unnecessary admissions to hospital at the EoL. However, despite these efforts, it was reported that many people were not able to die in their place of choice, and experienced physical, psychological and spiritual distress during EoLC, partly due to insufficient education for those delivering care at the EoL (DH 2008).

It was therefore identified within the 2008 End of Life Care Strategy that insufficient attention had been given to EoLC in the UK (DH 2008). The Strategy sought to improve EoLC based on three insights. Firstly, it aimed to prepare for greater numbers of people who are dying by supporting more community services such as care homes and community-based specialists such as GPs and outreach services such as palliative care teams to deliver high-quality EoLC,

rather than relying on hospitals to provide EoLC. Secondly, it aimed to enable more people to die in their place of choice reducing unnecessary hospital admissions at the EoL by widening access to advance care planning. Thirdly, it aimed to understand that not everyone received high-quality care and there was therefore a need to explore why in greater depth (DH 2008). The Strategy's launch in 2008 led to a number of both local and national efforts to improve EoLC across all settings. In terms of national impact, the 2008 Strategy led to the National End of Life Care Intelligence Network which focuses on improving the sustainability and quality of EoLC services by improving the collation and analysis of data related to EoLC (National End of Life Care Intelligence Network 2010). From this initiative came evidence on the public preference for place of death which suggested that the majority of those surveyed preferred to die at home (ONS 2016; National End of Life Care Intelligence Network 2010). Specifically, the VOICES survey of recently bereaved relatives found 81% would have preferred their loved one to die at home (National Voices 2017).

Based on this survey data it is a common assumption in policy documents that most people prefer to die at home. However, these surveys have limitations making it difficult to draw definitive conclusions. Firstly, it should be noted that this data was collected from people not receiving EoLC, and research has shown preferences for location of death change as a person's condition deteriorates (Hoare et al. 2015). Secondly, what people deem as 'home' is subjective, for some 'home' may not represent a physical structure but a feeling of safety and being surrounded by family and friends (Collier et al. 2015). For example, for permanent care home residents, the care home may be the place they associate with safety and being surrounded by family (ONS 2016; National End of Life Care Intelligence Network 2010). Furthermore, when people were asked about EoLC in general rather than just focusing on place of death it was found location was only one factor of many and people prioritised being cared for by well-trained staff, being able to make their own decisions, and being physically, emotionally, socially and spiritually supported at the end of their life (The Choice in End of Life Care Programme Board 2015).

As a result of public preference, over the years we have seen the delivery of EoLC move slowly away from hospital settings to the community (Georghiou 2014). Evidence suggests that people are generally supportive of this shift (The Choice in End of Life Care Programme Board 2015). Although this shift has helped reduce the burden on hospital services and enabled more people to die in their preferred setting, it has increased the demand on community services including care homes (Bone et al. 2018; Georghiou 2014; DH 2008; DH 2004; Institute for Public Policy Research 2018).

1.3.5 Person-centred care and advance care planning

A number of approaches to support high quality EoLC have been introduced and supported within UK policy (Institute for Public Policy Research 2018), with the most popular and widespread approach being person-centred care (LACDP 2014). The Leadership Alliance for the Care of Dying People (LACDP) published the report 'One Chance to Get it Right' which lays out an approach for caring for people who are dying (LACDP 2014). Priority areas include providing person-centred care and documenting peoples' holistic needs and wishes in advance care plans. In addition, the report adds that as well as the dying person all those identified as important to them should be involved in EoLC.

Person-centred care does not have one specific definition, it can also be referred to using a number of different terms such as individualised care, personalised care and family-centred care (Kitson et al. 2013). However, regardless of the term used it is generally taken to mean care which is based on an individual's needs which involves placing the person at the centre of their own care rather than basing care around their medical condition or the healthcare system (Cloninger 2011). Put simply, caring for the person, not their condition. However, a person-centred approach to EoLC is not just about giving the person whatever they want (Kitson et al. 2013). The approach is about considering peoples wishes, values, beliefs and family circumstances; and incorporating these factors into

their care (Health Innovation Network 2014). This approach to care is important in maintaining a person's dignity, which does not just apply to people's physical wellbeing, but aims to protect their autonomy by placing them at the centre of their care decisions (Health Innovation Network 2014; Kitson et al. 2013). Moreover, person-centred care also involves putting relatives/families at the centre of care and any decisions made and supporting them through the EoLC process, such as providing bereavement support after death (discussed in section 1.3) (Cloninger 2011).

Person-centred care has long been encouraged in the care home sector (DH, 2008). The Mental Capacity Act (2005) made it law for an adult with capacity to make advanced care directives and to appoint a lasting power of attorney to refuse specific treatment at a point in the future when they lack capacity. Advance care plans allow people to plan for their death and document their wishes and preferences, for example, funeral arrangements and where they would like to die, and should be updated regularly to meet the person's changing needs (The Mental Capacity Act 2005). Moreover, if an individual has lost mental capacity the Act makes it possible to appoint lasting power of attorney (usually a close relative) to make the decisions on a person's behalf, such as refusing treatment and the unnecessary prolongation of life. Thus, advance care plans are used by care home staff to gather information from residents and their relatives to be able to centre care around their needs and preferences (Stone et al. 2013).

Although advance care plans can be set up well before a person requires EoLC such as by their GP, often people come to care homes without an advance care plan in place (Gordon 2012; Mason et al. 2016; Stone et al. 2013). Moreover, given that residents preferences and situations change, advance care plans need to be updated regularly, thus even those who are admitted to care homes with advance care plans will need them updating by care home staff (Froggatt et al. 2009). Consequently, it is care home staff's responsibility to set one up and update advance care plans for residents to ensure they are receiving EoLC centred to their needs, preferences and wishes. Good practice has been evidenced in relation to advance care planning in care homes which has been

found to enable more residents to die in their preferred place (Kupeli et al. 2016a; Kupeli et al. 2016b). However, it has also been reported that some care home staff face difficulties with advance care planning (Handley et al. 2014; Mason et al. 2016). For example, Handley et al. (2014) report that care home staff felt unprepared and expressed hesitancy about how to start advance care planning discussions with residents.

1.3.6 Unnecessary admissions to hospital at the end of life

This variable practice in relation to care planning is important given that advance care planning plays a significant role in maintaining a person-centred approach to care ensuring residents are able to die in their preferred location and avoid unnecessary hospital admissions at the EoL (McDermott et al. 2012). It is therefore unsurprising that research suggests that unnecessary admissions at the EoL from care homes to hospital are persisting (Thwaites et al. 2017; Mason et al. 2016; Ong et al. 2011). A recent report by the Health Foundation (Wolters et al. 2019) looking at care homes also found that the numbers of admissions for residents aged over 65 from care homes in England in 2016/17 was roughly 192,000, of which 7.9% were unnecessary admissions from care homes at the EoL. Addressing this issue is important as unnecessary admissions to hospital at the EoL have been shown to expose residents and their relatives to increased stress and anxiety, and often lead to residents dying in unfamiliar clinical settings away from their loved ones (Gomes et al. 2012; ONS 2016).

Mason et al. (2016) describes unnecessary admissions as admissions to hospital at the EoL where the resident did not require or want medical treatment and died within 48 hours of unscheduled admission. Unnecessary admissions can occur when care home staff call emergency services such as out of hours doctors, GPs or ambulance staff. Current literature has explored unnecessary admissions from the perspectives of those working in emergency services (Hoare et al. 2018; Kupeli et al. 2016b; McDermott et al. 2012). Hoare et al. (2018) found that calls from care home staff to emergency services can often result in an unnecessary admission due to staff such as paramedics and doctors lacking information about

the resident and lacking alternative options. Similarly, Kupeli et al. (2016b) found that when care home staff rang hospital staff out of hours, they usually got in contact with junior doctors who often lacked information and experience which again was found to increase the likelihood of unnecessary admissions to hospital at the EoL.

However, it is also important to understand and explore the factors which cause care home staff to contact emergency services during residents EoLC. Despite this there is a sparsity of studies which have directly explored the factors which can influence care home staff's decisions to contact emergency services and request a resident be admitted to hospital. However, some evidence does exist, Barclay et al. (2014) found that residents' conditions and trajectory of decline impacted on care home staff's decision particularly when a resident's decline was unexpected and sudden. Furthermore, Handley et al. (2014) implies that care home staff's lack of awareness and knowledge of the stages of dying along with variable engagement in advance care planning may influence their decisions to reach out to emergency services. However, currently, there appears to be a lack of insight into the collective factors which influence care home staff's decision to call emergency services and request that the resident be admitted to hospital at the EoL.

It is known that in 2016-17 emergency admissions cost the NHS £17 billion pounds in total (National Audit Office 2018), thus there is a strong economic incentive to support 'home' deaths and reduce the unnecessary proportion of these emergency admissions to hospital at the EoL. Research has found that 55% of someone's whole lifetime cost is in the last years of life, and the last two weeks of life accounts for 37% of the total cost due to hospital use, such as unnecessary admissions at the EoL (Haltia et al. 2018).

1.3.7 The need for a systematic exploration of end of life care in UK care homes

This introductory chapter has set the foundations for this study by highlighting the increased reliance on UK care homes to deliver high quality EoLC, current policy initiatives and areas where improvements may need to be made in terms of advance care planning, the application of person centred EoLC and unnecessary admissions to hospital from care homes at the EoL. However, at the commencement of this study no systematic review of the literature exploring and describing current EoLC provision in UK care homes had been conducted. This is not only vital to determine the methodological quality of the existing research but is necessary to provide an overall view of the current standard of EoLC provided across the UK care home sector to provide a foundation for further empirical research. This overall view can be used to establish where good practice currently exists and where practice improvements need to be made. In order to provide more comprehensive information about contemporary EoLC provision a systematic examination of individual studies exploring EoLC in UK care homes is presented in chapter two.

1.4 Structure of thesis

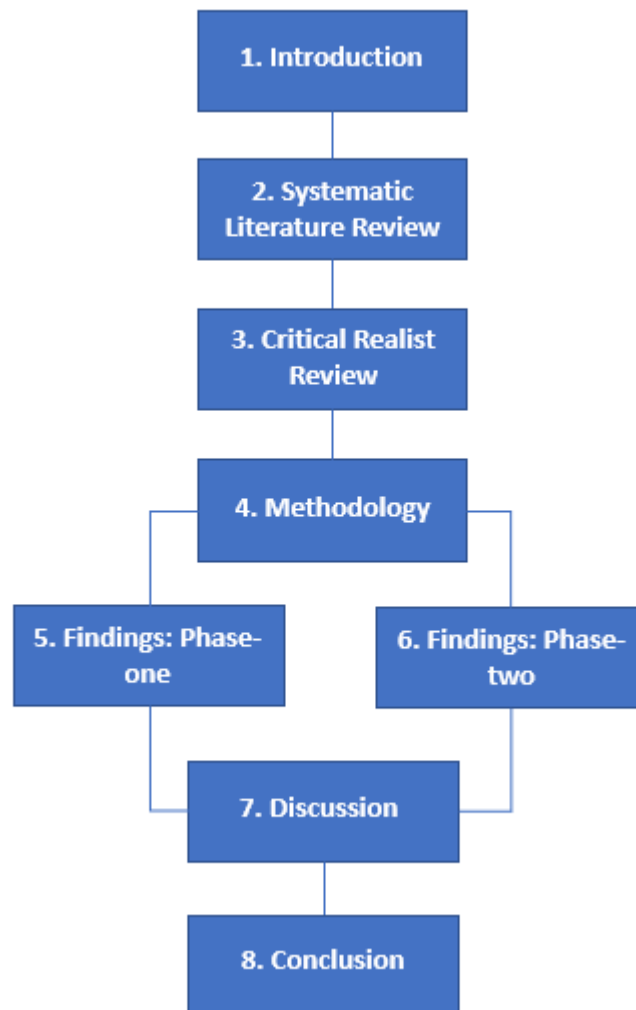
This thesis consists of 8 chapters (Figure: 1). Chapter one has provided an introduction to the thesis, overview of the context and rationale for further research in the form of a systematic review. Chapters two and three present a systematic literature review (chapter two) and critical realist review (chapter three), which provide a justification and rationale for the subsequent study and inform the study design. Chapter three concludes formulating the research aim and objectives.

Chapter four details the methodology and why it was chosen, and the research design and methods that accompany it. Chapter five presents the findings from phase-one of the data collection and analysis process, and the initial intervention theories developed from synthesising the analysed data and existing literature.

Chapter six presents phase-two of data collection and the refinement of the initial intervention theories developed in phase one.

Chapter seven presents the discussion, which discusses the research findings in relation to existing literature. This identifies where the study findings advance knowledge and where the findings corroborate existing knowledge. Chapter 8 of this thesis presents the study conclusion and highlights the impact of the study findings on practice, policy and research. The chapter ends by introducing the areas for further research in the light of this study. Lastly, the appendices present additional information to support the thesis.

Figure 1 Outline of thesis



The appendices listed in the table of contents provide supporting evidence for this thesis.

2 Systematic literature Review

2.1 Introduction

Building on chapter one, this chapter presents a systematic examination of existing research evidence to establish a comprehensive picture of EoLC provision in UK care homes. This is important because, as established in the introductory chapter, at the commencement of this study there was no overall view or understanding of the standard of EoLC across the UK care home sector. The aim of this review was to systematically review studies that describe EoLC in UK care homes. The findings from this systematic review influenced the later work presented in this thesis.

This chapter will begin by detailing why a systematic literature review was chosen; following this the results of this review are presented. The chapter concludes by providing a justification and rationale for a Critical Realist review of the literature. The review presented in this chapter was published in the Journal of Research in Nursing (see appendix 1).

2.2 Systematic Reviews

Systematic reviews of the literature provide a research method which identify, appraise and summarise studies of relevance to a particular topic (Webb and Roe 2007). Gathering and summarising current knowledge in the area of EoLC in UK care homes was a necessary starting point as it was identified in chapter one that currently there was no comprehensive overview of the standard of EoLC across the UK care home sector. Consequently, there was a need for current literature to be synthesised in order to provide a more comprehensive understanding of the standard of EoLC delivered across the UK care home sector.

Furthermore, systematic reviews employ a rigorous systematic search strategy which reduces selection bias and adds transparency (Gopalakrishnan and Ganeshkumar 2013; Singh 2017). For this reason, a systematic review was

chosen over another type of review such as a narrative review given that narrative reviews tend to adopt a less rigorous and transparent search strategy thus are left open to selection bias (Singh 2017). A central element to all systematic reviews is the search strategy, as it is important to include all relevant articles in the field to achieve the research aim (Mallett et al. 2012). Moreover, the search strategy is reported in detail in the Methods section of a systematic reviews to enable others to replicate the search and update it with changing and evolving fields (Mallett et al. 2012; Singh 2017). To further enhance transparency the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement was used to guide this review. PRISMA is an evidence-based minimum set of items which aims to help authors report their searches within systematic literature reviews (Moher et al. 2009).

Moreover, the systematic approach also excludes poor quality research through quality appraisal which may misinform conclusions (Gerrish and Lathlean 2015; Webb and Roe 2007). Quality appraisal is a vital aspect of systematic reviews to ensure the included articles are not overly biased or poor quality (Mhaskar et al. 2010; Singh, 2017). This is important especially for reviews which aim to change practice based on their findings. Thus, adopting a systematic approach best enables all relevant literature to be found on a given topic ensuring high validity and reliability (Singh, 2017).

2.3 The review

2.3.1 Aim

The aim of this study was to systematically review studies that describe end-of-life care in UK care homes.

2.3.2 Search strategy

Preliminary searches were conducted using the EBSCO database (which is an electronic database used to search for journals for articles of relevance). This provided insight into key terminology and relevant databases. Following on from the preliminary search, four main databases were systematically searched:

ScienceDirect; MEDLINE; PSYCINFO; and CINAHL. These databases were included because they had been identified in the preliminary search as containing the journals relevant to the research topic. Boolean techniques (Table 3) were used to ensure no relevant literature was missed in the search strategy (Gerrish and Lathlean 2015; Boland et al. 2014). Using this search strategy, the key components were entered into the database with their alternative subject headings.

Table 3 Search strategy

Element	Alternatives
1. "End-of Life care"	Pallia* "Terminal care"
2. "Care Home*"	"Nursing home*" "Residential home*" "Long term care facili*"
3. "United Kingdom"	"United Kingdom" UK England "Great Britain" GB Wales Scotland "Northern Ireland"
Boolean Operators	1. "End of life care" OR Pallia* OR "Terminal care"
	2. "Care home*" OR "Nursing home*" OR "Residential home*" OR "Long term care facili*"

	<p>3. "United Kingdom" OR UK OR England OR "Great Britain" OR GB OR Wales OR Scotland OR "Northern Ireland"</p>
--	---------------------------------------------------------------------------------------------------------------------------------

**(asterisk) represents any string of characters used in truncation*

2.3.3 Eligibility criteria

The literature was reviewed utilising the inclusion/exclusion criteria. The researcher firstly screened the literature based on their titles and abstracts. Following this initial screening a full text screening was conducted for all the potentially relevant literature, again conducted by the research and cross-checked by the supervisory team. The search was conducted on 25th April 2017, with the exclusion and inclusion criteria applied (Table: 4).

The search also included manual searching of the reference lists of papers and by hand searching the grey literature. The search was limited to papers published after the date of The End of Life Care Strategy (DH 2008), which heavily influenced the contemporary focus of policy and practice in terms of EoLC in UK care homes (NHS England 2014). A range of study types, including both qualitative and quantitative evidence were sought to explore how EoLC is currently being delivered in care homes in the UK. Critical Appraisal Skills Programme (CASP 2018) frameworks were applied to assess and appraise the quality of the included studies.

Table 4 Inclusion and Exclusion Criteria

Inclusion Criteria	Rationale
Studies must include a descriptive element regarding the nature of EoLC in care homes.	To ascertain how EoLC is currently being carried out in care homes in the UK.
Must be UK based.	EoLC policy and guidelines are national-specific, and this study is specific to UK care homes.
Exclusion Criteria	Rationale
Pre-dates 2008.	July 2008 was the date of a seminal policy publication which significantly changed the focus of EoLC delivery and research in the UK.
Studies evaluating a complex intervention designed to improve care.	Studies evaluating *complex interventions described EoLC in the context of the intervention rather than representing practice. Moreover, interventions designed to support EoLC in care homes were explored in chapter three.
Studies exploring EoLC outside of care home settings.	This review is focused on exploring the nature of EoLC in care homes.

**Complex interventions are defined by the Medical Research Council (MRC) as interventions that are made up of multiple and interacting components (MRC 2006).*

2.3.4 Quality assessment and data extraction

The Critical-Appraisal-Skills-Programme (CASP 2018) was chosen as the primary quality assessment tool for the selected literature. One of the reasons the CASP framework was chosen is because it has many individual checklists for different methodologies. The CASP framework firstly consists of screening questions which

can be graded numerically (0=No 1=Partly 2=Yes). A maximum score of 20 can be achieved for qualitative studies and reviews and 22 for quantitative. The quality of the selected literature was assessed by the researcher and the supervisory team. Studies with a score under 10 were excluded, but none of the selected studies were below this level of quality, and therefore no papers were excluded on the basis of quality.

2.3.5 A mixed methods systematic literature review

The synthesis of evidence forms a central and essential aspect to evidence-based practice which involves the integration of research findings in the form of systematic reviews of empirical evidence (Sandelowski et al. 2006). Synthesising research findings enables the researchers to increase the utility of existing research and potentially improve practice through doing so (Barbour and Barbour 2003).

Systematic literature reviews are associated with a high level of quality and validity in terms of their conclusions by bringing together multiple sources to draw conclusions for practice and policy (Jahan et al. 2016). Thus, due to the methodological diversity of research conducted in this area, this systematic review adopted a mixed methods synthesis. A systematic review of mixed research studies employs a synthesis that will be mixed, which synthesises both qualitative and quantitative data (Sandelowski et al. 2006; Harden 2010).

This review used an integrated methodology which combines both qualitative and quantitative data into a single mixed methods synthesis (Sandelowski et al. 2006). However, it is a requirement that both quantitative and qualitative data are similar enough to be combined into a single synthesis (Harden 2010), which was the case in this review. Therefore, the analytic focus was on converting or 'qualitising' quantitative findings into qualitative form so that they can be combined with the other qualitative data, and subject to qualitative thematic analysis (Sandelowski et al. 2006).

Mixed method synthesis was chosen over a single qualitative or quantitative synthesis because it has the potential to enhance both the significance and utility

of practice by exploring both qualitative and quantitative perspectives within studies (Pope, Mays and Popay 2008; Sandelowski et al. 2006). Moreover, the differences between the studies selected for this review did not warrant a separate qualitative and quantitative analysis (Sandelowski et al. 2006). Thematic analysis was used to analyse the combined data, a method that is recommended when the findings have relevance to practice and policy (Booth et al. 2016).

However, when using mixed method synthesis, it is important to acknowledge that the process is under continual development which can reduce the usability of the method (The Joanna Briggs Institute 2014). Specifically, instead of focusing on the conclusions resulting from the review, much energy is spent critiquing the method employed to derive these conclusions (Harden 2010).

2.4 Results

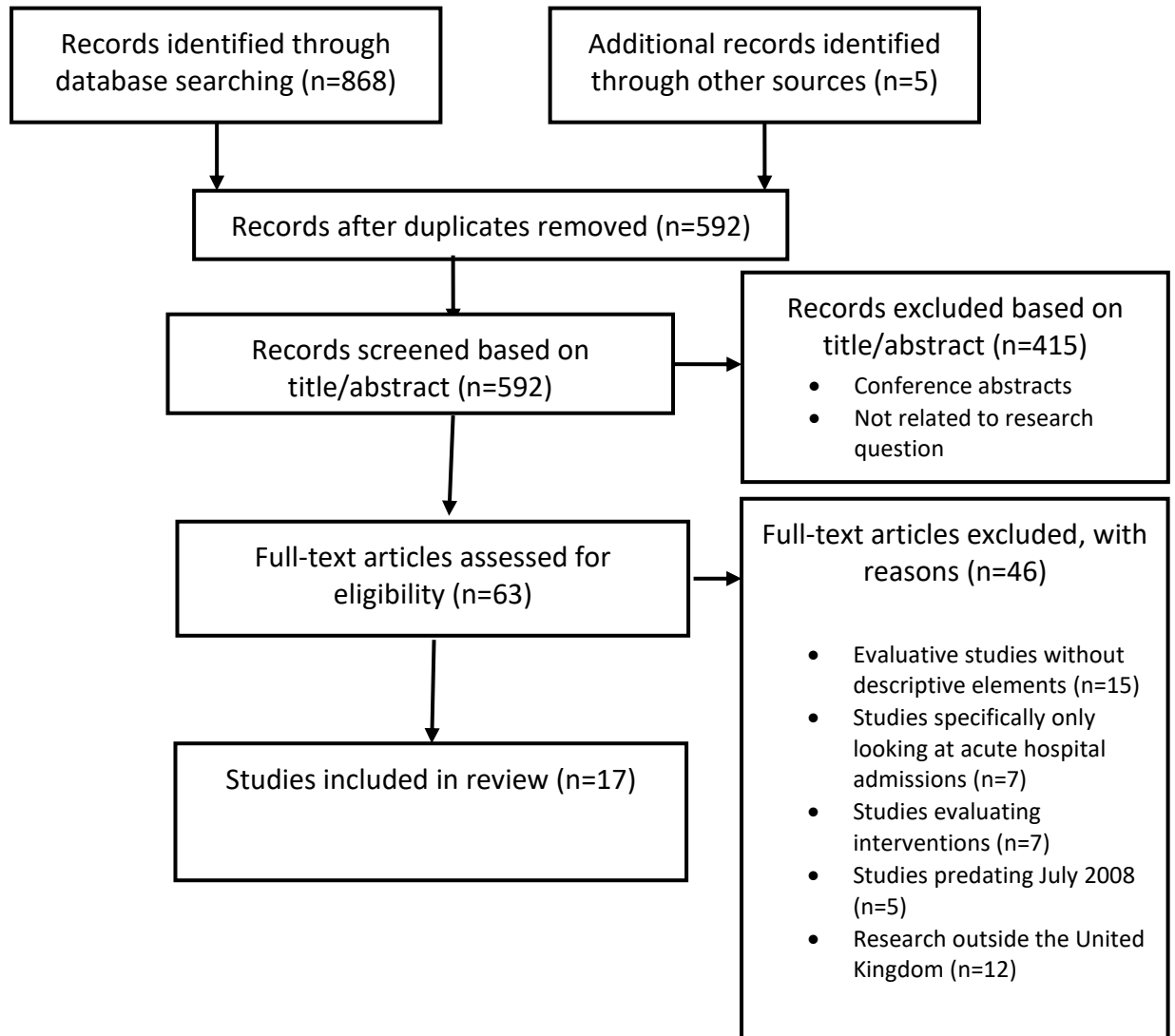
2.4.1 Included studies

A total of 868 records were retrieved through initial database searches, and a further 5 records were uncovered via hand searching and screened for relevance (Figure 2). 276 records were excluded at Stage 1 through duplication, a further 415 records were excluded based on title/abstract screening as they did not focus on the nature of EoLC in UK care homes. The remaining 63 full texts papers were then assessed against inclusion and exclusion criteria (Table 4), resulting in a further 46 papers being excluded (Figure 2). Finally, a total of 17 papers were selected, see appendix: 2 for table of all included articles.

Having constructed a search strategy using the PRISMA guidelines, the selected studies explored and described studies of EoLC in UK residential (n=5) and nursing homes (n=12) (collectively referred to as care homes). Participants mostly included care home staff (registered nurses, care assistants and care home managers) (n=12), however studies also included relatives (n=3), residents (n=3), and bereaved relatives (n=3). It is also worth noting that bereaved relatives' experiences were only explored from the perspective of EoLC in a nursing home. A total of 17 studies were included.

Thematic analysis was used (Sandelowski et al. 2006) to analyse the final selection of papers. Thematic synthesis of identified findings revealed five key themes. These key themes are: the phases of dying during EoLC; EoL preplanning processes; multidisciplinary EoLC provision and holistic EoLC. Figure: 2 below shows the study selection:

Figure 2 Study selection flow chart



2.4.2 The phases of dying during End of Life care

Whilst not described in every study, the phases of dying during EoLC was frequently acknowledged as impacting on the provision and delivery of EoLC (Barclay et al. 2014; Handley et al. 2014; Kinley et al. 2014). The phases of dying during EoLC were described as the different stages or trajectories that residents went through when nearing death. Specifically, the literature described how care home staff sometimes found it difficult to discriminate between residents who were near death and residents who were not. This impacted on EoLC provision by preventing care home staff from planning and 'readying' themselves for the end stages of residents' lives (Handley et al. 2014; Barclay et al. 2014; Kinley et al. 2014). This was often the case for residents on unclear or complex death trajectories (Barclay et al. 2014; Handley et al. 2014; Kinley et al. 2014).

Handley et al. (2014), Barclay et al. (2014) and Kinley et al. (2014) each used similar research methods to examine the phases of dying; however, the scale of each study varied considerably. Barclay et al. (2014) conducted a mixed methods study. Residents, care home staff and healthcare professionals were interviewed, and residents' case notes were reviewed. The study described trajectories to death, specifically how different illness types and death trajectories could influence healthcare staffs' ability to carry out appropriate EoLC. It was observed that certain unexpected lethal events such as having a heart attack or stroke were more likely to result in hospital admissions compared to the longer more gradual declines seen with some cancers and dementia. However, these findings are limited because, despite consent being obtained from 121 residents, the study focused mainly on only 23 participants who died during the 12 months of data collection. Additionally, the study stated that care home staff and healthcare professionals were interviewed but does not detail how many.

Despite their study being small in scale, the results from Barclay et al. (2014) supported similar findings by Handley et al. (2014) and Kinley et al. (2014). Handley et al. (2014) reported how different death trajectories, mostly when unclear or unexpected could impact on care home staffs' decisions, particularly regarding admissions to hospital at the EoL stage of care. The methodology of

Handley et al's study was similar to that used by Barclay et al. (2014). Handley et al. (2014) used a mixed method design utilising interviews and case note reviews. 63 residents, 30 care home staff and 19 NHS healthcare staff from different disciplines were interviewed. Handley et al. who only included care homes without on-site nursing provision, suggested that registered and non-registered care home staff may react differently when making decisions at the end of life stages. However, Kinley et al. (2014) and Barclay et al. (2014) found similar results in care homes with and without on-site nursing.

Kinley et al. (2014) also reported similar findings, describing stages of death which ranged from 'dwelling', which represents slow expected death, to 'sudden', which represents unexpected death. They also noted that these different death trajectories could influence staffs' decision-making ability. Kinley et al's study examined the case notes of residents who had died within 38 care homes over a three-year period, which equated to 2,444 residents, a considerably larger sample than either Barclay et al. (2014) or Handley et al. (2014). They used the case notes to extract specific data, including demographics; diagnoses; use of acute services; place and type of death and use of end-of-life care tools (e.g. advance care plans (ACPs) and EoL documentation).

Each of the three studies had a slightly different way of describing the phases of EoLC. Handley et al. (2014) referred to them as death trajectories ranging from 'clear' to 'unclear'. Barclay et al. (2014) used terms ranging from 'anticipated' to 'unpredictable', while Kinley et al. (2014) described the stages of death ranging from 'dwelling' to 'sudden'. Despite the different terminology, the overarching concept is consistent throughout, which is that the phases of dying experienced during EoLC seem to follow similar patterns ranging from steady decline to a complex and unpredictable trajectory.

All three studies also described how lack of knowledge and awareness of the phases of dying during EoLC can often result in care home staff making 'reactive' or 'in the moment' decisions (Barclay et al. 2014; Handley et al. 2014; Kinley et al. 2014). For example, Barclay et al. (2014) described how, particularly with 'uncertain' or 'unclear' dying trajectories, staff tended to panic when the

resident unexpectedly deteriorated and admitted the resident to hospital, where they died. However, Barclay et al. also reported how multidisciplinary team-working can help provide support in these moments. This multidisciplinary team-work will be discussed in a later theme.

Summary of main findings:

- Different phases/trajectories of death during EoLC were acknowledged in the literature.
- The phases /trajectories of death were recognised as impacting on EoLC.
- Healthcare staffs' understanding and knowledge of these phases was shown to influence decision making when providing EoLC.
- Sudden and unexpected death trajectories often caused care home staff to panic and send residents to hospital at the EoL.

2.4.3 End of life preplanning processes (advance care planning)

Preplanning processes or advance care planning was identified as playing a key role in the provision of EoLC, particularly in aiding staff to adhere to residents' wishes and avoiding unnecessary treatment and admission to hospital at the EoL. For example, advance care plans were used by a range of healthcare staff to communicate residents' preferences, notably preference for place of death, to other healthcare staff and external services, such as GPs and other out of hours services (Livingston et al. 2012; Stone et al. 2013; Froggatt et al. 2009; Goddard et al. 2013; Mathie et al. 2012; Kupeli et al. 2016b; Ong et al. 2011).

Preplanning tools such as advance care plans also appeared to focus outcomes and prepare care home staff for the different phases of dying during EoLC by providing information necessary for appropriate, personalised and planned EoLC. However, it was equally conveyed throughout the literature that engaging in EoL preplanning care discussions with residents and relatives was commonly avoided by care home staff (Handley et al. 2014; Froggatt et al. 2009; Wye et al. 2014; Ong et al. 2011).

Froggatt et al. (2009) found that the use of advance care plans can further help reduce reactive decisions during EoLC. Froggatt et al. (2009) conducted a mixed method study which specifically described and explored the use of advance care plans. Froggatt et al. used questionnaires (n=213) and interviews (n=15) to collect data from care home managers. Thematic analysis of this paper uncovered how advance care planning can help staff focus on structured pre-planned processes or instructions to help inform their EoLC decisions.

Froggatt et al.'s findings were supported by Ong et al. (2011) who conducted a study of eight care homes to explore reasons for admitting residents to hospitals at the end of their lives. The study found that out of 340 patients admitted to hospital from care homes, 40% died within 24 hours, suggesting a high level of less appropriate admissions. The study suggested that poor communication between care home staff and patients and relatives led to a lack of preplanning documentation, which contributed to decisions on admissions at the EoL.

The consequences of not having advance care plans in place was further supported by Kupeli et al. who explored the provision of EoLC in care homes for residents who have dementia. The study interviewed a range of care home staff (n=8) and healthcare staff working within the National Health Service (NHS) (n=6). Results indicated that study participants viewed advance care planning as a method to reduce unnecessary hospital admissions from the care home and unnecessary treatments (Kupeli et al. 2016a). However, Kupeli et al. (2016a) discussed that these positive views and understandings of advance care planning may not be representative of the views of care homes staff throughout the whole care home sector across the country. Furthermore, these findings may not represent the routine practice for the wider care home demographic as the study only explored the care of patients with dementia.

Livingston et al. (2012) exemplified Kupeli et al.'s (2016a) statement that positive practices may not be applied throughout the whole care home sector. Livingston et al. (2012) conducted a qualitative study that involved interviewing 58 care home staff in a 120-bed care home which provided both residential and nursing care. The interviews continued until data saturation was reached. The study

aimed to examine the barriers to and facilitators of good EoLC for residents with dementia. Results found that care staff, nurses and doctors did not see themselves as a team, but rather focused on their separate responsibilities. As a result, they communicated poorly with each other, residents and their families about approaching death. The study also reported that staff members were unaware of the benefits that advance care planning could provide at the end of life for residents and their families. It was also reported that staff were worried about being blamed for the residents' potential death, therefore tended to ignore preplanning information and admit residents to hospital from the care home based on fear of the consequences of not doing so.

Similar findings were evidenced by Stone et al. (2013), who carried out a qualitative descriptive study, interviewing 28 participants. The participants ranged from residents, family members and staff members from three nursing homes. The study described how care home staff would commonly avoid discussions about death and pre-planning, despite residents themselves often being willing to engage in such discussions. They concluded that it was staffs' lack of understanding of advance care planning and pre-planning documentation that led to their lack of engagement. The findings of Stone et al. (2013) are backed up by research projects with larger numbers of participants and data collection sites such as Froggatt et al. (2009), Mitchell and McGreevy (2016) and Handley et al. (2014). Froggatt et al. (2009) suggested that illness type and trajectory may be part of the reason why EoLC discussions did not take place. They discussed how residents with communication and cognition problems often found it hard to engage in EoLC discussions, and how care home staff themselves found it difficult to engage with residents in this category.

Handley et al. (2014) also explored how care home staff engaged in EoL discussions with residents. They found that all staff who were interviewed recognised the importance of initiating pre-planning discussions, particularly regarding preferred place of death. However, despite this understanding of the overall benefit of pre-planning discussions, they reported that care home staff in two homes expressed hesitancy and uncertainty about how to start discussions

with residents about death. Specifically, they were unsure when the right time to start discussions was, and how to involve family members in these discussions. Some care home staff even expressed they felt it was more appropriate for the relatives to discuss death and dying with their loved one rather than getting involved themselves. Moreover, many care home staff hoped that district nurses and GPs would take the lead in such conversations.

This lack of EoLC discussions was also acknowledged by Wye et al. (2014), who conducted a qualitative realist evaluation which aimed to evaluate EoL services in English care homes. Methods of data collection included 15 observations of services, interviews with family carers (n=43) and healthcare professionals (n=105) and analysis of documentation. Their results supported findings that suggest that EoLC discussions are often neglected in practice. Wye et al. noted how time restrictions and poor staffing levels forced care home staff to rush and miss out or avoid vital aspects of EoLC, such as discussions with residents and family about death and dying.

Despite the infrequency of EoLC discussions, Goddard et al. (2013) found that care home staff and community nurses did recognise the importance of establishing EoLC preferences and encouraging advance care planning discussions. However, the study acknowledged it was small in scale and only explored practice in two care homes, which limited the generalizability of its findings. Moreover, Mathie et al. (2012) carried out a qualitative study which interviewed 63 care home residents recruited from 6 UK care homes. The study highlighted the importance of ongoing discussions with care home residents and their relatives, revealing that these discussions can produce opportunities to talk about dying and preplanning. Furthermore, the study revealed that facilitating these discussions earlier rather than later may be important, particularly for residents with dementia (Mathie et al. 2012).

Summary of main findings:

- Evidence suggests that good practice is not always applied throughout the care home sector in the UK.
- It is important to facilitate ongoing discussions with care home residents and their families throughout their time in the care home.
- Engaging in EoLC discussions with residents and family members to gather information for preplanning processes was acknowledged as lacking in care homes.
- The most commonly used preplanning tool appeared to be advance care planning.
- Advance care plans were an effective tool in disseminating vital preferences of residents amongst multidisciplinary healthcare staff and external services.
- Advance care plans improved decision-making by helping staff prepare and plan for unexpected or sudden death trajectories experienced during EoLC.

2.4.4 Multidisciplinary End of life care provision

Multidisciplinary EoLC provision manifested itself as a range of professional groups working together to provide EoLC to residents and their families in care homes. Specifically, it was frequently conveyed that general practitioners (GPs) and district nurses (DNs) worked together with care home staff, residents and families to share and discuss decisions about the management and planning of EoLC. For example, GPs often needed input from DNs, family, care home staff and residents to ascertain key information; e.g. preference for place of death (Kinley et al. 2014; Handley et al. 2014; Barclay et al. 2014; Wye et al. 2014; Froggatt et al. 2009; Livingston et al. 2012; Kupeli et al. 2016b). Despite this multidisciplinary approach, uncertainty was expressed by healthcare staff in relation to who should be involved in EoLC provision and at what stages (Handley et al. 2014; Kupeli et al. 2016b).

Kinley et al's large study which included 38 care homes and analysed the case notes of 2,444 residents found that multidisciplinary working played an important role in EoLC provision. For example, they note that GPs and DNs often relied on each other for information and support. However, the exclusive reliance of this study on case note examination meant that it was unable to capture the in-depth experiences of multidisciplinary care provision. However, Kinley et al's findings were supported by both Barclay et al. (2014) and Handley et al. (2014), who used interviews alongside the examination of case notes.

For example, Barclay et al. (2014) reported how GP support was essential in enabling multidisciplinary collaboration and teamwork. Specifically, care home staff stated that they felt supported by the presence of a GP. This finding was echoed by Handley et al. (2014) and Kinley et al. (2014), who also found that collaborative working helped coordinate decisions and prevent reactive approaches to care by helping care home staff feel supported and part of a team.

Nonetheless, Handley et al. (2014) described how staff members involved in the provision of EoLC were often unclear about who was responsible for providing particular aspects of that care. For example, uncertainty was expressed about who should initiate and be involved in EoL discussions. Handley et al. found that this uncertainty often resulted in residents not being formally diagnosed as nearing the EoL. Uncertainty about who should be involved in EoLC and lack of formal diagnoses for residents nearing the EoL tended to be particularly impactful in a crisis, heavily influencing decisions about whether to admit residents to hospital (Handley et al. 2014). This finding was supported by Froggatt et al. (2009) who observed that care home staff were unclear about who should engage in EoL discussions and when. They recommended a more discriminating approach should be taken in regard to who is responsible for which elements of EoLC discussions. Barclay et al. (2014) and Kinley et al. (2014) noted that clear multidisciplinary working arrangements were essential in preventing unnecessary admissions to acute services.

Wye et al. (2014) also supported the idea that multidisciplinary teamwork is an essential part of EoLC. Despite this, they found that important members of the

team, such as GPs and DNs, who were not based in care homes, were frequently not present at crucial moments, which undermined the level of support that care home staff felt they were given (Barclay et al. 2014; Handley et al. 2014; Kinley et al. 2014; Ong et al. 2011).

Similar findings were highlighted by Kupeli et al. (2016b) who explored the attitudes of a range of healthcare staff (n=14). These professionals ranged from commissioners to home managers. The study revealed a fragmented approach to care. Specifically, poor relationships between care home staff and external healthcare professionals was evidenced. Care home staff who participated in the study commonly highlighted that they felt undervalued by external healthcare professionals (Kupeli et al. 2016b). Handley et al. (2014) also discussed that care home staff often felt their expertise and knowledge was undervalued.

Furthermore, interaction between care home staff and specialist palliative care services appeared to be limited. Lawrence et al. (2011) observed limited access to palliative care services and acknowledged this as a common phenomenon throughout the care home sector. However, where available, it was found that input from specialist palliative care services provided valuable instruction and support, helping to instil staff with the confidence to carry out and manage EoLC themselves. These findings were echoed by Handley et al. (2014) who added that care homes without on-site nursing provision tended to rely more heavily on external palliative care services for support carrying out EoLC. However, Ong et al. (2011) found that access and communication between palliative care services was equally poor in both nursing and residential care homes.

Summary of main findings:

- Multidisciplinary collaboration is an essential part to providing EoLC, however poor relationships between care home staff and external services were highlighted as impacting on Multidisciplinary collaboration.
- Support from a range of professionals, notably GPs and DNs, helped care home staff feel part of a team and better able to make decisions.

- It was noted that staff expressed uncertainty as to who should be involved in EoLC and at what stages, which was found to be particularly impactful in a crisis.
- A lack of interaction between specialist palliative care services and care homes was highlighted.

2.4.5 Holistic and person-centred care at the end of life

It was reported care home staff had the tendency to focus on resident physical needs and overlook their emotional, spiritual and social needs (Kinley et al. 2018; Kupeli et al. 2016b; Lawrence et al. 2011). Moreover, a varied application of person-centred care was noted throughout the literature with evidence of residents' emotional, social and spiritual needs being overlooked for their medical needs (Kinley et al. 2018).

In terms of addressing physical needs it was evidenced that care home staff had a good understanding of the importance of symptom and pain management, particularly in getting the 'balance' correct (Kinley et al. 2018; Kupeli et al. 2016b). Pain and breathing difficulties were identified as the main symptoms prompting medical attention (Kinley et al. 2018). Despite this, Kupeli et al. (2016b) found that care home staff recognised the importance of not 'over-doing' pain relief medication to ensure residents were able to die comfortably and peacefully, placing the resident at the centre of their own care rather than solely focusing on their medical needs. Furthermore, Kinley et al. found that anticipatory medication helped care home staff manage residents' pain in the care home and reducing care home staff's need to contact emergency services which in turn reduced the likelihood of unnecessary admissions to hospital at the EoL. Kupeli et al. also highlighted the importance of timely prescription of anticipatory medication by GPs.

However, it was evident that sometimes the focus on residents' physical needs caused care home staff to overlook the holistic needs of residents limiting their ability to provide person-centred care. Kinley et al. (2018) analysed 869 mixed method questionnaires which were sent to bereaved relatives three to six

months following residents' deaths. While the study found that bereaved relatives rated their experience of EoLC in care home as good, they highlighted that they liked it when they were included in EoLC. Despite this, it was revealed that some care home staff would overlook relatives focusing on resident's needs. Moreover, bereaved relatives expressed disappointment when they were expecting care home staff to attend their loved one's funeral and they did not show up. This highlights the need to integrate relatives into holistic EoLC to a greater extent, and the importance of continuing holistic care after death into bereavement support.

Similarly, variable knowledge of holistic care was reported by Mitchell and McGreevy (2016), who analysed questionnaires completed by 56 care home managers. The study found that managers' overall knowledge of EoLC was variable with an average score of 12.89 out of a possible 20. While managers tended to be knowledgeable in areas such as symptom management and pain-relieving strategies, knowledge was poorer in the social and emotional aspects of EoLC such as person-centeredness and centring care on residents' social, emotional and spiritual needs. Therefore, Mitchell and McGreevy highlighted the need to develop the knowledge and competence of care home managers through education. However, the study only included care home managers, thus the understandings and knowledge of other care home staff such as care assistants and registered nurses was not explored.

Lawrence et al. (2011) conducted a qualitative study using interviews to explore how EoLC was experienced from the perspectives of frontline care home staff (n=23). Participants were recruited from care homes, general hospitals and the community. Similar to Kinley et al. (2018) and Mitchell and McGreevy (2016), Lawrence et al. (2011) revealed variations in approaches and understandings of holistic EoLC. Specifically, although some care staff focused on providing emotional comfort, others listed the practical tasks that had to be completed at that time which was found to inhibit care addressing the social, spiritual and emotional needs of residents. Lawrence et al. (2011) recommended education as

part of care home staffs' training to address the issues and improve the provision of EoLC.

Kupeli et al. (2016b) highlighted that participants described the need for care home staff to adopt a more holistic approach to EoLC. Specifically, care home staff were seen as doing the basic and minimum. It was highlighted that staff would ensure residents are pain free, tidy and had eaten, but the residents were often just left, and their social needs were not met. Therefore, while care home staff addressed the basic physical needs, they did not always provide emotional, social and spiritual care.

In contrast, Goddard et al. (2013) conducted a qualitative study which used interviews to explore the views of care home staff (n=80) on providing EoLC in care homes. The study found that care home staff had a good knowledge of EoLC. The study reported that care home staff understood EoLC as a holistic and person-centred approach supporting the emotional and spiritual needs of residents and their relatives as well as medical and physical support. Moreover, Livingston et al. (2012) reported that care home staff integrated relatives into an holistic approach to EoLC and often developed close relationships throughout the care process and into the bereavement period.

Similarly, Bamford et al. (2018) also identified strong understandings of the importance of holistic and person-centred care within the care home workforce, which involved supporting relatives as well as residents through the emotional, spiritual and social journey of EoLC. These results were expanded on by Lee et al. (2017) who used the same qualitative data set to explore the views of home managers and frontline care home staff in relation to providing EoLC for residents with dementia. Lee et al. reported that values and ethos of individual care homes impacted on the degree of education and training they provided for their staff. For example, in some care homes a holistic approach to care informed not only the care of dying residents, but how they cared for relatives too regardless of workload.

Summary of main findings:

- A holistic approach to EoLC was described as care which is focused on meeting and addressing the physical, social, spiritual and emotional needs of residents as well as supporting relatives
- Care home staff had a tendency to focus on medical and physical needs of residents rather than supporting them emotionally, socially and spiritually.
- The emotional, social and spiritual needs of relatives was sometimes overlooked for the needs of residents.
- Many of the issues identified related to gaps in educational training for care home staff.

2.5 Discussion

This review has provided a comprehensive overview of EoLC in UK care homes and has identified a number of areas of concern in relation to the phases of dying; advance care planning, multidisciplinary care provision and holistic end of life care. Analysis suggests that each of these areas were important in influencing the quality of EoLC in UK care homes through enabling EoLC to be tailored to the needs of residents and their relatives and avoiding unnecessary admissions to hospital at the EoL. However, it is important not to exaggerate the extent of these areas of concern given that the findings referred to variations in care, meaning that examples of high quality EoLC were also noted throughout the literature.

Exploring the factors which can influence care home staff's decisions to contact emergency services during EoLC is important given literature exploring the perspectives and experiences of those working in emergency services suggests that it can often lead to unnecessary admissions at the EoL (Hoare et al. 2018; Wolters et al. 2019). Hoare et al. (2018) and Kupeli et al. (2016b) found that emergency staff contacted by care home staff such as ambulance staff and junior doctors often lack information about residents which often leads to them being unnecessary admitted to hospital at the EoL. Thus, although studies have explored the perspectives of emergency services in relation to unnecessary admissions this review highlights a sparsity of research exploring relatives and care home staff's perspectives and experiences, particularly those in residential care homes.

Nonetheless, this review identified some evidence in relation to the factors which can influence care home staff's choice to contact emergency services during EoLC. Specifically, it was found that residents' conditions and trajectories of decline influenced care home staff's tendency to contact emergency services during EoLC. However, care home staff are not alone in finding difficulty caring effectively for people who have complex EoL trajectories. The lack of prognostic clarity that is associated with chronic life-limiting diseases, such as non-

malignant respiratory disease which are characterised by intermittent acute-on-chronic episodes, entails a significant challenge to EoLC for healthcare professionals, regardless of the care setting or professional background (Crawford et al. 2013; McVeigh et al. 2017). However, findings of this review suggest that care home staff's lack of knowledge and awareness of trajectories was associated with increasing the likelihood of panic and unnecessary admissions to hospital at the EoL (Barclay et al. 2014; Handley et al. 2014). This is important given research has long highlighted the poor education and training opportunities available for care home staff, especially non-registered staff (Spilsbury et al. 2015; Bamford et al. 2018). Nonetheless, how contextual factors associated with care homes such as commercial interests, ownership which outstrip that of acute care (Griffiths et al. 2019) can influence care home staff's access to appropriate EoLC education and training was seldom acknowledged within the included studies.

Addressing these issues is essential given that with the increasing older population residing in UK care homes presenting with multi-morbidities making these trajectories of decline harder to predict and more complex (Julien and Jose-Luis 2011; World Health Organisation 2011). For example, more care home residents now have dementia, frailty and heart and lung diseases meaning there can be more variation and complexities in their trajectories of decline (Schiltz et al. 2018). However, people with single conditions tend to have more predictable trajectories of decline, such as people living with cancer who often experience sudden trajectories of decline (Lunney et al. 2003). In contrast, the trajectory of decline seen with frailty and dementia is much more gradual over a number of years (Murray et al. 2005). Therefore, given the increasing numbers of residents presenting with multiple morbidities, it is important to provide care home staff with the knowledge to support them to better manage the complex needs of those residents dying with multiple conditions (Leadership Alliance for the Care of Dying People 2014; Barclay et al. 2014).

In addition, this review presented evidence which suggests that engagement in advance care planning is far less than it should be. However, there is evidence

that staff members appreciate the benefits of planning, and only avoid engaging in it because they lack the confidence and knowledge to do so. This is important because it means that the problem is not caused by staff resistance to new practice, which implies that if the appropriate education and support is provided, then the successful implementation and sustainability of pre-planning more widely across the sector is achievable. Aside from the lack of training and education, Wye et al. (2014) found that high workloads prevented some staff from engaging in advance care planning as they did not have enough time to get to know residents and develop relationships. Despite this insight there was a notable lack of studies exploring the underlying processes influencing care home staff's engagement in advance care planning with residents and relatives. This is important as research has shown that when residents' wishes are documented and updated, residents are more likely to receive EoLC in their preferred place rather than being unnecessarily given medical treatment at the EoL (Garden et al. 2016; Froggatt et al. 2009; Livingston et al. 2013).

In terms of multidisciplinary care provision, it was highlighted that often collaboration between care home staff and external staff was negatively impacted by a lack of knowledge of each other's roles, key staff not being present in crucial moments and external professionals not listening to or respecting care home staff (Handley et al. 2014; Kinley et al. 2014; Ong et al. 2011). This is important given the findings presented in this review imply that multidisciplinary care provision can influence admissions to hospital at the EoL and ability of care home staff to provide high quality EoLC in situ. Pfaff and Markaki (2017) describe multidisciplinary practice during EoLC as multiple disciplines of health and social care staff working together to facilitate the sharing of knowledge relevant to residents EoLC. Although it has been found that education can help improve multidisciplinary care provision (Badger et al. 2012), Ho et al. (2016) identified that relationships and valued based social issues between services may require more than education.

The final area noted within this review was the application of person-centred holistic care, it was found that most care home staff understood that these care

models involved caring for the whole person (spiritually, emotionally and socially) rather than just focusing on their medical needs (Goddard et al. 2013; Lee et al. 2017). However, good practice in relation to person centred care was not consistent throughout all the studies, for example, it was identified that some care home staff still tended to focus on residents medical and physical needs overlooking their emotional, social and spiritual needs (Kinley et al. 2018; Lawrence et al. 2011). However, it was noted by Lee et al. (2017) that staff turnover and retention were factors which could inhibit the delivery of holistic care. Thus, care home staff working in these conditions may struggle to find the time to spend with residents and provide holistic care.

Improving the application of person-centred care across the UK care home sector is important given that recent evidence suggests that still more needs to be done to gather information on residents to tailor EoLC to their needs and avoid unnecessary admissions to hospital (Hoare et al. 2018; Wolters et al. 2019). Thwaites et al. (2017) conducted a review exploring admissions to hospital. The review highlights that current explanations for unnecessary admissions at the EoL are over-simplified and under-evidenced. Thus, this current review has provided a valuable insight into some of the factors which can influence care home staff's tendency to contact emergency services during EoLC. However, further research into processes behind care home staff's decisions is needed to develop appropriate solutions.

2.5.1 Further research

Findings suggest that problems in the provision of EoLC in UK care homes are persisting, such as care home staff's engagement in advance care planning, multidisciplinary practice, application of person-centred care and unnecessary admissions at the EoL. Thus, the next logical step is to review current interventions designed to improve EoLC in care homes and address these outcomes. At the time of conducting this review no systematic review of interventions designed to improve EoLC existed. Although individual studies have evaluated interventions (Badger et al. 2012; Nash and Fitzpatrick 2015), there was no overall comprehensive review of interventions designed to improve EoLC

in care homes. There was therefore a need for a systematic review of interventions designed to improve EoLC in care home to establish their effectiveness.

Furthermore, the findings of this current review highlighted that there is a lack of research exploring the effects of contextual factors such as high workloads and the financial limitations of care homes in terms of offering education and training opportunities for staff (Lee et al. 2017; Handley et al. 2014; Wye et al. 2014). The findings also highlight a lack of insight into agency and how care home staff's behaviour and actions can impact on outcomes. Thus, rather than simply evaluating effectiveness of interventions by reporting on outcomes, there was a need to identify the mechanisms contained in the interventions designed to change behaviour, the resources and restrictions embedded in the social and organisational context which may inhibit or promote effectiveness, and how stakeholders respond to these mechanisms. Identifying these factors is key to evaluating the effectiveness of interventions designed to improve EoLC and to inform the design of future interventions. Based on this need, a critical realist review was deemed more appropriate than a systematic literature review due to their ability to uncover the underlying processes behind outcomes (Wong et al. 2013; Pawson et al. 2005). Specifically, critical realist reviews enable research to explore and explain outcomes rather than simply identifying them (Pawson and Tilley 1997; Wong et al. 2013).

2.5.2 Limitations

The review being limited to UK studies was a limitation in terms of the research aim; it meant that potential international studies exploring EoLC in multiple countries may have been missed from the review. These studies may have offered more insight into the factors highlighted in this review and potential new themes. Nonetheless, the aim of this review was to develop a comprehensive overview of EoLC in UK care homes. Thus, this review provides an enhanced understanding of the reviewed literature by providing comprehensive information about contemporary EoLC provision, which was missing from the literature prior to this review.

2.6 Conclusion and chapter summary

The findings from this review suggest that more needs to be done to address the persisting issues in the provision of EoLC in UK care homes. Although a number of interventions have been designed to improve EoLC in care homes, at the time of conducting this review there was no comprehensive overview exploring their effectiveness. Thus, there was a clear need for a systematic analysis of current interventions to establish where current interventions are effective, and where improvements need to be made. A critical realist review was chosen over a conventional systematic literature review given its ability to identify and evaluate key process information enabling them to explain outcomes (Wong et al. 2013; Pawson et al. 2005). The following chapter will detail the reasons behind this choice in more depth and presents a critical realist review of interventions designed to improve EoLC in care homes.

The systematic review presented in this chapter was published in the Journal of Research in Nursing (Spacey et al. 2018), see appendix: 1.

3 Critical Realist Review

3.1 Introduction

The demand for high quality end of life care is rising (Bone et al. 2018). Frequently evidenced concerns about the provision of EoLC in care homes relate to engagement in advance care planning, multidisciplinary collaboration and unnecessary admissions to hospital at the EoLC (Mason et al. 2016; Thwaites et al. 2017; Spacey et al., 2018). A number of interventions employing different mechanisms have been designed to address these issues.

This chapter presents a critical realist review which explores the effectiveness of interventions designed to address these issues in relation to EoLC in care homes. This is important as it was highlighted in chapter two that currently no comprehensive review evaluating the effectiveness of interventions designed to improve EoLC exists. The chapter will begin by detailing why a critical realist review was chosen; following this the results, discussions and conclusion of the review are presented. The chapter concludes by identifying a gap in knowledge and need for further research, providing a rationale for this PhD study. This review was published in the Journal of Nursing and Health Sciences (Spacey et al. 2019) (appendix 3).

3.2 Critical realist reviews

In order to achieve the aims and objectives of the review, a systematic critical realist review methodology was chosen. Central to critical realism is a rejection of the assumption that the effectiveness of an intervention is based only on its inherent qualities. Critical realism instead proposes that outcomes result from complex interactions of causal mechanisms which differ according to context (Blackwood et al. 2010). Mechanisms are embedded in both the intervention itself and in the social and organisational context in which the intervention is introduced (in this case care homes). Moreover, these mechanisms are filtered through people, who have an ability to interpret and respond to them

differently. Therefore, evaluation of an intervention’s effectiveness should include how different people experience and respond to it and why (Porter 2015a).

This approach to evaluating the effectiveness of interventions designed to improve EoLC can be summarised using the following formula: intervention mechanisms + contextual mechanisms + human agency = Outcome (see table: 5) (Porter 2015b). Adhering to this formula, the review identifies the mechanisms built into interventions designed to improve EoLC. It then explores how these mechanisms are supported or inhibited by contextual mechanisms within the care home context. These mechanisms are then analysed in terms of evidence about how people experience and respond to them. Finally, the review explores the outcomes that result from the interaction between intervention mechanisms, contextual mechanisms and human response (Porter 2015a; Porter 2015b). This review was designed in accordance with the RAMESES guidelines (Wong et al. 2013).

Table 5 Critical realist review terminology

Terminology	Definition
Intervention mechanisms	The mechanisms contained in interventions that are designed to change the behaviour of those at whom they are targeted.
Contextual mechanisms	The resources and restrictions embedded in the social and organisational context which may inhibit or promote the effectiveness of intervention mechanisms.
Human agency	People’s experiences and interpretations of, and responses to the intervention and contextual mechanisms.
Outcome	The changes in behaviour that result from how people respond to the intervention and contextual mechanisms.

3.3 The review

3.3.1 Aim and objectives

The aim of this review is to describe and explain the effectiveness of interventions designed to support end of life care in care homes. In order to achieve this aim, the following objectives were set:

- To identify theories in the literature about how interventions support EoLC in care homes work (intervention mechanisms).
- To identify how the context of care homes influence how interventions work (contextual mechanisms).
- To identify how the various stakeholders tend to respond to interventions in the context of EoLC in care homes (human agency).
- To identify the outcomes resulting from the interventions.

3.3.2 Search strategy

A rigorous systematic PRISMA approach was used to search for relevant literature to inform the review (Bettany-Saltikov 2012). The search strategy aimed to identify relevant literature that described and evaluated complex interventions designed to support EoLC in care homes. Preliminary searches were conducted using the EBSCO database. This provided insight into key terminology and relevant databases. Following on from the preliminary search, four main databases were systematically searched: ScienceDirect; MEDLINE; PubMed; PsychINFO and CINAHL. These databases were included because they had been identified in the preliminary search as containing the journals relevant to the research topic. The search also included manual searching of the reference lists of papers and hand searching of the grey literature. Boolean techniques (Table: 6) were used to help capture relevant literature (Gerrish and Lathlean 2015).

This search was conducted on 25th August 2018. It included studies relating to EoLC interventions in care homes (both nursing and residential homes), dated from January 2000 to August 2018. Using this search strategy, the key

components were entered into the database with their alternative subject headings (Table: 6). The electronic databases were searched from 2000 to August 2018. No location restrictions were implemented. The purpose of having no location restrictions and a large date range was to include a wider range of relevant empirical studies exploring EoLC interventions in care homes internationally. This was important in identifying supportive mechanisms in use internationally which can be used to improve EoLC.

Table 6 Search terms

Element	Alternatives	
4. End of Life care	Pallia* "Terminal care" Dying Death* Die	
5. "Care Home*"	"Nursing home*" "Nursing care home*" "Residential home*" "Residential care home*" "Long term care facili*"	"Rest home*" "Respite care" "Long-term care*" "Resident*" "Respite care"
6. Intervention*	Strategy* Scheme* Pathway* Procedure* Project* Approach* Framework*	Program* Educat* Communication Plan* Training

Boolean Operators	1. End of Life care OR pallia* OR "Terminal care"
	2. "Care home*" OR "Nursing home*" OR "residential home*" OR "Long-term care*" OR "Nursing care home*" OR "Residential care home*" OR "resident*" OR "Long term care facili*" OR "Rest home*" OR "Respite care"
	3. Intervention* OR Strategy* OR Scheme* OR Pathway* OR Procedure* OR Approach* OR Framework* OR Program* OR Educat* OR Communication OR Plan* OR Training OR
	4. 1 AND 2 AND 3

**(asterisk) signifies any series of characters used in truncation*

3.3.3 Eligibility criteria

The review includes primary research studies evaluating interventions aimed at supporting EoLC in care homes internationally. These included both nursing and residential care homes. Interventions operating in hospices or hospitals were excluded. Policy documents were also excluded.

All included studies were written in English and published from 2000-August 2018. Types of participants included in this review were aged care residents, relatives, bereaved relatives, care home staff including managers, registered nurses and care assistants. Studies which include healthcare professionals alongside the participants listed above were included.

3.3.4 Study screening process

The data extraction was carried out by the researcher and cross-checked by the supervisory team to minimise selection bias (Holloway and Galvin 2017). The initial process chosen for data extraction was title screening. All the articles were assessed and only the titles relevant to the review were selected. However, if

titles did not contain enough information to make a judgment, the articles were included and filtered in later processes. Following title screening, abstract screening commenced, which involved a detailed reading of each abstract. Only abstracts which met the inclusion and exclusion criteria were included (See figure: 3). Again, if the abstract only included limited information, the study was included and filtered in later processes.

3.3.5 Quality appraisal

The Critical Appraisal Skills Programme (CASP) was used to assess the quality of the included studies (CASP 2018). A numerical assignment of 0, 1 or 2 was awarded according to how effectively the study answered the questions (0=no, 1=not sure 2=yes). Qualitative studies were rated out of 20, quantitative studies were rated out of 22, and randomised controlled trials were rated out of 22 and cohort studies were rated out of 24. Quality assessment was carried out by the researcher and cross-checked by the supervisory team. The overall quality of the studies was moderate (appendix 4). No studies were excluded on the grounds of quality assessment as the aim of this review was to uncover theories of change and to capture rich detail on processes which may influence outcomes.

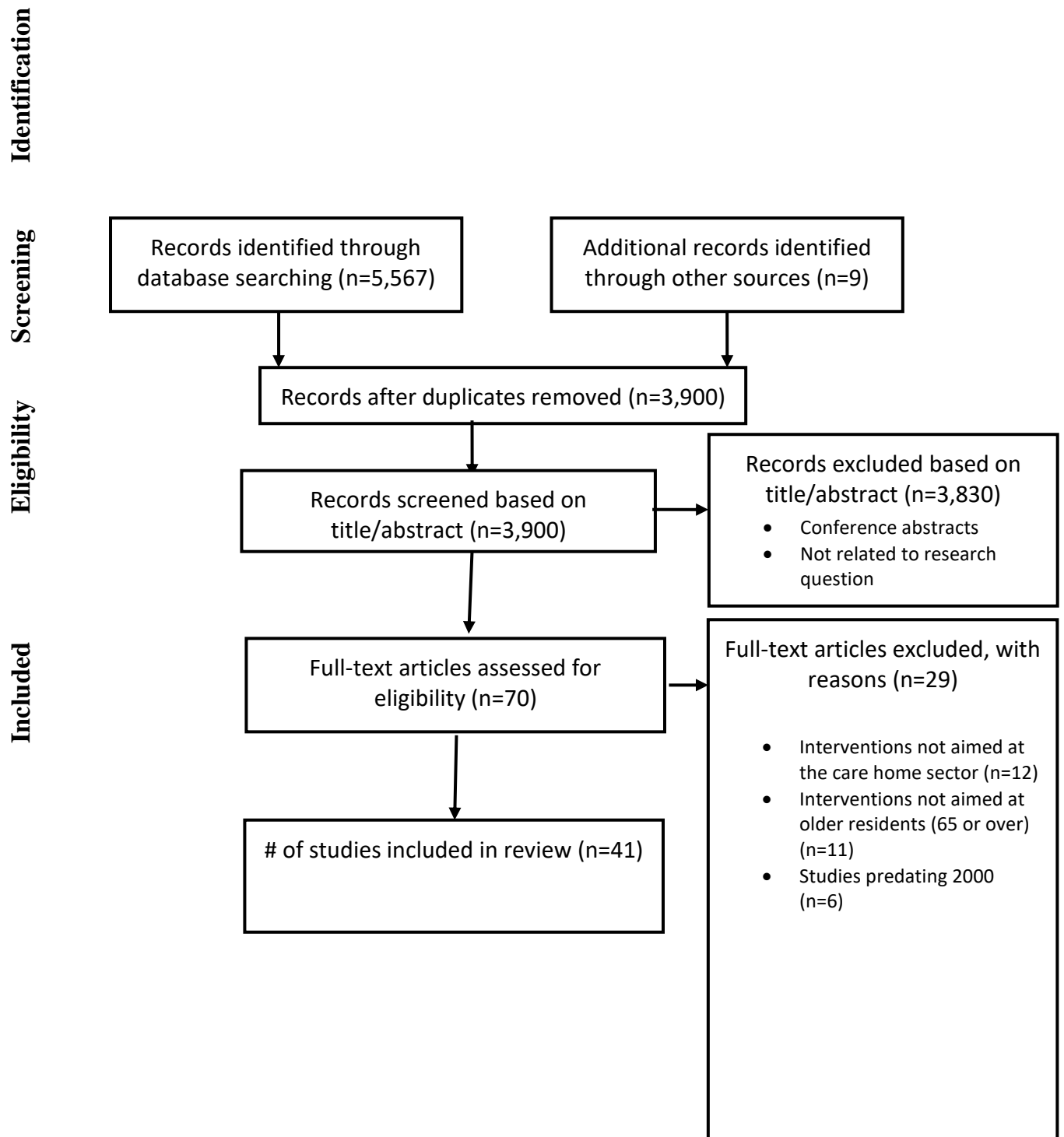
3.3.6 Data extraction and synthesis

Following title and abstract screening, the resultant full-text evidence was read by the researcher and supervisory team. Articles were included if they met the inclusion and exclusion criteria. See figure 1 for a breakdown of the included articles and the process of filtration. The included articles were weighted on their ability to provide rich detail on mechanisms, context and agency and how these processes influence interventions.

Data synthesis and thematic analysis was carried out (Braun and Clarke 2006). The data was coded, and reoccurring patterns were noted and organised into sub-themes and themes. In depth realist synthesis (Wong et al. 2013) was then used to conceptualise and arrange the thematically analysed data in accordance with mechanisms and agency. Independent thematic analysis of selected articles

was carried out by the supervisory team in order to optimise robustness by means of triangulation.

Figure 3 PRISMA Flow Chart – Article flow during the selection process of the studies



3.4 Results

3.4.1 Description of articles

41 studies pertaining to 34 different interventions were included. 26 of the studies were UK-based, 11 from the USA, three from Sweden, and one from Ireland. Interventions were predominately implemented into nursing homes (n=35) with only two studies specifically focusing on residential homes and four focusing on both nursing and residential homes.

3.4.2 Participants

Participants in most studies were care home staff (n=35/41), including care assistants, care home managers, registered nurses, doctors and palliative care specialists. Fewer studies included residents (n=8), relatives (n=4) and bereaved relatives (n=3). Six interventions also involved case note analysis of deceased residents. See summary table of all 41 articles in appendix 4.

3.4.3 Intervention mechanisms

This section identifies the mechanisms contained in the interventions that were designed to change the behaviour of those at whom the intervention was aimed.

All of the included interventions contained mechanisms related to education, although their educational focus differed, including:

- EoL discussions with residents and relatives and advance care planning (n=19);
- Leadership and communication with external services (n=10);
- Overarching principles such as person-centred and dignified EoLC (n=12);
- Education on identifying the signs and symptoms of the EoL (n=4);
- Dementia education (n=5);
- Symptom and pain management (n=8).

As can be seen from the numbers above interventions often included more than one educational focus. For example, some interventions included both education on the overarching principles of EoLC and advanced care planning (Farrington 2014; Cox et al. 2017; Dobie et al. 2016), while others focused on education

related to advanced care planning for residents with dementia (Livingston et al. 2013; Garden et al. 2016). The majority of the educational interventions were designed for registered nursing staff. Seven studies provided education for non-registered care home staff (Baron et al. 2015; Dowding, and Homer 2000; Farrington 2014; Hall et al. 2011; Kunte et al. 2017; Brännström et al. 2016; Kinley et al. 2017), and only one study was explicit about providing education for non-registered staff, such as housekeeping and administrative staff, who did not have a clinical role (Badger et al. 2012).

In most studies (n=35) it was hypothesised that education was the most effective mechanism to address the common issues associated with EoLC. For example, O’Sullivan et al. (2016) identified residents not having advance care plans in place as a problem which persisted because care home staff lacked the knowledge and confidence to engage in advance care planning. Therefore, they used education to provide care home staff with the knowledge and confidence to effectively engage in advance care planning. Similarly, Arcand et al. (2009) noted that communication between care home staff and residents living with dementia was poor due to staffs’ lack of knowledge of the symptoms of dementia. Consequently, education on symptoms of dementia was used to improve staffs’ knowledge and ability to communicate more effectively with residents with dementia.

Education tended to be delivered through either a fixed number of sessions or as an ongoing process. 29 studies evaluated time-limited interventions, while 12 studies evaluated ongoing interventions (see appendix 4 for a comprehensive overview of all interventions). The most significant intervention in the UK, the Gold Standards Framework for Care Homes (GSFCH) offers ongoing access to educational content (Badger et al. 2012; Finucane et al. 2013; Hall et al. 2011). It was hypothesised that the ongoing design enabled the educational content to be updated and evolve over time to meet the changing needs of the care homes and their workforce (Kinley et al. 2017; Badger et al. 2012). However, most interventions were designed to deliver a fixed amount or length of education (n=29) with the shortest being one away day (Dobie et al. 2016) and the longest

being 35 workshops over two years (Finucane et al. 2013). For example, Livingston et al. (2013) delivered ten education sessions, while Cox et al. (2017) delivered 18 sessions. Only one study provided a clear rationale for the length of delivery. Dobie et al. (2016) delivered education over a one-day period, justifying this length on the grounds of the limited time available to staff for EoLC training.

While there was a lack of explicit rationales for the length of delivery, the mode of education delivery appeared to influence length. Modes of delivery included workshops, peer-training, online modules, lectures, action learning and away days. Peer-training and action learning tended to be delivered on a longer and more ongoing basis (Finucane et al. 2013; O'Brien et al. 2016; Kinley et al. 2014; Hockley et al. 2005). Conversely, interventions consisting of lectures and away-days tended to be 'short lived' in comparison (Dobie et al. 2016; Parks et al. 2005; Wen et al. 2012; Garden et al. 2016; Cox et al. 2017; Livingston et al. 2013). The use of educational workshops varied in length from three workshops (Mayrhofer et al. 2016) to 35 workshops (Finucane et al. 2013).

Some interventions used multiple modes of delivery; for example, delivering knowledge to a small group of staff via lectures and workshops, then expecting the staff to cascade their knowledge down to the wider workforce through shadowing (O'Brien et al. 2016; Finucane et al. 2013; Mayrhofer et al. 2016). For example, O'Brien et al. (2016) educated a small group of staff through workshops, who then cascaded their knowledge to the wider care home workforce through getting other staff to shadow them. However, the number of workshops and lectures were often limited, with some only being delivered once which was found to have an impact on the quality and quantity of the knowledge cascaded to the workforce (Kinley et al. 2018; Finucane et al. 2013; O'Brien et al. 2016).

Many interventions contained mechanisms additional to education. Such as those aiming to improve collaborations with external services via collaborative meetings (n=9). Non-educational mechanisms included setting up and

documenting multi-disciplinary meetings between care homes and external services such as GP services and hospice staff (Badger et al. 2012; Casarett et al. 2005; Froggatt et al. 2017b; Livingston et al. 2013; Kinley et al. 2014; Wen et al. 2013). For example, Badger et al. (2012) describes that the GSFCH involved regular meetings between care home staff and specialist palliative care nurses, hypothesising that the meetings would enable support to become freely available to care homes rather than them having to actively seek it. Although not clear in all studies, it was generally believed that enhancing the quantity and quality of the interactions between care homes and external services would enable them to share knowledge and experiences (Badger et al. 2012; Cox et al. 2017).

Other non-educational mechanisms included the introduction of formalised reflective practice sessions introduced through supervision which gave staff the opportunity to reflect on their practice or an event such as a death. However, only three studies briefly discussed reflection, all involving reflective sessions with home managers (Hockley et al. 2005; Nash and Fitzpatrick 2015; Cox et al. 2017; Hewison, Badger and Swani 2011). These studies reported that reflection encouraged staff to understand what they did well and how they could improve their EoLC delivery. However, there was no rationale for confining the facilitation of reflection to managers.

The introduction of external professionals into care homes to help facilitate and support interventions was a common mechanism used (Kinley et al. 2014; Temkin-Greener et al. 2017; Finucane et al. 2013; Kinley et al. 2018). For example, Finucane et al. (2013) introduced two palliative care specialist nurses to facilitate training and to support care home staff deliver EoLC and help with aspects such as collaboration. Similarly, Temkin-Greener et al. (2017) introduced palliative care teams into care homes to support and educate care home staff. It was hypothesised that experienced external professionals would support and pass on knowledge to care home staff.

Some studies (N=7) evaluated multicomponent interventions with three or more mechanisms. The most prominent being the GSFCH which provides educational content, combined with multidisciplinary meetings and reflection sessions (Nash and Fitzpatrick 2015; Kinley et al. 2014; Badger et al. 2012; Hall et al. 2011). However, information on the interactions between these multiple mechanisms was missing from the literature. Most of the interventions in this review were smaller and employed mechanisms in isolation. The most frequent example of this phenomenon was the use of standalone educational interventions (Dobie et al. 2016; Wen et al. 2013; Arcand et al. 2009; Braun et al. 2005; Baron et al. 2015). The reasons for this will be discussed further in the following section.

3.4.4 Contextual mechanisms

Contextual mechanisms represent the resources and restrictions embedded in the social and organisational context which may inhibit or promote the effectiveness of intervention mechanisms.

While the rationale for only including a limited amount of education sessions and the lack of multicomponent interventions was not clear in any of the included studies, two studies implied that it was to ensure that interventions were manageable for the care home, many of which were small organisations with limited funding and resources. The implication was that the resource and financial capabilities of care homes impacted on their ability to engage with interventions requiring extended time and resources (Kinley et al. 2017; Hewison, Badger and Swani 2011). Thus, Hewison, Badger and Swani's (2011) intervention was terminated due to the lack of time and resources of care home managers to engage in 'active learning meetings'. Furthermore, a number of other studies noted that existing work schedules of care home staff impacted on sustainability. It was found that care home staff often had to create time to engage with an intervention (Braun and Zir 2005; Waldron et al. 2008; Phillips et al. 2008; Mayrhofer et al. 2016; McGlade et al. 2017; Froggatt et al. 2017b), and

lack of time for staff to engage with the interventions was a common barrier to implementing and maintaining effective change (Wen et al. 2013). For example, Dobie et al. (2016) only delivered one study day as it was the only period of time managers and staff felt they could accommodate. However, in the majority of studies the rationale for the length and mode of education was absent. Resource issues also affected researchers who implemented interventions. One study reported they had to abandon the intervention because it had not secured the research funding to continue (Temkin-Greener et al. 2017).

Kinley et al. (2017) found that delivering a small amount of education sessions was not effective in care homes with high staff turnover, as knowledge and skills were lost when staff left. Kinley et al. (2017) identified ongoing education as necessary to sustaining and embedding knowledge in contexts where staff turnover is high. This was supported by an earlier study conducted by Kinley et al. (2014) which found that the three care homes included in the intervention which reported increases in hospital deaths, experienced managerial change.

The organisational structures of care homes were similar. Specifically, the size of the workforce was often small, meaning that interventions such as education sessions could reach and impact the whole workforce relatively easily and quickly (Nash and Fitzpatrick 2015; Hewison, Badger and Swani 2011; Hall et al. 2011; Mayrhofer et al. 2016). However, the small workforce also posed problems because knowledge and skills tended to be concentrated in fewer individuals, so when those individuals left the care home, their repository of knowledge was lost (Finucane et al. 2013; Kinley et al. 2014). This was a particular issue for interventions which cascaded knowledge from a few individuals to the wider workforce, as staff who were 'nominated' to cascade knowledge frequently left the care homes after receiving education and training and were therefore, not available to support the wider care home workforce (Finucane et al. 2013; O'Sullivan et al. 2016; Mayrhofer et al. 2016). For example, Finucane et al. (2013)

noted that only three of the original 16 key nominated care home staff remained following the study.

Despite similarities, there were also differences noted in the organisational structure of care homes. Kinley et al. (2017) highlighted that, because residential homes did not employ registered nurses, they tended to have an increased reliance on GPs and district nurses (Kinley et al. 2017). This meant that education content aimed at residential care home staff tended to be related to collaboration and was non-specialist to meet the need of non-registered care home staff (O'Brien et al. 2016; Mayrhofer et al. 2016; McGlade et al. 2017; Dobie et al. 2016; Kinley et al. 2017).

The workloads of those at whom the interventions were aimed was found to influence their ability to engage in interventions. In particular, Hewison, Badger and Swani (2011) and Wen et al. (2013) set up collaborative meetings which gave care home managers the opportunity to discuss common issues related to EoLC and share experiences and knowledge. However, the lack of time of home managers negatively influenced their engagement in the meetings (Hewison, Badger and Swani 2011; Wen et al. 2013). For example, Hewison, Badger and Swani (2011) reported that all 22 care homes involved in the intervention decided not to continue with the meetings due to the high workloads of their managers, thus the intervention was not sustained.

3.4.5 Human agency

This section will explore human agency which represents stakeholders' responses, interpretations and experiences of the contextual and intervention mechanisms.

Care home staff involved in the interventions were frequently described as being passionate and engaged and driven by a desire to improve the experiences of families and residents receiving EoLC (Braun and Zir 2005; Casarett et al. 2005; Dobie et al. 2016; Farrington 2014; Froggatt et al. 2017b). It appeared that this passion also came from a desire for self-improvement through knowledge and

learning (Dobie et al. 2016; Mayrhofer et al. 2016; Froggatt 2000; Keay et al. 2003; Kunte et al. 2017).

Nonetheless, motivation did not always translate into engagement. Specifically, studies reported that the ability of care home staff to cascade knowledge varied (O'Brien et al. 2016; Finucane et al. 2013; Mayrhofer et al. 2016). For instance, it was found that care home staff were often too junior or not ready to receive training at a particular level, and thus were unable to effectively cascade knowledge to other care home staff because they did not have the confidence and knowledge to do so (O'Brien et al. 2016). This may be a particular issue for homes with high staff turnover, which leads to an increased reliance on junior or new staff (O'Brien et al. 2016; Kinley et al. 2017; Mayrhofer et al. 2016).

At a more senior level, lack of motivation may result from less commitment being given to EoLC in comparison to other activities. Thus, for example, the lack of engagement of care home managers in collaborative meetings due to lack of available time, also indicates that they gave EoLC a lower priority than other aspects of their role.

Additionally, some care staff found the application of what they learnt into real-world practice emotionally difficult (Mayrhofer et al. 2016; Braun and Zir 2005; McGlade et al. 2017; Cox et al. 2017). For example, Hockley et al. (2005) found that in most of the eight care homes involved in the intervention, a culture of dealing covertly with death and dying reduced staffs' confidence to discuss death with residents. Similarly, despite going through education and training on advance care planning and engaging in conversations about dying, some staff still found talking about dying challenging (Cronfalk et al. 2015; Mayrhofer et al. 2016; Braun and Zir 2005; Temkin-Greener et al. 2017; McGlade et al. 2017). It was reported that staffs' personal backgrounds and experiences could influence their ability to discuss dying with residents and relatives (Hall et al. 2001; Cox et al. 2017). For example, Hall et al. (2011) found that some staffs' personal background and culture caused them to look at death as a taboo subject.

Similarly, residents and relatives also tended to experience and react to dying and EoLC differently, which again appeared to be influenced by their personal background and experiences. For example, some relatives were reported as not supporting the notion of planning for their relatives' death (Livingston et al. 2013; Casarett et al. 2005; Hall et al. 2011). This conflict tended to arise when relatives were 'not ready', 'not accepting', or 'not understanding' about approaching death, and often would not 'give up' (Nash and Fitzpatrick 2015).

As well as conflict within care homes, conflict was also apparent between care home staff and external services. Despite intervention mechanisms to encourage collaboration, external services staff, particularly out of hours (OOH) services such as OOH GPs were in some cases unwilling to cooperate due to negative attitudes toward care home staff (Badger et al. 2012; Kinley et al. 2014; Ashton et al. 2010). For instance, it was reported that OOH service staff tended not to advise or listen to care homes, but instead overrode their decisions (with a belief that they knew better than the care home), with a tendency to admit residents living with frailty to hospital at the end of their lives (Badger et al. 2012; Kinley et al. 2014). However, by way of qualification, it should be noted that these studies relied on information from care home staff and did not include the perspectives of OOH staff.

3.4.6 Outcomes

Outcome measures can be split into two main categories: objective and self-reported outcomes. Objective and the most commonly measured outcomes used to determine high quality EoLC included the numbers of advance care plans completed and reductions in unnecessary admissions to hospital at the EoL (place of death). Less common objective outcome measures included numbers of residents with Cardiopulmonary resuscitation orders in place. Self-reported outcomes included levels of confidence and knowledge when delivering EoLC.

Subjective self-reported outcome measures such as self-proclaimed improvements in knowledge and confidence tended to be positive, while

objective outcome measures such as numbers of unnecessary admissions and place of death were more mixed and poorer in comparison. An example of objective measurement can be found in Temkin-Greener et al.'s (2017) evaluation of the introduction of palliative care teams into care homes to support and educate care home staff. No statistically significant differences between the treatment and the control arms in any quality measures (which included numbers of unnecessary admissions to hospital at the EoL and advance care planning documentation in place) were reported during three years of their intervention.

In contrast, results relating to subjective outcome measures of ongoing interventions tended to be more positive. For example, O'Brien et al.'s (2016) evaluation of the "six steps to success" intervention reported improvements in staff confidence and knowledge. Similarly, studies evaluating the GSFCH reported positive subjective outcome measures such as perceived benefits and improvements in knowledge and confidence delivering EoLC (Hall et al. 2011; Badger et al. 2012; Nash and Fitzpatrick 2015). Nonetheless, Kinley et al. (2014) and Hockley et al. (2005) both reported increases in advance care planning documentation during the GSFCH programme. However, Kinley et al. (2014) reported that high facilitation such as consistent managerial support and leadership was needed to maintain these outcomes. In homes which were not exposed to high facilitation only 7% (n=1/11) completed the GSFCH programme through to accreditation.

Differences in outcomes were also related to the time points at which they were measured. It was common practice to confine measurement of outcomes to the period during which interventions were running or shortly after their completion (Dobie et al. 2016; Baron et al. 2015; Farrington 2014; Finucane et al. 2013; Wen et al. 2012; Mayrhofer et al. 2016; Hewison, Badger and Swani 2011; Cox et al. 2017; Braun and Zir 2005). This is significant because studies measuring immediate outcomes tended to report more positive outcomes than studies measuring longer term outcomes. For example, Farrington (2014) reported improvements in care home staff's confidence, in symptom management and

communication after only six modules of education, each taking an hour to complete. Moreover, Dobie et al. (2016) reported increases in staff knowledge and confidence following only one study day. Short-term improvements were also noted in objective measurements. O'Sullivan et al. (2016) implemented a palliative care educational programme consisting of four half-day workshops for 90 staff in three nursing homes. Immediate outcomes suggested improved staff knowledge and confidence with higher uptake of advance care plans, resulting in a decreased percentage of hospital deaths from 22.9% to 8.4%, $z = 3.22$, $p = 0.001$.

However, the sustainability of these interventions over time was rarely established because few of the included studies evaluated the effectiveness of interventions for long beyond the time of implementation or completion. This is important because most interventions ($n=29$) delivered time-limited or brief stints of education. For example, Hewison, Badger and Swani (2011) facilitated collaborative meetings with care home managers over an eight-month period. Despite initially reporting positive outcomes (such as the more consistent use of advance care plans) during the running period of the intervention, it was reported that attendance rates dropped, and it was known that the collaborative meetings were not continued after the intervention period. However, Hewison, Badger and Swani did not explore post-intervention outcomes to assess the sustainability of outcomes.

The few studies which measured outcome over longer periods of time reported poorer outcomes over time, even when the intervention was still in place. For example, Finucane et al. (2013) reported that, following the delivery of 35 workshops over two years, the proportion of deceased residents with advanced care plans in place, and the proportion of those with Do Not Attempt Cardiopulmonary Resuscitation (CPR) documentation in place increased but, reductions in unnecessary admissions from care homes at the EoL to hospitals were not sustained. However, because of the lack of process data included in this study it was unclear why these outcomes were not sustained.

Subjective and objective outcome measures were reported in studies evaluating multicomponent interventions. Compared to isolated educational interventions, studies evaluating multicomponent interventions tended to report more positive outcomes. For example, results highlight increases in advance care plans as well as increases in care home staff's perceived knowledge and confidence, and improved collaboration and networking between services to preventing unnecessary admissions to hospital at the EoL (Hall et al. 2011; Badger et al. 2012; Kingly et al. 2014; Nash and Fitzpatrick 2015). However, given the lack of longitudinal data, the sustainability of these outcomes is uncertain.

In sum, outcomes were generally measured immediately after or during the running period of time-limited interventions, which tended to produce better outcomes compared to studies which measured outcomes over longer periods of time. The most common outcome measures were number of advance care plans in place and reductions in unnecessary admissions to hospital at the EoL. However, subjective outcomes measures such as self-reported increases in confidence tended to be more positive in comparison to objective measures. Moreover, because most studies reported outcome measures over short periods of time, sustainability of outcomes is unclear, and the effectiveness of most interventions may not have been as great as has sometimes been represented.

3.5 Discussion

This review has identified that the most common outcomes used to determine success and high quality EoLC in care homes were; numbers of advance care plans and unnecessary admissions to hospital at the EoL (Finucane et al. 2013; Kinley et al. 2014; Cox et al. 2017; Temkin-Greener et al. 2017). These outcomes are also a common feature of UK policy initiatives (DH 2008; DH 2014). However, the data collated in this review indicates that due to the lack of understanding and exploration of the processes behind these outcomes in current literature, interventions seldom sustain positive outcomes (Finucane et al. 2013; Temkin-Greener et al. 2017).

While some information about the processes involved in the interventions was apparent in all of the included studies, explicit identification of the hypothesised intervention mechanisms, the influence of context on the interventions' effectiveness, or of the responses of those involved was often absent. These findings are supported by wider research which suggests that clear descriptions of intervention theory and identification of processes are lacking in current research approaches (Moore et al. 2015).

Despite the sparsity of process data, this review was still able to provide some useful insights which suggest that outcomes were influenced by intervention mechanisms, contextual mechanisms and human agency. By exploring the interrelation between mechanisms, agency and outcomes, a number of key insights were identified. It was revealed that, despite the effectiveness of multicompetent interventions, they were less frequently delivered than interventions using isolated components such as education only. This suggests that contextual mechanisms such as limited resources, high workloads and high staff turnover led to the adoption of single 'short-lived' interventions on pragmatic grounds rather than effectiveness criteria. This hypothesis is reinforced by the fact that the pragmatic adoption of less effective interventions in the care of this population is not confined to end-of-life care. Thus, for example, Bunn et al.'s (2015) systematic review of hydration interventions for

people with dementia found that, while multicomponent interventions were more effective, they were rarely delivered.

In an attempt to meet the contextual needs of care homes, education was delivered in a number of different ways which impacted on effectiveness. Although education delivery has been identified as an effective method to address many of the problems highlighted with current EoLC provision in care homes (Nevis 2014), this review uncovered a huge variation in the 'dosage' entailed in different educational interventions. This disparate approach towards EoLC education and training for care home staff is unsurprising given that in most countries, including the UK, there are no specific recommendations about the appropriate amount of formal EoLC education (Froggatt et al. 2017a; WHO 2011; DH 2008). At present, there is a lack of policy guidance for care homes on how much and which mode of education delivery should be used to deliver EoLC education.

Moreover, studies did not evaluate their effectiveness long enough after the education had been completed to assess the sustainability of outcomes. Studies evaluating ongoing education interventions tended to measure outcomes over longer time periods (Temkin-Greener et al. 2017; Kinley et al. 2014; Badger et al. 2012). These showed some evidence that effectiveness diminished over time according to some indicators (Temkin-Greener et al. 2017; Kinley et al. 2014; Finucane et al. 2013). However, there is insufficient evidence to draw definite conclusions about the relationship between length of education delivery and sustainability.

High staff turnover was the most common contextual mechanism reported in the studies as compromising the effectiveness of interventions (Badger et al. 2012; Nash and Fitzpatrick 2015; Kinley et al. 2014; Hewison, Badger and Swani 2011). However, although staff turnover in care homes across the globe is typically high (Halter et al. 2017; Tilden et al. 2012), Gatherum (2017) provides evidence which suggests that often staff who leave care homes tend not to leave the social care sector but move to other nearby homes. This suggests that interventions delivered in multiple homes could be more sustainable by virtue of having cross-

pollination of staff. However, although some studies in this review included up to 37 homes, most interventions were implemented in fewer than five care homes (see table 3).

Despite acknowledging workloads and high staff turnover, the included studies did not reflect the diverse context of care homes. For example, one important contextual factor that has not been given adequate attention is the type of care home. Most interventions were designed for nursing homes (n=35) with only two studies focusing only on residential homes (Brännström et al. 2016; Kinley et al. 2017) and four focusing on both nursing and residential homes (O'Brien et al. 2016; Mayrhofer et al. 2016; McGlade et al. 2017; Cox et al. 2017). This lack of attention to the specific context of residential homes is concerning, given that they usually do not have on-site registered nursing staff and, as a consequence have to rely more on external support from GPs, hospital staff and visits from district nurses (Handley et al. 2014; Davies et al. 2011). Moreover, most interventions were designed for registered nursing staff, while far fewer offered education to non-registered care home staff (Baron et al. 2015; Dowding, and Homer 2000; Farrington 2014; Hall et al. 2011; Kunte et al. 2017), and even less to those such as housekeeping and administrative staff, who did not have a clinical patient care role (Badger et al. 2012). There is therefore a need to better illustrate the diverse contextual mechanisms present in care homes, and the potential impact on the effectiveness of interventions in future studies.

Despite limited evidence, this review was able to identify how those involved tended to respond to the intervention and contextual mechanisms. One aspect that the studies are largely agreed upon is that motivation is not a significant problem. Evidence suggests the majority of care home staff were highly engaged and motivated to provide high quality EoLC (Braun and Zir 2005; Casarett et al. 2005; Dobie et al. 2016; Farrington 2014; Froggatt et al. 2017b). This finding appears to be consistent across other healthcare settings such as hospices and hospitals, which report that delivering EoLC can be rewarding and satisfying if done well (Gillman et al. 2012; Hospice UK 2015).

Nonetheless, results indicated that while care home staff found delivering EoLC rewarding they also found it emotionally challenging, especially in relation to discussing death and dying (Hall et al. 2011; Braun and Zir 2005; Hockley et al. 2005; Cox et al. 2017). These findings are corroborated by existing literature which found emotional aspects of EoLC were often heightened by close attachments with residents and relatives (Vandrevala et al. 2017). Few interventions focused on supporting the mental health and wellbeing of care home staff delivering EoLC.

Explicit detail on how those involved responded to interventions was largely absent. Despite all the interventions aiming to improve and support the EoLC experience for service users, few studies explored perceptions and interpretations of service users or their close others. This lack of insight is significant, given the increasing acceptance that EoLC should be everyone's business (RCP 2015; RCP 2016), and that a wider range of people should be involved and given a voice in service provision and improvement (RCP 2015). These findings are corroborated by a recent systematic literature review conducted by Greenwood et al. (2018), which explored the experiences of older people in care homes and found a dearth of qualitative research from the perspectives of those most closely involved in older people's death. Moreover, the lack of this perspective was particularly evident within residential care homes (Greenwood et al. 2018).

This review has provided a useful insight into the impact of intervention mechanisms, contextual mechanisms and human agency on outcomes from interventions designed to improve EoLC in care homes. However, this insight was limited by the sparsity of research exploring and documenting these underlying processes. Findings indicate that a lack of knowledge in relation to processes behind outcomes has limited the effectiveness and design of current interventions in this area. Given this lack of understanding and its apparent effect, there a need for further critical realist-based research exploring underlying processes behind these outcomes.

3.5.1 Limitations

The strength of findings in this review are dependent upon the strengths of outcomes findings in the studies it reviewed, along with the comprehensiveness of their information about hypothesised intervention mechanisms, contextual mechanisms and human response. The weaknesses displayed by those studies in these areas are therefore reflected here. For example, care homes were often viewed as a singular context with little evidence about resident populations, funding structures or locations of the homes and how these factors influence how care is delivered and received.

The researcher recognizes that restricting the search to English language articles may mean some relevant papers may have been missed. In addition, a large proportion of included studies were conducted in the United Kingdom (n=26), which may limit the transferability of the findings and recommendations.

3.6 Conclusion

The most obvious conclusions from this review relate to the gaps in the current literature. In terms of outcomes, much of the current data is neither robust enough nor sufficiently longitudinal to draw conclusions about the effectiveness or sustainability of the interventions that have been developed. In terms of inputs, there is a paucity of information about the rationale behind the selection of active components in the interventions, about the most salient contextual factors affecting effectiveness, and of the responses to the interventions by stakeholding actors.

Nonetheless, the review does indicate some of the issues that are required to be dealt with in order to improve the effectiveness and sustainability of interventions designed to improve EoLC in care homes. It was consistently found that high staff turnover and care home staffs' varying enthusiasm and readiness to accept change impacted on the sustainability and embedding of change into practice. Specifically, education delivery, which was too demanding on resources and time, was often not sustained by care homes. However, these contextual barriers were generally only identified in studies evaluating outcomes over

longer periods of time. Studies reporting on immediate outcomes following an intervention tended to report more positive outcomes.

In summation, if future interventions are to ensure effective and sustainable delivery of high quality EoLC across the care home sector, their design will need to be based on an explicit and evidence-based hypothesized mechanism of the change mechanisms they contain. They will also need to take into account the influence of contexts in the interventions will operate, and the attitudes and responses of those whom they will affect.

3.7 Formulation of research aim and objectives

It is predicated that care homes will become the most common place of death in the UK (Bone et al. 2018), and all residents in care home are entitled to dignified death and EoLC centred and personalised to their individual needs (DH 2014; DH 2008; Institute for Public Policy Research 2018). Advance care planning is one method used to achieve these care goals, which allows care home staff to document, share and update residents' preferences based on their own needs and wishes, and if permitted their relatives (LACDP 2014). Although not true for all residents, survey results have suggested that most residents choose to die in the familiar surroundings of a care home surrounded by their family rather than in an acute hospital setting (ONS 2016; National End of Life Care Intelligence Network 2010).

Despite this, the systematic literature review presented in chapter two highlighted variable engagement in advance care planning and persisting levels of unnecessary admissions from care homes to hospital at the EoL within the UK sector (Spacey et al. 2018). The critical realist review presented in chapter three identified that although the most common outcome measures for interventions designed to improve EoLC were numbers of advance care plans and reductions in unnecessary admissions to hospital at the EoL, there was sparsity of research exploring the processes behind these outcomes. Specifically, the review identified that currently evidence about the rationale behind intervention

design, the effect of context, and the response of stakeholders is sparse. This means that the impact of these factors on outcomes has thus far not been adequately established. Evidence presented in the realist review suggests that this gap in knowledge has limited the effectiveness of interventions designed to achieve these outcomes and improve end of life care in care homes (Spacey et al. 2019).

Consequently, research designed to uncover how these factors support or inhibit high quality EoLC, is needed in order to provide an adequate foundation for future interventions designed to achieve and sustain these outcomes to support the delivery of high quality EoLC in care homes. The aim of this study was therefore to inform the design and development of interventions capable of supporting the delivery of high-quality end-of-life care in UK care homes. This thesis used critical realist evaluation to address this gap in knowledge and achieve the research aim.

Both reviews identified a sparsity of current research exploring registered, and non-registered care home staff's influence on and experiences of outcomes related to unnecessary admissions and advance care planning and advance care planning. In particular, it was apparent that research capturing the views and experiences of those care home staff working in residential homes was sparse with only six studies examining interventions in residential homes. As a result, the contextual differences between residential and nursing homes and their impact on EoLC is largely overlooked. Thus, more research in residential homes is needed in order to inform the development of future interventions based on the needs and issues of EoLC in that context. Additionally, both reviews uncovered a lack of research incorporating the perspectives and viewpoints of care home staff with non-formal caring roles. This is important given findings suggest that they play a part of the delivery of EoLC.

As well as care home staff, both reviews identified a lack of perspective and insight from bereaved relatives and the influence they may have on outcomes related to high quality EoLC. Thus, as death changes the lives of significant

others, it is recommended that the viewpoint of those closest to dying residents are included, as not only are their viewpoints important and underrepresented but can act as a proxy for dying residents' experiences.

Based on this synthesis the following research aim and objectives were formulated.

The **aim** of the empirical component of this study was to inform the design and development of interventions capable of supporting the delivery of high-quality end-of-life care in UK care homes. To achieve this aim, the following objectives were set:

- To identify current intervention mechanisms designed to improve the delivery of high-quality end of life care in care homes.
- To identify the contextual mechanisms which inhibit or promote the effectiveness of the intervention mechanisms.
- To identify how stakeholders respond to the identified mechanisms (Human agency).
- To develop intervention theories which incorporate these findings to support the delivery of high-quality end of life care in UK care homes.

3.8 Chapter summary

This chapter has presented a critical realist review on interventions designed to improve EoLC in care homes. The chapter began by presenting a rationale for the review and the methods used within the review. The results of the review were then presented along with the discussion and conclusion highlighting a gap in knowledge and need for further research. The chapter ended by formulating the research aim and objectives for the next stage of the study; empirical data collection. The following chapter will present the methodology chosen to achieve the research aim and objectives.

4 Methodology, Rationale and Study Design

4.1 Introduction

To achieve the aim and objectives of the study Critical Realist Evaluation (CRE) which is a methodological approach underpinned by Critical Realism (CR) will be used. This section will detail why this CRE was chosen, and the research design and methods that accompany it. In addition, this chapter will cover the methods of data analysis as well as the ethical considerations of the study.

4.2 Methodological Approach

The term methodology is used to describe the underlying philosophical paradigm which informs the research and its methods (Guba and Lincoln 1994). A paradigm has been described as a set of beliefs that influence and guide action (Kuhn 1970). There are two main paradigms positivism and constructivism. Positivism tends to be experimental and objective and concerned with testing measurable or 'provable' data. Thus, positivists believe that culture is relatively stable and consequently can be isolated and tested for research purposes (Carson et al. 2001). On the other end of the spectrum is constructivism (sometimes referred to as interpretivism) i.e. how individuals construct their world or reality. Thus, a constructivist paradigm is concerned with subjective meaning as each individual constructs their own reality meaning there are multiple interpretations of reality (Fosnot 1996). For example, an individual's interpretation of reality may be influenced by their education, illness or where they live. Therefore, a researcher's paradigm governs the inquiry and how it should be set up. A researcher's theories about knowledge (epistemology), and reality (ontology), and how to obtain knowledge (methodology) uncovers their paradigm (Guba and Lincoln 1994).

This researcher's paradigm, and the paradigm selected to achieve the aim of this research stems from Critical Realism (CR). A key principle of CR is that human knowledge represents only a fraction of a deeper reality (Bhaskar 1998; Collier

1994). Therefore, CR shifts the focus to theories about reality and what is real (ontology), rather than our knowledge of what is real and reality (epistemology) (Bhaskar 1998; Archer 1995). Based on this CR diverges from both constructivism and positivism; as positivism limits reality to what can be known for example, through experimentation (Carson et al. 2001), and constructivism views reality as entirely constructed within human knowledge (Fosnot 1996). Therefore, both constructivism and positivism reduce reality to human knowledge (Bhaskar 1998).

Nonetheless, CR does not dispute the existence of the social world (Bhaskar 1998; Collier 1994; Archer 1995). However, CR explores this world by gathering knowledge through theories about reality, with a critical understanding that some theories may be closer to reality than others (Bhaskar 1998). Although theories can be correct ontologically, these theories are open to criticism and interpretation which may lead to improvements, therefore there is no absolute or certainty in knowledge (Bhaskar 1975; Bhaskar 1997; Archer 1995).

To further complicate matters, reality is an 'open system' meaning it is prone to change over time (Archer 1995). Open systems have a number of mechanisms operating within them, thus what happens in open systems will depend on the interaction of these mechanisms. The term mechanism refers to the notion of causation, thus the gathering of different mechanisms can be used to explain the usually inflexible relationship between cause and effect. Moreover, CR emphasises that in social systems people have their own causal powers of interpretation thus can influence what happens in open systems (Bhaskar 1998; Archer 1995). Therefore, theories derived from open systems aim to explore mechanisms and agency to enable an understanding past simple identification to explanation of these casual relationships. Specifically, allowing an explanation of why and how causal mechanisms and peoples interpretations can result in different effects or outcomes. In relation to this study, it is important to understand that care homes represent constantly changing open systems; consequently, any theories derived from these environments should be exposed to criticism and interpretation in order to be refined and improved.

It is argued that qualitative methods are more suited to exploring the ‘openness’ and ‘messiness’ of reality in open systems which influence experiences (Oppenheim 1992; Bhaskar 1998). Nonetheless, CR is not associated with any particular set of methods, thus qualitative and quantitative methods can be utilised (Bhaskar 1998; Collier 1994; Archer 1995). Quantitative methods can also capture this messiness and openness, however, they tend to encourage generalisations of causality, for instance exploring interaction in closed systems such as a laboratory (Oppenheim 1992).

4.3 Critical Realist Evaluation

4.3.1 The evolution of Critical Realist Evaluation

Realist Evaluation (RE) is an approach built on the philosophical foundations of CR which aims to improve traditional evaluative approaches which only focus on outcomes to explain success or failure (outcomes) (Pawson and Tilley 1997). Therefore, RE adopts assumptions or theories about causality which involve explaining outcomes in relation to ‘Mechanisms’ and ‘Context’. Mechanisms are used to describe causal laws, for example, X happened because of Y, while context represents the setting where an intervention operates which includes social context. Acknowledging both mechanisms and context is important given that outcomes are seldom the result of isolated causal mechanisms (from an intervention) but are instead influenced by the setting in which they operate, and the people involved (Context). This evaluative process of RE has been summarised in the following formula: “Context + Mechanism = Outcome” (Pawson and Tilley 1997).

Since its beginning, RE has been used in a plethora of research progressively becoming a popular methodological approach in healthcare and nursing research (Nurjono et al. 2018; Dalkin 2012; McConnell and Porter 2016). However, the increasing use of RE has come with several problems. Mainly, healthcare researcher’s difficulties interpreting and understanding the philosophical and

methodological foundations of RE, which Porter (2015b) argues are as a result of the methodological and philosophical inconsistencies apparent within RE.

Several areas where Pawson's RE diverges from CR have been attributed to these inconsistencies. Specifically, Pawson's RE combines agency and structure into social mechanisms (Pawson and Tilley 1997). Conversely, CR regards agency and structure as separate entities. Although CR acknowledges that agents can influence and be influenced by social systems, Bhaskar (1989) differentiates social structure from agency due to agents' ability to think and choose, which is not true of social structures. Therefore, while it is accepted that social mechanisms will have an impact on agents' choices, they are not involved in the making of the choices (Porter 2015b).

Furthermore, it is argued that RE takes a linear approach to causality in its view of context and mechanisms. For example, RE discriminates between 'context' and 'mechanisms' which has posed problems for healthcare researchers who have evidenced similarities and overlaps between context and mechanisms (Tolson and Schofield 2011). Porter argues against the linearity of causality proposing that there are multiple domains of causality, specifically, contexts also contain interacting mechanisms as well as the ones coming from the intervention itself, thus recognises these as contextual mechanisms (Porter 2015b; Porter 2015a).

Critical Realist Evaluation (CRE) was conceived from this critique and aims to improve the use of RE by addressing the arguments discussed above. Thus, where inconsistencies and differences between the two realisms exist the positions of CR will be adopted. In light of these arguments CRE involves explaining outcomes in terms of a combination of intervention mechanisms + contextual mechanisms + agency (Porter 2015b). Thus, CRE mandates that in order to explain outcomes it is necessary to understand how they are influenced by the interactions of mechanisms and agency.

4.3.2 Why Critical Realist Evaluation was chosen

In relation to this present study, CRE was chosen to untangle the complexities of outcomes used to determine high quality EoLC in care homes, to provide explanations rather than judgements to identify what works, for whom, why, and in what circumstances (Pawson and Tilley 1997). Specifically, CRE was used to evaluate and identify causal mechanisms embedded in the context of care homes, and the processes behind agents' behaviour. This is important given that in chapter three it was identified that research in the field tends to report on outcomes with little attention given to the processes behind those outcomes, which was shown to inhibit the effectiveness of interventions designed to improve EoLC in care homes (Spacey et al. 2019). Thus, gathering this information as part of the empirical stage of this study can be used to inform the development of future interventions capable of improving EoLC in care homes.

Prior to choosing CRE other methods of inquiry were explored such as action research, ethnographic and case study research which would all have allowed for the exploration of EoLC in care homes (McNiff 2013; Hockley et al. 2013; Yin 2013). Nevertheless, such methods tend to seek answers to questions such as 'what works', without exploring outcomes in terms of mechanisms and agency to understand what works, why, for whom and in what circumstances (Pawson and Tilley 1997). This extra level of analysis that comes with using CRE was deemed necessary in order to explain outcomes and provide extra depth and understanding offering a contribution to knowledge.

4.3.2.1 Intervention Mechanisms

CRE will provide this extra level of analysis by exploring EoLC in care homes in accordance with mechanisms and agency and their impact/influence on outcomes. Specifically, CRE will be used to identify *intervention mechanisms*, which are the mechanisms contained within interventions which are designed to change the behaviour of those at whom they are targeted (Porter 2015b).

Identification of intervention mechanisms can be used to identify supportive mechanisms which can be used to facilitate high-quality EoLC, and also why certain intervention mechanisms may be ineffective. However, there is no such thing as a context-free intervention; specifically, the impact of an intervention depends on where it is placed (Pawson and Tilley 1997) and the interactions and responses of the people involved in it (Porter 2015b). Therefore, in addition to intervention mechanisms CRE involves exploring *contextual mechanisms* and *human agency* to explain outcomes.

4.3.2.2 Contextual Mechanisms

Contextual mechanisms are the resources and restrictions embedded in the social and organisational context, which may inhibit or promote the effectiveness of *intervention mechanisms*. This is important given the contextual diversity of UK care homes, for example, some are small and independently run, while others are run by corporate chains (Competition and Markets Authority 2017). It is therefore important to capture this contextual depth and its influence, which is again missing from current research in the field (Spacey et al. 2019). However, as well as having an influence on intervention mechanisms, contextual mechanisms can have an impact on human agency (Porter et al. 2015b).

4.3.2.3 Human agency

Human agency represents people's experiences, interpretations and responses to the intervention and contextual mechanisms. Furthermore, as identified in chapter three human agency and stakeholders' responses and interpretations to mechanisms is something which has been sparsely reported on in previous research in the field, especially the viewpoints of those recently bereaved (Spacey et al. 2019).

4.3.2.4 Outcomes

Exploring these three components enables outcomes to be understood by explaining the complex reasons for underlying failure or success in different settings (Pawson and Tilley 1997). Therefore, in CRE outcomes alone are not enough to determine causality, contextual and intervention mechanisms and human agency also need to be accounted for (Porter 2015b). Based on this

understanding the study will use the following formula: Contextual mechanisms + Intervention Mechanisms + Human Agency = Outcome.

4.4 Intervention theories

This study aimed to inform the design and development of interventions to support the delivery of high-quality end of life care in UK care homes. Thus, the study was not content with simply explaining outcomes. The findings were used to develop intervention theories. Intervention theories are theories which explain a notion or idea that is expected to produce a desired outcome, incorporating intervention and contextual mechanisms and human agency into the theory (Pawson and Tilley, 1997).

Subsequently, intervention theories can be used to provide evidence-based informed insights into what can be done to address identified problems and facilitate supportive mechanisms. Due to the incorporation of mechanisms and agency, intervention theories take account of the different contexts and individuals thus are more likely to promote high quality EoLC compared to current interventions which as chapter three outlined are seldom based on systematic analysis process.

It must be understood that all interventions or programmes begin life as theories (Pawson and Tilley 1997). Therefore, the intervention theories produced in this study can not only be used to inform future policy and research but can be developed into future evidence-based interventions to support high quality EoLC in care homes. The following section will detail the research design and how it will be used to achieve the aim and objectives of this study.

4.5 Research design

4.5.1 The research aim and objectives

The research design acts as a plan or structure for how the research process will be conducted in order to address the research aim and objectives (Martino et al. 2013). Therefore, the research design acts as a blueprint for the research and includes the methods for collecting and analysing the data (McMillan and Schumacher 2001). This section will detail how a two-phase design using CRE with qualitative data collection methods will be used to achieve the aim and objectives of the empirical stage of this study:

The **aim** of this study was to inform the design and development of interventions capable of supporting the delivery of high-quality end-of-life care in UK care homes. To achieve this aim, the following objectives were set:

- To identify current intervention mechanisms designed to improve the delivery of high-quality end of life care in care homes.
- To identify the contextual mechanisms which inhibit or promote the effectiveness of the intervention mechanisms.
- To identify how stakeholders respond to the identified mechanisms (Human agency).
- To develop intervention theories which incorporate these findings to support the delivery of high-quality end of life care in UK care homes.

4.5.2 Phase-one: Data collection stage

Phase-one consisted of a data collection stage followed by data analysis and synthesis stages. CRE mandates that the data collection methods should be selected on the basis of how informative they will be to the study (Pawson and Tilley 1997). Consequently, CRE adopts a 'method neutral' approach meaning qualitative or quantitative methods can be utilised (Porter 2015b; Pawson and Tilley 1997). In relation to this study, qualitative methods were chosen to capture and explore the 'openness' and 'messiness' of EoLC in care homes necessary to achieve the research aim and objectives. This is important as it has been

established in chapter three that research tends to quantitatively report on outcomes to determine high quality EoLC in care homes without exploring the underlying processes behind those outcomes. As a result, semi-structured interviews and focus group discussions were chosen as data collection methods in phase-one of this study.

Semi-structured interviews were selected because they enable the exploration of lived individual experiences and attitudes of participants (Patton 1990; Britten 1995), necessary to understand and highlight some of the underlying processes which may impact on outcomes related to EoLC in different settings from different perspectives. Furthermore, the semi-structured nature facilitates a conversational manner enabling the participants to explore and divulge what they feel is relevant to the topic (Kvale 2007; Patton 1990). This flexibility allows the researcher to explore new areas and yield richer data (Mason 2002; Britten 1995). However, a good level of self-awareness and reflection (by the researcher) is necessary to reduce potential bias (Holloway and Galvin 2017). The researcher has reflected on their positionality throughout the course of the study to maintain a good level of self-awareness (see section 4.6).

Focus group discussions were chosen as a data collection method, as like semi-structured interviews they are useful in generating rich data on experiences and understandings (Kitzinger 1995). However, unlike individual interviews focus group discussions gather information on collective views and the understandings and meanings behind those views (Bloor et al. 2001; Kitzinger 1995). Moreover, group members often motivate and encourage each other to think more deeply about topics and may challenge each other (Van Teijlingen and Pitchforth 2006). The sizes of focus groups can vary from six to eight participants, however, focus groups can be effective with as little as three and as many as 14 participants (Bloor et al. 2001).

Despite these benefits focus group also have a number of weaknesses. For example, focus groups require more management as they often involve a minimum of two participants and average roughly six participants (Van Teijlingen and Pitchforth 2006). Thus, it can often be a challenging task to manage talkative

and quiet participants to ensure both can contribute to the discussion, which often requires a skilled moderator and facilitator (Williams et al. 2005; Van Teijlingen and Pitchforth 2006). Moreover, pre-planning is often necessary to enable the researchers to prepare themselves and get the most out of the method (Van Teijlingen and Pitchforth 2006). The researcher planned each focus group in advance, undertook focus group training, and used both a facilitator and moderator to manage different group dynamics.

The setting in which a focus group take place can also influence the behaviour of participants. Van Teijlingen and Pitchforth (2006) discuss that participants familiarity with each other may mean they do not feel able to speak openly about certain topics or conversely this familiarity may help participants feel more at ease with each other and talk more in the group. Furthermore, Boateng (2012) adds that this situation can lead to a phenomenon called 'groupthink' which is where one dominant member gives their answer first and the rest of the group agrees without contributing any of their own ideas or opinions. Boateng also discusses that 'groupthink' occurs because the other focus group members are scared of what others may think if they voice an unsupported opinion. Therefore, 'groupthink' may limit some of the benefits discussed above including group members motivating and encouraging each other to think more deeply about topics and may challenge each other (Van Teijlingen and Pitchforth 2006). In order to mediate and help manage this issue, the researcher explained (in the preamble) before each focus group that confidentiality should be respected, and the information discussed should not be discussed outside the room. The researcher also stated before each focus group that all answers would be valued and there are no wrong or right answers, in order to encourage others to speak up about what they believe.

The focus groups were conducted before the semi-structured interviews, giving the researcher the opportunity to develop on, and explore in more depth any concepts or issues of relevance raised in the focus group discussions. The interview guides developed for the focus groups and semi-structured interviews were informed by the two literature reviews and the philosophical frame of this

study. Moreover, the supervisory team and the ethics committee (consisting of both lay and professional people) cross-checked the questions and provided feedback and amendments. All the questions asked were open questions giving the participants the opportunity to expand, rather than being led by a specific question requiring a specific answer. The questions used in the focus groups and semi-structured interviews can be found in appendix: 5.

The questions were given to all the participants in advance, which was a strength and a weakness. Providing participants with the interview questions beforehand can give them time to reflect on the questions and their answers, potentially increasing the depth and richness of the discussion (Kvale 2007; Patton 1990; Van Teijlingen and Pitchforth 2006). However, it may also diminish the openness of the questions and participants may plan and get a specific answer ready (Kvale 2007; Patton 1990). To minimise the risk of participants planning answers in advance, all the participants were told prior to the interviews that they were informal unplanned discussions which did not require planned answers.

4.5.3 Phase-one: Analysis and synthesis stage

Central to qualitative research is data interpretations (Flick 2009). Data interpretation involves organising the data in ways that enable researchers to recognise patterns, relationships and identify themes (Macnee and McCable 2008; Flick 2009). There are a range of methods that can be used to interpret data (Flick 2009), and more than one analysis method can be used to interpret data to deepen understanding. In phase-one, thematic analysis and CRE were used to interpret the qualitative data. CRE was used as well as thematic analysis to deepen understandings and provide explanations rather than simple identification or judgment. Specifically, the data was firstly analysed using thematic analysis and following this CRE was used to conceptualise the data in accordance with mechanisms and agency. This chapter has already explained

why CRE was chosen, thus this section will now explain what thematic analysis is and why it was chosen.

Thematic analysis is a method used to identify and analyse patterns in data (themes), and it is the most popular method for qualitative analysis (Braun and Clarke 2012). “Themes are results in qualitative research that are areas or concepts that are implicit in the data and are recurrent throughout the data; that appear repeatedly as the researcher analyses what people have said about a particular experience, feeling or situation” (Macnee and McCable 2008, p. 424). Thus, thematic analysis suits research which is interested in people’s views of the world, feelings and experiences (Braun and Clarke 2006).

There are different approaches that can be used when conducting thematic analysis; namely deductive and inductive coding. Inductive coding is influenced by the content of the data, while deductive coding is influenced by existing concepts or idea (Patton 1990; Hayes 1997). This study used inductive coding as the development of the themes/codes was directed and influenced by the data collected, rather than pre-existing ideas and concepts. However, in reality, deductive coding may have also taken place as pre-existing knowledge from conducting two reviews of the literature (presented in chapters two and three) most likely influenced the researcher to a degree in the coding process. Nonetheless, as will be discussed below the analyses of the transcripts were cross-checked by the supervisory team, who each conducted their own thematic analysis of randomly selected data to reduce the influence of deductive coding taking place.

Although a number of scholars have written about thematic analysis, this study used Braun and Clarke’s (2012) six step approach. Braun and Clarke’s particular approach was chosen because it is a flexible method of analysis which is not fixed to any particular philosophical framework (Braun and Clarke 2006), thus can be used and applied to this study’s critical realist perspective. Moreover, although the six steps set out by Braun and Clarke are sequential each step builds on the previous one and the analysis process is iterative thus movement back and forth between the six stages is to be expected (Braun and Clarke 2012). Consequently,

the six-step process is not rigid, and the analytic process can at times merge some of the steps together (Braun and Clarke 2006). Table: 7 below summarises the steps that were undertaken to thematically analyse the qualitative data from phase-one:

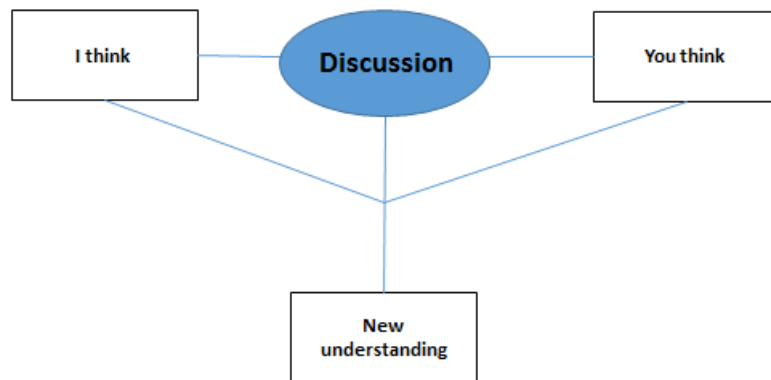
Table 7 Phases of thematic analysis adapted from Braun and Clarke (2006)

Phase	Description
Data familiarisation	Data transcription, following transcription the data was read and re-read a number of times, and any early ideas were written down.
Developing initial codes	Relevant and interesting elements of the data were coded in a systematic approach and data was assembled to each code.
Searching for themes	Themes were then assembled from the coded data compiling all the data relevant to each theme.
Revising themes	The assembled themes were then checked in related to the codes (1), and the entire data set (2).
Naming and defining themes	Analysis as ongoing to not only refine each theme but the overall frame of the analysis and the study developing clear definitions and names for each theme.
Developing the report	The most relevant and important examples following final analysis were

	chosen linking the analysis product to the research aim and objectives.
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The raw data was arranged into themes and sub-themes. The analysis was triangulated by the supervisory team on the basis of one randomly selected full focus group transcript and two interview transcripts. This process was followed by a discussion to confirm key themes and sub-themes (figure 4). In addition, the supervisory team checked over the final draft of the findings.

Figure 4 Cross-checking process



Following thematic analysis, CRE was used to conceptualise the thematically analysed data (themes) in accordance with mechanisms and agency (table: 8) (Porter 2015b). This second stage of analysis was necessary in order to explain outcomes and the processes behind them, rather than simply identify them. This systematic analysis process was necessary to produce data that could be integrated into intervention theories which each account for mechanisms and agency in their design.

Table 8 Critical realist evaluation

Terminology	Definition
Intervention mechanisms	The mechanisms contained in interventions that are designed to change the behaviour of those at whom they are targeted.
Contextual mechanisms	The resources and restrictions embedded in the social and organisational context which may inhibit or promote the effectiveness of intervention mechanisms.
Human agency	People's experiences, interpretations and responses to the intervention and contextual mechanisms.
Outcome	The changes in behaviour that result from how people respond to the intervention and contextual mechanisms.
Intervention theories	Intervention theories should describe/explain a notion or idea that is expected to produce change, incorporating intervention and contextual mechanisms and human agency into the explanation.

4.5.3.1 Theory development and data synthesis

The findings from this evaluation process were synthesised with the results from the reviews of the literature presented in chapters two and three. This synthesis process was used to develop initial intervention theories. As discussed in section 4.4 and table 8, intervention theories are theories which describe/explain a notion or idea that is expected to produce change, incorporating intervention and contextual mechanisms and human agency into the explanation.

Moreover, it is important to understand the theories will then be left open to interpretation and refinement as there is no absolute certainty in knowledge (Bhaskar 1975; Archer 1995). However, as discussed earlier some theories are closer to reality than others (Bhaskar 1998), therefore criticism and refinement

of theories can lead to improvements (Bhaskar 1975; Bhaskar 1997; Archer 1995). In order to enable the criticism and refinement of the initial intervention theories phase-two was designed.

4.5.4 Phase-two: Data collection and theory refinement

The purpose of phase-two was to refine and increase the feasibility of the initial intervention theories developed from phase-one of this study. Realist semi-structured interviews and focus groups were used in phase-two of this study to present the initial intervention theories to the participants allowing them to provide feedback and refine each theory.

Conventional interviews and focus groups (discussed previously) tend to explore aspects and concepts, while realist interviews and focus groups are interested in investigating theories or propositions (Pawson and Tilley 1997). Realist interviews consist of two main processes: the teacher-learner process and the conceptual refinement process. The interviewee is constantly trying to guess or make sense of what the researcher is looking for during an interview. So, the role of a realist interview is to make this process transparent ensuring understanding of the concepts being discussed (Pawson and Tilley 1997; Manzano 2016). Therefore, the teacher-learner relationship consists of the researcher playing an active role in enabling the interviewee to understand the intervention theory being discussed.

Consequently, realist interviews begin by teaching or introducing the initial intervention theory to the interviewee. This process enables the interviewee to learn and understand the theory. Once this understanding is reached the interviewee can refine the theory by teaching the researcher i.e. sharing their experiences and expertise in relation to the theory (Manzano 2016; Pawson 2013). Therefore, the teacher-learner relationship is a dynamic process and changes throughout the course of the interview and theory refinement.

The conceptual refinement process consists of the interviewee conveying their own thoughts and experiences towards the intervention theory (Pawson and Tilley 1997). An example of these two processes is displayed below (table: 9):

Table 9 Example realist interview

Realist interviewer: the interviewer is an expert in the intervention theory therefore will share the theory with the interviewee, asking questions such as: the intervention is supposed to do **X** which causes **Y**, what do you think?

Interviewee: the interviewee is an expert in mechanisms thus can help explain what works, for whom and in what circumstances to refine the theory and increase its feasibility.

Therefore, sharing the intervention theories with the interviewee enables study participants to explain what works, for whom and in what circumstances. This allows the conceptual refinement of the initial intervention theories to occur (Pawson and Tilley 1997). The purpose of the interviews is to refine the theories developed from phase-one.

Realist focus groups were used to achieve a similar process to the realist interviews – to test and refine the initial theories developed from phase-one. Like the realist interviews realist focus groups consist of two processes; the teacher-learner process and the conceptual refinement process, which works in the same way as explained above. However, the purpose of using realist focus groups was to allow the participants to generate responses and build on the contributions of others in relation to the intervention theories. For example, disagreement may occur, and one participant may think one thing about a theory, and another may think differently (Pawson and Tilley 1997). These disagreements and discussions can help uncover not only what people think about the theory, but how they think and why they think that way (Kitzinger 1995). These traits of focus groups are essential to enable the conceptual refinement of the intervention theories to occur (Pawson and Tilley 1997),

adding a different dimension to the data collected from the one-to-one realist interviews.

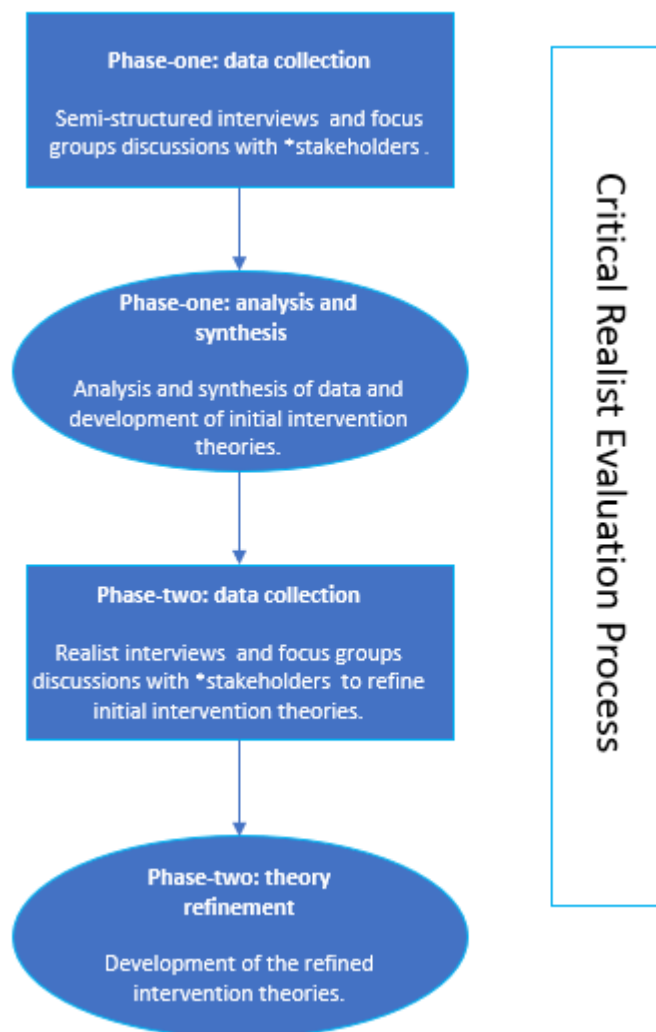
4.5.4.1 Partial knowledge

The purpose of this two-phased process was to produce refined and tested intervention theories which can be used to achieve the aim of this study to inform the design and development of interventions to support the delivery of high-quality end of life care in UK care homes. However, it is important to understand that the findings from the study will always be partial. Nonetheless, partial knowledge is important and useful, specifically partial knowledge allows aspects to be focused on and evaluated further (Pawson 2013). Therefore, the refined theories developed from this two-phase process are not absolute and can be further refined and improved. Although partial the evidence-based intervention theories developed in this study still provide a valuable insight which can be used to inform practice and future interventions developed to support EoLC in care homes. The two phased study design is illustrated in figure 5.

Summary of methods

- 1.** A systematic literature review was conducted which provided a comprehensive overview of EoLC in UK care homes.
- 2.** A critical Realist review was conducted which uncovered theories that explain current practices and identified a gap in knowledge.
- 3.** Semi-structured individual and focus group interviews were carried out which uncovered stakeholders' experiences and interpretations of the current context and practice of EoLC in care homes.
- 4.** Analysis of stages 1-3 was used to develop initial intervention theories about the mechanisms required to support high quality EoLC.
- 5.** Realist interviews with stakeholders were carried out to refine the initial intervention theories and to enhance the feasibility.

Figure 5 The two phased study design using Critical Realist Evaluation



*Stakeholders refer to participants who took part in the study. The study participants and sampling strategy is discussed in section 4.7 of this thesis.

4.6 Rigour of the study

Evidencing the rigour of a study is an important aspect of ensuring confidence (Sandelowski 1997), and confidence is essential in ensuring that the knowledge presented in research will inform and improve practice (Porter 2007). There are four established mechanisms for ensuring rigour within qualitative research; credibility, confirmability, dependability and transferability (Guba and Lincoln 1985).

4.6.1 Credibility

The purpose of credibility is to ensure that the study data is valid, and a true representation of the participants views and being able to demonstrate that the data is credible. In relation to the present study, there were two phases of data collection meaning participants were interviewed twice. This was important in capturing more detailed responses from participants rather than just a 'one-off' single interview, thus interviewing participants twice helped to ensure that their experiences were credible and valid. Similarly, Murray et al. (2009) found that the use of repeating or serial interviews helped to uncover the complexities of individual situations by allowing narratives to develop. Specifically, a participant's experiences following the initial interview can be shared in the second interview allowing the initial findings from the first interview to be developed and reflected on. These benefits of serial interviews were demonstrated in a study conducted by Lee et al. (2016) which used three different types of interviewing and included the use of serial interviews. The study found that serial interviews allowed the participants to develop and expand further on points made in earlier interviews to enhance understanding.

In addition, the two phased design (discussed previously in section 4.5.3 and 4.5.4) allowed the participants to refine and comment on the findings from phase one. This not only helped ensure the findings were relevant to practice and feasible by subjecting them to external scrutiny. Moreover, this approach adhered to the methodological foundation of this study, critical realism, which

proposes that knowledge is not absolute thus should be subject to criticism and scrutiny to improve refine the findings (Bhaskar 1998; Collier 1994). This helped ensure that the intervention theories were shaped in accordance with the participant's experiences.

To further ensure that the research findings (or theories) were shaped by the participant's experiences, Holloway and Galvin (2017) state the researcher-participant relationship should be addressed and reflected upon before and during a study as it is methodologically relevant to study. Specifically, positivists seek to objectively gather facts about external reality, whereas constructivists believe that reality is constructed by the researcher (Fosnot 1996). Related to this is the issue of insider and outsider perspectives, specifically, because positivists believe in the unbiased collection of data, they tend to favour the researcher taking a detached approach to research participants (Merriam et al. 2001). Conversely, because constructivists believe that good research involves the shared construction of an account of reality with participants, they tend to promote a closer relationship with those participants (Fosnot 1996). Therefore, there is a relationship between the seeking of an objective position with adopting an outsider approach, and there is similarly a connection between seeking a shared construction of reality with adopting an insider approach (Merriam et al. 2001).

Whilst Critical Realists assert the existence of objective social relations, they accept that those relations will be interpreted in different ways by different people including themselves (Bhaskar 1998). Thus, rather than adopting the objectivist outsider approach of positivism or the subjectivist immersion of constructivism, Critical Realists use a theory-driven approach that, in addition to elucidating the lived experience of the social actors involved from their own perspectives, also seeks to uncover the social relations that influence those experiences (Bhaskar 1975; Bhaskar 1998).

However, the researcher-participant relationship can evolve over time (Holloway and Galvin 2017), especially in relation to this study as there were two phases. For example, over time the participants can become closer to the researcher. To address this potential for bias the researcher engaged in fortnightly meetings with the supervisory team where reflection occurred to distance the researcher from the participants. This included discussing the researcher's evolving relationships with the participants and any instances where these relationships may have been compromised. Moreover, the researcher noted down their experiences during data collection and analysis in a reflexive account which is presented in chapter 7 section 7.3. This reflexive diary details the researcher's experiences with the insider/outsider perspective and the difficulties experienced throughout the study.

4.6.2 Dependability and confirmability

Confirmability refers to the accuracy of the data, whilst dependability assesses whether the research processes were transparent (Guba and Lincoln 1985). Confirmability and dependability of the research was established through on-going peer review and on-going discussion and critique of the research journey. The research was subject to peer review through conference attendances and publication of the findings in international journals (see section 7.4). Sharing the research with external experts in the field helped refine and rationalise the study.

Moreover, sharing the research journey with supervisors through fortnightly meetings was key as they were able to question and challenge the research when clarity was not evident. For example, the supervisory team were closely involved in all aspects of the study from data collection to analysis. Being involved in the data analysis enabled the supervisors to be able to challenge and question my initial analysis. This cross-checking process was key to ensuring the data was accurately represented (discussed further in section 4.5.2).

4.6.3 Transferability

Transferability relates to the extent in which the research findings can be transferred from one context to another (Guba and Lincoln 1985). The study makes it clear that the findings are relevant for the participants and care homes involved in the study, in that the intervention theories are based on the data collated from these settings.

Westhorp (2014) has highlighted that within the context of realist evaluation, an evaluation can only ever be 'partial' and that it is not possible to do an evaluation of all the aspects of the wider context through data collection. Thus, this study was able to explore EoLC in the context of three UK care homes in-depth using data collection methods. Although the findings generated in this study are 'partial' they may have some potential transferability to other contexts, for example, other care homes across the UK sector. Moreover, in order to establish the wider context, the synthesis of phase-one findings with existing literature places the study findings in the context of existing literature. This process also aimed to increase the generalizability and transferability of the theories, and feasibility in different care home settings.

Furthermore, in the discussion and conclusion chapters of this thesis the transferability of the research findings is discussed in more detail. These chapters discuss what was identified in the study and how the findings can be used to positively impact on service provision and policy in the context of EoLC in care homes. Moreover, section 7.4 within the discussion chapter discusses the impact the findings have had on other aspects of society such as the bereaved and student nurses. However, further research is recommended (chapter 8) to replicate the study in different contexts such as rural care home settings to assess the generalisability of the findings.

4.6.4 Ethics

In terms of ethics, this study has gone through vigorous ethical scrutiny by an external ethics committee (consisting of 10 members), as part of the IRAS NHS

ethics approval process granted 15/01/2018, see appendix: 6. The ethical considerations of this study are discussed further in section 4.8.

4.7 Sampling strategy

4.7.1 Participant selection

Purposive sampling selects a sample based on their known characteristics and the aim of a study (Tongco 2007). Therefore, purposive sampling was used in this study because the study sample was determined by the findings of the systematic literature review and the critical realist review (chapters two and three). Specifically, the literature reviews highlighted a need to explore from not only care home staff's perspectives, but also the perspectives of service users. It was found that few studies reported on EoLC experiences from the perspectives of bereaved relatives (Kinley et al. 2018; Spacey et al. 2018), in particular exploring the views and experiences of bereaved relatives from residential homes (Spacey et al. 2018). Additionally, most of the current literature explored the experiences of registered care home staff, overlooking the perspectives on non-registered care home staff, especially those with non-formal caring roles such as housekeeping staff (Spacey et al. 2019).

The researcher discussed with the three care homes and the ethics committee what was possible in terms of participants and numbers. After discussion with the participating care homes and the ethics committee, it was deemed inappropriate to include residents who were receiving EoLC in this study. Specifically, the researcher could not be aware of residents' level of knowledge as to whether they knew they were receiving EoLC, so it was deemed insensitive and unethical to ask them about EoLC. It was therefore thought to be more sensitive to include bereaved relatives as they could be approached 3 months post bereavement to offer their experiences of EoLC in the care home from a service user's perspective. Bereaved relatives can also act as a proxy for residents who have received EoLC. Moreover, at the time of this study bereaved relatives' perspective of EoLC in care homes was lacking.

Lastly, the philosophical underpinning of this study influenced participant selection. As discussed by Westhorp (2014) exploration within the context of critical realism can only ever be ‘partial’ as it is not possible to explore and evaluate all layers of context. Therefore, participant selection was based on exploring the context of EoLC in care homes thus the study did not seek to explore primary or acute care. This is later acknowledged within the strengths and limitations section of this study (section 7.4.2).

Based on the discussion with the care homes, the ethics committee, the time-frame of the study and the two reviews of the literature and the critical realist approach, it was decided that bereaved relatives, registered and non-registered care home staff will be included in this study.

Table 10 summarises which qualitative data collection methods will be used and with which participants:

Table 10 Methods and participants

Method	Participants and numbers
Phase-one	
Individual semi-structured interviews	Bereaved relatives Care home managers
Focus group discussions	*Registered and **non-registered care home staff
Phase-two	
Realist interviews	Bereaved relatives Care home managers
Realist focus group discussions	*Registered and **non-registered care home staff

**Registered care home staff can include registered nurses. **non-registered care home staff included care assistants, administrative staff and housekeeping staff.*

4.7.2 Selection of data collection sites

The Care Quality Commission's (CQC) electronic database was used to search for care homes within the South West of England to include both residential and nursing homes. Purposive sampling was also used for the selection of data collection sites (Tongco 2007) to ensure variation in the care homes settings. The care homes were strategically selected to reflect diversity in size and location, a mix of larger and smaller care homes. This was important given the findings of the reviews in chapters two and three both revealed a lack research exploring EoLC in both residential and nursing home settings. The study was conducted in the South West of England because it is the location of the University where this study was based and supervised. Thus, convenience sampling was conducted to the extent that eligible sites were restricted to those within traveling distance of the University. The consequence of convenience sampling was that the profile of the participants had specific characteristics such as ethnic homogeneity which may not reflect participants from care homes elsewhere in the UK.

The regional Clinical Commissioning Group (CCG) and Care Choices (2018) provided guidance and advice on the search strategy for care homes in the area. At the time the CQC electronic database results showed 179 care homes within the area. Moreover, the regional CCG provided advice throughout the process which was used to develop the following purposive sampling variables and eligibility criteria:

Table 11 Sampling variables

Purposive sampling variables	<ul style="list-style-type: none">• Ownership of care home – Single owner/Corporate owner/Local authority owned• Size of home – Small/Medium/Large• Setting – Urban/Rural
-------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

	<ul style="list-style-type: none"> • Care home registration status - Nursing /Residential/Dual (both residential and nursing)
Eligibility criteria	<ul style="list-style-type: none"> • The care homes (both residential and nursing) must provide end of life care for older residents. • Included care homes must be located in the South West of England for pragmatic reasons as this is the local area for the research project and team. • Included care homes must be privately owned, as the private sector significantly represents the largest care home sector in the UK.

Using the purposive sampling method and the unpublished data on the variables from regional CCG (table 11), a number of care homes were selected and approached. The first three care homes that agreed to participate that met the eligibility criteria were invited to take part in the study. Three variations of care homes were chosen because they represent the largest proportion of care homes types in the UK (Competition and Markets Authority 2017; Laing and Buisson 2015) (see table: 12). Local authority care homes were excluded as they only represent a small proportion of UK care homes (Laing and Buisson 2015). In addition, these three variations in care home sites are an essential aspect of the critical realist methodology in order to understand EoLC in different care home contexts.

Three care homes were selected to take part in the study (see table 12). A larger number of care homes was not necessary given the qualitative nature of this

study. Specifically, qualitative research aims to provide an in-depth understanding of a phenomenon, thus, is less reliant on quantity (Dworkin 2012). Additionally, three care homes were selected to keep the workload manageable within the timeframe of the study taking into account the amount of data that was generated.

Table 12 Selected Care Homes

Care home	Ownership	Size	Setting	Registration status
Care home one (C1)	Single owner private sector care home	32 bed home	Urban	Residential care
Care home two (C2)	Corporately (chain) owned private	42 bed home	Urban	Joint nursing and residential care
Care home three (C3)	Single owner private sector care home	75 bed home	Urban	Nursing care

4.8 Ethical considerations

4.8.1 Recruitment and consent

The recruitment and consent process for this project has been carefully considered throughout. Participation in the study was entirely voluntary, and the consent process aligned with the Health Research Authority consent and participation guidance (HRA 2017). In order to successfully follow the HRA guidance participant consent was carried out in the following way during recruitment:

4.8.2 Bereaved relatives

Gatekeepers (care home managers) were contacted through a letter of invitation sent by the research team. Bereaved relatives were contacted through Gatekeepers at the participating care homes using an invitation letter (appendix: 7), which included contact details. This allowed bereaved relatives to get in contact with the researcher. When the potential participants expressed an interest in taking part in the study, they were provided with participant information sheets, and a consent form. The purpose of these documents was to inform them about the study and their participation.

The researcher arranged a time and date and interview location with the participants who expressed an interest in taking part in the study. The consent forms were signed prior to any data collection. Additionally, all participants were given an opportunity to discuss any questions before agreeing to take part. Both the consent form and Participant Information Sheets included contact details allowing the potential participants to ask any further questions. Continued consent was rechecked and confirmed prior to phase-two of data collection.

4.8.3 Care home staff

The researcher attended staff meetings at the selected care homes to inform the staff about the study and hand out invitation letters (appendix: 8) to any interested potential participants. The invitation letters contained further information about the study and contact information which allowed any potential participant to contact the researcher. This method enabled potential participants to come forward, preventing gatekeepers selecting who they send the information to, reducing potential selection bias. Thus, potential participants who expressed an interest in the study could contact the researcher independently of the care home manager.

The researcher returned to the care homes to provide the participants who expressed an interest in the study with participant information sheets (appendix: 9, 10 and 11) and consent forms (appendix: 12) to read and sign before any data

collection occurred. All the participants were given an opportunity to discuss any questions before agreeing to take part.

The consent form and Participant Information Sheets included the contact details of the research team. This allowed participants to ask any further questions. A number of participants did this to clarify how long the study would take and what they were expected to do. Continued consent was rechecked and confirmed prior to phase-two of data collection.

4.8.4 Potential for recruitment bias

A potential limitation of this recruitment strategy is the element of trust placed on the care homes involved in the study, and potential bias. Specifically, the care homes were trusted to distribute the study invitations to bereaved relatives. However, the care homes may only contact who they want, for example, only bereaved relatives who have had a good EoLC experience, rather than ones who had bad experiences. So, there was a potential for selection bias in this aspect of the study design. Moreover, although invitation letters were distributed at staff meetings (see section 4.8.3), the researcher was unaware of what happened after these meetings. Therefore, it is possible that gatekeepers (care home managers) may have encouraged their 'best' staff to participate in the focus groups. The strengths and limitations of the study are presented in more detail in chapter 7.

4.8.5 Recruitment and consent for phase-two of data collection

Five months following phase-one of data collection (this time was used to analyse the data and develop the initial intervention theories), phase-two of data collection commenced. The recruitment process followed the HRA approved procedure detailed above.

4.8.6 Participant support

It is acknowledged that the researcher asked participants questions on the difficult and potentially distressing subject of EoLC. The researcher was therefore aware that throughout the duration of the study participants had the potential

to become upset and distressed. Sadness and emotion were apparent during the interviews particularly in the case of bereaved relatives who spoke about their experience of losing their loved one. However, the researcher was aware of this throughout the data collection aspect of the study and was therefore able to conduct the interviews carefully, making sure the questions were asked sensitively, and the participants' interests and wellbeing were already put first. For example, on one occasion it was noticed that a bereaved relative started to show signs of emotional distress (through tone of voice or body language), the researcher therefore moved on from that particular question and changed the focus. The researcher was able to learn and develop these skills in the prior training undertaken on discussing sensitive topics at the University. Moreover, the researcher's experience of working in the National Health Service caring for patients helped.

Additionally, the bereaved relatives were contacted three months or longer after experiencing bereavement. A three-month gap was intended to give them time to grieve and be with family while still being able to closely reflect on their experience. However, the researcher is aware that the length of a grief period does vary for different people. However, it was hoped that discussing their experiences in an interview setting helped them share and reflect.

As well as bereaved relatives the researcher was aware that care home staff also had the potential to become upset and emotionally distressed. To help mitigate and support staff all the interviews and focus groups occurred in the three care homes which have mechanisms and procedures in place to support care home staff. To the researcher's knowledge no care home staff showed signs of emotional trauma or distress during the study. However, these mechanisms were still there to support care home staff.

Moreover, if any of the participants did become upset and made it apparent, they were given the opportunity to stop or pause the interview. The researcher was also prepared to signpost any upset participants to the relevant support services. One of these services was '*cruse bereavement care*' (<http://www.cruse.org.uk/>) which is a national charity aimed at supporting

bereaved relatives. However, none of the study participants expressed upset or showed signs of needing support.

4.8.7 Emotional distress to the researcher

Due to the research project being on EoLC it was possible that the researcher may have experienced some emotional stresses throughout the project. Additionally, qualitative research exploring emotions and experiences may induce further emotional stress. To manage the potential of emotional stress the researcher discussed issues with the supervisory team and had the option to contact the University's counselling service.

4.8.8 Anonymity and withdrawal from the study

The data collected from the focus groups and interviews was recorded on a secure audio recording device. Following data collection, the researcher transcribed the recordings onto a secure password protected University computer. While transcription occurred the recording-device was locked in a secure location within the University. Once transcription had taken place the recordings were deleted.

The identity of anyone involved in the project was anonymised by removing any personal identifiable information and allocating participants nominal pseudonyms. This anonymity was applied for all participants in the project, for example:

- Nominal pseudonyms were used to hide the identity of the participant e.g. staff member 'James' would be identified as 'P1'.
- Only the researcher had access to personal contact details.
- Any contact details were stored separately on a secure University password protected computer and deleted at the end of the study.

Participants were free to withdraw at any point. For the individual interviews, participants could request that their data be withheld or destroyed up until the point of anonymization. For the focus group discussions, participants were informed (before commencement) that post commencement of the focus group discussions their data cannot be withheld or destroyed. Further details on study

withdrawal and confidentiality are included in appendix 9, 10 and 11 which presents the participant information sheets (PIS) for all participants, which were approved by the NHS ethics committee on 15/01/2018.

4.8.9 Assessment and management of risk: Lone working

Attending bereaved relatives' homes to conduct interviews, involved lone working. It was therefore the responsibility of the researcher to alert the University and supervisory team when and for how long lone working would be occurring. This allowed the University/supervisory team to manage the risks, see appendix: 13 for the University's lone working policy.

4.8.10 Risk of injury

Given that part of the data collection occurred in the care homes the researcher was surrounded by care home staff trained in preventing the risk of injuries. Additionally, the researcher is a healthcare professional who has undergone an array of health and safety training to reduce the risk of injury (HCPC 2013). In addition, the researcher completed risk assessments which took into account the researchers own safety and the emotional wellbeing and safety of the participants. The University's lone worker policy and risk assessment policy (Appendix: 13) was followed to manage these risks.

Furthermore, as part of this study, the researcher met people who were already potentially vulnerable in terms of emotions, therefore the researcher engaged in reflection to prepare how to cope if any participant became very distressed. As mentioned, none of the participants become very distressed (to the extent of needing professional help and support) during the study, however these mechanisms and preparations were still in place. One of the services that were able to offer additional support to bereaved relatives was '*Cruse Bereavement Care*' which is discussed above in section 4.8.6. Furthermore, each of the included care homes had support services in place.

If the bereaved relatives become unwell during data collection the researcher put mechanisms in place to call for a General Practitioner (GP) or emergency

help if appropriate. If any such event had occurred the researcher would have also called the supervisory team to let them know what had happened.

4.8.11 Reporting practice

As a healthcare professional the researcher had a legal, ethical and professional duty to report any instances of foreseeable risk to the safety of the public and patients and staff and any unsafe practice (HCPC 2017). Throughout the duration of the project, there was a chance that malpractice/unsafe practice may be discussed in an interview or focus group discussion. Although this did not occur during the study, the researcher still prepared and put mechanisms in place. For example, if the situation occurred where the researcher was informed of a foreseeable risk to safety by a participant, the researcher would have adhered to their professional code of practice (HCPC 2017), and the individual care home policy regarding reporting instances. This obligation was highlighted in the participant information sheets stating the researcher's duty to report any unsafe practice.

4.9 Chapter summary

The chapter has described and explained the underlying philosophical frame of this study, the strategy of inquiry, research design, data collection and analysis. The rationale for the use of CRE has been justified along with the sampling strategy and recruitment of participants was discussed in relation to the study aim and objectives. Lastly, the chapter discussed the ethical considerations. The following chapter will present the findings from phase-one of this study.

5 Findings: Phase-one

5.1 Introduction

The chapter presents the nine themes derived from phase-one of data collection and analysis. The data were collected using two qualitative methods: focus group discussions and semi-structured interviews with staff members and bereaved relatives from three care homes in the South West of England. This data was then thematically analysed, and CRE was used to conceptualise the data in accordance with mechanisms and agency. Ten categorised themes were developed (See table 13).

Table 13 Identified and categorised themes

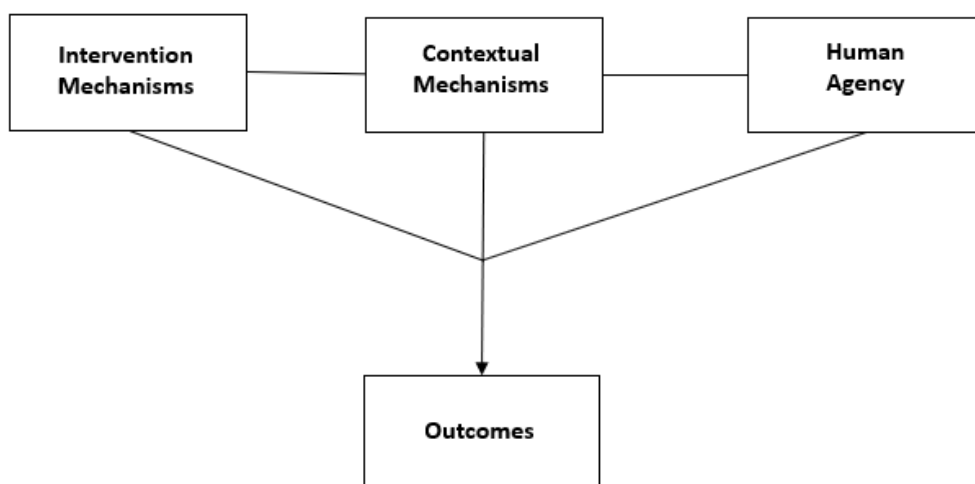
Critical realist category	Themes	Sub-themes
Intervention mechanisms	Theme one: Multidisciplinary collaboration during end of life care	Multidisciplinary communication, external services, hospice specialists, GPs, sharing knowledge and expertise, anticipatory actions, networking, collaboration, recording interactions, sustainability of relationships.
	Theme two: Advance care planning and person-centredness	Advance care planning, person-centeredness, individualising care to resident's needs, inter-communicating about resident's needs, maintaining dignity, handover, time spent with residents.
	Theme three: Involving relatives in end of life care	Encompassing relatives in EoLC, practical support, emotional support, recognising relatives'

		emotional needs, preparing relatives for death of loved one.
	Theme four: Education mechanisms to facilitate person-centred holistic care	Recognition of care home staff with non-formal caring roles, education and training mechanisms, maintaining person-centred care.
Contextual mechanisms	Theme five: Financial and organisational variability	Financial context of care homes, organisational context of care homes, variability in education and training intervention in EoLC, presence of on-site registered nurses, evidence-based education.
	Theme six: The diverse resident population	Short-stay residents, EoLC more frequent and more complex, applying existing intervention mechanisms to the diverse resident population, current education mechanisms, experiences of short stay residents from bereaved relatives' perspectives, spending last moments of life in a care home opposed to a more acute setting.
	Theme seven: Organisational barriers to multidisciplinary collaboration	High workloads, time pressures, policies and procedures, GP visits, taking time to build relationships, understanding each other.
Human agency	Theme eight: Perceptions and attitudes of multidisciplinary practice	Care home staffs' attitudes and perceptions of external care home staff, care home

		staffs' reactions and responses to high workloads, short staffing and limited time/availability of external staff, perceptual barriers between services, attitudes towards other care homes, competitive culture.
	Theme nine: Bereaved relatives' views of and responses to end of life care in care homes	Types of bereavement, medical focus, loss of identity, emotions, accepting death, lasting nature of emotions.
	Theme ten: Staff's emotional experiences and responses to end of life care	The emotional labour of providing EoLC (staff grief), the emotional challenges of experiencing EoLC, relationships with residents, reluctances to talk about death and dying with residents and relatives.

This process was used to explore the impact of intervention mechanisms, contextual mechanisms and human agency on outcomes used to determine high quality EoLC in UK care homes. As discussed in the methodology chapter (Chapter 4: Section 4.3), CRE involves explaining outcomes in terms of a combination of intervention mechanisms + contextual mechanisms + human agency, using the following formula $IM+CM+A=O$ (Porter 2015b).

Figure 6 Critical realist evaluation process



The thematically analysed data was split up into four categories; intervention mechanisms, contextual mechanisms, human agency and outcomes (Porter 2015b). *Intervention mechanisms* represent the mechanisms designed to change the behaviour of those at whom they are targeted. *Contextual mechanisms* represent the resources and restrictions embedded in the social, economic and organisational contexts of care homes which were theorised as either promoting or inhibiting the effectiveness of intervention mechanisms. *Human agency* represents how people experience, interpret and respond to the identified intervention and contextual mechanisms. Lastly, outcomes represent the changes in the behaviour of those at whom the intervention was aimed.

Exploring intervention mechanism, contextual mechanisms, agency and outcomes within the context of EoLC in care homes has enabled the results of this current study to explain rather than simply identify outcomes. The findings were then synthesised with the literature from the systematic review (chapter two) and the critical realist review (chapter 3) to develop initial intervention theories, which incorporate mechanisms, agency into their design. These initial intervention theories were presented to participants in phase-two (chapter 6) to assess their feasibility.

Participants included both registered and non-registered care home staff, care home managers and bereaved relatives. Each participant was allocated a pseudonym (See table: 14):

Table 14 Pseudonyms used for participants: Phase-one

Care homes	Participants		
	Care home managers	*Registered and **non-registered care home staff	Bereaved relatives (BR)
C1: Care home one	Manager C1 (10 years' experience and registered nurse)	Care assistant 1 C1 (5 years' experience) Care assistant 2 C1 (10 years' experience) Care assistant 3 C1 (3 years' experience)	BR1 C1 BR2 C1 BR3 C1
C2: Care home two	Manager C2 (15 years' experience and registered nurse)	Housekeeping C2 (1-year experience) Care assistant 1 C2 (29 years' experience) Care assistant 2 C2 (14 years' experience)	BR4 C2 BR5 C2
C3: Care home three	Manager C3 (6 years' experience and registered nurse)	Registered nurse 1 C3 (19 years' experience) Care assistant 1 C3 (28 years' experience) Care assistant 2 C3 (2 years' experience) Care assistant 3 C3 (2 years' experience)	BR6 C3 BR7 C3

		Administrator C3 (5 years' experience) Housekeeping C3 (5 years' experience)	
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**registered care home staff can include registered nurses. **non-registered care home staff included care assistants, administrative staff and housekeeping staff.*

5.2 Intervention mechanisms

This section will identify and explore the different intervention mechanisms currently contained in the care homes, and their hypothesised effects on behaviour. Four themes emerged.

5.2.1 Theme one: Multidisciplinary collaboration during end of life care

Effective multidisciplinary collaboration between care home staff, GPs and hospice specialists was theorised as being essential to enabling the sharing of knowledge and expertise to support staff to deliver EoLC in the care home. This was found to help staff avoid unnecessary admissions, especially for residents with complex EoLC needs requiring a multidisciplinary approach. For example, the manager from care home three spoke about the importance of effective collaboration with their local hospice specialists which enabled the sharing of knowledge and expertise between hospice specialists and care home staff to manage the residents complex EoLC needs in terms of medication and monitoring.

Manager C3: *"[...] just making regular use of the palliative care specialist nurse community has helped us get to know each other [...]"*

We need to work very closely with external services such as the palliative care specialist nurse community. We've got a husband here whose wife was dying last year, and she wanted to come to our care home to spend her last few days. She come here from hospital and she had a very complicated cancer,

they don't usually come out with this type of cancer. So, we needed extra help in terms of medication, monitoring and support to manage her end of life, it was a very complicated cancer."

Furthermore, this data illustrates the importance of effective multidisciplinary collaboration in enabling the residents and relatives to experience EoLC in the care home, rather than in an acute hospital or hospice. A key facet of effective collaboration was regular communication and good relationships with external staff such as GPs and hospice specialists.

It was identified that staff from care home three used monthly meetings to facilitate this regular communication and contact. It was theorised that engaging in regular communication via monthly meeting would help develop shared understandings between care homes and their GP service, as well as developing relationships to improve collaboration. It was evident that the interactions and communication during collaborative meetings was recorded and documented by care home staff, it was believed that this would enhance communication to avoid unnecessary admissions to hospital:

Care assistant 1 C3: *"One of the aims of the GSF is to help with better communication with externals like GPs and it does. We have gold standard monthly meetings to avoid inappropriate hospital admissions... We record and document what goes on which all helps us to develop relationships... they get to know us and our staff, and we get to know them."*

These findings suggest that staff from care home three recognised the importance of multidisciplinary practice and proactive mechanisms (such as regular communication via meetings and recording and documenting interactions) needed to achieve and sustain it.

In comparison, the evidence gathered from care homes one and two suggested a much less proactive approach, especially in relation to hospices. Specifically, rather than proactively attempting to collaborate with their local services

through meetings no mechanisms to promote collaboration were apparent in care homes one and two. Instead, staff from these care homes expected hospice staff to come and visit the care home rather than reaching out to the hospice staff. As a result, it was apparent that care home staff in these homes struggled to develop similar working relationships with their local hospice specialists.

Care assistant 2 C1: *“They [hospice specialists] do not really have much to do with us they could come visit ... our managers sometimes ask them for advice, but we don’t have regular contact with them.”*

Care assistant 1 C2: *“I’d say hospices... they could reach out to us and visit the home. I know our local hospices are good we have Macmillan here and another one I forget the name...but they have a lot of end of life [care] there so I would like them to do more.”*

As well as hospice specialists, the data highlighted that GPs also play an important role in multidisciplinary EoLC in care homes, especially in relation to avoiding unnecessary hospital admissions. Analysis of the transcripts imply that fortnightly GP visits to homes to support the staff and check up on residents and prescribe anticipatory medication for residents receiving EoLC were all vital to supporting residents and building relationships with care home staff. Staff expressed that GP visits to the home helped take some pressure and responsibility off them by reassuring the staff they were *‘doing things right’*:

Care assistant 1 C2: *“We have policy where GP has to see end of life care patient every two weeks”*

Care assistant 2 C1: *“It takes some pressure off us and it’s nice to have GP come visit and say nice things and just let us know we’re doing things right.”*

As well as providing reassurance, it was identified that GP visits were essential in supporting care home staff to manage residents’ symptoms and plan out EoLC.

Specifically, care home staff highlighted that the prescription of anticipatory medications was essential in helping them prepare for residents' death and manage their symptoms in the care home rather than having to admit residents to hospital for unnecessary treatment. Care assistant 1 C2 spoke about how having anticipatory medication gave a sense of preparedness in relation to everything being in place to give residents a pain free comfortable passing in the home.

Manager C2: *"In terms of what their [GPs] expectations are they'll do DNRs and prescribe anticipatory medication..."*

Care assistant 1 C2: *"When anticipatory medication is prescribed it helps me plan and prepare because I know everything is there to give that resident conformable and pain free care."*

Although staff from care homes one and two recognised the importance of developing good relationships with their local GPs and hospices; they waited for the GPs to visit them rather than proactively setting up collaborative meetings like the staff from care home three.

Care assistant 2 C1: *"We contact them only when we need them so if someone declines or medications need changing."*

The lack of pro-activeness in these care homes points to further underlying factors which may influence mechanisms put in place to improve multidisciplinary collaboration. These underlying factors will be discussed in later sections.

In sum, this theme has highlighted the importance and impact of effective multidisciplinary collaboration as part of EoLC. The section has also highlighted key mechanisms used to facilitate this collaboration which consisted of multidisciplinary meetings, regular communication and use of services to develop effective working relationships. However, these supportive mechanisms were identified mostly in care home three who developed an overall proactive

approach to collaboration. In contrast, staff from care homes one and two had a more reactive approach and waited for external services to come to them.

5.2.2 Theme two: Advance care planning and person-centredness

Analysis of the transcripts identified that advance care planning was a main mechanism used across all three care homes to individualise residents' EoLC and ensure a person-centred approach. Individualising care to residents' needs was theorised by care home staff as being essential to maintaining their dignity during EoLC by facilitating choice and autonomy. Specifically, care home staff spoke about how they had advance care planning conversations with residents and relatives about their preferences and wishes as they approach the end of their life. It was evident that the care home staff then used this information to centre care around the residents and relatives, for example, providing them with their favourite food and identifying where they would prefer to die.

Manager C3: *"It is about making sure people die in a dignified and respectable way. Also trying to assist them to reach their goals of end of life care. So, if someone is saying I do want to go to Poole and have fish and chips, I'll go out my way to make sure that happens. If someone says I don't want my family with me when I die...because you do get that, so don't want family around."*

Care assistant 2 C2: *"We use care plans to record important information so we can tailor end of life care to their [residents'] exact needs. We ask if they would like CPR.... we ask about funerals if they have anything arranged and where they would like to die if they are in the care home its usually here."*

Evidence implies that advance care planning and documenting residents' wishes is an essential mechanism to not only applying person-centred care but avoiding any unnecessary treatment and admission to hospital at the EoL by allowing care home staff to have access to the residents' wishes and preferences.

Care assistant 3 C1: *“They [advance care plans] document if residents would like to be resuscitated, where they would like to die and if they want pain relief... So, for end of life care we know what to do if a resident has documented they don’t want treatment we do not need to call the hospital.”*

Enabling care home staff to have access to this information about residents’ wishes and preferences was highlighted as being essential in ensuring the continuity of care. Although it was noted that residents on EoLC were assigned keyworkers who spend the most time with that resident, it was identified that still EoLC is provided by a number of care home staff. Thus, all staff having access to vital care planning information and passing on information to colleagues was deemed to be an essential aspect of care.

Care assistant 1 C2: *“It’s when we lack the information that problems happen.”*

Care assistant 2 C2: *“Yes... that’s why here we make sure we all know how to access care plans. We have keyworkers who spend the most time with the residents, so they know what is going on and can pass that onto the next person.”*

Analysis indicates when care home staff lack knowledge of the residents in terms of their preferences and wishes, mistakes are more likely to happen.

In sum, this theme has highlighted the central role of advance care planning and its importance in individualising EoLC to the needs of residents. Documenting and updating residents’ preferences and wishes was found to be essential in maintaining person-centred care through ensuring all staff involved in the EoLC had vital information to centre care to residents’ needs.

5.2.3 Theme three: Involving relatives in end of life care

It was apparent that a person-centred approach to EoLC involved including significant others such as relatives as well as residents. Care home staff frequently cited the importance of incorporating relatives in EoLC as well as the residents. Although residents were acknowledged as the 'primary person', care home staff spoke about the need to involve relatives in all aspects of the care (if the resident permitted) which included supporting them throughout the EoLC process and meeting their needs as well as the needs of the resident.

Care assistant 1 C3: *"Part of the ethos of this place is that we encompass the families as well. So, although the resident is the primary person we care for, we equally care for the families as well."*

Care assistant 3 C3: *"Don't forgot you're dealing with the families emotional needs as well as looking after the resident. We had a resident die in one of our rooms who brought his whole family playing music and it was a really good atmosphere."*

Care home staff highlighted that involving relatives in EoLC means meeting their emotional and bereavement needs as well as the residents. It was theorised if relatives understood what was going on and were emotionally supported by care home staff it would reduce the likelihood of them wanting to prolong their loved one's life and admit their loved one for unnecessary treatment.

Care assistant 2 C3: *"We often have conflict with family members towards the end of life, but I've found building up trust with the families really helps avoid this by helping them understand and also helping us to understand them."*

This view was echoed by the staff in care home one, who highlighted that conflicts with families were common and usually occurred because they did not want to accept the death of their loved one.

Care assistant 1 C1: *“Sometimes they [families] do not want to listen to us and will fight us, they lose sight of what’s important and what their relative actually wants.”*

Therefore, this data implies that being able to emotionally support relatives and help them to accept the wishes of their loved one is essential. Several mechanisms were identified which were used by care home staff to emotionally support relatives through the process of losing a loved one. Care home staff spoke about preparing relatives for the death of their loved one by talking to them in advance and giving them the information, so they knew what to expect, rather than having the death come as a surprise. It was expressed that advance care planning conversation (discussed in the previous theme) can be used as a mechanism to help facilitate a conversation to prepare relatives for what is to come. However, analysis implies that these advanced care planning conversations may not be as personal as having dedicated discussions with relatives about EoLC.

Manager C2: *“... for families that idea of losing someone... can be really difficult. So, end of life care is not just about the final few days it may be preparing someone in their journey at any time. This can be done as part of care planning, but I think it’s good to have separate more personal conversations.”*

Manager C1: *“I can use care planning to break the ice and to start a conversation about what is going to happen and what plans they may want to put in place.”*

As well as mechanisms aimed at emotionally supporting relatives, care home staff also gave practical support. Practical support mechanisms consisted of providing vital information about funeral plans and signposting bereaved relatives to relevant services.

BR1 C1: *“They explained to us and helped us understand what to do after death, with stuff like name of coroner, number and where the coroner was. All the support networks we could get*

if we were in need. Often, I found that the practical help was as useful as the emotional help. So just addresses name of people they could go to, just stuff like that.”

However, it was identified that most mechanisms to support relatives were put in place after the death of their loved one. Key mechanisms used to provide this bereavement support after death included attending funerals and supporting relatives through communication and setting up remembrance days. It was theorised that these mechanisms were essential in providing bereaved relatives with on-going support through the grieving process:

Manager C3: *“Every year we do a Remembrance Day. So, when someone’s died, and we’ve got their funeral things I put it in a folder and that comes out in our celebration of life day. So, it’s about bringing people together after death, we invite their families to come meet us again, because they’ve not seen us. Embracing death as well as the end of life bit really.”*

Care assistant 3 C1: *“... in terms of aftercare we wait for the families to come sort out the belongings and move out the room, we don’t throw them out.”*

In sum, this theme has highlighted the mechanisms involved in providing relatives with the necessary information and support to be involved in the EoLC process. However, it was identified that at present most intervention mechanisms are focused on supporting relatives after death into bereavement. While bereavement support is an essential part of EoLC (Fisher et al. 2000), these findings suggest that more needs to be done in terms of intervention mechanisms to provide emotional support before death.

5.2.4 Theme four: Education mechanisms to facilitate person-centred holistic care

Education mechanisms were identified as being key to providing care home staff with the skills and knowledge to carry out person-centred care and engage in advance care planning. The main education mechanism used throughout all three care homes was on-the-job training (shadowing). Care home staff spoke about how they shadowed their colleagues to pick up the practical skills associated with advance care planning such as developing relationships with residents and relatives. From a care assistant perspective, it was implied that they learnt better from these practical methods due to the 'practical' nature of their job rather than having more formal education.

Care assistant 1 C1: *"Its [EoLC] very practical you just have to get it done we learn from watching each other on the job that's how I learnt anyway.... when we get new staff, we put them with the older staff so they can pick things up and learn. I learn better from watching something being done rather than reading it in a book, talking to residents and planning their care and developing a relationship - these are all practical skills."*

Although this evidence highlights the benefits of shadowing particularly in relation to learning the more practical aspects of the job, it was unclear what exactly care home staff were learning during shadowing sessions with more experienced and 'older' colleagues. This is important because the analysis throughout this study suggests that being 'older' and more experienced does not necessarily equate to more knowledge and evidence-based practice. For example, some older more experienced staff may be 'stuck in their ways' meaning they are unwilling to change their practice and will continue to spread poor practice (this will be discussed further in section 5.4 – human agency).

On-the-job training (shadowing) was not the only education mechanism identified. Analysis of the transcripts from care home three uncovered a range of

education mechanisms used by the care home staff from workshops to video sessions. The workshops and video sessions were provided to the home staff as part of the GSFCH programme (discussed in chapter three) which care home three were a part of.

It was apparent that the GSFCH provided wider training to include care and planning around residents' holistic needs rather than simply shadowing a more experienced colleague. Whilst the staff from care home three still engaged in shadowing it was apparent that it was based on the knowledge from the workshops rather than 'older' more experienced members of care home staff. The quotes below imply that basing shadowing on evidence-based workshops was essential in ensuring the care home staff were 'on the same page' in terms of their application of person-centred care.

Registered nurse 1 C3: *"Training is provided through workshops and paperwork like the portfolio that come with the framework we have video sessions that we watch throughout the year too..."*

Researcher: *"What do you learn in the workshops?"*

Care assistant 3 C3: *"They cover how to approach topics with them [residents] and for us have a person-centred approach...some of our residents do not want their families with them at the end. Our practice is based on this which I think is important so we're all on the same page."*

Manager C3: *"We give our staff training to be able to deliver holistic care to make sure you've got everything planned from funerals plans to burial cremation. The funeral people that they're going to go to. Who wants to be there, who doesn't want to be there. Looking at the residents themselves...what's their pain now and what's their goals in pain relief...do they not want any pain at all you know."*

In terms of frequency of education, and who was included in education, it was apparent that workshops and video sessions included a wider range of care home staff compared to on-the-job training and were delivered periodically (three times a year). In contrast, the frequency of shadowing sessions was not clear, appearing to be used when necessary such as introducing a new starter to advance care planning.

Care assistant 1 C3: *“We have three set training days every year for everybody. So even someone working in the kitchen is inducted into care, they may not do the care, but they get training on dignity and respect, even if they don’t go in and out the rooms much.”*

Care assistant 1 C2: *“Shadowing is used for new starters to get them used to end of life care or if one of us wants to learn something new.”*

The educational workshops used in care home three involved a diverse range of care home staff from those with non-formal caring roles such as housekeeping staff to registered staff such as nurses and managers. The inclusion of staff with non-formal caring roles in EoLC training was not apparent in care homes one and two who used shadowing:

Housekeeping C2: *“Cleaners are not involved in the end of life care training in the same way the carers and nurses are. I would like to learn more about end of life care because like the carers I also come across it a lot.”*

This is important because the data highlight that being included in education and training helped staff with non-formal caring roles contribute more to EoLC. Specifically, it was apparent that often care home staff with non-formal caring roles indirectly contributed to advance care planning and individualising EoLC by passing on information to the more ‘experienced’ care home staff. For example, the housekeeping staff from care home three spoke about getting to know the residents and building a relationship with them by having conversations while

cleaning the rooms and passing any information relevant to their care (with residents' and relatives' consent) onto care home staff responsible for care planning.

Housekeeping C3: *"They [the residents] become a part of your family I go in everyday to clean the rooms. We see more of the residents then we do our own families, I always chat to them about little things. I often pass this information on the other staff which helps them get to know the resident too."*

As well as housekeeping staff, analysis revealed that administrative staff had an important role in EoLC care planning. Specifically, Administrator C3 spoke about being responsible for recording and updating information such as residents EoLC preferences to enable all care home staff to be able to see changes and updates in relation to residents' preferences:

Administrator C3: *"As an admin I record the information on our systems so the residents' preferences can also be found. I update the system regularly so if a resident's preferences change, we all know."*

This evidence implies that adopting a 'whole home' approach and involving a range of care home staff in education helped staff in care home three gather and update important information for advance care plans. Furthermore, several bereaved relatives spoke about their interactions with a "range of staff" from cooks, to receptionists to housekeeping staff:

BR5 C2: *"I also dealt a lot with cleaning staff when they would come in the room, they made conversation with us, my aunt took a liking to one of them. Erm so I did interact with a wide range of staff and that was a good point of the care there. I also interacted with the cleaning staff in the corridors and it was important that they knew my aunt was on end of life care and they could deal with me and her in an appropriate manner."*

BR6 C3: *“Even when I walked in the lady at the desk knew exactly who I was and what was going on with my mother. I hadn’t met her, but she knew me, and knew who my mother was. Every time I went in, they knew the state of play with my mother.”*

In sum, this theme has highlighted the main education mechanisms used to facilitate person-centred EoLC in care homes. Education appeared to centre around helping care home staff gather and document information for advance care plans to tailor care to residents’ and relatives’ wishes and preferences. Mode and type of education delivery were found to influence the frequency and involvement in education. For example, workshops and video sessions were delivered three times a year and included all care home staff, while shadowing was delivered infrequently and appeared to only include staff with formal caring roles such as registered nurses and care assistants.

5.3 Contextual mechanisms

This section will explore the resources and restrictions embedded in the social and organisational context which were hypothesised as either promoting or inhibiting the effectiveness of intervention mechanisms. Three themes emerged:

5.3.1 Theme five: Financial and organisational variability

It was identified that the financial and organisational contexts of the care homes influenced a number of the intervention mechanisms discussed in the previous section. Specifically, many of the mechanisms discussed in the previous section such as collaborative meetings and workshops come as part of the GSFCH. However, analysis identified financial and organisational barriers to the implementation of these intervention mechanisms. For example, managers from care homes one and two spoke about the time commitments with setting up such large-scale interventions, compounded by the costs that come with implementing and sustaining such a programme.

Manager C2: *“Programmes like the Gold Standards do cost a lot to implement but I also hear it takes up a lot of time to run and keep it up. I looked into it...it’s a big commitment.”*

Manager C1: *“Lots of homes are signed up for the Gold Standards Framework then you have to update it and keep paying... we are a residential small home so would rather not be paying for training that may not work for us and that may be phased out soon. We cannot afford to waste money like that.”*

This data suggests that financial and organisational contexts are preventing these homes from benefiting from many of the supportive mechanisms that come with the GSFCH, that care home three was able to utilise. The manager from care home three highlighted that they had more financial freedom compared to other homes which allowed for flexibility in terms of training and education. However,

the manager from care home three also highlighted that providing EoLC is an important priority which should not come down to financial resources.

Manager C3: *“We’ve got that flexibility and I just wish other homes had that. There is a financial thing in that. But you can’t put a price on end of life care; the memories are everything to a loved one, if you don’t get it right you’ve had it.”*

It was apparent that the type and size of care home influenced their financial and organisational ability to deliver and sustain intervention mechanisms. Specifically, care home one was a small residential home with 32 beds, which delivered EoLC a few times a year, while care home three was a 75-bed nursing home where EoLC was delivered far more frequently.

Care assistant 2 C1: *“We do not deliver much end of life care here, so we only have a few deaths a year. Usually quite a few in a short amount of time, then you’ll go through a period where lots die. It’s always Christmas before or after. So, when a death comes it can be hard hitting, we’re not as used to it as some other places may be.”*

As a result, the data suggest that the staff from care home one require more support and help as they become ‘rusty’ due to the lack of practice and exposure to EoLC. These findings imply that the care home which was most in need of education, support and guidance was least likely to receive it due to limited financial and organisational barriers (i.e. having no onsite registered nurses) that come with being a smaller residential home.

Furthermore, because care homes two and three were nursing homes they had registered nurses on site 24 hours a day to provide guidance and support. Care assistant 1 C3 spoke about how having registered nurses on site provided support and reassurance, especially during EoLC. Despite care home two being dual registered, the residential floor still had access to registered nursing staff who were located upstairs on the nursing floor. Consequently, it was evident

that non-registered care home staff felt more supported delivering EoLC with the presence and oversight of on-site nursing staff.

Care assistant 1 C3: *“We have the nurses who check what we are doing is right...it just gives that reassurance...”*

Care assistant 1 C2: *“They [on-site nurses] help support us so if we need any help, we just ask... without the nurses I would definitely feel more vulnerable as they’d be no one to ask...apart from our managers...but they are too busy. It would be nice I suppose to have more nurses, but we do well with what we have.”*

It was further highlighted that this onsite support and reassurance from in-house nurses meant that staff from care homes one and two did not have to rely as heavily on outside services such as district nurses, and external services like care home one for guidance and support during EoLC. For example, the analysis of the data suggests that non-registered staff from care home one were more likely to call emergency services during EoLC because of the lack of internal support from registered nurses. It is apparent that on-site nursing can help give non-registered care home staff a feeling of safety and reassurance during EoLC that was not apparent with district nurses in care home one.

Care assistant 1 C1: *“We do rely on outside services more because we don’t have nurses here, so they need to come faster for us. We don’t have that medical support so it’s harder for us to give them [residents] what they need. So, we need to call the direct nurse or emergency services if something happens.”*

Manager C1: *“We don’t use nurses on site we use district nurses, so training programmes need to pay attention to stuff like this because we still provide end of life care.”*

Additionally, as highlighted earlier, the staff in care home one emphasised they delivered EoLC infrequently compared to nursing homes, thus, require more support and help as they become 'rusty' with the lack of practice and exposure to EoLC. Therefore, as well as the lack of on-site nursing support, it was evident that the confidence to deliver EoLC in care home one was further impacted by the lower frequency of EoLC delivery.

In sum, this theme has highlighted the impact of organisational contexts on care homes' ability to provide EoLC. It was identified that having on-site registered nurses and delivering EoLC frequently were both contextual factors which were found to provide staff with reassurance and confidence. It was evident that having no on-site nursing and infrequent delivery of EoLC negatively impacted confidence of staff in care home one (a residential home) which influenced their tendency to use emergency services and request outside support. As well as organisational factors impacting on EoLC delivery directly, this theme also recognised that financial limitations prevented care homes one and two from engaging in more substantial EoLC education and training programmes.

5.3.2 Theme six: The diverse resident population

It was found that the care homes in this study were accepting residents from hospital and hospices and the community who come to the care home for usually short periods to receive EoLC. However, analysis revealed that the EoLC of residents admitted to care homes for short periods of time was often poorer compared to residents who had been in the home for longer periods of time. Care home staff spoke about their difficulties developing relationships with residents who had been admitted for short periods to receive EoLC. Specifically, Care assistant 1 C2 revealed that developing relationships with residents admitted to the care home for short periods of time was difficult as they were often only in the homes for a few weeks, and some arrive without any family.

Care assistant 3 C3: *"It is hard to build that relationship with residents who are admitted here for end of life care from the*

community, we often have that here. We take a lot of emergencies too from hospital.”

Care assistant 1 C2: *“So residents who come to the home for only three weeks with no family just for end of life care. It is difficult to build a relationship in that short time.”*

This evidence suggests that current intervention mechanisms such as education on advance care planning are not equipping care home staff with the knowledge and skills to meet the EoLC needs of residents admitted to care homes for short periods of time to receive EoLC. Nonetheless, some care home staff argued that it was still possible to develop a relationship and provide individualised person-centred EoLC with short stay residents.

Registered nurse 1 C3: *“I disagree with that I think you can still build relationships with these temporary residents [short-stay residents] and their families. Because even if just one day you start in the morning by speaking to them and by the end of the day you’ve developed something...you know something about them. Then tomorrow you carry on. So even if they’re here for the week you can build up a certain percentage of trust.”*

Furthermore, one bereaved relative included in this study experienced EoLC in a short period (5 days), and also expressed gratitude for their EoLC experience in the care home comparing it to what could have been a negative experience in a hospital.

BR6 C3: *“My mother went in on the Tuesday afternoon and she died on the Saturday. Everyone was surprised by the speed of her decline... We are incredibly grateful to [name of care home] for accepting my mother on such short notice...”*

This evidence identifies that residents and their relatives experiencing EoLC in care homes over short periods of time highly valued being able to spend their last few days/weeks together in the comfort of the care home setting, rather

than in a hospital or hospice setting. It also highlights that despite the evidenced challenges (in relation to some care home staff's difficulties developing relationships) it is still possible to develop meaningful relationships with these residents and relatives and deliver EoLC in the care home rather than having to admit them to hospital at the EoL.

As well as residents admitted to care homes for short periods of time for EoLC, care home staff spoke about the increasingly demanding and complex EoLC needs of residents. The complex needs of residents on EoLC were highlighted across all three care homes including the residential home (care home one). The manager from care home two spoke about how residents on EoLC usually have multiple conditions such as frailty and dementia.

Manager C2: *"I'm also very much into dementia care and with end of life care they often have lots of illnesses not just dementia but also frailty and other illnesses at the end of life."*

Despite residents presenting with the more complex conditions, the manager from care home one expressed that their EoLC could still be provided in the care home, and often did not warrant admission to hospital or unnecessary medical treatments. However, the data suggest that increasing staffing levels in the care home was essential to managing these increasing needs and avoiding unnecessary admissions to hospital.

Manager C1: *"Residents are becoming older now with more complex conditions we have also in our home experienced much greater numbers of residents. It is really hard. Over the last 10 year I think we used to have 6 carers on the floor now we have to have at least 12 and that's regardless of end of life care. Everybody is older and more complex. But just because someone has a complex condition it does not mean they necessarily need medical care, many of our residents do not want medical treatment, so don't get these two things confused."*

In sum, this theme has highlighted the impact of the diverse nature of the care home residents and the difficulties posed to care home staff delivering EoLC to this resident population. For example, despite engaging in advance care planning, staff still struggled to develop relationships with residents admitted to the care home for short periods of time to receive EoLC. The evidence presented in this theme indicates that more needs to be done in terms of education and training to support care home staff providing EoLC for an increasingly diverse and complex resident population.

5.3.3 Theme seven: Organisational barriers to multidisciplinary collaboration

Despite the importance of multidisciplinary collaboration (theme two), it was noted that high workloads and time pressures were found to inhibit the interactions and communication between multidisciplinary services during EoLC. Care home staff talked about how they felt these contextual mechanisms prevented GPs from regularly visiting the home to check up on residents receiving EoLC. This is important as care home staff expressed visits from GPs provided them with reassurance through the sharing of knowledge and expertise, and prescriptions of anticipatory medication.

Care assistant 2 C1: *“They [GPs] are supposed to check end of life residents every two weeks. But some of the surgeries here are just too busy to come do that.”*

Care assistant 1 C2: *“I can give you an example not long ago... we have policy where a GP has to come see residents on end of life every two weeks to come for review. In the end they did not come, and we ended up putting in a complaint.”*

Manager C2: *“In terms of what their expectations are they’ll do DNRs and prescribe anticipatory medication if you’re lucky. But they [GPs] don’t support the home with visits. Which is*

something that does give relatives and residents and staff a bit of comfort that someone was overseeing what we're doing."

Despite care home staff placing the blame on GPs services, it was apparent that the high workloads of care home staff also impacted on their own ability to reach out to external service staff such as hospice and GP service staff. Specifically, findings suggest that high workloads and time pressures impacted on care home staff's ability to proactively collaborate and contact GPs, and instead only interacted with GPs on a reactive basis.

Care assistant 3 C1: *"It's it not easy for us either we are busy, so we don't always get the time to talk to GPs even when they do come."*

As well as GPs the data suggests that despite care home staff recognising the value of hospice specialists, they often felt they were too busy to contact hospice specialists to ask for guidance and develop relationships between the services. For example, the manager from care home two spoke about how her workloads in terms of accepting lots of new residents and being 'busy' stopped her from contacting their local hospice specialists for support with their EoLC delivery.

Manager C2: *"We could do more with [name of the local hospice], we can ring them and ask for their help or advice with end of life care, and I encourage my nurses to do this... we could be doing a lot more with them but we get busy here, in the last few weeks we have moved a lot of new residents in so it has been a very busy period."*

In contrast, staff from care home three highlighted that they had a good relationship with their local services because they took the time to develop and build relationships and develop shared understandings. The manager from care home three spoke about opening up to external services and allowing them to see and understand what they do in the care home in terms of EoLC. It was expressed that this transparency and openness gave external service staff an understanding of the care home staff's limitations and exactly where support

was needed. Consequently, it was evident that despite high workloads GPs were still able to support care home three with visits every two weeks to check up on residents during EoLC.

Manager C3: *“It’s about the teams we’re working with the doctor’s surgery. They know us very well, so it’s about letting them see our practice and trust us. They also know our limitations and they know me, and the owner and they know we know our own limitations, we also know them very well and how they work, so we can understand their perspectives.”*

Registered nurse 1 C3: *“We have a very good GP system here the GP comes and visits every Tuesday without fail, it really helps us. Even if she goes, she will come back you can call her anytime.”*

In sum, this theme has highlighted how high workloads, and limited availability of care home staff can negatively impact on multidisciplinary collaboration during EoLC in care homes. The data collected from care home three identified that shared understandings were vital to sustaining effective relationships with external services and understanding each other’s limitations such as limited time and high workloads. The impact of these contextual mechanisms on care home staff’s perceptions of external service staff is explored in the following theme 5.4.1.

5.4 Human agency

Human agency represents how stakeholders interpret and respond to the identified intervention and contextual mechanisms. Three themes emerged.

5.4.1 Theme eight: Perceptions and attitudes of care home staff towards multidisciplinary practice

The data collected from this study indicates that care home staff understood and valued multidisciplinary collaboration as part of EoLC deliver. Despite this, analysis suggests that care home staff's perceptions of external service staff such as GPs were negatively influenced by contextual mechanisms such as high workloads discussed in the previous theme. For example, it was evident that staff from care home one and two perceived the lack of visits from GPs to mean they do not understand or care about the needs of care home residents receiving EoLC.

Care assistant 2 C2: *"GPs. I appreciate they are busy but we're all busy, but if you have someone on end of life care and you call them out for something they don't really care. What do you want me to do if they're on end of life care; it's all about the living they don't care about the dying."*

Similar perceptions were evident in care home one. However, the staff from care home one added that it is more than high workloads and perceived the lack of time and attention given to them by external service staff was a result of a lack of respect for care home staff in general and their knowledge of residents.

Care assistant 2 C1: *"They [external service staff] are busy but sometimes it's more than that. When we ring the hospitals, they do not ask us what we think or what we know about the resident."*

These findings suggest that care home staff were left with negative perceptions and attitudes towards external service staff as a result of the lack of visits and poor interactions. However, there was no evidence to suggest that staff's

negative perceptions and attitudes negatively impacted on their motivation to improve their future relationships and collaborations with external service staff. Nonetheless, across all three care home staff understood the importance and value of multidisciplinary collaboration.

As well as care home staff's perceptions of external services, it was also evident that staff's perceptions of other care homes influenced EoLC. Specifically, analysis identified that different economic and organisational contexts of care homes impacted on staff's willingness to engage in education and learning with other care homes. Care home staff tended to adopt a defensive and competitive stance assuming their way of delivering EoLC was superior, rather than wanting to learn and improve:

Manager C1: *"We are better than other homes here because we have a very personal feel, we're like one big family. Larger home loose this feeling that is why people keep coming to us."*

Care assistant 1 C3: *"We already do things the best we can here, we are all passionate about end of life and our residents so it's hard to think of what we can improve on."*

Analysis of the data uncovered that these perceptions impacted on care home staff's willingness to learn from each other and share best practice with other local homes to collectively improve. Some care home staff even spoke about other local care homes as competitors thus were not always happy to share and collaborate with these homes during EoLC. This was particularly apparent within the residential home (care home one) where staff spoke about not wanting to get EoLC related support from local nursing homes out of fear they would attempt to take their residents.

Administrator C3: *"Would you be open to sharing your best practice though? So, if you had a care home up the road who was wanting to learn and improve would you be happy if one of their seniors come over and shadowed us? Or even just*

come talked to us? They are our competitor. Do you see what I'm saying? Would we really want to? Personally, I'm not sure."

Manager C1: *"We don't work closely with nursing homes as in my 10 years of experience we have always tried to keep them here."*

Moreover, it was also uncovered that the different educational mechanisms used in the different care homes affected care home staff's perceptions and attitudes towards other care homes. For example, staff from care home three who used the GSFCH felt unable to share their good practice with care homes who do not use the GSFCH, as they paid and invested in the education and other homes did not:

Administrator 1 C3: *"We pay for that so we can't really share that with other homes. The codes of practice give a minimum standard for these other homes.... also, what we do adheres to the GSF because we belong to the GSF I don't think we would be allowed to show what we do ..."*

Therefore, it is clear that care home staff's perceptions of other care homes, and external services is impacting on their willingness to share knowledge and expertise. It was also evident that the economic context of the care home sector and the use of different education mechanisms influenced care home staff's perceptions, making them defensive and competitive. However, not all care home staff held these perceptions, and some care home staff were less defensive and more inquisitive and enthusiastic about sharing and learning from other care homes. For example, some staff adopted positive perceptions and attitudes of other care homes highlighting they could not only learn and help other care home staff but help other local care homes by sharing their good practice.

Administrator 2 C3: *"It's got to be good for other care homes if we share our practice because if the best practice is shared*

surely that will help reduce the variation in end of life care standards.”

Administrator 1 C2: *“I would like to see how other homes provide end of life care because I think we all have slightly difference ways of providing it. I know some homes have the Gold standard tool; we don’t have that here so it would be interesting to see how they do things.”*

In sum, this theme has highlighted how contextual and intervention mechanisms were interpreted by care home staff. This theme has identified that some care home staff were positive and enthusiastic about the multidisciplinary collaboration. However, high workloads, and poor interactions often led to care home staff developing negative perceptions and attitudes of external service staff. Poor collaboration between care homes themselves was also noted in this theme. Findings suggest that some care home staff adopted negative and competitive perceptions about other care homes and services, which inhibited the sharing of knowledge and expertise.

5.4.2 Theme nine: Bereaved relatives’ views of and responses to end of life care in care homes

As discussed in theme three, including relatives in the EoLC process and supporting their bereavement needs was found to be essential to avoid conflicts at the EoL. This theme will build on theme three by exploring human agency to understand why conflict can occur between care home staff and relatives during EoLC.

Bereaved relatives described initially feeling a sense of relief that come from their loved one receiving EoLC in a care home. Feelings of relief were particularly expressed by those relatives who had previously cared for their loved one in their home before coming to a care home. BR7 C3 implied that handing over the responsibility of the care of her husband to care home staff allowed her to get

her life back and regain her dignity, which she felt was lost during the struggles of caring for her husband in their own home. This sense of relief that come with handing over caring responsibilities was expressed by several bereaved relatives.

BR7 C3: *“End of life care gave my husband the physical support he needed, they [care home staff] were all qualified to give this sort of care...I just couldn’t do it anymore by myself. I must say, it came with a great sense of relief...I no longer had the responsibility of being the sole carer. I felt a weight being lifted from my shoulders, the people in the home were wonderful.”*

Researcher: *“in what way?”*

BR7 C3: *“The indignity the discomfort, the pain... it was all taken away.”*

However, despite these initial feelings of relief it was evident that bereaved relatives also felt a strong sense of guilt and failure for having to leave their loved one in a care home and not being able to continue caring for them in the comfort and familiar surroundings of their own home. Although bereaved relatives expressed enjoying the freedom and time that was given to them, it was evident these feelings were accompanied with underlying feelings of guilt and grief.

BR7 C3: *“I felt a deep feeling of failure and guilt leaving him and having to rely on others to give him care. I broke my promise to care for him in our home till his death. Certainly, I enjoyed the freedom, it was nice to be able to make myself something to eat when I wanted and in my own time rather than having all my time taken up. But I remember questioning myself during this time. I was left questioning who I was.”*

Further analysis suggested that feelings of guilt and failure were particularly apparent in cases where relatives’ caring responsibilities were no longer needed in the same capacity due to care home staff taking over the delivery of care.

BR7 C3: *“Mmm I would describe it as being like ‘caring withdrawal’ my life was caring for [name of husband] when that was suddenly taken away. I was bereft but at the time he was not dead.”*

Furthermore, bereaved relatives spoke about how leaving their loved one in the care of others was in a sense like losing them. These feelings of ‘early’ bereavement were particularly expressed by bereaved relatives who had long cared for their loved one in their own home before they went into the care home. The feeling was described as ‘carer withdrawal’ and came when caring responsibilities for their loved one were suddenly taken away. Bereaved relatives spoke about how the abrupt end to caring responsibilities led to them to questioning their identity and purpose.

This is an important insight given that trouble establishing an identity was found to heighten bereaved relatives’ emotions particularly towards the end stages of their loved one’s life when unnecessary admissions to hospital to prolong life were more likely. Bereaved relatives expressed ‘coming to terms with’ and ‘accepting’ that their loved one was nearing the end of their life was particularly difficult as life without their loved one left them questioning their purpose and identity.

BR3 C1: *“The hardest part for me and I’m sure for others too was coming to terms with it all and accepting that my mother was leaving us. I remember a sinking feeling and not wanting to believe it.... I had seen her deteriorate and I knew what was eventually going to happen, but it still come as a great shock. I’d had my mother my whole life.”*

Furthermore, the above quote suggests that the emotions discussed throughout this theme such as relief, grief, guilt and failure stayed with bereaved relatives into the bereavement period and often for the rest of their life. Therefore, as well as including relatives throughout the EoLC process supporting them into the bereavement process is also just as important.

However, it was apparent that bereaved relatives experienced and expressed feelings of emotion towards their loved ones differently. Although the quotes above suggest bereaved relatives had difficulty accepting death and letting go towards the end, this was not true across all the transcripts. For example, some bereaved relatives emphasised that they accepted death as part of life, and therefore wanted the care home staff to be direct with them in relation to death.

BR5 C2: *“I don’t have any great emotional hang-up about death. So, I instructed the staff at the home to tell me as it is not to beat around the bush. Some people need emotional help and reassurance, but I don’t want to be clucked over by people who I know professionally and don’t know personally.”*

The evidence presented here does not suggest that BR5 C2 did not experience emotion or difficulty accepting their significant other’s death. However, it does show how different individuals approach death and losing a loved one, and how it can potentially impact on EoLC and care home staff’s approach.

In sum, this theme has uncovered some of the reasons why conflict between care home staff and relatives occurs during EoLC. This is important as the analysis presented in theme three implied that this conflict can lead to unnecessary admissions and prolongation of life. However, this present theme has uncovered that bereaved relatives had difficulty re-establishing their identity and purpose in life without their significant other. For example, some bereaved relatives expressed having difficulty accepting death and moving on. However, it was also evidenced that bereaved relatives expressed emotion differently.

5.4.3 Theme ten: Care home staff’s emotional experiences and responses to end of life care

As well as service users, it was evident that care home staff found delivering EoLC emotional. Care home staff spoke about the close relationships they often developed with residents. Some staff even described residents as being like a second family to them, especially in cases where residents’ own family was not present. Consequently, it was evident that some care home staff found it

emotionally difficult delivering EoLC to residents, especially towards the end stages of their life. The emotional labour of delivering EoLC was expressed by a range of care home staff from housekeeping, to care assistants to registered nurses and managers with their years of experience ranging from two to 29 years.

Care assistant 2 C1: *“In some ways you become their family because you’re spending more time with them than their family. Often families stay away as they don’t want to see their loved one dying so often you take their place. You try being their family for them. So, losing a resident like that can be very emotional yes.”*

Housekeeping C3: *“We get very emotional because we get attached to them, you can’t help that you’re human.”*

In addition, it was apparent staff’s emotional attachment to residents impacted on their ability to discuss death and dying as part of advanced care planning. Analysis implies that staff’s close attachments with residents led to them feeling uncomfortable discussing sensitive and potentially upsetting topics, such as death and dying. Despite the reluctance to discuss death and dying it was well understood by all care home staff that advance care planning was part of their ‘professional job’, thus it was not avoided. However, it was evident throughout the transcripts that discussions about death and dying as part of advance care planning were sometimes rushed and overlooked.

Manager C2: *“We often shy away because we feel uncomfortable... But we really don’t talk about that...we really don’t explore that. So, it makes us come across as a bit stilted and a bit stiff.”*

Care assistant 2 C1: *“I try to change the subject when they [residents] ask about it [death and dying] it best to concentrate on life and the time they have left.”*

Care assistant 3 C1: *“You just have to try to put it to the back of your mind. Although it’s upsetting it is your professional job at the end of the day, you can’t let it affect your work and how you are.”*

However, these quotes suggest that it is more than just care home staff’s relationships with residents. This data uncovers a defence mechanism utilised by care home staff which may be detrimental to residents and relatives. Specifically, the quotes imply that some care home staff are avoiding discussions about death and dying, not only to prevent upset to residents, but to also protect themselves from upset. This is important given this study and previous literature (chapter three) evidence that care home staff find delivering EoLC emotionally stressful. Thus, the data presented here suggests that staff are protecting themselves from further emotional strain by avoiding sensitive conversations about death and dying.

In sum, this theme has highlighted that care home staff developed close emotional attachments to residents. It was apparent that care home staff found delivering EoLC emotionally difficult and did not want to upset residents, especially those residents they had close relationships with. Findings presented in this theme suggest that care home staffs’ emotional responses and attachment to residents impacted on their ability to engage effectively in discussions about death and dying due to them feeling uncomfortable with the emotive subject of death.

5.5 Outcomes

Outcomes are defined as the changes in behaviour that result from how people respond to the intervention and contextual mechanisms. This section will illustrate how outcomes related to advance care planning and unnecessary admissions to hospital from care homes at the EoL can be influenced by interventions mechanisms, contextual mechanisms and human agency.

5.5.1 Outcomes related to advance care planning

Advance care planning was theorised to enable residents to maintain dignity towards the end of their lives by allowing care home staff to delivered person-centred EoLC individualised to residents' needs. Intervention mechanisms such as on-the-job training (shadowing), and workshops were commonly used to help care home staff engage in sensitive EoL discussions as part of advance care planning.

Despite these intervention mechanisms (shadowing and workshops), findings imply that care home staff adopted a defence mechanism which led them to avoiding discussions about death and dying with residents and relatives, particularly with residents they had developed close relationships with (human agency). Additionally, contextual mechanisms such as residents time in the care home and complex conditions were found to further hinder EoL discussions. For example, BR6 C3 spoke about her mother's short time in the care home, although expressing gratitude for her mother's care, BR6 C3 highlighted that she would have liked the care home staff to have discussed the EoL process with her to a greater extent.

BR6 C3: *"It was all planned, but it would have been nice if they talked us through it a little bit more..."*

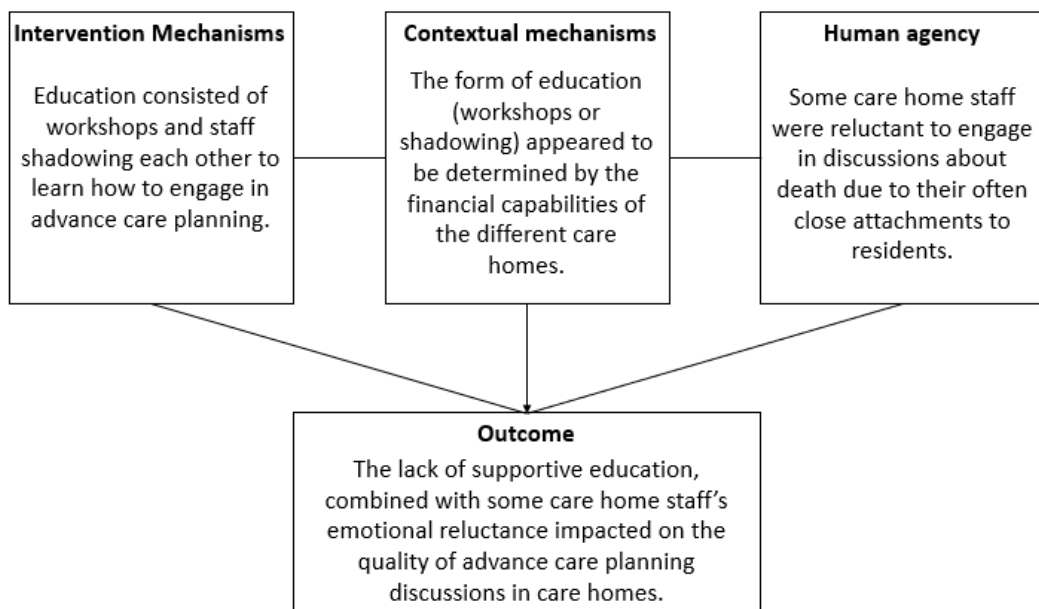
This data indicates that despite the use of advance care planning and educational mechanisms care home staff's reluctance to discuss death and dying negatively impacted on their ability to sensitively engage in advance care planning discussions with residents and relatives. Evidence implies that this unaddressed

behaviour subsequently led to the negative experience of services users. Similar outcomes were identified in all three care homes which suggest education and training in this area needs to be improved.

Nonetheless, positive outcomes were apparent in relation to including a wider range of care home staff in advance care planning and education. Specifically, findings suggest that staff with non-formal caring roles such as housekeeping developed relationships with residents and were able to contribute to advance care planning.

In sum, this section has uncovered the underlying processes behind outcomes in terms of advance care planning. This process has highlighted both supportive and inhibitory factors which were found to impact on outcomes.

Figure 7 Influence of mechanisms and agency on outcomes related to advance care planning



5.5.2 Outcomes related to multidisciplinary practice and unnecessary hospital admissions at the end of life

Phase-one identified that multidisciplinary collaboration plays an essential role in enabling care home staff to provide high quality EoLC in care homes. As a result of care home three's use of collaborative meetings (Intervention mechanism), combined with staff's enthusiasm to improve relationships with external staff (Human agency) the data presented in this study suggests that the rate of collaboration and regular communication between care home staff and external service (local GP and hospice) staff increased.

Staff from care home three spoke about how this improved collaboration facilitated the sharing of knowledge and expertise between care homes and external services leading to care home three being able to provide EoLC for residents with more complex EoLC needs, rather than having to admit these residents to hospital for EoLC (Outcome). The data suggested that this outcome had a positive experiential effect on service users, for example, one bereaved relative noted:

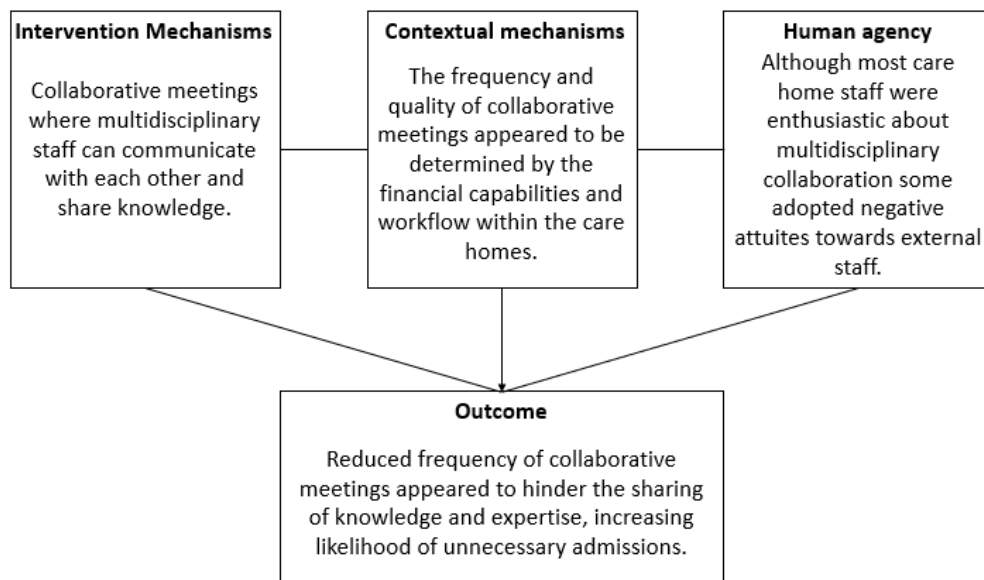
BR6 C3: *"We are incredibly grateful to [name of care home] for accepting my mother on such short notice..."*

In contrast, due to limited resources and varied financial and organisational contexts (contextual mechanism) care homes one and two did not engage in collaborative meeting and instead adopted a reactive approach expecting external services to come to them. This led to poor relationships preventing knowledge and expertise from being shared in the same way seen with care home three.

This lack of effective collaboration appeared to be particularly detrimental for care home one, the residential care home. Specifically, it was found that having no on-site nursing and infrequent delivery of EoLC meant staff from the residential home (care home one) relied more on external services for support (Contextual mechanisms).

This section has highlighted the impact of multidisciplinary collaboration during EoLC in relation to outcomes associated with unnecessary admissions to hospital at the EoL. Collaborative meetings were found to increase rates of collaboration, which enabled care home three to provide EoLC to meet the needs of a more diverse range of service users in the care home and avoid unnecessary trips to hospital at the EoL. However, contextual mechanisms such as care home’s financial constraints influenced the uptake of collaborative meetings.

Figure 8 Influence of mechanisms and agency on outcomes related to multidisciplinary collaboration



5.5.3 Outcomes related to involving relatives in end of life care

Involving relatives as well as residents in EoLC was established as being an important part of person-centred care. Findings suggest that including relatives and keeping them involved in decisions and emotionally supported is key to avoiding disputes and unnecessary admissions and treatment to prolong life. Bereaved relatives expressed that accepting that their loved one was going to die was one of the most emotional parts of the EoLC process for them, especially establishing an identity and purpose following the loss of their loved one (Human agency). Findings suggest that their desire to hold onto their identity made

relatives more likely to want to unnecessarily prolong their loved one's life and increase the likelihood of unnecessary admissions to hospital at the EoL. Moreover, it was apparent that relatives who had been carers for their loved one prior to their admission into the care home had particular difficulty re-establishing an identity with the often-abrupt cessation of caring responsibilities upon admission to the care home (Contextual mechanism).

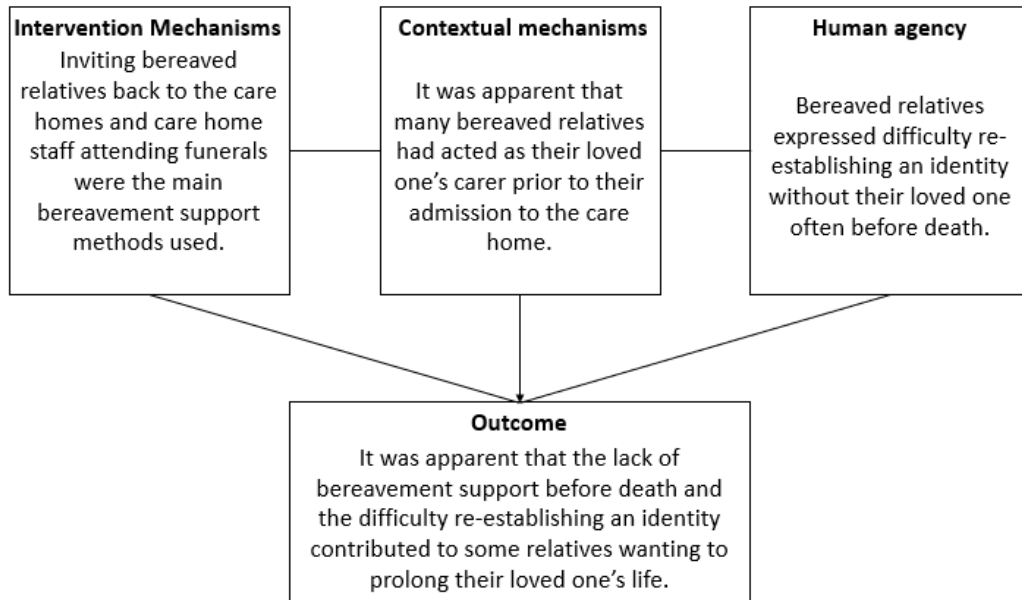
Despite these findings, it was uncovered that currently most intervention mechanisms such as attending funerals and arranging 'celebration of life days' are focused on bereavement and emotional support after death. Mechanisms in place to support relatives accept and come to terms with death before the death of their loved one appeared sparse.

Nonetheless, some evidence of preparing and supporting relatives for death of their loved one was apparent. Care home staff highlighted how they used advance care planning discussions to prepare relatives for the death of their loved ones (Intervention mechanisms). However, it was apparent that care home staff's emotional reluctance to discuss death and dying (Human agency) inhibited their ability to prepare relatives for the death of their loved one (Outcome).

However, positive outcomes were highlighted in relation to bereavement support after death. Specifically, positive outcomes were expressed in relation to celebration of life days which invited bereaved relatives back to the home to remember their loved one and provide support and company.

BR7 C3: *"Keeping in contact with me afterwards was a big thing, they asked me to come back [to the home] you know. That meant the world to me."*

Figure 9 Influence of mechanisms and agency on outcomes related to involving relatives in end of life care



5.6 Initial Intervention Theories

The analysis presented in this chapter has contributed to filling the gaps in the literature identified in chapter three by uncovering the underlying processes behind outcomes. To further strengthen the findings, they will now be synthesised with the findings from the critical realist review (chapter three) and the systematic literature review (chapter two) and used to develop initial intervention theories. Unlike the previous interventions, the initial intervention theories presented below were designed by systematically incorporating mechanisms and agency into their design to address the outcomes outlined in the previous section. Four initial intervention theories were developed.

5.6.1 Initial intervention theory one: Advance care planning and discussing death and dying

The systematic literature review presented in chapter two highlighted the importance of providing individualised person-centred care through the use of advance care plans to meet residents needs and wishes (Froggatt et al. 2009; Kinley et al. 2018; Ong et al. 2011). Many residents come to care homes without completed advance care planning documentation, and those that do, still need to have their preferences and wishes updated to meet their changing needs (Gordon 2012; DH 2008). It is, therefore, one of the central roles for care home staff to attempt to access and record the preferences of residents receiving EoLC (DH 2008), for example, the type of care they would like to receive, who they want around them, and their preference for place of death. Given this importance, it was unsurprising that chapter three identified that advance care planning interventions were the most common type of intervention developed to improve EoLC in care homes.

However, findings from the empirical part of this study identified that care home staff's reluctance to discuss death and dying inhibited the effectiveness of advance care planning discussions. It was found that care home staff avoided discussions about death and dying in an attempt to not upset residents.

However, deeper analysis suggested as well as not wanting to upset residents; staff's reluctance to discuss death and dying was also a defence mechanism to protect their own emotional wellbeing. These insights are valuable as the research reviewed in chapter three tended to focus more on the numbers of advance care plans to determine success (Handley et al. 2014; Ong et al. 2011; Stone et al. 2013) and less on the quality and impact of the interactions.

As well as care home staff, it has been reported that some residents and relatives were also reluctant to discussing death and dying. It was noted in critical realist review that religion, and background and life experience all influenced how individuals approached death and dying (Hall et al. 2011). However, the findings from phase-one suggest that bereaved relatives were open to discussing death and dying and were held back by care home staff's reluctance rather than their own. Nonetheless, phase-one did not explore and note how people's background and culture may influence their acceptance of death and dying, thus this will be explored further in phase-two.

In addition, the findings from the critical realist review suggested that a taboo culture surrounding death and dying caused staff to avoid such conversations with residents and relatives (Hall et al. 2011; Hockley et al. 2005). Although findings from phase-one identified a reluctance to discuss death amongst care home staff, a taboo culture was not identified, therefore contextual barriers such as cultures in care homes will be explored further in phase-two and incorporated in the initial intervention theory. Exploring the impact of these cultures and background on individual behaviour is important given the current mechanisms used to train and educate care home staff. Specifically, current education mechanisms mostly consisted of on-the-job training (shadowing) which may allow care home staff to pass their beliefs and attitudes (such as their reluctance to discuss death and focusing on living) onto less experienced care home staff.

Given the apparent impact of care home staff's reluctance to discuss death and dying on current intervention mechanisms such as advance care planning, there is a need to implement evidence-based education into care homes to provide staff with the knowledge and support to sensitively engage in discussions about

death and dying. The critical realist review highlighted that evidence-based education workshops improved staff's knowledge and confidence (Finucane et al. 2013; O'Brien et al. 2016; Kinley et al. 2014). Furthermore, the data from phase-one identified that workshops can be accompanied by existing methods such as shadowing to provide a foundation of evidence-based knowledge to be disseminated. Thus, workshops may be an effective format to deliver the education.

Findings from this study suggest that the educational content of these workshops need to be based on supporting care home staff from different culture and backgrounds to sensitively engage in discussions about death and dying as part of advance care planning and in general. This is important given the literature reviewed in chapter three suggested that workshops are currently more focused on supporting care home staff to gather information for advance care plans rather than supporting sensitive discussions about death and dying. From this synthesis the following initial intervention theory was developed:

Given some care home staff's emotional reluctance to discussing death and dying (Human agency) and cultures within care homes which perceive death as taboo (Contextual mechanism) there is a need to introduce educational workshops (Intervention mechanism) focused on supporting more care home staff to engage in sensitive discussions rather than simply gathering information for advance care plans (Outcome).

Questions for care home staff:

- What do you think?
- How do you feel about discussing death and dying?
- How do you think information on end of life care should be effectively conveyed to residents and relatives?

Questions for bereaved relatives:

- What do you think?
- Did you feel you had an understanding of end of life care?

5.6.2 Initial intervention theory two: A whole home approach to advance care planning

Findings from this study and existing literature reviewed in chapters two and three all highlight the importance of care home staff developing relationships with residents and relatives (McGlade et al. 2017; Hickman et al. 2016).

Specifically, good relationships between care home staff and residents and relatives was found to help them more openly share information pertaining to EoLC.

Although literature reviewed in chapters two and three acknowledged the importance of relationships in advance care planning and care (Froggatt et al. 2009; McGlade et al. 2017; Hickman et al. 2016), current research only explores relationships between care home staff with direct caring roles such as registered nurses, and care assistants with residents and relatives. However, this present study identified relationships were developed between residents, relatives and range of care home staff including those with non-formal caring roles. Bereaved relatives highlighted that as well as care home staff with formal caring roles, they developed close relationships with staff with non-formal caring roles and therefore would often talk to and share their preferences with the staff. For example, housekeeping staff highlighted that residents and relatives would often share information useful to EoLC with them while they cleaned their rooms, which they were able to pass on (with consent) to inform advance care plans. It was apparent that these small inputs from staff with non-formal caring roles accumulated to have a big impact on bereaved relatives' experiences. Recognising the role of staff with non-formal caring roles is important as it has not been previously reported or recognised in the literature.

Moreover, utilising the skills and qualities of staff with non-formal roles was found to be particularly effective for residents and relatives in the home for a short period of time to receive EoLC. This is important as findings from phase-one highlighted that care home staff often had difficulty developing relationships with residents who had been admitted to the care home for only a short period of time to receive EoLC. However, findings suggested that the additional

relationships and inputs from those staff with non-formal caring roles were found to help staff develop more effective relationships in short time periods and enabling staff to collect and pass on more information to inform care planning.

Despite this, only staff from care home three included staff with non-formal caring roles in education to support their contribution to EoLC. However, care home three used workshops which were easier to include all staff in while care homes one and two only used on-the-job training which appeared to not include staff with non-formal caring roles. Further to this, the critical realist review uncovered that only staff with formal caring roles (care assistants and registered nurses) were included in interventions on advance care planning. From this synthesis the following initial intervention theory was developed to add to initial intervention theory one:

Care home staff with non-formal caring roles developed close relationships with residents and relatives (Human Agency) including short stay residents who were admitted to the home for a short period of time to receive end of life care (Contextual mechanism). Thus, including staff with non-formal caring roles in the educational workshops introduced in the previous theory (Intervention mechanism) is necessary to help staff more effectively develop relationships with residents and relatives improving advance care planning (Outcome).

Questions for care home staff:

- What do you think?
- What are your thoughts on involving all care home staff?
- What care home staff would you like to see more involved?

Questions for bereaved relatives:

- What do you think?
- Did you feel a range of care home staff were involved in the end of life care for you and your relative?

5.6.3 Initial intervention theory three: Bereavement support

It has been reported that losing those whom our lives are entangled with is associated with deep sadness, grief and feeling of loss (Relf et al. 2010). For most support from family, friends and personal life is enough to help them manage their feeling of grief and sadness, however, others may find it harder to adjust to life without their loved one and require more support (Relf et al. 2010).

Therefore, current research and policy promote the need to support to facilitate grieving to prevent detrimental consequences of bereavement, which can include depression and lasting fatigue (RCN 2019; NICE 2004).

Findings from phase-one highlight supportive mechanisms and elements of good bereavement support such as celebration of life days and attending funerals. This type of bereavement support for relatives is important as it was revealed in the systematic literature review that bereaved relatives appreciated it when staff attended funerals and supported them through regular communication and interactions following a death (Kinley et al. 2018).

However, findings suggest that there is currently a lack of intervention mechanisms focused on supporting relatives before the death of their loved one, preparing relatives for the death of their loved one. This is important as it was found that providing bereavement support before death is essential to avoiding conflict at the EoL. Specifically, findings imply that supporting relatives to accept the death of their loved one and re-establishing their identity was essential to avoiding conflict and unnecessarily prolongation of life via admissions and treatment. Pre-death bereavement support such as talking to residents and preparing them for death was a key element to supporting them through the EoLC process, to gradually help them to accept their loved one was going to die. However, care home staff's own emotional reluctance to discuss death and dying impacted on their ability to provide this type of bereavement support.

The critical realist review in chapter three also identified a lack of current intervention mechanisms in place to support care home staff to manage their emotion and overcome these reluctances. For example, only four studies

implemented reflection for care home staff, which was often not effective due to high workloads and time pressures preventing reflection from taking place (Hockley et al. 2005; Nash and Fitzpatrick 2015; Cox et al. 2017; Hewison, Badger and Swani 2011). This is important given findings from this present study suggest that staff's reluctance to discuss death and dying was linked to the emotional stresses of delivering EoLC.

Moreover, from the data collected in phase-one it was unclear what emotional support was given to care home staff, as care home staff tended to speak about and focus on the needs of residents and relatives rather than their own emotional needs. Thus, the findings from phase-one of this study suggest a need to provide better emotional and bereavement support for care home staff to help them more effectively support the bereavement needs of relatives. Specifically, it was apparent that care home staff become attached to residents often developing close relationships, even in cases seeing residents as family. Therefore, staff would grieve and require emotional support when residents died, especially those they were close to. The current emotional support mechanisms in place for care home staff will be further explored in phase-two.

Literature highlights that the lack of emotional support mechanisms in place for care home staff is a result of financial limitations and high workloads, causing the needs of care home staff to be overlooked (Vandrevala et al. 2017). Despite this, Marcella and Kelley (2015) and Learner (2016) argue that emotionally supporting care home staff is essential in enabling them to deliver high quality care consistently. Together, the findings from the review and phase-one of this present study suggest more needs to be done to explore and support the emotional needs of care home staff delivering EoLC. From these findings the following initial intervention theory was developed:

Despite limited finances and high workloads (Contextual mechanism) evidence-based education on bereavement support to give care home staff the knowledge to support their own emotional needs as well as the emotional needs of bereaved relatives (Intervention Mechanism) is necessary given the varied

bereavement experiences (Outcome) and the emotional challenges faced by both staff and service users (Human agency).

Questions for care home staff:

- What do you think?
- What does bereavement support mean to you?
- What kind of emotional support currently receive?

Questions for bereaved relatives:

- What do you think?
- What if any bereavement support and emotional support did you receive from care home staff during end of life care?

5.6.4 Initial intervention theory four: Sharing of knowledge and expertise between care homes and external services

Findings identified that multidisciplinary collaboration was essential to enable the sharing of knowledge and expertise between care home staff and external service staff. Current literature reviewed in chapters two and three support these findings. For example, Kinley et al. (2018) and Kupeli et al. (2016b) also found that sharing knowledge and expertise with multidisciplinary teams helped care home staff manage residents' pain and medication avoiding potentially unnecessary use of emergency services at the EoL.

This present study suggests that these poor outcomes were because of contextual mechanisms such as high workloads and limited availability of both care home staff and external service staff, which was found to inhibit effective multidisciplinary collaboration. For example, it was highlighted that GPs did not support some of the care homes in this study with regular visits. The critical realist review uncovered similar issues experienced with GP services (Kinley et al. 2014; Badger et al. 2012). A range of research has been conducted in this area exploring interactions between care homes and GPs services, which has concluded that high workloads, short staffing and limited funding led to GP

services struggling to support care homes (Mitchell et al. 2016; Goodman et al. 2015; Lee et al. 2017; Ho et al. 2016).

Phase-one of this study has evidenced that issues in relation to high workloads are not just seen on the side of GPs but are problems very much apparent for care home staff too. Moreover, it was also reported in chapter three that high staff turnover in care homes caused relationships with external service staff and care home staff to break down due to staff with relationships with external service staff leaving care homes (Finucane et al. 2013; O'Brien et al. 2016; Mayrhofer et al. 2016).

Monthly meetings with external services used by staff from care home three were found to contribute towards effective collaboration. However, it was found that because of the care homes diverse financial and organisational context setting up and sustaining these monthly meetings was not an option for care homes one and two. Similarly, the results of the critical realist review also noted that many care homes struggled to sustain the GSFCH due to its resource heavy requirements (Kinley et al. 2014).

As well as collaboration with external services, findings from phase-one suggest that knowledge and expertise can be shared between care homes. Despite this, a competitive culture within the care home sector was identified, which often caused care home staff to perceive other homes as competition, thus developed a defensive stance. For example, it was evidenced that despite wanting to provide the best EoLC for residents, staff felt they were in competition and had to compete for residents. Moreover, the systematic search strategy as part of the critical realist review only uncovered two studies which promoted sharing between care homes (Wen et al. 2013; Hewison, Badger and Swani 2011), which were not sustained due to the limited resource and time restrictions of the participating care homes.

In order to help facilitate more effective collaboration accounting for high staff turnover and resource limitations, and the financial limitations of care homes, an externally funded liaison nurse is proposed. It was revealed in the critical realist

review that interventions utilised an external professional to come into the homes and provide educational and collaborative support (Kinley et al. 2014; Temkin-Greener et al. 2017; Finucane et al. 2013; Waldron et al. 2008). Analysis of outcomes suggested that a liaison nurse could be an effective mechanism, especially in the context of high staff turnover as an external professional can provide a consistent means of collaboration and a source of guidance and support regardless of staff turnover (Finucane et al. 2013; Waldron et al. 2008). However, financial support would have to be acquired to fund the implementation of liaison nurse. Nonetheless, prior to funding proposals, the theory was first proposed to the care home staff in the form of the following initial intervention theory:

Negative relationships between care home and external service staff are persisting (Human Agency) due to high workloads, staff turnover and a competitive culture (Contextual mechanism). Therefore, a dedicated end of life care liaison nurse (Intervention Mechanism) is necessary to build the knowledge and confidence to improve the rate of collaborations between care homes and external services (Outcome).

Questions for care home staff:

- What do you think about using an external liaison nurse to support your collaboration?

5.7 Chapter summary

The chapter commenced by presenting the thematically analysed data organised and categorised in accordance with CRE. This process of analysis helped provide a systematic understanding of outcomes used to determine high quality EoLC in care homes. This data was then synthesised with existing literature and used to develop four initial intervention theories.

However, no theory is absolute; thus, should be exposed to external criticism and interpretation which may lead to improvement (Bhaskar 1975).

Subsequently, the initial intervention theories developed in this chapter were presented to the study participants in phase-two of this study subjecting them to external interpretation and scrutiny which led to further refinement. Phase-two of this study is presented in the following chapter.

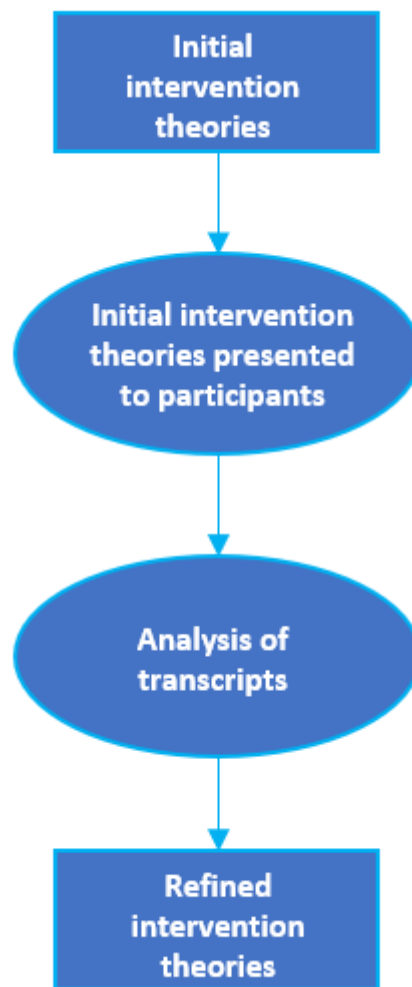
6 Findings: Phase-two

6.1 Introduction

The aim of this chapter was to refine and increase the feasibility of the initial intervention theories developed as part of phase-one of data collection and analysis (chapter 5). Using realist semi-structured interviews and realist focus group discussions, phase-two presented the initial intervention theories to the participants allowing them to provide feedback on each theory.

The chapter consists of five sections where each of the initial intervention theories are refined based on the data collected in this second phase of data collection. Each section begins by presenting the initial intervention theory, then CRE was used to refine the initial intervention theories based on the data collected from this phase. This process aimed to support, improve and increase the feasibility of the initial intervention theories (See figure 10). Each section ends by presenting the refined intervention theory. Lastly, section 6.2.6 presents an 'overall' intervention theory which theorises the need for deliver the intervention theories as a multicomponent intervention.

Figure 10 Critical realist evaluation flowchart – phase-two



As with phase-one, participants included registered and non-registered care home staff, care home managers and bereaved relatives. Many of the participants in this second phase of data collection were those who participated in phase-one (chapter 5, table 14). However, in addition some new participants participated in phase-two due to different shift patterns and lack of availability of all those who participated in phase-one. Participants were each allocated a nominal pseudonym. See table 15 for overview of anonymised participants in phase-two.

Table 15 Pseudonyms used for participants: Phase-two

Care homes	Participants		
	Care home managers	*Registered and **non-registered care home staff	Bereaved relatives (BR)
C1: Care home one	Manager C1 (10 years' experience and registered nurse)	Care assistant 1 C1 (5 years' experience) Care assistant 2 C1 (10 years' experience) Care assistant 3 C1 (3 years' experience)	BR1 C1 BR2 C1
C2: Care home two	Manager C2 (15 years' experience and registered nurse)	Housekeeping C2 (1-year experience) Care assistant 1 C2 (29 years' experience) Care assistant 2 C2 (14 years' experience) Registered nurse 1 C2 (2 years' experience)	BR4 C2
C3: Care home three	Manager C3 (6 years' experience and registered nurse)	Care assistant 1 C3 (28 years' experience) Care assistant 2 C3 (2 years' experience) Care assistant 3 C3 (2 years' experience) Care assistant 4 C3 (4 years' experience) Administrator C3 (5 years' experience) Housekeeping C3 (5 years' experience)	BR6 C3 BR7 C3

**registered care home staff can include registered nurses. **non-registered care home staff included care assistants, administrative staff and housekeeping staff.*

6.2 Refined intervention theories

6.2.1 Intervention theory one: Education on discussing death and dying

Initial intervention theory presented to participants: *Given some care home staff's emotional reluctances to discussing death and dying (Human agency) and cultures within care homes which perceive death as taboo (Contextual mechanism) there is a need to introduce educational workshops (Intervention mechanism) focused on supporting more care home staff to engage in sensitive discussions rather than simply gathering information for advance care plans (Outcome).*

When presented with intervention theory one, care home staff supported the theory that educational content on discussing death and dying was necessary to develop their skills and confidence and address their reluctance. The data collected from phase-two supported the theory that current education was predominantly focused on gathering information for advance care plans, rather than supporting care home staff to sensitively engage in discussions about death and dying.

Registered nurse 1 C2: *“Education helping us to approach the subject of death with our residents would be useful because we don't really have anything in place at the moment for that side of things. I have seen staff just focus on care plans and information and not going into details...”*

Moreover, it was also apparent that care home staff's close attachments to residents influenced discussions about death and dying. Care home staff spoke about how discussing death and dying would upset residents and relatives, and how it was a difficult subject to approach especially with those they had become close to. This evidence reaffirms that care home staff's close relationships with residents and relatives can have an influence on how they approach advance care planning, particularly discussing death and dying. As a consequence, it was found that some care home staff avoided talking about death and dying with

residents and relatives, even when residents or relatives would ask about death. Care home staff expressed they did not want to discuss death and dying with relatives when they would ask questions, rationalising it by assuming it would upset them.

Care assistant 3 C1: *“The hardest thing to deal with is the families asking the questions. You know when they come in and they look really bad today and they looked ok yesterday...why is that they ask. It’s difficult to speak about this to the families because they are obviously emotional.*

... sometimes the resident will say to you ‘I’m dying’ and there is nothing you can say I just try and change the subject. It can be really hard because you become attached”

Further to this, phase-two identified that the reluctance/avoidance appeared to be particularly detrimental for residents living with dementia. The data collected throughout phase-two imply that some care home staff assumed residents with dementia would get too upset or would not understand if they talked to them about death and dying. Due to this, the data suggests that care home staff tended to go straight to the next of kin to have advance care planning discussions, rather than attempting to engage with the residents living with dementia. This perception that residents with dementia would become too upset was expressed by staff with a range of experience and roles from managers to care assistants.

Manager C1: *“Over the past few months a lot of our residents have become high needs and we haven’t got many that have [mental] capacity. So mostly it’s about discussing it with the next of kin and not the resident. You’ve got to think what is right for that person, so if they don’t understand what you’re talking about, why you going to talk to them about dying that’s not nice.”*

Care assistant 1 C2: *“...for residents who have dementia we go to their families directly because it can be very upsetting, and it can confuse the resident even more if we start asking too much questions. It’s about supporting them to enjoy the time they have left.”*

This data suggests that care home staff did not attempt to engage or assume capacity, but rather assumed a lack of capacity and went straight to the family, excluding the resident with dementia from contributing or attempting to understand EoLC. Similar findings in regard to discussing death and dying as part of advance care planning were also evident when analysing the bereaved relatives’ experiences. Specifically, one bereaved relative explained that the care home staff went directly to her as the next of kin to ask about her husband’s preferences for EoLC who was living with dementia.

BR2 C1: *“They wanted to know what my wishes were you know for him I didn’t mention any of this to him and I don’t think he knew I let them know.”*

Moreover, care home staff explained how as well as condition, resident’s religion and background often meant that they did not want to discuss death and dying.

Registered nurse 1 C2: *“We get a lot of residents here who are Jewish which can change how they deal with death and how they talk about it. They usually don’t want to talk about it. So, it’s about being sensitive to the different the religions.”*

Analysis indicates that some care home staff assumed that residents with dementia and different cultures meant that they did not want to talk about death and dying. These findings support intervention theory one as they highlight the need for education to provide staff with the knowledge and skills to be able sensitively engage in discussions about death and dying with a range of residents with diverse needs, cultures and backgrounds.

Bereaved relatives expressed that they would like to be a part of the educational workshops to offer their perspectives to the staff. This is particularly important given that bereaved relatives expressed in both phases of this study that they wanted to discuss death and dying to a greater extent than care home staff perceived.

BR7 C3: *“I would happily go back to the home to share my views yes I think it’s good to share good things to help others giving something back for all they did for us. I remember the time the nurse spent with me to explain my husband was dying and what would happen helped me make sense of everything that was going on.”*

Thus, this data suggests that involving bereaved relatives in the education to share their viewpoints may help change staff’s perceptions and reduce their reluctance to discuss death and dying. This may also help address the current taboo culture associated with death and dying. Specifically, phase-two supported the findings from existing literature in that it found evidence of a taboo culture in all three care homes which appeared to influence care home staff’s perceptions and attitudes towards death and dying.

Care assistant 3 C1: *“Death is still a taboo in care homes even here because most of us still do not want to talk about it.”*

Care assistant 2 C1: *“Yes but we still do have talk about death as part of residents care plans it does come up, we just don’t like talking about it.”*

These quotes suggest that there is still a taboo culture associated with death and dying in care homes, and it can negatively affect care home staff’s discussions about death and dying. It is apparent that this taboo culture also contributes to the perception that talking about death and dying will upset residents.

However, phase-two suggested that care home staff’s ability to discuss death and dying was influenced by more than just their desire to not upset residents. It

was identified that care home staff's reluctance to discuss death and dying could be influenced by their cultural beliefs, backgrounds and life experiences. For example, staff gave the example of a Bulgarian member of staff who was uncomfortable discussing death and dying because of their background, thus did not take part in EoLC in the care home. Although Care assistant 2 C2 acknowledged the staff members Bulgarian background the quote implies a lack of understanding and recognition in regard to how a person's culture and background can influence their approach to EoLC and discussing death and dying.

Care assistant 2 C2: *"We had a Bulgarian member of staff who did not want to do end of life care, we had to get someone else to do it. None of us understood why because she worked here so you'd expect her to know."*

A similar lack of recognition and understanding for individual's personal backgrounds, cultures and life experiences was noted during the focus group conversation in care home one. Specifically, it appeared that care home staff did not acknowledge each other's backgrounds and culture in relation to EoLC, and just expected each other to get on with the job in the same way.

Care assistant 1 C1: *"No matter what our backgrounds are you just have to get on with it because it's our job. We have staff here from all over, but they all just get on with it. It doesn't matter what background or religion we all find it difficult to talk about it [death]"*

Analysis suggests that talking about death and dying is not only a problem for staff from different cultures. However, these quotes suggest a lack of acknowledgment for each other's background and culture, which is surprising because as discussed earlier care home staff seemed to acknowledge the different backgrounds and culture of residents and the impact of discussing death and dying. These findings indicate that there is a need to include education on the different backgrounds and cultures of care home staff and how they can influence aspects of EoLC. This may help care home staff to acknowledge each

other's cultures and backgrounds to a greater extent, enabling them to better support each other. In light of these new insights, the initial intervention theory was amended.

In sum, this section has supported the need for education on discussing death and dying for care home staff. Although there is a plethora of research exploring the quantity of advance care plans (Fleming et al. 2016; Weathers et al. 2016), the findings from this study have highlighted the need to improve the quality of advance care planning discussions. Phase-two uncovered a number of insights to improve quality. For example, the need to include bereaved relatives in education delivery to offer their perspectives. The data collected during phase-two has also highlighted the need to provide all care home staff (including those from different cultures and backgrounds) with the knowledge and insight to more effectively support each other to engage in discussions about death and dying. Based on this evidence the following refined intervention theory was developed:

Refined intervention theory one: *Incorporating the experiences and viewpoints of bereaved relatives into educational workshops on discussing death and dying for care home staff (Intervention mechanism) is important as currently a taboo culture surrounding death and dying (Contextual mechanism), and a common perception amongst care homes staff that talking about death will upset residents and relatives (Human agency) is preventing discussions about death and dying in care homes (Outcome).*

6.2.2 Intervention theory two: Maintaining a person-centred approach to care towards the end stages of life

Initial intervention theory presented to participants: *Care home staff with non-formal caring roles developed close relationships with residents and relatives (Human Agency) including short stay residents who were admitted to the home for a short period of time to receive end of life care (Contextual mechanism). Thus, including staff with non-formal caring roles in the educational workshops introduced in the previous theory (Intervention mechanism) is necessary to help staff more effectively develop relationships with residents and relatives improving advance care planning (Outcome).*

Intervention theory two was designed to accompany the educational workshops on advance care planning introduced as part of intervention theory one. When presented with intervention theory two, care home staff agreed that including staff with non-formal caring roles could help promote person-centred care. It was recognised that staff with non-formal care roles developed relationships with residents and helped contribute to individualising EoLC by passing on non-medical information for care plans. The quotes highlight that including staff with non-formal caring roles in education on discussing death and dying may help them feel more comfortable in terms of knowing what to say, how to interact with residents on EoLC, and when/if it is appropriate to pass on information.

Housekeeping C2: *“You cannot never benefit from training, it’s always good to know how to deal with situations.... it’s knowing what you can and what you cannot say that’s the most important thing and how to pass on information.”*

Registered nurse 1 C2: *“We do aim to do this yes, but mostly only carers and nurses are included.”*

As well as including staff with non-formal caring roles to a greater extent, phase-two highlights that more needs to be done to maintain a person-centred

approach towards the end stages of life. Although phase-one evidences care home staff's close relationships with residents, the data from phase-two indicates that these relationships can lead to some care home staff focusing too much on the medical aspects of EoLC towards the very end stages.

Manager C2: *"It can be really rewarding to sit with somebody until they die, you can get a lot of great memories. It's getting our staff to believe and understand this towards the end of people's lives, that is the key to preventing unnecessary trips to hospital..."*

It is important to acknowledge that overall the data from this study suggests that care home staff were able to provide the emotional and social aspects of EoLC. However, the data implies that some care home staff may benefit from education and training to help them maintain a person-centred approach towards the end stages of life.

Findings imply that care home staff's decision to focus on medical care and contact emergency services at the EoLC was influenced by a range of factors. Specifically, findings suggest that a lack of support during out of hours shifts influenced some care home staff's decision-making and judgment when delivering care at the EoL. This was particularly evident in care home one which is a residential care home with no on-site registered nurses for support (as discussed in phase-one). Analysis indicates that this can lead to some staff calling emergency services sooner.

Manager C1: *"We try to keep all our residents here. If anything goes wrong, they can ring me. But we don't have nurses so it can be tricky out of hours because there isn't the same support around them..."*

Care assistant 3 C1 (3 years' experience): *"We ring 999 much sooner here rather than wait because if they do deteriorate there is nothing we can do. It's best to be on the safe side..."*

Interpretation of the quote above suggests that doing something medical ‘to be on the safe side’ was deemed to be better than doing nothing. The data imply that this fear of doing nothing influenced care home staff’s judgment as it was evident that it caused them to focus on the medical and physical aspects of EoLC, with little focus on residents advance care wishes and preferences.

The fear of responsibility and letting residents die without medical intervention was commonly noted throughout the transcripts particularly with the less experienced care home staff, and in situations (such as out of hours) where support and guidance was not immediately available. This was apparent for both care assistants and registered nursing staff.

Registered nurse 1 C2 (2 years’ experience): *“...it can be a challenge to sit with them till the end especially those you’ve grown close to. You feel a responsibility.... I suppose some think that getting others involved will take that away.”*

Care home staff’s close relationships with residents and relatives discussed previously was found to increase this feeling of responsibility and therefore their judgment. The registered nurse from care home two spoke about how she felt a responsibility for letting a resident die in her care, especially those she had developed close relationships with.

Phase-two identified a key intervention mechanism used in care home three to help address this. Specifically, staff from care home three used a coding system to code residents on EoLC based on how much time they were expected to have left. For example, blue indicates months, green indicates weeks and red indicates days. It was hypothesised that this coding system helps care home staff to plan and prepare for residents’ deaths avoiding any unnecessary treatment and admissions to hospital that may come with an unexpected decline.

Care assistant 1 C3: *“The GSF has a coding system so the moment you see that a person’s health is altering. So good health is blue if it changes to months its green then if it goes to weeks it changed to yellow and if its days our hours it goes to*

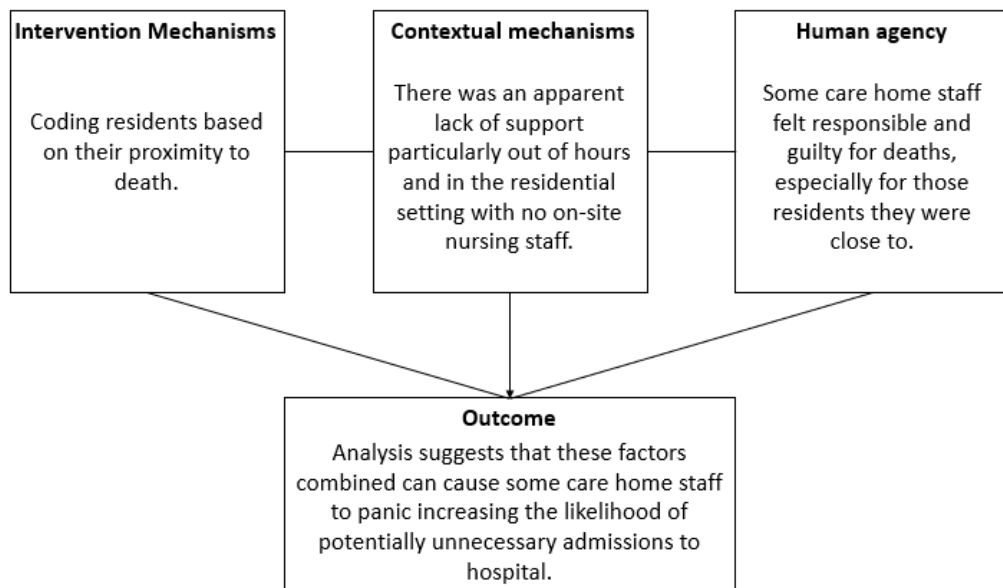
red. But as those changes are going there is certain things the nurses have to do. Even with this though sometimes people do die unexpectedly.”

Care assistant 2 C3: *“I sometimes think coding people is not caring through. It’s very clinical.”*

However, this data indicates that some care home staff felt that coding residents based on their time left to live was too ‘clinical’ suggesting it causes staff to care for the illnesses rather than the individual.

Overall, these findings evidence how a lack of support out of hours, (contextual mechanism), current medically focused education mechanisms (intervention mechanism), and care home staff’s feeling of responsibility (human agency) all impacted on care home staff’s judgment and decision making skills; influencing management and the likelihood of unnecessary admissions at the EoL (Outcome). Figure 11 below helps illustrate this process.

Figure 11 Outcomes related to the medicalisation of end of life care



It is important to note that these findings do not suggest unnecessary treatment and admissions are common in the care homes, but simply highlight the factors that can influence their likelihood from the perspectives of care home staff.

In sum, the data collected from phase-two has supported many aspects of the initial intervention theory such as the importance of staff with non-formal care roles in individualising care. However, phase-two has added to the findings from phase-one by uncovering the need to better support care home staff to maintain a person-centred approach to care towards the end stages of residents' lives and in contexts such as out of hours where guidance is limited. Based on this data the following refined intervention theory was developed:

Refined intervention theory two: *Given care home staff's tendency to focus on the medical aspects of end of life care (Human agency) out of hours where less support and guidance is available (Contextual Mechanism) educational workshops are necessary (Intervention Mechanism) to provide staff with guidance on how to channel their care to maintain a person-centred approach in relation to their decision making towards the end of residents' lives, and in situations where they must work more independently (Outcome).*

6.2.3 Intervention theory three: Bereavement support for service users

Initial intervention theory presented to participants: *Despite limited finances and high workloads (Contextual mechanism) evidence-based education on bereavement support to give care home staff the knowledge to support their own emotional needs as well as the emotional needs of bereaved relatives (Intervention Mechanism) is necessary given the varied bereavement experiences (Outcome) and the emotional challenges faced by both staff and service users (Human agency).*

It was identified in phase-one that involving relatives throughout the EoLC process and preparing them for the death of their loved one decision was vital to avoiding conflict towards the EoL. However, a lack of intervention mechanisms in place to support and prepare relatives before death was apparent. Despite, this when presented with intervention theory three in phase-two, it was evident that some care home staff believed their bereavement support was already good, reemphasising the different mechanisms they use to provide it. These mechanisms were which predominately focused on supporting residents after death were highlighted in phase-one therefore will not be repeated here.

Despite some care home staff's confidence in their bereavement support, phase-two uncovered a number of concerning areas which were not recognised. Specifically, analysis uncovered a covert taboo culture associated with death and dying which negatively influenced bereavement support. It was found that bodies of deceased residents and death in general was often hidden and covered up in an attempt to cover up death from other residents, relatives and clients to maintain a positive image of the care home.

Manager C2: *“One of the things that we do try and do is keep the undertakers out the way because we can't have them carrying a body through our front doors or in front of relatives and residents. That wouldn't be nice for them or us.”*

The quote from the manager of care home two identifies that managerial leadership can play a part in sustaining and manifesting views and cultures about death and dying. It was also worth noting that this quote is out of character for that particular manager who had previously spoken about how more staff need to embrace death (section 6.2.2). Analysis of this quote suggests that the manager from care home two adopted a different view and perception in her role as manager to maintain a positive image of the care home.

The data collected from bereaved relatives uncovered that this culture of covering up death was experienced across all the homes in this study. A number of bereaved relatives highlighted that they were displeased with the treatment of their loved one's body and would have liked more dignity and respect from the care home staff. Moreover, bereaved relatives spoke about the efforts care home staff put into covering up the deaths of other residents in the home.

BR1 C1: *"They wanted to take her out the back door, but I wanted her to be taken out the front door. If you come in through the front door you have to go out through the front door. It's good for other residents to see this too because it's part of the care home you can't hide end of life from other residents its part of the life there. So, if other residents see this they will also know when they die, they will be treated with the same dignity and respect rather than going out through the back door.*

BR2 C1: *"I noticed at the home people simply disappeared and we were all tactful enough not to ask. I think we were told they had gone to the hospital or something. I'm pretty sure they died in the night. I mean that's what they there for, let's face it."*

These findings suggest that rather than preparing relatives for death and supporting them to accept death as part of life, the taboo culture led to care home staff covering up death. This is important as it was identified in phase-one

that supporting relatives to accept their loved one's death in advance was essential to avoiding conflict at the EoL and the unnecessary prolongation of life. These findings also show how relatives experienced symptoms of bereavement before the death of their loved one.

Another finding that emerged during phase-two was that the medical condition in which a resident is dying from can affect bereavement experience and support needed. Bereaved relatives expressed that the symptoms and decline associated with dementia meant that they felt they had lost their loved one before they had died; therefore, started grieving earlier in the EoLC process. The data from several bereaved relatives suggests that they would have benefited from bereavement support starting before the death of their loved one.

BR7 C3: *"I recognised him as my husband, but he was not my husband he had gone. We spoke about it a bit last time... I was a bereft wife with my husband still alive it was a peculiar thing which is really unrecognised at the moment. Because my husband was still alive everyone thought I was ok."*

This is important given that findings from phase-one suggest that issues re-establishing an identity can influence relatives' decisions to prolong life and disagreements at the EoL with care home staff. From these quotes it is evident that care home staff did not fully understand or recognise the importance of starting bereavement support before death. However, it should also be noted that although bereaved relatives in this study felt they lost their loved one before death because of the symptoms associated with dementia, this may not reflect the views of others.

These issues in relation to bereavement support in care homes are unsurprising as little education on bereavement was noted, with most focusing on support after death. The findings from this present study therefore provide valuable knowledge which can be integrated into education. For example, highlighting the need for education for care home staff on the stages of bereavement to help them better support relatives before the death of their loved one.

In sum, this refinement process has highlighted clear support and need for greater access to education on the stages of bereavement to provide care home staff with the knowledge to more effectively provide support throughout the stages of bereavement. Evidence suggests effectively supporting relatives throughout the earlier stages of the EoLC process may help reduce conflict and a desire to prolong life. Based on this evidence the following refined intervention theory was developed:

Refined intervention theory three: *Relatives difficulty to re-establish identity and accepting the death of their loved one (Human agency), particularly those who were previously caregivers (Contextual mechanism) was found to increase likelihood of unnecessary prolongation of life (Outcome). There is therefore a need for educational workshops for care home staff on the stages of grief (Intervention mechanism).*

6.2.4 Intervention theory four: Bereavement support for care home staff

Initial intervention theory three was split up into two separate intervention theories; three (6.2.3) and four (6.2.4) as a result of the data collected during phase-two. While intervention theory three focuses on bereavement support for services users, intervention theory four discussed here focuses on bereavement support for care home staff.

When presented with the initial intervention theory, care home staff highlighted that they felt delivering EoLC and sharing the last moments of someone life was a privilege.

Manager C2: *“It can also be really rewarding to sit with somebody until they die, you can get a lot of great memories...”*

However, care home staff also reemphasised the emotional labour that come with delivering EoLC describing emotions such as sadness, loss and grief. Findings also suggest that these emotional attachments with residents can influence care home staff’s ability to deliver EoLC. For example, one care assistant from care home three spoke about how they found it hard to let go of a resident they had developed a close relationship with.

Registered nurse 1 C2: *“Holding their hand in the final moments. It’s very hard and you never get used to it.”*

Care assistant 4 C3: *“I had one [a resident] last week who was with us for a long time. I spent the last moments with her... because we were close it was difficult...I wanted to do something for her anything really...”*

Given these signs of emotional labour, care home staff in phase-two spoke about the need to feel supported when delivering EoLC. This is important because the emotional and bereavement needs of care home staff was less evident in phase-one as staff predominately focused on the needs of residents and relatives. A

similar lack of focus on the needs of care home staff was also noted in chapter three, with only four interventions related to care home staff's emotional and bereavement needs. However, the quotes presented here from phase-two suggest that providing care home staff with emotional and bereavement support is essential to their ability to consistently deliver high quality EoLC.

Two mechanisms for providing emotional support of this nature to care home staff were evidenced in phase-two; formal support from managers and informal peer support from colleagues. Informal peer support consisted of colleagues supporting each other through informal conversations and support. Staff spoke about 'looking out' for each other like a 'family' and if they noticed a colleague struggling emotionally, they would support them through providing reassurance.

Care assistant 1 C1: *"It can be hard to say goodbye to a resident you've got to know but we're like a family so support each other through it."*

Care assistant 2 C2: *"If you see someone is struggling, we will go support them."*

Despite the positives of peer-support, analysis of the transcripts identified that different individuals had different perceptions and attitudes towards expressing emotion. For example, some care home staff believed that outwardly expressing emotion was unprofessional. Specifically, Care assistant 1 C2 expressed; *"it would be unprofessional if you were so upset."* This data implies that care home staff's attitudes and perceptions in regard to expressing emotion may hinder peer-support by preventing colleagues seeking support from each other.

In addition to emotional support from colleagues, the data indicated that formal emotional support and guidance was received from managers which consisted of reflection sessions and opportunities to have a conversation and ask questions about an experience.

Care assistant 2 C3: *“You also mentioned reflection; when we have lots of deaths in one period our manager organises a reflection meeting.”*

Care assistant 2 C2: *“If we have any questions or anything we are always supported in that way by our managers.”*

However, analysis revealed that when staff did seek support, managers found it difficult to provide it due to their high workloads and busy schedules. Managers highlighted that they were not always in the home and had their own jobs to do thus were unable to always be there when their staff required emotional support. These quotes highlight managers struggle to support care home staff, despite being relied on.

Manager C1: *“...it is hard to always thank every staff member because I am busy and I’m not always in the home, so I don’t spot everything.”*

Manager C2: *“But it can be hard for me because as I said I am not here all the time...”*

This is important as the quotes presented here highlight that currently managers provide key guidance and support. However, given managers cannot always be in the home to provide this support, rather than relying on only managers for formal support, and given that peer-support is already given by colleagues, there is a logic in providing education to train a wider range of care home staff to provide emotional support for their colleagues on a more formal basis. Moreover, staff suggested that because they were ‘comfortable’ around each other they were best placed to support each other, rather than only relying on managers.

Care assistant 2 C2: *“...we support each anyway but if we knew more about this process and how to do reflection with each other that would help for sure.”*

Care assistant 1 C1: *“How to do professional reflection with each other what questions to ask and what to look out for. We are more comfortable around each other, so I think it’s better than using managers.”*

Findings imply that providing care home staff with the knowledge and confidence to effectively support each other will help to facilitate the more consistent and reliable peer support, while reducing reliance on managers and addressing the pitfalls of informal support from colleagues. This approach was supported by managers who welcomed the change.

Manager C2: *“It can be hard for me because as I said I am not here all the time and I have to manage everything so more support would be a good thing especially for managers.”*

In sum, this refinement process has supported the findings from phase-one by highlighting a lack of emotional and bereavement support for care home staff. However, phase-two has built on the findings from phase-one by uncovering limitations of current support such as attitudes towards expressing emotion and the limited availability of care home managers. Findings support the need for educational content on emotional/bereavement support for care home staff enabling them to more effectively support each other. From this data, the following refined intervention theory was developed.

Refined intervention theory four: *Given the emotional and bereavement needs of care home staff (Human agency) and the current reliance on time-poor home managers for this support (Contextual mechanism) there is a need to provide care home staff with the knowledge and skills via evidence-based education (Intervention mechanism) to more effectively support their own and their colleagues’ mental health during and after end of life care (Outcome).*

6.2.5 Refinement of intervention theory five: facilitating the sharing of knowledge and expertise

Initial intervention theory presented to participants: *Negative relationships between care home and external service staff are persisting (Human Agency) due to high workloads, staff turnover and a competitive culture (Contextual mechanism). Therefore, a dedicated end of life care liaison nurse (Intervention Mechanism) is necessary to build the knowledge and confidence to improve the rate of collaborations between care homes and external services (Outcome).*

The initial intervention theory theorised that a liaison nurse could help facilitate more effective collaboration (initial intervention theory five). This is important given that it was identified that multidisciplinary collaboration was essential to providing care home staff with the knowledge and confidence to be able to deliver EoLC in the care home, especially for residents with complex needs.

However, when presented with intervention theory five care home staff rejected the theory that a liaison nurse would improve collaboration, expressing that they wanted to develop their own knowledge and skills in collaboration. Care home staff spoke about a desire to establish personal links with their local services themselves to develop their own skills rather than using a liaison nurse. This view was echoed throughout the transcripts. It was believed that an external liaison nurse would be less personal; therefore, care home staff expressed the desire and enthusiasm to build and maintain personal relationships with their local services.

Care assistant 1 C3: *“We all work to establish links with external services I don’t think having a liaison nurse would help this...it’s a skill we all need to learn. ...there could be better ways to help us all get involved with these services.”*

Registered nurse 1 C2: *“I know how to speak with the GP they know me and the home, if you had someone external, they*

would have to build the relationships up again it's not personal..."

Despite the rejection of the liaison nurse theory, it is apparent from this data that care home staff still understood the importance of improving their collaboration during EoLC. Thus, instead of a liaison nurse to facilitate this collaboration, participants highlighted that the use of proactive collaborative meetings to enable multiple services and care homes to develop shared understandings of each other roles, develop shared goals, and provide a more joined up approach to collaboration. It was identified in phase-one that care home three developed strong relationships because of their proactive use of collaborative meetings as part of the GSFCH which provided them with a medium to share knowledge and expertise.

Manager C2: *"Definitely having more meetings with other services [that] we use a lot during end of life care. [...] what do the other professionals do? our staff are really interested in stuff like that, but they are very distant. You know why they need to know this and ...what is the process for that. So that they can answer each other's questions."*

These findings were echoed by the manager of care home one who expressed that being able to share experience and knowledge between services would enable them to offer a more joined up approach to multidisciplinary collaboration during EoLC.

Manager C1: *"There is a need to share experiences between the different professionals so coming face to face and letting them know about us and they can let us know about themselves, what they do, what they don't like, what they like, how we can best accommodate to themjust working together really"*

Therefore, this data supports the data collected throughout phase-one in that it evidenced the importance of collaborative meetings in promoting and

supporting multidisciplinary practice in care homes. However, it must not be forgotten that meetings were only used by one care home in this study because of the costs and resources attributed to them in their current form. Moreover, existing research reviewed in chapter three found that expecting others to travel to care homes or external sites inhibited the sustainability of the meetings (Hewison, Badger and Swani 2011).

To address these contextual mechanisms, care home staff in this present study suggested the use of videoconferencing as a supportive mechanism to facilitate meetings without the associated costs and commitments. Care home staff referenced that they had used videoconferencing tools before and found the mechanism to be more personal than a phone call and easier than going to a meeting location in person.

Manager C1: *“...but they [collaborative meetings] need to be set up in a way that is easy to access. No emails! they can be held as part of existing meetings so we don’t have to schedule anything new... we do not have time to travel so they need to come to us, or we can join a group call... This would be the only way it would work, sorry but I have to keep staff on the frontline.”*

Therefore, this data suggests that videoconferencing can be used to help lower the cost and time commitment of collaborative meetings to enable more care home staff to benefit from the mechanism.

As well as promoting collaborative meetings between external services, the data suggest that there is scope to also use these collaborative meetings to promote better collaboration between care homes themselves. Specifically, it was noted in phase-one that despite the outlined benefits, collaboration between care homes was rare. When presented with the theory in phase-two, still some care home staff expressed mixed feelings about the notion of collaborating with other homes to share knowledge and expertise.

Care assistant 2 C3: *“You spoke last time about how we would feel about sharing the end of life care we give. But it’s down to management isn’t it. I don’t think the manager here would like us going into another care home.”*

Manager C1: *“If you care about people in the whole of the community why would you not share something that could potentially help someone else in another home that is dying? It shouldn’t matter whether that person lives in your care home or the care home down the road.”*

In sum, phase-two identified that the use of a liaison nurse to improve collaboration was not supported by staff who wanted to develop personal relationships with their local services and build their own knowledge and skills. Multi-disciplinary meetings were therefore highlighted as a proactive collaborative mechanism to improve communication between multiple services involved in providing EoLC. Additionally, phase-two identified the use of information technology to address barriers to collaboration such as high workloads and time constraints. From this knowledge the following refined intervention theory was developed:

Refined intervention theory five: *Use of information technology to facilitate collaborative meetings between care home staff and external service staff (Intervention mechanism) will provide a more time and cost-effective mechanism for time poor services (Contextual mechanism) to share knowledge and expertise and develop relationships (Outcome) and the opportunity to utilise staff’s enthusiasm to work together to meet residents’ needs (Human agency).*

6.3 The overall intervention theory: A cross-sector multicomponent end of life care intervention

Care home staff highlighted that more needed to be done in terms of the delivery and implementation of the intervention theories to address the disparities present with current EoLC education across the sector. It was proposed that combining the individual theories into a cross-sector multicomponent intervention would help more care homes implement the intervention rather than keeping the intervention theories separate, improving the overall feasibility. It was believed that combining the theories into one intervention would help promote a recognised evidence-based approach to EoLC across the sector. Developing this level of continuity is important given that several staff commented on the inconsistency of current EoLC training and education.

Care assistant 2 C2: *"... I know homes do things very differently.... the last home I worked at gave me different training."*

Care assistant 1 C2: *"Yes that's true. You could combine all the aspects of your study [the intervention theories] into one training package to make it easier for homes to follow. Getting it into as many homes is important for you because I do agree that we need more consistency in end of life."*

The notion of combining the intervention theories to form one multicomponent intervention was also highlighted in the interview with the manager from care home three. Given care home staff's experience with training issues, the manager from care home three concluded that getting the intervention into as many care homes as possible would help to contribute towards a minimum evidence-based standard of EoLC across the sector.

Manager C3: *"If we all went off the same sort of training it would help create minimum standard of end of life care....as*

we'd all be following the same material instead of all doing different things."

However, analysis highlighted that for the multicomponent intervention to be implemented and sustained in a diverse range of care homes it would need to be financially viable. As discussed in chapter three although multicomponent interventions were more effective, they were rarely delivered because of contextual factors such as high costs and resources attributed to implementing and sustaining them. Staff from care homes one and two highlighted in phase-one that they did not use the GSFCH because of the implementation costs and resource requirements, and even staff from care home three who used the GSFCH acknowledged its high costs. Thus, the data suggests that being able to keep costs and time requirements down, is an essential attribute to ensure the sustainability of the multicomponent EoLC intervention across the diverse care home sector.

Manager C3: *"The Gold Standards Framework is very expensive for something that should be done anyway. I told the GSF that as well it is very expensive."*

A potential solution that emerged from managerial level to lower the costs and best manage their limited financial resources was to deliver the multicomponent EoLC intervention using a flexible in-house method of delivery. For the education delivery aspects of the intervention (such as the workshops) it was theorised that in-house delivery methods utilising care home staff would enable the care homes to deliver education at times convenient to them, without the need to travel or use external staff to deliver it. As well as flexible delivery, it was highlighted that for any intervention to be sustainable across the diverse sector it would need to be free and not require an implementation or upkeep fee. The manager from care home one spoke about how other interventions on the market do not account for the diverse needs of care homes in this respect.

Manager C1: *"Provide us with the content for it all and we can deliver it all at once here... that would probably be best so I*

don't have to send staff to the university all the time, and I can deliver it at the best times for us. It would have to be accessible to us as well, we do not want to pay an implementation fee that is key to having an impact in all homes and that is where the gold framework [GSFCH] fails."

Manager C3: *"Leave it up to us when and how the education parts are delivered because we can deliver it at times that are best for us rather than having someone come in at a set time.... that just won't work. The topics can be set, but we can mould it and deliver it in ways to fit our home..."*

As well as financial considerations, regulatory barriers to implementing the multicomponent intervention were highlighted. Specifically, care home staff expressed that the intervention could be made mandatory to get more care homes across the sector to implement it. It was emphasised that mandatory training requirements are not new to the sector with some training already been mandatory.

Care assistant 1 C2: *"It [the multicomponent intervention] would definitely have to be mandatory yes or homes would not listen to you. We already have it on manual handling it's already like this."*

This is an important finding given that it was identified in phase-one, and the critical realist review (chapter three) that care homes delivered different forms and amounts of EoLC education/training. For example, due to the lack of regulation care homes used on-the-job training (shadowing) rather than providing evidence-based workshops like care home three. Similarly, the critical realist review identified significant disparities in the amount of EoLC education delivered across the sector (Dobie et al. 2016; Finucane et al. 2013). Thus, although keeping the time and financial requirements as low as possible, this data suggests that still care home managers may choose not to implement an

evidence-based approach in the context of little regulation in EoLC provision in UK care homes.

Specifically, analysis of the data collected in this study highlighted that home managers had varying enthusiasm for change implementation. For example, the manager from care home three spoke about the passion she had for EoLC and improving EoLC in her care home through developing the skills of the workforce. The transcripts suggest that the manager's leadership and commitment towards EoLC was instrumental in implementing and sustaining the GSFCH and giving her staff the space and time to learn and develop their EoLC skills.

Manager C3: *"That's my positivity... I'm very passionate about end of life care. When I came to [name of the care home] the first thing I did was get them to bring in the GSFCH, I know not all care homes can do this, but it isn't just about money it is about listening to the staff ...trying to empower them. I'm a great believer of empowerment and seeing the benefits of each person. The staff can see my passion they know I want to help them develop and improve end of life care...they know I will support them. So, I'll say let's talk about your five-year plan."*

On the other hand, this level of managerial passion towards EoLC training appeared to be lacking in care homes one and two. Although the managers from care homes one and two expressed an interest in EoLC, they referred to high workloads and limited finances as preventing more adequate EoLC education for their staff (discussed in phase-one: theme four). The data implies leadership style and passion for EoLC is a personal attribute and whilst it helps, the level of managerial passion is subjective and is likely to vary.

However, analysis highlighted a number of benefits of adopting a multicomponent approach to delivery rather than delivering the interventions theories separately. It was highlighted that adopting a more consistent approach to EoLC education that could be implemented and sustained by care home across

the sector may help address issues related to high staff turnover. Specifically, findings from this study and wider literature (Gatherum 2017) suggest that despite staff turnover being high, care home staff often leave one home to go onto working in another home, indicating high staff mobility within the UK sector. Therefore, analysis implies that if homes were using or recognised the same evidence based EoLC training it would mean staff across the care home sector would have a recognised minimum level of EoLC training. Thus, when staff leave to go to work in another care home, they go with a recognised standard of EoLC training.

Care assistant 2 C2: *“Many staff come and go that’s the way it’s been now for years, we have all come from different care homes ...”*

However, as noted in the critical realist review (chapter three) the financial insensitivity of current multicomponent interventions is limiting their sustainability and implementation across the diverse care home sector.

Lastly, analysis of bereaved relatives’ transcripts suggested that adopting a multicomponent and more consistent approach to EoLC education and training is necessary to help address the stigma associated with care home staff and the sector as a whole. It was evidenced that some bereaved relative held ingrained perceptions and negative attitudes towards EoLC in care homes. Bereaved relatives spoke about the fear they had of sending their loved one to a care home which was not able to deliver high quality EoLC.

BR6 C3: *“One of the essential things is the quality of the staff first of all I had to spend many hours going through the reports [CQC reports] and ringing up homes because I know some are bad.”*

Thus, analysis suggests that providing a more consistent approach to EoLC training across the sector (via the multicomponent intervention proposed in this study) may give the public reassurance that they are going to get a certain level of care, regardless of care home.

In sum, this final section has evidenced a need to combine the intervention theories to improve feasibility and to support more care homes to implement the intervention. Analysis suggests that the multicomponent intervention will help provide the sector with a more consistent evidence-based approach to EoLC education and training. Findings suggest that adopting the multicomponent intervention can help contribute towards addressing issues such as staff turnover and the stigma associated with care homes. However, identified barriers to getting homes to adopt the intervention included the costs associated with implementation, and the enforcement of such an intervention across the UK care home sector. From this data the following overall intervention theory was developed:

Overall intervention theory: *Combining the intervention theories to form one multicomponent intervention (Intervention mechanism) will help address the current disparities in end of life care education (Outcome) by improving the uptake and consistency of evidence-based end of life care education and training across the diverse sector (Contextual mechanism) which is an outcome generally supported by care home staff and service users (Human Agency).*

6.4 Chapter summary

This chapter presented phase-two of data collection, which used realist interviews and focus groups to gather participants' feedback on the initial intervention theories developed from phase-one. The participant's responses to the initial intervention theories were used to refine the initial intervention theories. In addition, the refinement process highlighted the benefits of combining the intervention theories to form an 'overall' intervention theory. The following discussion chapter will discuss the findings of this present study in relation to relevant literature and policy.

7 Discussion

7.1 Introduction and overview

Continuing issues have been evidenced in the provision of EoLC in UK care homes in relation to care home staff's engagement in advance care planning and persisting levels of unnecessary admissions to hospital at the EoL from care homes (Spacey et al. 2018; Thwaites et al. 2017; Mason et al. 2016; Ong et al. 2011; Wolters et al. 2019). Yet, prior to this study there was a sparsity of research exploring the underlying processes behind outcomes related to advance care planning and unnecessary admissions at the EoL. This gap in knowledge was found to limit the effectiveness of interventions designed to improve end of life care in care homes (Spacey et al. 2019).

This study has contributed to filling this gap in knowledge by systematically exploring the underlying processes behind these outcomes. This evaluation process has provided a deeper understanding of these outcomes, why they persist, and what needs to be done to mitigate them. Findings were used to develop six intervention theories which incorporate the process data into their design.

This chapter comprises of four parts and brings together the two phases of this study. The first part discusses the study findings in the context of relevant literature and policy, highlighting where this current study adds to the existing knowledge in the field. The second part discusses the implementation, delivery and feasibility of the intervention theories in practice. Part three then presents the strengths and limitations of the study and lastly part four provides a brief reflexive diary.

7.2 Part one: Discussion of the key findings in relation to existing literature

7.2.1 Talking about death and dying in care homes

This first section will discuss the processes behind outcomes related to advance care planning in care homes. Despite residents having advance care plans in place, this study evidenced the variable quality of advance care planning discussions. Findings revealed how education mechanisms mostly focused on information gathering combined with some care home staff's emotional reluctance to discuss death and dying, and a taboo culture in care homes which impacted on their ability to engage in advance care planning discussions with residents and relatives.

In terms of human agency, findings identified that some care home staff had a reluctance to talk about death and dying. It was found that care home staff's backgrounds, cultures and personal experiences influenced how they approached death and dying when delivering EoLC. However, most literature reports on supporting care home staff to manage the cultural needs and backgrounds of residents receiving EoLC (Givler et al. 2019), with only a handful of studies reporting on how care home staff's personal backgrounds and cultures can influence how they approach death and dying in the care home (Hall et al. 2011; Xiao et al. 2017). For example, Hall et al. (2011) highlighted a lack of confidence in staff from different cultures towards death and dying. Although, the findings from this present study support Hall et al., it was found that reluctances to talk about death and dying were experienced by all care home staff, not just those with cultural beliefs.

This collective difficulty in relation to talking about death and dying led some care home staff to have less sympathy and understanding towards their colleagues' cultures and backgrounds. For example, despite care home staff recognising diversity in the workforce, they did not expect the different cultures and backgrounds of their colleagues to hinder discussions about death and dying because it is 'part of the job' and all staff 'should know what to expect'. This lack

of understanding and support has implications for practice as globalisation has resulted in increased cultural diversity in care homes across the world (World Health Organisation 2015). Moreover, in the UK, recruitment and staffing difficulties in care homes have increased their reliance on skilled and unskilled migrant labour from the European Union (Independent Age 2016). This reliance on migrant labour and globalisation has led to a more diverse care home workforce with different cultures and backgrounds. Therefore, although all care home staff to an extent found it difficult to talk about death and dying, these findings suggest that more needs to be done to provide care home staff with the knowledge to help them recognise and support each other's different cultures and backgrounds, and the potential impact this may have on discussions about death and dying.

There was also evidence to suggest that some care home staff were did not want to talk about death and dying to avoid upsetting residents. This was particularly apparent with residents with dementia. Specifically, some care home staff went straight to the next of kin to conduct the advance care plan as they believed that residents with dementia would not understand and would become too upset if they discussed death and dying with them. This poses implications for practice not only because of the rising numbers of residents living with dementia in UK care homes (Alzheimer's Society 2018), but because research has found that residents who are cognitively impaired such as those living with dementia have a greater chance of being unnecessarily admitted to hospital at the EoL (Perrels et al. 2014). Moreover, the Alzheimer's Society has long called for people with dementia to be able to contribute to advance care planning discussions, even if they lack capacity (Alzheimer's Society 2012), as capacity can fluctuate; meaning one day a resident may be able to understand more than on another day (Alzheimer's Society 2018). Therefore, it is key for care home staff to ensure that residents living with dementia have an advance care plan in place which reflects their needs. These findings again suggest that need to provide care home staff with the knowledge to be able to sensitively engage in discussions about death and dying with a diverse range of residents, including those with dementia.

As well as the needs of residents and relatives, findings from this present study imply staff's avoidance of conversations about death and dying was also about protecting their own emotional wellbeing. Specifically, analysis suggested that some care home staff avoided the subject of death and dying with residents as a defense mechanism. Similar behaviour has been found in professionals who are regularly exposed to emotional and traumatic experiences (Drury et al. 2014). It has been found that being continually exposed to these situations without support can lead to compassion fatigue, which is described as a state of mental exhaustion triggered by a decreased ability to cope with everyday settings (Baranowsky et al. 1999).

Findings from this study suggest that care home staff's way of managing compassion fatigue was to avoid sensitive subjects with residents and relatives about death and dying. However, this behaviour (reluctance) appeared detrimental to care home staff's ability to engage in meaningful advance care planning conversations with residents and relatives. This issue is explored further in regard to support for care home staff in section 7.2.4.

In terms of contextual mechanisms, an ingrained taboo culture associated with death and dying was evident in the care homes which was found to negatively impact on discussions about death and dying. A taboo culture in relation to death and dying has been previously recognised by Hockley et al. (2005) and Hall et al. (2011) who reported a covert culture in care homes which negatively influenced care home staff's perceptions and attitudes in relation to talking about death and dying with residents and relatives in the care home. However, this culture is not confined to care home settings, Gire (2014) discusses that a taboo culture surrounding death is ingrained in UK society. Thus, Gire adds that in order to implement change, the negative perceptions of death and dying first need to be addressed at a societal level.

Despite death being more openly accepted in Swedish culture compared to countries like the UK, a recent study looking at Swedish care homes has reported similar results to the ones found in this UK based study (Alftberg et al. 2018). Specifically, Alftberg et al. found that despite using advance care planning to

guide conversations, staff felt held back by their own reluctance to discuss death. Similarly, Morin et al. (2016) reported that discussions about death occurred with a minority of residents and relatives in care homes in countries such as the Netherlands, which again traditionally have a more open and accepting culture towards death (Gibbs et al. 2016).

This persisting culture amongst care home staff even in traditionally more accepting countries may be explained by looking into education. Findings from this present study suggest that care home staff's views and cultures towards death and dying can be influenced by education. Wisnewski (2015) argues that education for registered nurses in most countries is still predominately focused on life preservation and what nurses can do to save lives. This is important as it has been found that the traditional medical focus of education for healthcare professionals can influence how they perceive death and dying later in their careers (Burger et al. 2018). Thus, these findings imply that current education mechanisms can have an impact on staff's openness to discuss death and dying as part of advance care planning conversations.

Despite this, it was apparent that most education and training pertaining to advance care planning was focused on information gathering, rather than providing staff with the knowledge to be able to sensitively engage in discussions about death and dying. This approach to education and training is unsurprising given current research and interventions in the field are predominately concerned with numbers of advance care plans (O'Sullivan et al. 2016; Kinley et al. 2014; Finucane et al. 2013; Temkin-Greener et al. 2017). Whilst the numbers of advance care plans in place are important, findings presented in this study suggest that more needs to be done to support staff to sensitively engage in discussions about death and dying as part of their training to help improve the quality as well as the quantity of advance care plans.

These findings on intervention mechanisms, contextual mechanisms and human agency were used to develop intervention theory one, which proposed the use of educational workshops with content focused on supporting staff to sensitively

discuss death and dying. The review of current interventions presented in chapter three identified that workshops can be based around pre-selected areas of content and help reduce the dissemination of non-evidence based poor practice (Finucane et al. 2013; Mayrhofer et al. 2016). This is important as the most common education mechanism used in the care homes was shadowing or on-the-job training. However, it was evident that shadowing was often not based on evidence and instead relied on the expertise of more experienced staff members. Consequently, Wilson et al. (2009) and Schuler (2015) argue that although shadowing can be an effective method to bridge the gap between theory and practice it can lead to care home staff passing on their perceptions and attitudes to others. This is relevant as it was found that some care home staff held negative views and cultures in relation to death and dying. Therefore, the workshops can be used to accompany current methods of education such as shadowing to provide an evidence-based foundation.

Moreover, findings suggest that workshops enable a diverse range of care home staff to be involved. This is important because it was found that staff with non-formal caring roles such as housekeeping staff had a significant experiential impact; bereaved relatives noted the relationships they developed with these staff and how they helped pass on information for advance care plans. Despite this, it was found that staff with non-formal caring roles were excluded from modes of education such as on-the-job training. This is important and highlights an underutilised resource as ancillary roles including administrative, housekeeping and cooks make up 11% of the workforce across the UK care home sector (Griffiths et al. 2019). Moreover, given the limited resources and staffing challenges within the sector (Bulman 2017), utilising and recognising the value of the whole workforce is essential. These findings consequently suggest that a valuable resource is being undervalued and poorly prepared.

As well as including a diverse range of care home staff, bereaved relatives expressed that they wanted to participate in the education of care home staff in this area to share their viewpoints and experiences. Ronch (2004) found that including the different perspectives of residents and relatives can form an

important part of learning for care home staff by exposing them to different perspectives. Nonetheless, it must be remembered that vulnerable groups need to be protected and not made more vulnerable. For example, bereaved relatives are associated with high levels of distress (Keilman et al. 2014). Therefore, in order to support vulnerable individuals such as bereaved relatives, strict ethical codes and guidelines should be set, and researchers must diligently respect and listen to recommendations (Dyregov 2004; Keilman et al. 2014).

7.2.2 Maintaining person-centred end of life care

Despite the importance of a person-centred approach to care, it was identified that towards the end stages of residents' lives with a sparsity of support during out of hour shifts, some care home staff had an increased tendency to overlook residents emotional and social needs and contribute towards unnecessary admissions at the EoL.

Clinical judgement is a process key in nursing in which a decision or conclusion is reached based on a process of observation, reflection and analysis of available information (Standing 2017; Potgieter 2012). Despite mistakes in clinical judgment being one of the main causes of adverse events such as unnecessary admissions to hospital, the current body of literature has tended to focus on clinical judgements from a nursing perspective (Graan et al. 2016; Potgieter 2012), with much less emphasis on exploring the decisions and experiences of non-registered care home staff such as care assistants. This is important as it was evident throughout this present study that non-registered care home staff also have important decisions to make in terms of providing EoLC in the home, and like registered staff poor judgments/decisions can lead to adverse events.

In terms of contextual mechanisms, it was identified that care home staff's decision making out of hours was negatively impacted by less support from managers and fewer experienced colleagues to receive guidance from. Current literature suggests the issues related to the lack of experienced support out of hours are only getting worse in the sector due to recruitment and staffing

shortages, causing care homes to rely on fewer and less experienced staff to deliver EoLC (Griffiths et al. 2019). Literature often associates the low pay associated with social care jobs and the lack of progression and training opportunities for registered nurses for staffing issues (Gershlick et al. 2017). However, the recruitment and staffing shortages are not unique to care homes and are being experienced by healthcare services across the UK as a result of a lack of funding and an increasing demand on existing services (Gershlick et al. 2017; Cooper et al. 2017). For example, Morris (2017) reports that these funding and staffing issues have had a particular influence on district nursing support. Analysis published by the Queens Nursing Institute (2018) has highlighted that the number of admissions into district-nurse programmes reduced by 2.5% in 2016-17. Furthermore, despite policy initiatives pushing for more EoLC in the community investment in the UK of specialist district nursing education and training has fallen (Morris 2017).

The impact of the lack of funding was noted in this present study, particularly in the residential care home. Staff working in the residential home expressed they had an increased tendency to call emergency services because of the lack of support as they had no on-site nursing. Davies et al. (2011) and Handley et al. (2014) also reported that staff working in residential care homes had a greater reliance on external services than nursing home staff as they rely on district nurses who are not always on site. Findings from this present study suggest that a lack of support influenced care home staff's clinical judgment and decision-making skills. Specifically, it was apparent that care home staff who felt unsupported were more likely to focus on residents' medical needs and contact emergency services. Although this response was more pronounced in the residential home it was also apparent the nursing homes.

A lack of support was not the only factor negatively impacting care home staff's judgments and decisions. In regard to human agency, it was evident that some care home staff's decision making, and judgment when providing EoLC was influenced by a fear of responsibility. Specifically, some care home staff highlighted they would call emergency services to get others involved, despite

residents wishes, to help relieve and share the emotional responsibly. This response highlights another defence mechanism used by staff to protect themselves from the emotional trauma of death. Previous research has identified the emotional journey care home staff go through while delivering EoLC, which has highlighted that they can experience stress, anxiety and grief when caring for residents at the EoL (Vandrevala et al. 2017). Marcella and Kelley (2015) found that these emotions are often heightened in care home staff who become emotionally attached/close to the residents they care for, as they often find detaching from these residents difficult.

However, developing close relationships with residents is part of the process of delivering EoLC (Funk et al. 2017; Wilson et al. 2009). Wilson et al. (2009) found that care home staff develop close relationships with residents primarily through frequent interaction during care delivery, which Funk et al. (2017) found often leads to staff seeing residents as family and developing close emotional bonds. Moreover, close attachments and relationships with residents form a key part of person-centred approach to care (Barry and Edgman-Levitan 2012). Thus, despite the importance of developing relationships with residents, findings from this present study suggest that care home staff's close attachments to residents can contribute to their on their decision-making skills and use of emergency services.

In addition to the close relationships with residents, findings suggest that some care home staff were fearful of blame and letting residents die in their care without medical intervention. Similarly, Rapaport et al. (2018) and Perkins et al. (2016) found that staff working in care homes often felt doing something medical would help protect them from blame, thus often made a clinical judgment to get emergency services involved. Barclay et al. (2014) found that this response can be heightened in cases where residents declined suddenly and unexpectedly which was found to often lead to staff panicking and resulting in some staff going against residents documented wishes. Thus, the judgment and decision-making of care home staff can be influenced by a range of factors. There is therefore a need for education and training to prepare all care home staff (not just nursing staff) with the knowledge and confidence to make informed

decisions based on resident's needs, in situations where support and guidance is limited.

One mechanism used to support care home staff to make more objective decisions in these situations is coding system used as part of the GCFCH (GSFCH Good Practice Guide 2014). The coding system used in care home three colour coded residents based on their proximity to death with blue indicating months and red indicating days left to live. Although the coding system may help care home staff make decisions and plan for uncertainty and the different trajectories of decline; findings suggest it does not help address the underlying factors outlined in this present study. Specifically, it was apparent that some care home staff's decision making was impacted by factors such as their close relationships with residents and their perceptions and attitudes towards death and dying.

Nonetheless, the findings of this study suggest that shadowing was used to accompany the coding system. Although shadowing can give care home staff the chance to ask questions and follow the lead of more experienced senior colleagues (Mayrhofer et al. 2016), it often consists of following and copying rather than critical thinking and challenging existing practice and ideas (Graan et al. 2016; Wiig et al. 2018). Furthermore, as discussed in chapter three less experienced and newer members of care home staff can often be afraid and unlikely to challenge their more senior colleagues during shadowing (O'Brien et al. 2016). This is important as Papathanasiou et al. (2014) adds that critical thinking makes up an essential component of decision making as it leads to the questioning and challenging of existing ways of practice which is necessary to understand why something is being done in a certain way.

As a consequence, intervention theory two proposes the need for educational workshops focused on promoting and supporting critical thinking within the care home workforce. It is theorised that this will help inform judgments and decisions made by staff to maintain a person-centred approach, especially in situations where support is guidance is limited and emotions are high. The workshops can be accompanied by shadowing to help bridge the gap between theory and practice and give care home staff a chance to use their critical

thinking skills. The implementation and delivery of the intervention theories is discussed in part two of this chapter.

7.2.3 Bereavement support and identity

Findings from this current study identified the importance of care home staff being able to adequately support relatives' bereavement needs during EoLC. Bereavement support appeared to be particularly important in helping bereaved relatives accept a different identity when their caring role ceases, and then when bereaved.

In terms of human agency, analysis of the bereaved relatives' transcripts identified that while their loved one was being given EoLC in the care home they found it difficult to develop an identity without their loved one. Caradec (2004) discusses that an individual's identity is determined by a person's life experiences as well as current relationships and evolving social network. Therefore, life events such as bereavement are relevant to an individual's identity. Caradec adds that identity construction and transition is marked by these events which often leads to individuals needing to re-establish their identity. In the context of this present study, findings suggest that identity transition can start before the death of a loved one. Specifically, it was found that relatives' difficulty accepting life without their loved one and re-establishing their identity led to them wanting to prolong their loved one's life.

Difficulty re-establishing identity was particularly apparent in the transcripts of bereaved relatives who had been a caregiver for their loved one before they were admitted to a care home. Similar findings have been reported by Orzeck (2016) who explored the identity of home carers. Orzeck found that due to the significant time and commitment involved, caregivers often ignore their own interests, work lives, and relationships which all form identity. Orzeck's findings reiterate the earlier findings from Pruchno and Resch (1989) who discuss that the during the caring period, caregivers' own life and personal goals and plans are interrupted leading to their existence and identity increasingly been centred

around caring for the individual. The difficulty re-establishing an identity following the cessation of previous caring responsibilities outlined in this present study suggest the need to include some relatives to a greater extent earlier on in the EoLC process and to more slowly and progressively reduce their caring responsibilities.

Moreover, although not identified in this present study, previous research suggests race and cultural backgrounds can also influence caregivers' emotions in relation to re-establishing an identity. It has been reported that compared to white Americans, African-Americans have been found to have stronger cultural values and beliefs towards caring for a family member, such as setting an example for their children in line with their religious and spiritual beliefs (Pyke and Bengston 1996; Dilworth-Anderson et al. 2005). Thus, those caregivers with stronger cultural and religious beliefs towards caregiving may find it more difficult to evolve and accept a different identity when their caring role ceases. This is important, as it has been reported that care home residents are becoming increasingly more culturally and spiritually diverse as a result of increasing globalisation (Independent Age 2016; World Health Organisation 2015). Thus, acknowledging how these factors can impact on people's bereavement experience in the context of EoLC in care homes warrants further research.

Additionally, it was identified that residents' conditions influenced the bereavement process. For example, one bereaved relative expressed that the symptoms and decline associated with dementia made them feel that they felt they had lost their loved one before they had died; therefore, started grieving earlier in the EoLC process. Although this is just the view of one individual and others may feel very different, it is well known that the symptoms associated with dementia such as memory loss and loss of speech ability can make meaningful communication more difficult resulting in emotional difficulties for families (Alzheimer's Society 2012; Pyke and Bengston 1996). However, UK policy highlights the need to not let dementia define the individual, reminding those involved to maintain a dignified and compassionate approach by placing the person at the centre of their care and including them in any decisions made on

their behalf (DH, 2018). In light of these policies, this study has raised the need to provide relatives of those dying with dementia with greater support in terms of bereavement care to help them cope with and understand the symptoms associated with dementia.

As well as residents' condition, it was highlighted that contextual mechanisms such as time limitations negatively influenced care home staff's ability to prepare relatives for the death of their loved one. Findings suggest that care home staff found it more difficult to develop relationships with short-stay residents and their relatives, particularly having the time to prepare relatives for the death of their loved one. Previous research has also recognised that a shorter length of stay in care homes was associated with poorer quality of EoLC (Pivodic et al. 2018). Therefore, addressing this issue is important given Public Health (2017) highlighted the numbers of short-stay residents being transferred to care homes from hospital and hospices are increasing, in part due to more people preferring to die in care home settings compared to acute settings.

Despite this apparent difficulty in care homes, hospitals and hospices staff regularly experience and deliver EoLC in short periods (NHS England 2019). Although care outcomes are equally not always positive in these settings, there has traditionally been a greater training focus centred around providing care in short periods of time (NHS England 2019; Public Health 2017), unlike care home staff whose education and training appeared to be based on longer-term care. These findings suggest a need to better prepare care home staff through education and training to deliver bereavement support for those service users who experience EoLC in a short period of time.

However, as well as time limitations, findings suggest that more bereavement care needs to be focused on the 'pre-death period' as most issues reported in this study arose prior to death in terms of preparing and supporting relatives to come to terms with the future. Although care home staff engaged in advance care planning and discussions about death and dying to an extent (discussed in section 7.1.1) to help prepare relatives and residents for death, most intervention mechanisms identified in this study were focused on delivering

support after death, such as celebration of life days and attending funerals. The focus on bereavement support after death is also apparent throughout existing research, for example, a sparsity of mechanisms to help support relatives before the death of their loved one was noted in the critical realist review (chapter three), with interventions mostly focused on 'after death' support (Hockley et al. 2005; Nash and Fitzpatrick 2015; Cox et al. 2017; Hewison, Badger and Swani 2011). Previous work has established that this bereavement support provided after death is also important in helping bereaved relatives re-establish an identity and purpose after death (Orzeck 2016). Whilst findings from this present study do not disagree with this, they do suggest that more can be done to provide care home staff with the knowledge and skills to better prepare relatives for accepting the death of their loved and starting bereavement support earlier on in the EoLC process.

These findings have been used to develop intervention theory three which proposes the need to provide care home staff with greater knowledge via educational workshops on the stages of bereavement to help them understand the importance of preparing relatives to evolve and accept a different identity following cessation of their caring role. Moreover, it is recommended that content focuses on helping staff support residents and relatives who are only in the home for a short period of time. The delivery of the educational workshops proposed in this study is discussed in section two of this chapter.

7.2.4 Bereavement support for care home staff

As well as residents and relatives, delivering EoLC was found to have an emotional impact on care home staff which influenced advance care planning and decisions at the EoL.

In terms of human agency, it was apparent that some staff felt a great deal of sadness and grief when delivering care. Several studies have also reported the emotional labour of delivering EoLC associating it with high stress and anxiety for care home staff (Vandrevala et al. 2016; Marcella and Kelley 2015). Harrad and Sulla (2018) report that care home staff's frequent exposure to emotional

trauma can lead to emotional burnout, which is described as a state of mental strain resulting from negative and demanding circumstances. However, this body of literature tends to mainly focus on the negative emotions of care home staff, with little focus on the positive emotional experiences of delivering EoLC. Nonetheless, the findings from this study found that negative emotions associated with providing EoLC were often contrasted with positive emotions such as feelings of privilege (to share the last moments of someone's life with them). Other staff also emphasised feeling proud if the resident experienced a pain free peaceful death. These findings suggest that the positive emotions associated with delivering EoLC are used by care home staff as a source of support and reassurance.

Although previously research has tended to only focus on the emotional and bereavement needs of healthcare professionals working in oncology and palliative care (Drury et al. 2014; Gillman et al. 2012) a growing body of literature is now exploring the emotional and bereavement needs of those delivering EoLC in care homes (Vandrevala et al. 2016; Funk et al. 2017; Costello et al. 2019). For example, it has long been thought that emotional stress and burnout is high within the care home sector and is attributed with high turnover of staff (Schaefer and Moos 1996; Larrabee et al. 2010). However, a recent study by Costello et al. (2019) found that it is a 'myth' that stress and burnout levels are high within the care home workforce reporting no association between staff turnover in care homes and burnout. While emotional trauma and burnout for care home staff delivering EoLC may not be as high as previously thought, findings from this present study still suggest that some staff experience emotional trauma and compassion fatigue from delivering EoLC, which had implications for practice such as advanced care planning and decision making (discussed in sections 7.2.1 and 7.2.2).

The deficiency of emotional support for care home staff was also noted by Vandrevala et al. (2016) who highlighted a lack of interventions to support the emotional needs of staff delivering EoLC in care homes. Nonetheless, this

present study identified some intervention mechanisms in place to emotionally support care home staff, which included peer-support from colleagues and managerial support. Peer support consisted of informal communication, reassurance and chats between care home staff to support each other, usually following a death. However, findings suggest that this informal means of support was often negatively impacted by some care home staffs' ingrained beliefs and perceptions. For example, some believed that expressions of emotions in the care home were unprofessional and that there was no time to get upset. Similarly, Funk et al. (2017) found that providing EoLC can often result in conflicting role identities from 'caring' to 'professional' for care home staff. With some staff adopting professional identities which involved showing less emotional towards residents, and others adopting a more caring identity which involved develop closer relationships with residents, some even seeing them as family. In contrast, Marcella and Kelley (2015) found that care home staff were best placed to support each other and felt comfortable expressing emotions around each other. Collectively these findings suggest that more needs to be done to help care home staff manage their roles to more consistently provide emotional support to each other.

Care home staff also relied on managers for support, which consisted of reflection and one-to-one conversations. For instance, the manager from care home three used the GSFCH reflection model which focuses on past events; what went well, why, and what did not go well, and why (Hansford and Meehan 2007). The benefits of reflection have been reported across research in the field and consist of being able to revisit, come to terms with, and learn from the situation (Frias et al. 2011; Nash and Fitzpatrick 2015; Hewison, Badger and Swani 2011). It has long been reported that care home managers have a significant influence on staff emotionally supporting their workforce and managing staff morale, therefore, managers have been traditionally relied upon to provide support for the workforce (Wang et al. 2018). However, a number of contextual mechanisms were found to inhibit the application of managerial reflection sessions.

It was reported throughout this present study that home managers often lacked time, faced high workloads thus were not always able to consistently provide emotional and support for care home staff. Similarly, Baker et al. (2015) note that home managers often struggle to manage their own workloads and emotional wellbeing without the extra responsibilities of supporting their staff, with high levels of managerial turnover been a common feature within the sector (Griffiths et al. 2019) which was also highlighted in the critical realist review presented in chapter three (Kinley et al. 2014; Finucane et al. 2013). It is therefore unsurprising that the managers in this current study were supportive of providing care home staff with more formal training and education to enable them to more effectively support each other, lessening the reliance on managers.

Hospices in the UK have long used resilience training to provide their staff with the skills and knowledge to effectively support each other and build emotional resilience (Hospice UK 2015). For example, altering the way hospice specialists interact with each other to focus more on the positives of care rather than solely focusing on mistakes or issues. This method is used across hospices in the UK and has been found to build emotional resilience within a workforce routinely exposed to death (Hospice UK 2015; Hospice Friendly Hospitals Programme 2013). Despite hospice staff being trained to support each other, findings from this present study noted that this was not the case in the care home sector, regardless of the apparent need for it. Thus, intervention theory four theorises that there is a need to provide resilience training for care home staff to enable them to more effectively support themselves and their colleagues, reducing managerial reliance. Findings imply that moving closer to a 'hospice style' of resilience training and support can better help improve care home staff's emotional wellbeing and ability to consistently provide high quality EoLC.

7.2.5 Multidisciplinary collaboration during end of life care

The sharing of knowledge and expertise through multidisciplinary collaboration was found to be key in enabling care home staff to deliver EoLC in the care home rather than having to admit residents to acute services. However, collaboration in tandem with high workloads and time pressures led some care home staff to develop negative perceptions of external service staff.

In terms of contextual mechanisms, findings from this present study suggest that short staffing, high workloads and high staff turnover were significant barriers to effective communication and collaboration between care homes and external services. Care home staff in this present study not only highlighted how their own workloads prevented them from collaboration but highlighted that they felt GPs and other external staff were often too 'busy' to adequately support them through EoLC delivery, such as prescribing anticipatory medications and providing reassurance and guidance. Similar views have been reported by Croxson et al. (2017) and Fisher et al. (2017) who found that GPs felt workloads were unsustainable particularly given the diminishing workforce which significantly hindered their ability to carry out responsibilities such as visits to care homes. Contextual mechanisms such as workloads and staffing shortages have also been reported in the hospice sector, preventing effective relationships between care homes and hospice services (Marie Curie Palliative Care Research Centre 2017).

Thus, these staffing and workloads related issues are not unique to care homes, Cromarty (2019) argues that they have manifested and persisted within UK health and social care mainly as a result of funding and resource allocation not keeping up with the increasing demands on the services (The Health Foundation 2018). Moreover, despite the UK government promoting an extra £20.5 billion pounds for the NHS by 2024 no such promise has been made for adult social care funding (NHS Funding Bill 2020), meaning the workload and staffing issues associated with a lack of funding are unlikely to change.

In terms of human agency, it was apparent that most care home staff poorly managed these contextual mechanisms, often developing negative attitudes and perceptions of external service staff. For example, some care home staff interpreted the lack of GP visits to mean GPs do not care about EoLC in care homes and prioritise other areas. Similar findings have been reported in existing literature which has also found problematic relationships with GPs who were unable to visit care homes due to high workloads (Robbins et al. 2013). However, these negative perceptions and attitudes have been reported on both sides. For examples, previous research has reported that some hospital professionals believed they knew more than care home staff, thus often overruled the decisions of care home staff and undervalued their knowledge and ability (Baylis and Baker 2017; Kinley et al. 2014; Popejoy et al. 2014).

It has been reported that these perceptions of care home staff have partly manifested from the negative media coverage of the care home sector, with most media outlets reporting on poor care and training for care home staff, and few highlighting the vital and important care that staff in the deliver daily (Miller et al. 2017; Howard 2013). For example, Baylis and Baker (2017) found that after coming together with care home staff, hospital professionals realised that they were learning from care home staff and their often-detailed knowledge of residents, something which they did not originally anticipate. This suggest that negative perceptions and attitudes from both care home staff, and external service staff can be partly addressed by simply coming together.

It is therefore unsurprising that UK policy recommends that organisations to a much greater extent must work collaboratively to find new ways of delivering better EoLC as part of the integrated care agenda (National Palliative and End of Life Care Partnership 2015; NHS England 2018). Despite this, only staff from care home three adopted a proactive approach to collaboration and set up monthly meetings as part of the GSFCH to engage in regular communication and collaboration. These collaborative meetings were found to provide a medium for multidisciplinary staff to share knowledge and expertise and facilitate joint understandings to work around challenges such as high workloads and ingrained

perceptions. Recognising these examples of supportive mechanisms to facilitate effective collaboration is essential as research in the field has predominately focused on reporting on poor examples of collaboration (Bardsley et al. 2016) with sparse research highlighting what effective collaboration looks like and the mechanisms involved in it.

However, the cost of implementation and sustainability monthly meetings was found to be too high for care homes one and two in this study. Similarly, research has reported that although a number of collaborative interventions have been introduced in care homes, they tend to be resource-heavy and seldom account for contextual mechanisms such as the high workloads and limited funding within the sector (Badger et al. 2012; Cox et al. 2017; Hewison, Badger and Swani 2011; Kinley et al. 2014). As a consequence, most evidence of multidisciplinary communication between care homes and external service staff identified in this study was reactive. These findings suggest a need for more accessible, sustainable and proactive mechanisms to enable more effective multidisciplinary collaboration across the diverse care home sector. Given the success of existing multidisciplinary meetings in care home three, findings from this present study suggest the need for multidisciplinary collaborative meetings to be more widely accessible across the sector.

To address the cost associated with collaborative meetings, it was suggested that videoconferencing can be used as a mechanism to increase ease of access to meetings and enable their wider use across the diverse sector. Care home staff in this study were supportive of the introduction of new and more accessible methods for improving collaboration. Although it is becoming increasingly prevalent, Hex et al. (2015) argue that the use of information technology is still an underutilised resource in care homes. Newbould et al. (2017) evaluated the use of videoconferencing in care homes as a method for collaboration with external services and found that it reduced the cost and time commitments by enabling a range of care homes and external services to more easily communicate. Furthermore, Hall et al. (2016) found that videoconferencing in care homes led to quicker resident assessments and monitoring. Moreover,

increased access to specialist knowledge (that comes with using videoconferencing) was found to provide care home staff with the skills and confidence to provide care for complex residents in the home avoiding unnecessary admissions to hospital.

These findings were used to develop intervention theory five. Intervention theory five theorises that using information technology (videoconferencing) can make effective multidisciplinary collaboration more accessible for a diverse range of care homes. Findings suggest that making collaboration more accessible will help improve care home staff's access to specialist knowledge to enable more residents with complex needs to die in a care home rather than in an acute hospital or hospice setting. However, despite this study identifying and advocating mechanisms to help improve the efficiency, findings suggest this alone is not enough to sustain effective change in relation to collaboration during EoLC. Specifically, although intervention theory five may help improve collaboration by making communication easier and more efficient, it is only addressing a symptom of a large issue. Findings discussed in relation to existing literature and policy therefore suggest a need for more funding and support for services to manage contextual mechanisms such as staff shortages and increasing workloads across all healthcare settings.

7.3 Part two: Implementation and delivery: A multicomponent end of life care intervention

Findings from this study have uncovered the processes behind outcomes used to determine high quality EoLC in UK care homes. This process data was used to develop intervention theories (table 16) which systematically incorporate mechanisms and agency into their design.

Findings from phase-two of this study highlighted the need to combine the theories into one multicomponent intervention to not only make it easier for care homes to follow but to affect more consistency within EoLC education and training. Phase-two of this study provided the foundational components and rationale for the development of the multicomponent intervention (see table 16). The following sections will discuss the implications of introducing the multicomponent intervention into practice in relation to existing research to further establish feasibility.

Table 16 The intervention theories

<p>Intervention theory one</p>	<p><i>Incorporating the experiences and viewpoints of bereaved relatives into educational workshops on discussing death and dying for care home staff (Intervention mechanism) is important as currently a taboo culture surrounding death and dying (Contextual mechanism), and a common perception amongst care homes staff that talking about death will upset residents and relatives (Human agency) is preventing discussions about death and dying in care homes (Outcome).</i></p>
<p>Intervention theory two</p>	<p><i>Given care home staff's tendency to focus on the medical aspects of end of life care (Human agency) out of hours where less support and guidance is available (Contextual Mechanism) educational workshops are necessary (Intervention Mechanism) to provide staff with guidance on how to channel their care to maintain a person-centred approach in relation to their decision</i></p>

	<i>making towards the end of residents' lives, and in situations where they must work more independently (Outcome).</i>
Intervention theory three	<i>Relatives difficulty to re-establishing an identity and accepting the death of their loved one (Human agency), particularly those who were previously caregivers (Contextual mechanism) was found to increase likelihood of unnecessary prolongation of life (Outcome). There is therefore a need for educational workshops for care home staff on the stages of grief (Intervention mechanism).</i>
Intervention theory four	<i>Given the emotional and bereavement needs of care home staff (Human agency) and the current reliance on time-poor home managers for this support (Contextual mechanism) there is a need to provide care home staff with the knowledge and skills via evidence-based education (Intervention mechanism) to more effectively support their own and their colleagues' mental health during and after end of life care (Outcome).</i>
Intervention theory five	<i>Use of information technology to facilitate collaborative meetings between care home staff and external service staff (Intervention mechanism) will provide a more time and cost-effective mechanism for time poor services (Contextual mechanism) to share knowledge and expertise and develop relationships (Outcome) and the opportunity to utilise staff's enthusiasm to work together to meet residents' needs (Human agency).</i>
The overall intervention theory	
<i>Combining the intervention theories to form one multicomponent intervention (Intervention mechanism) will help address the current disparities in end of life care education (Outcome) by improving the uptake and consistency of evidence-based end of life care education and training across the diverse sector</i>	

(Contextual mechanism) which is an outcome generally supported by care home staff and service users (Human Agency).

7.3.1 Disparities in end of life care education

Currently, within the UK there is no legal requirement for a minimum level of EoLC education for staff providing EoLC in care homes, which as identified in chapter three has contributed to unequal education and training opportunities for care home staff delivering EoLC. Spilsbury et al. (2015) argue the most significant barrier to the delivery of high quality EoLC in care homes is the lack of education and training with most care home staff not being given appropriate training in EoLC. To address this, care home staff supported the notion of combining the intervention theories to form a multicomponent intervention. It was believed that combining the intervention theories would provide a set of evidence-based content for care homes to model and base their EoLC delivery on.

Although there are already a number of multicomponent interventions in EoLC such as the GSFCH, chapter three uncovered that the uptake of these interventions across the diverse sector was often hindered by the high implementation and sustainability costs associated with multicomponent interventions (Kinley et al. 2014; Nash and Fitzpatrick 2015). Thus, often only a select proportion of the care home sector is benefitting from current interventions on the market. It is argued that this current approach has led to high quality EoLC only being available for people who can pay for it and choose which care home they go into, which is a luxury not afforded to recipients of social care who have limited to no ability to choose which care home they go into (Age UK 2019). As a result, access to high quality EoLC is becoming increasingly dependent on what people can afford and where they live (Institute for Public Policy Research. 2018). These findings highlight the need for a more even distribution of evidence based EoLC education and training which can be accessed by a wider range of care homes.

The intervention theories developed in this study help to address this need given the systematic incorporation of mechanisms and agency into their design. Thus, the intervention theories developed in this study can be used inform future interventions which are more likely to be implemented and sustained across the diverse care home sector.

7.3.2 Delivery mode and cost effectiveness

One of the contextual mechanisms incorporated into the design of the intervention theories was the need to be cost effective, to enable uptake across the sector. For example, in terms of educational workshops it was found that an in-house delivery mode could be used which would allow care home staff to flexibly deliver the educational content around their current responsibilities. Previous literature has also reported that in cases where education was delivered more flexibly uptake was increased and outcomes were sustained to a greater extent (O'Brien et al. 2016) compared to education delivery which was less flexible such as study days or lectures (Dobie et al. 2016; Parks et al. 2005; Wen et al. 2012). Findings from the present study suggested that ensuring cost effectiveness is important to allow a diverse range of care homes to implement the multicomponent intervention rather than it only being available to the homes who can afford it.

Widening access to education and training is particularly important in the current political climate, as a lack of funding for social care services in the UK has led to local authorities having to reduce the prices paid to care home providers (Cromarty 2019), thus increasing numbers of UK care homes struggling to stay open (The Health Foundation 2018). This situation has so far affected several UK care home chains causing them to go into administration, with the most recent being one of Britain's largest groups; Four Seasons Health Care (BBC 2019). Furthermore, all three care homes managers in this present study highlighted that part of their job was to ensure any change implemented was within the home financial and resource capabilities. Previous research has also reported on managers 'market orientated' leadership style suggesting that it can prevent managers being open to new ideas due to a focus on saving money (Rockstad et

al. 2015). Nonetheless, the findings from this present study suggest that the managers were still open to change, however, they were clear that change had to be financially viable, especially in the light of increasing demands and the lack of funding.

7.3.3 Staff mobility and perceptions of the care home workforce

As well as making high quality EoLC more widely available for service users, findings suggest that increasing access to evidence based EoLC education and training (through the development of a cost-effective multicomponent intervention) can benefit the care home workforce.

High staff turnover in UK care homes has long been blamed for negatively impacting the effectiveness and delivery of education across the care home sector (Halter et al. 2017). For example, it was reported in chapter three that knowledge and skills gained through education and training were lost when staff left the care home (Kinley et al. 2018; Finucane et al. 2013; Temkin-Greener et al. 2017). However, statistics on turnover rates in UK care homes suggests the problem is only getting worse, for example, the data show a steady increase in turnover in care home staff from 23.1% in 2012-13 to 32.2% in 2018-19 (Griffiths et al. 2019). Despite these high turnover rates, findings from this present study indicate that many of the staff who leave do not leave the sector but leave to go to work in another care home. These findings are supported by a survey of 161 care homes in Scotland which found that 61-70% of the staff who leave go on to work in other care homes, which highlights a significant level of mobility within the sector (Gatherum 2017). Although the survey was only in Scotland the qualitative data collected from this present study in South West England suggest similar patterns of mobility. Thus, if more care home staff were provided with a recognised level of evidence based education when a member of staff leaves a care home and joins another, they will transfer this foundational knowledge which can be recognised by homes across the sector.

Additionally, findings imply that increasing access to evidence based education through the multicomponent intervention can help address the image and

stigma associated with care homes. Specifically, some bereaved relatives expressed anxiety and beliefs that care homes were not able to provide high quality care. Existing research has identified that often the care home sector is looked upon in a negative light, and that people attribute care home staff with poor training and education (Stajduhar et al. 2017; Utley-Smith et al. 2009). These societal perceptions of care home staff and the sector can manifest from the media, which frequently reports on the negatives such as lack of training, poor pay and instances of poor care with little reporting of the good care being delivered (Bloch-Budzier 2018). Whilst increasing access to education and training for care home staff providing EoLC may help address the belief that care home staff are poorly trained, these findings suggest that care homes alone cannot change societal perceptions, and a wider and multifaceted approach may be needed.

7.3.4 Moving towards a cross-sectoral approach to end of life care education

As well as making evidence based EoLC education more accessible by lowering costs, findings from this study suggest that still some care homes would choose to not to deliver education. Consequently, the notion of making the proposed multicomponent intervention mandatory was suggested. However, it was evident from the findings that care homes alone could not enforce a mandatory approach. Greenhalgh et al., (2004) describes the notion of an inner and outer context, which can both influence the adoption, spread and sustainability of change. So, an intervention can be impacted by both the outer context and inner context. The inner context refers to the inner organisational environment which can include demographics such as clinical experience, and attitudes and openness towards an intervention. The outer context refers to the service environment, which can include political climate, external funding and policies (Aarons et al., 2011).

Whilst this study had explored both inner and outer contexts, findings suggest more work is needed particularly to explore the potential impact of outer context on the multicomponent intervention. This is important because it was identified that a number of independent organisations can impact on care homes

uptake of change. For example, in the UK the CQC regulate and review mandatory training such as health and safety. Additionally, the CQC is responsible for regulating and managing the standard and quality of care in care homes through conducting independent reports which grade homes based on set criteria such as care and welfare of service users (CQC 2019). Therefore, for any mandatory education to be introduced it would have to be developed in collaboration with the CQC as they are in the position to enforce and review its delivery in accordance with their set criteria.

However, in terms of the current political climate in the UK, now may not be the most appropriate time to enforce mandatory education. As discussed earlier the care home sector is currently experiencing financial difficulties as a result of a lack of funding from government (Cromarty 2019), which has led to care homes closing around the UK (BBC 2019). Furthermore, politics in the UK is currently focused on issues with Brexit which had led to less attention being placed on social care issues such as the lack of funding (Stewart et al. 2019). Thus, introducing a mandatory intervention at this time may cause more homes to run into financial difficulty leading to more closures. As a consequence, the multicomponent intervention proposed in this study is not a mandatory or a 'cross-sectoral' approach, nonetheless, its design was heavily shaped by the evident need to make EoLC education more accessible across the diverse sector. However, further research beyond the scope of this thesis is recommended to explore the potential impact of a mandatory approach to the delivery of EoLC education (discussed as part of future research in chapter 8).

7.4 Part three: Strengths and limitations of the study

7.4.1 Strengths of the study

These were several strengths to this study. The use of Critical Realist Evaluation (CRE) (Porter 2015a; Porter 2015b), was an advantage which helped the study explain the processes behind outcomes rather than simply identifying outcomes. For example, rather than simply reporting on the number of advance care plans in place, the findings were able to explain how care home staff's emotional reluctance, combined with a taboo culture and a lack of supportive education hindered the quality of advance care planning discussions. This is important as it has shown that more work is needed to improve the quality as well as the quantity of advance care plans, and how to do about doing it. This attribute has allowed for a deeper understanding of the processes behind outcomes which was essential in informing and developing the intervention theories, which act as recommendations for practice.

Additionally, the use of two systematic literature reviews was a significant strength as they helped to firmly root the study in the context of academic literature. The first review provided a comprehensive overview of EoLC in UK care homes to identify areas of concern, while the second review evaluated current interventions designed to improve EoLC in care homes. Thus, the reviews not only identified what the current problems are, but what is being done to address them which helped inform and shape the research aim and objectives. Additionally, both the reviews were systematic meaning selection bias was reduced and all relevant articles were included.

As well as having two reviews, having two-phases to the study was also a strength. The two phases helped refine and develop the intervention theories to improve their feasibility in practice. This was not only important in refining the individual theories, for example, care home staff rejected the proposition of a liaison nurse because they felt it was impersonal and preferred collaborative meetings. It was also essential in identifying the need to combine the individual intervention theories into one multicomponent intervention to improve

feasibility and to ensure a more consistent level of evidence-based education across the sector. Moreover, the two-phased design integrated the participants in the research process. Participants expressed that they were excited to see what the findings were and were grateful that their opinions were sought.

Another key strength of this study was the care homes which were selected for data collection. Selecting a diverse range of care home contexts was not only methodologically important, but also representative of the current UK care home sector (Competition and Markets Authority 2017; Laing and Buisson 2015). Specifically, exploring EoLC across a diverse range of care homes allowed the study to capture processes which would have otherwise been overlooked if only one care home or a selection of similar care homes types were explored. For example, if this study excluded residential care homes it would not have captured key findings such as the lack of confidence some residential care home staff felt delivering EoLC infrequently without the support of on-site registered nursing staff.

As well as the data collection sites, another notable strength of this study was its range of participants. The two literature reviews (chapters two and three) revealed that previous research often excluded key members of the care home staff involved in EoLC such as housekeeping and administrative staff. Moreover, it was also noted that the experiences and perceptions of bereaved relatives were often overlooked, especially in relation to their interpretations of interventions. Pawson and Tilley (1997) acknowledge that different stakeholders have different expertise and knowledge, and therefore presenting the theories to a range of stakeholders can offer new insights and improvements to the theories. Consequently, the range of insight and viewpoints from the different participants has strengthened the study findings by exploring previously under-represented perspectives. It has also helped to give bereaved relatives a voice in the design of future interventions intended to improve EoLC.

Lastly, the supervisory team's consistent involvement and guidance through each aspect of the study was a strength. The supervisory team were involved in both

data collection and analysis. Having the supervisory team analyse the transcripts was vital in triangulating the data and increasing the accuracy and depth of the analysis. Additionally, the supervisory team were involved in the collection of the data from both phases, which enabled the focus groups to be conducted with a moderator and a facilitator. This allowed the moderator to take notes while the facilitator asked questions. It also provided an opportunity for the supervisory team to give constructive feedback to the researcher to enable improvements in the researchers' ability to conduct qualitative data collection methods.

7.4.2 Limitations of the study

The study had several limitations. The study did not include residents receiving EoLC. This is recognised as a limitation given that service users' perspectives and experiences are often overlooked (Spacey et al. 2018). However, following communication with the participating care homes and the NHS ethics committee, it was deemed insensitive and unethical to ask clients about EoLC. This was because we could not be aware of residents' level of knowledge as to whether they knew they were receiving EoLC, as well as wider health and wellbeing issues such as condition and trajectory. Nevertheless, it was viewed as highly beneficial to include some service users' perspectives and so it was deemed more sensitive to include bereaved relatives as they could be approached three months post bereavement. Furthermore, bereaved relatives in this study had been through the EoLC experience therefore offered a unique, personal and detailed experience, rather than anticipating what EoLC may like.

In terms of the study's selection criteria, it may be assumed that potentially only care homes that were likely to provide access to their staff and services users were those that were confident that the care they deliver is good. Consequently, care homes which were less confident in their ability to deliver high quality EoLC may not have been included in this study. Moreover, it is important to note that some care homes did not want to grant access to bereaved relatives, therefore were excluded on this basis.

In addition, the study only explored EoLC in care home settings, which has been recognised as a limitation, especially given the findings evidenced issues between care homes and a number of external services. However, the purpose of this study was to explore the outcomes in-depth from a care home perspective. Furthermore, it must be understood that critical realist evaluation can only ever provide a 'partial' understanding and it is not possible to do an evaluation of all the aspects of the wider context through data collection (Westhorp 2014). Despite the partiality of the findings they still provide a valuable contribution to knowledge in the field and have the potential to be used in other settings. Future research is recommended to explore the layers of context in external services (chapter 8).

Most care home staff who participated were female, with only n=1 male, which is recognised as a limitation. However, these participant demographics are typical of the current UK adult social care workforce which is predominately made up of females (82%) (Griffiths et al. 2019). This lack of male perspective was also evident amongst bereaved relatives, with only one out of seven being male. However, this could not be avoided as bereaved relatives were randomly sent invitations to the study by each care home (see chapter four), and their participation was voluntary.

Participant numbers were limited in each of the three care homes, data could only be collected from a proportion of the workforce during the focus group discussions to maintain the daily and safe running of the care homes. This is recognised as a limitation. However, this limited access is to be expected in any research involving working care home sites, thus it was incorporated into the research design prior to data collection. For example, data was collected at convenient times for the care homes, and they were notified six weeks in advance enabling them to prepare. Furthermore, the qualitative aim and objectives of this study were not reliant on large participant numbers but were concerned with in depth data from few participants.

The number of care homes involved in the study was also a limitation, three care homes were selected, limiting the transferability and generalisability of the

findings. However, these homes were carefully selected to fit with the methodological approach taken. Moreover, while the two-phased data collection and analysis process was necessary to deepen understanding and advance knowledge, it was also a time consuming and difficult process (discussed above). Therefore, to ensure the study was achievable three care homes were chosen. However, as discussed, the positives of using critical realist evaluation far outweighed the negatives.

7.5 Part four: Reflective diary and dissemination of study findings

This section will explore the potential influence I may have had on the research process as well as the influence the research process may have had on me. In the realms of qualitative research reflexivity involves the researcher critically reflecting on how they perceive they have influenced the research, and how the research has influenced them (Holloway and Galvin 2017; Gilgun 2011). As a researcher, I therefore sought to critically reflect on my experiences of conducting this study.

7.5.1 The impact I had on the research

My presence as a researcher in the interviews and focus groups, particularly for staff, may have influenced the research process. I attempted to adopt a theory-driven approach which in addition to elucidating the lived experience of the social actors involved from their own perspectives, also seeks to uncover the social relations that influence those experiences (Bhaskar 1975; Bhaskar 1998). Thus, during the interviews and focus groups, it was important to maintain a level of objectivity towards participants' viewpoints and thoughts. Yet, because I have experienced the death of a loved one and am therefore a bereaved relative myself, maintaining this objectivity and distance was challenging.

Initially, I found that it was easy to become too emotionally involved in the topic inhibiting my ability to stay focused when collecting and analysing the data. For example, I recall the occasion a bereaved relative described her experience of spending the last few moments together with her husband, which I found to be a saddening experience, but I was able to continue with the interview. It was not

until I later listened to the recording (during transcription) that I felt a great deal of sadness and had to stop the transcription process. While these emotions are inevitable to some degree with qualitative work in this field, I put a number of mechanisms in place to minimise the impact of my emotions on the data. For example, I engaged in self and group reflection with supervisors to distance myself from the participants and the data. I believe this process had a substantial and positive impact on the validity of the study findings. The impact this process had on me as a researcher is discussed later in this section.

In relation to collecting the data, following one of the focus groups, my supervisor who acted as a moderator in the focus group, noted that my body language (crossing my arms) may have made the participants feel nervous and uncomfortable which may have made them hold back information. I consequently changed my body language for the subsequent interviews and focus groups. For example, I did not cross my arms and developed a more relaxed posture. However, as well as body language my supervisors (MB and JS) also noted that the way I was asking the questions was a little formal. Specifically, I used the phrase 'next question' when moving onto the next question rather than allowing the conversation to flow more naturally. I also tended to ask the questions in order, rather than asking a question out of order if the conversation went in that direction. It was noted that this tactic may have made the participants feel like they were being tested, rather than encouraging a relaxed discussion.

I therefore reflected on this feedback from my supervisors and again changed the way I interacted with the participants. For example, I did not refer to the interview/focus group triggers as 'questions' and allowed the conversation to flow, rather than strictly following the order of the schedule. The feedback from my supervisors following these changes was positive, they each noted an improvement in the quality of the focus groups and that they needed to intervene less. Moreover, it was fortunate that I was able to receive this feedback early on in the focus group discussions so that I could not only change the way I approached the subsequent focus groups, but also the individual

interviews. Following this early feedback, my supervisory team noted a significant improvement. Going through this process allowed me to understand and appreciate that adopting the role of a qualitative researcher is very different from being a clinician. In addition, this process also helped me appreciate that the PhD process is a learning one.

Furthermore, it was evident that as the research progressed in phases the participants become more relaxed and engaged with myself and the study. As a researcher, I also felt more relaxed and engaged in 'small talk' with participants such as asking how their shifts were going. I found that this 'small talk' helped the participants become more comfortable with my presence as a researcher. This more comfortable and relaxed atmosphere led to participants being more talkative and engaging in more debate and discussion amongst themselves.

Another factor that may have influenced the research was how I introduced myself to participants. Specifically, I introduced myself as a healthcare professional conducting the research project, and so did my supervisors (who are all registered nurses) in the focus groups. I had anticipated that by introducing ourselves as healthcare professionals rather than researchers, would help participants relate to us, seeing us as having some insight into the care setting and their work. On reflection, this introduction had both positive and negative influences. On the one hand, it led to occasions where the participants felt they were being tested, for instance, I was asked 'am I right?'. This perception of being tested appeared to make participants more reluctant to discuss aspects of EoLC out of fear they may be perceived as being 'wrong'. It may have also prevented them from discussing aspects they were unsure about or even admitting they did not know something. However, on the other hand, being healthcare professionals who have cared for older patients may have enabled the participants to better identify with us. Overall, I felt introducing ourselves as healthcare professionals put us in a difficult situation and in cases led to participants potentially holding back some of their responses. Therefore, on reflection, in future I would simply introduce myself as a researcher from the University.

Managers were interviewed separately from general care home staff in order to create a less pressured conditions, as some care home staff may not feel comfortable to share their experiences with their 'boss' in the room. However, in reality, the variety of care home staff in the focus groups meant they consisted of staff with different years of experience, roles and knowledge. For example, one focus group consisted of nurses, senior carers, housekeeping and administrative staff. Consequently, at times it was evident that staff with less senior roles would hold back and not talk as much as the more senior staff. On one occasion the housekeeping staff even expressed they felt out of place in the room. To address this, I reassured the housekeeping staff that their place in the room was as important as anyone else's and encouraged their participation. I was supported by other participants, for example, a senior carer in focus group three reassured housekeeping staff they were all part of the same team and equally important, and any input from them was valuable.

In addition, this reassurance also helped to encourage the quieter members of the discussion to get more involved by giving them direct eye contact and asking directly 'what do you think?' This appeared to work as over time the quieter members of the group did start to have more input. It was also noted that other more senior members of the focus group would encourage and support input from everyone. Furthermore, involving such a mixed group of staff sparked contrasting viewpoints which helped deepen the findings. For example, housekeeping staff had an opportunity to share their experiences and perspectives with other care home staff and highlight areas of EoLC important to them.

I also found that my increased understanding of care home staff influenced the research. As a bereaved relative who has experienced the loss of a loved one in a care home, and a healthcare professional who has worked with carers and residents from care homes, I had developed my own perception of EoLC in care homes. It is also fair to say my perceptions of care homes may have been influenced by the media and its predominately negative reporting of the sector. However, throughout this research project, I have come to understand that a

great deal of good care and practice goes on in care homes, from dedicated and passionate staff.

This increased understanding and respect for the care home workforce impacted the research. Specifically, it helped me appreciate the importance of working with care homes and their staff, rather than against them when designing studies in care home settings. For example, I came to each home with a basic outline of what I wanted to do and what the study was about. From there the homes each contributed to the study design. For instance, care home staff expressed what they deemed was possible for them in terms of recruitment and time allocations, such as convenient times to conduct data collection, the length of the focus groups.

7.5.2 The impact the research had on me

This section will now discuss the impact the research has had on me. As to be expected with qualitative research looking into EoLC the research journey had an emotional impact on me. For example, I have experienced the death of a loved one in a care home and found that going into care homes and meeting other bereaved people reminded me of my own experience. This was initially hard for me, for example, one aspect of the study I found particularly emotional was transcribing the recordings from the bereaved relatives. As briefly discussed above I recall one recording where I could hear the sadness in the bereaved relative's voice as she was remembering the last moments with her husband and recalling the happy memories, she had with him throughout their time together. This was especially difficult as I have to listen to each recording a number of times to ensure accurate transcription.

Reflecting on this situation helped me to regain focus by enabling a level of objectivity towards the data. However, my personal experiences of EoLC I felt were also a strength, as I could empathise with bereaved relatives, and recognise when they were becoming upset, giving them the option to pause or stop the interview. As discussed, regular reflection with my supervisory team and colleagues helped me build emotional resilience and distance myself from the

research. Additionally, my supervisory team analysed a selection of the transcripts, which I believe further reduced the impact of my emotions on the data set.

I also found that the positive emotions and experiences associated with EoLC in care homes had an impact on me. Specifically, I found that having the opportunity to explore and understand other people's experiences helped me understand that death is part of life which everyone goes through, and for many it is associated with positive and peaceful memories. For example, I remember one bereaved relative talking about how grateful she was to the care home staff for the care they provided to her husband enabling him to die in comfort surrounded by his family. I feel privileged that bereaved relatives felt able to share these sensitive, personal and emotional memories with me, and it is something that I will forever be grateful for. Experiencing death and dying from the perspectives of others has given me an appreciation for how short life is – helping me to accept and come to terms with my own mortality. We will all die one day, and the care given to us at the end of our life is integral to those we leave behind.

In addition, my experience of recruitment had an impact on me in terms of helping me to understand myself and how I deal with disappointment. I experienced a number of recruitment difficulties during this study, for example, many homes chose not to take part because of the inclusion of bereaved relatives in the study. Several Gatekeepers that I initially approached expressed that they felt including bereaved relatives in the research would be too upsetting for them thus chosen not to take part. I reflected on my experiences with the Gatekeepers with a fellow postgraduate research student. We believed that reflection would help us share and identify useful strategies and build our resilience when experiencing challenges with Gatekeepers. Specifically, I found that reflection helped me to identify how I and my colleague dealt with the challenges we faced, which helped us identify useful strategies if we were to face similar situations in the future. For example, I learnt that my persistence was a key attribute to getting care homes involved in the study, despite facing initial

rejections. Additionally, rather than obsessing and fixating on issues with Gatekeepers I found working on other aspects of the PhD such as the literature reviews to be a useful distraction technique while waiting for gatekeepers to contact me.

7.6 Dissemination of research findings

In order to have a local impact as well as an international impact, the findings from this study have been disseminated in a number of ways using a range of different methods and events.

7.6.1 International impact

The results of the systematic literature review were published in the Journal of Research in Nursing. The systematic review findings were presented at Bournemouth University and the Palliative care-national conference in Oxford March 15th 2018. The preliminary results of this review were also discussed with a panel in January 2018 at improving standards for palliative and end of life care: delivering a co-ordinated, compassionate & personalised approach conference in London.

Spacey, A., Scammell, J., Board, M. and Porter, S., 2018. End-of-life care in UK care homes: a systematic review of the literature. Journal of Research in nursing. 0 (0) 1–21.

The results of the Critical Realist review presented in chapter three were published in the Journal of Nursing and Health Sciences (Appendix: 3).

Spacey A., Scammell, J., Board, M., Porter, S., 2019. Systematic critical realist review of interventions designed to improve end-of-life care in care homes. Nurs Health Sci. 1–12.

The Study findings were presented a Bournemouth University 11th Postgraduate Conference (Bournemouth, December 2019). Additionally, the study findings were presented virtually to an international audience at the Coimbra and Sigma Theta Tau International's 5th Biennial European Conference on 27th May 2020:

"NURSING'S INNOVATION, INFLUENCE AND IMPACT ON GLOBAL HEALTH: LOOKING BACK AND MOVING FORWARD". See appendix 15.

My personal experiences of researching EoLC in care homes and conducting a systematic literature review in the field was captured and disseminated in a published article aimed at supporting new researchers engage in EoLC research. This article has been published in Sage Research Methods (Spacey 2020) (Appendix: 14). It is hoped that by sharing my personal journey this article can be used to help support others researching in similar sensitive areas.

Spacey., A. 2020. The Challenges and Benefits of Conducting a Systematic Literature Review of End-of-Life Care in U.K Care Homes. *SAGE Research Methods*. doi: 10.4135/9781529720594.

7.6.2 Service impact

In order to gauge the impact of the findings on practice at a local level the findings were presented to all participants during and after the study. Specifically, the study findings were presented to care home staff and managers giving them an insight into the factors inhibiting and promoting high quality EoLC (August 2019). The care home staff responded positively to all the intervention theories, and the notion of implementing the multicomponent intervention as part of future research stemming from this initial project. All three care homes expressed they wanted to continue to work with Bournemouth University to implement the intervention, despite a managerial change at two of the homes.

In terms of the individual theories, all the homes expressed they will now include staff with nonformal caring roles in EoLC education to a greater extent and appreciate their impact on EoLC. Another key aspect of the study which the care home appreciated was sharing the views and perspectives of bereaved relatives, particularly in relation to understanding their identities and understanding the bereavement process can start before death. As well as the care home staff, the findings were present to bereaved relatives who were individually contacted due

to ethical reasons. All the bereaved relatives contacted responded positively to the study findings and were grateful to be included in the PhD throughout.

The findings were also presented to the CQC management (August 2019), and HealthWatch (August 2019). The CQC management were grateful we presented the findings and expressed an interest in working with the research team to develop the multicomponent intervention across a group of care homes in the South West of England (discussed further in chapter 8). To help set up this project, the CQC put the research team in contact with HealthWatch which is an independent organisation affiliated with the CQC which represents the collective voice of service users to improve service delivery (HealthWatch 2019).

Lastly, the results of the study were presented to future service providers (March 2019). I designed and presented a lecture on the findings of the literature reviews which was presented to BSc student nurses at Bournemouth University. There were over 300 student nurses in attendance, which exposed the audience to some of the barriers and facilitators facing staff providing EoLC in UK care homes. Many of the students expressed they were going to do their third-year dissertation (literature review) on exploring some of these issues. Other student feedback highlighted that the lecture had given them a greater understanding of evidence-based practice and increased their understandings of how research can fit within their role as a nurse. Bournemouth University invited me back to give the talk again in 2020.

7.7 Chapter summary

This chapter has discussed the findings of the study in relation to relevant policy and literature, highlighting where findings from this present study add to existing knowledge. The chapter ended by presenting the strengths and limitations of the study along with a reflective diary and discussing the dissemination of the research findings. The final chapter of this thesis presents the implications of the study findings on policy and practice before concluding with the areas for further research

8 Conclusion

8.1 Background and gap in knowledge

The purpose of this study was to inform the design and development of interventions capable of supporting the delivery of high-quality end-of-life care in UK care homes. This is important because variable engagement in advance care planning and persisting levels of unnecessary admissions have been reported in the provision of EoLC in UK care homes (Spacey et al. 2018; Thwaites et al. 2017; Mason et al. 2016; Ong et al. 2011). However, the effectiveness of interventions designed to improve practice in these areas were found to be limited by a sparsity of research exploring processes behind these outcomes (Spacey et al. 2019). This study contributed towards filling this gap, and the knowledge generated was used to develop intervention theories to achieve the research aim.

8.2 Implications for practice and policy

In terms of this study's immediate impact findings provide care home staff, policy makers, regulators and researchers with a deeper insight into what needs to be done to support high quality sustainable EoLC in UK care homes, and how to go about doing it. Rather than simply reporting findings, this study has organised the findings into intervention theories. The systematic incorporation of mechanisms and agency into the design of the theories has enabled them to better account for the different social, economic and organisational contexts of care homes. For example, currently, a lot of research and attention goes into increasing the numbers of advance care plans in place (chapter three), and whilst this is important; findings from this present study suggest that more research needs to go into improving the quality of advance care plans as well as the quantity. It was found that the current educational focus on gathering information, combined with some care home staff's emotional reluctance to discuss death and dying, and the taboo culture (associated with death) in some

care homes negatively impacted on the quality of advance care planning discussions in care homes.

Additionally, reducing the numbers of unnecessary admissions to hospital at the EoL has remained a main focus of interventions designed to improve EoLC in care homes (chapter three). Findings from this study have added to knowledge in this area by identifying how care home staff can influence outcomes in relation to unnecessary admissions. Specifically, it was evidenced that towards the end stages of residents' lives and with a sparsity of support during out of hour shifts, some care home staff had an increased tendency to overlook residents emotional and social needs and contribute towards unnecessary admissions at the EoL. Although multidisciplinary collaboration was found to help, it was often hindered by high workloads and care home staff perceptions that staff from external services do not respect or listen to them. This response was further compounded by some relatives' difficulties re-establishing an identity when their caring role ceases and then when bereaved. It was apparent that this difficulty re-establishing an identity made the bereavement process more challenging and painful for some relatives.

These findings were used to develop six interventions theories which provide recommendations on how to improve EoLC in care homes in these areas accounting for mechanisms and agency within their design (table 16). The incorporation of the study findings into intervention theories represents a valuable contribution to the field, as previous interventions evaluated in chapter three did not fully recognise or incorporate mechanisms and agency into their design which was found to limit their effectiveness. These intervention theories can therefore be used to inform the development and design of future interventions that are more likely to be capable of improving EoLC in UK care homes.

In terms of implementation and delivery, findings suggest that combining the intervention theories to form one multicomponent intervention would increase the feasibility and uptake of the intervention across the sector. However, the development and evaluation of the multicomponent EoLC intervention proposed

in this study requires further research (section 8.3). Thus, in terms of the study's longer-term impact it has provided a sound basis for future research developing and evaluating the multicomponent intervention.

Lastly, the findings have provided a voice for a number of previously overlooked stakeholders such as bereaved relatives, residential care home staff, and those with non-formal caring roles by exploring their viewpoints and experiences. Specifically, the viewpoints and experiences of all these groups were integrated into and used to develop the intervention theories. For example, findings highlighted the value and role of staff such as housekeeping in the provision of EoLC, thus, advocates their inclusion to a greater extent in the intervention theories proposed.

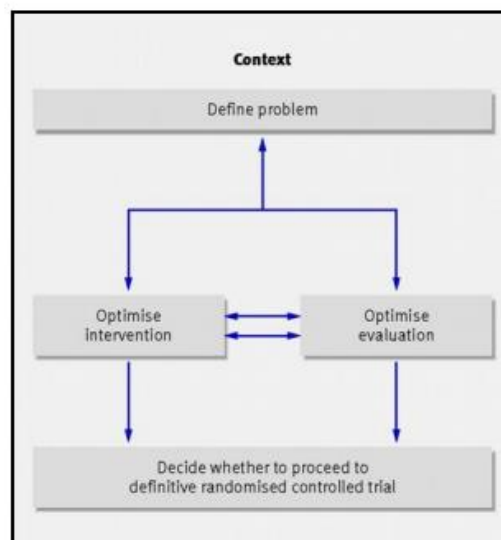
8.3 Implications for further research

In terms of this study's longer-term impact, it is important to remember that all interventions begin as theories (Pawson and Tilley 1997). Therefore, this study should not be seen as an end in itself, but as the initial phase of a comprehensive research programme. It has provided a sound basis for the development and robust evaluation of the multicomponent EoLC intervention in the form of a feasibility study, followed by a Phase III randomised controlled trial (RCT) and critical realist evaluation of processes and experiential consequences.

The methodological strategy of combining critical realist evaluation with traditional RCT design will add methodological significance to the study and has been previously established by Porter et al. (2015b). Moreover, combining critical realist evaluation with traditional RCT design has the ability to address weaknesses associated with traditional RCT methodology. For example, being able to more effectively evaluate the 'real world' effectiveness by accounting for the impact of context and human agency on outcomes (Porter et al. 2015b). Nonetheless, the challenge for such an RCT would be to measure outcomes following a long enough period to determine sustainability and to acquire a large enough sample size of diverse care homes to produce generalisable results.

However, prior to an RCT, there needs to be further optimisation and development of the multicomponent intervention to develop it from theory form into a workable 'real world' intervention. This further research will require close collaboration with the CQC and HealthWatch to optimise and develop the intervention. Furthermore, this study only explored EoLC in three care homes in the South West of England, thus it may be useful to replicate this study in another part of the country, perhaps in a large city or rural area providing further data to further increase the feasibility of the intervention theories developed in this study. The need to develop, optimise and fully understand an intervention is essential before subjecting it to evaluation (MRC 2006) (See Figure 12):

Figure 12 Stages of the Medical Research Council's framework for developing and evaluating complex intervention



Thus in the longer term, further research stemming from this initial study has the potential to produce results from the implementation of a multicomponent EoLC intervention which may have considerable societal impact in that its findings (whether they demonstrate or refute the intervention's effectiveness) will provide an important resource for national and international policies in relation to the EoLC of older people in care homes.

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10 Appendices

Appendix 1: Systematic Review, published in the Journal of Research in Nursing.

End-of-life care in UK care homes: a systematic review of the literature

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Abstract

Background: The number of people requiring end-of-life care provision in care homes has grown significantly. There is a need for a systematic examination of individual studies to provide more comprehensive information about contemporary care provision.

Aims: The aim of this study was to systematically review studies that describe end-of-life care in UK care homes.

Method: A systematic PRISMA review of the literature published between 2008 and April 2017 was carried out. A total of 14 studies were included in the review.

Results: A number of areas of concern were identified in the literature in relation to the phases of dying during end-of-life care: end-of-life pre-planning processes; understandings of end-of-life care; and interprofessional end-of-life care provision.

Conclusions: Given that the problems identified in the literature concerning end-of-life care of residents in care homes are similar to those encountered in other healthcare environments, there is logic in considering how generalised solutions that have been proposed could be applied to the specifics of care homes. Further research is necessary to explore how barriers to good end-of-life care can be mitigated, and facilitators strengthened.

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Appendix 2: Table of included articles and CASP scores (review one)

Study	Aim	Study type	Methods and participants	Results	*Quality score
Barclay et al. (2014)	Aim: To describe care home residents' trajectories to death and care provision in their final weeks of life.	Mixed method design	Case note reviews and interviews with residents, care home staff, and healthcare professionals. Location: six residential care homes in three English localities.	For some care home residents there was an identifiable period when they were approaching the end-of-life and planned care was put in place. For others, death came unexpectedly or during a period of considerable uncertainty, with care largely unplanned and reactive to events.	16/22 15/20
Froggatt et al. (2009)	Aim: To describe current advanced care planning practice in care homes for older people.	Mixed method design	The study used questionnaire surveys (n = 213) with care home staff, and 15 qualitative interviews with care home managers.	Advanced care planning helped inform care home staffs' end of life care decisions. However, the number of advanced care plans completed by residents varied.	18/22 15/20

Goddard et al. (2013)	Aim: To explore the views of care home staff and community nurses on providing end-of-life care in care homes.	Qualitative	Qualitative interviews conducted with 80 care home staff and 10 community nurses. Care homes providing care for older people (65 years or older) in two London boroughs took part in the study.	Care home staff acknowledged that improvements in their skills and the resources available to them were needed to manage end of life care effectively.	17/20
Handley et al. (2014)	Aim: To describe the expectations and experiences of end-of-life care of older people in care homes .	Mixed method design	121 residents from six care homes in the East of England were tracked; 63 residents, 30 care home staff with assorted roles and 19 NHS staff from different disciplines were interviewed and the case notes of residents were analysed.	An ongoing lack of clarity about roles and responsibilities in providing end-of-life care , and doubts from care home and primary healthcare staff about their capacity to work together was uncovered.	14/22 16/20
Kinley et al. (2014)	Aim: To identify the care currently provided to residents dying in UK nursing care homes.	Mixed method design	Review of case notes took place for study participants who were residents who had died within 38 nursing care homes in southeast England over a 3-year period.	Nursing care homes have established links with some external healthcare providers. These links included the GP, palliative care nurses and physiotherapy. However, with 56% residents dying within a year of admission these links need to be expanded.	17/22 16/20

Kupeli et al. (2016a)	Aim: To explore the context, mechanisms and outcomes for providing good palliative care to people with advanced dementia residing in UK care homes from the perspective of health and social care providers.	Qualitative	Qualitative interviews with 14 health and social care professionals including care home managers, commissioners for older adults' services and nursing staff.	Changes to the care home environment are necessary to promote consistent, sustainable high-quality end of life dementia care. For example, how care staff understand and use advanced care plans.	16/20
Kupeli et al. (2016b)	Aim: To improve our understanding of healthcare professionals' attitudes and knowledge of the barriers to integrated care for people with advanced dementia .	Qualitative	Qualitative interviews were carried out with 14 healthcare professionals including care home managers, care assistants and nurses.	Barriers to effective end of life care included poor relationships between care homes and external services, care home often felt undervalued by external healthcare professionals.	16/20
Lawrence et al. (2011)	Aim: To define and describe good end-of-life care for people with dementia and identify how it can be delivered across care settings in the UK.	Qualitative	Qualitative interviews were conducted with 27 bereaved family carers and 23 care professionals recruited from the community, care homes and general hospitals.	The data reveal key elements of good end-of-life care and that staff education, supervision and specialist input can enable its provision.	14/20

Livingston et al. (2012)	Aim: To examine barriers and facilitators to providing effective end-of-life care for people with dementia in care homes .	Qualitative	Qualitative interviews of 58 staff in a 120-bed nursing home where the staff and the residents' religion differed were carried out.	Care staff, nurses and doctors did not see themselves as a team and communicated poorly with relatives about approaching death. The staff used opaque euphemisms and worried about being blamed.	16/20
Mathie et al. (2012)	Aim: To explore the views , experiences and expectations of end-of-life care among care home residents to understand if key events or living in a care home.	Qualitative	The paper draws on the qualitative interviews of 63 care home residents who were interviewed up to three times over a year.	The study highlighted the importance of ongoing discussions with care home residents and their relatives.	15/20
Mitchell and McGreevy (2016)	Aim: To determine and describe care home managers' knowledge of palliative care.	Mixed method design	56 care home managers (all nurses) completed a validated questionnaire that is used to assess a nurse's knowledge of palliative care.	The average score was 12.89 correct answers out of a possible 20 (64.45%). This study uncovered a need to develop care home managers knowledge of palliative care.	13/22 14/20
Ong et al. (2011)	Aim: To better understand and gain deeper insight into the reasons/rationales that leads to a decision to admit a care home resident to hospital.	Mixed method design	Questionnaires were used to explore current practice in care homes, eight care homes were included.	Lack of advance care plans, and poor access to General Practitioners was uncovered as being the most common reason leading to admission.	16/22 17/20

Stone, Kinley and Hockley (2013)	Aim: To explore and describe the experiences of stakeholders initiating and completing EoL care discussions in care homes.	Qualitative	A qualitative descriptive study was carried out in three nursing care homes. Qualitative interviews were conducted with the resident, a family member, and the staff member.	Staff understanding of advanced care planning varied, affecting the depth of their discussions. Education was identified as being important, and role modelling advance care planning enabled a member of staff to develop their skills and confidence.	14/20
Wye et al. (2014)	Aim: To discuss and evaluate end of life services in care homes in English counties.	Mixed method design	Data collection included documentation (e.g. referral databases), 15 observations of services and interviews with 43 family carers and 105 professionals.	Results showed that time restrictions and poor staffing levels forced care home staff to rush and miss out or avoid vital aspects of end of life care, such as discussions with residents and family.	17/22 16/20
Kinley et al. (2018)	Aim: To report on the experiences of bereaved family members receiving EoLC in care homes.	Mixed method design	Bereaved relatives of residents who had died in a care home/hospital were sent the questionnaire to evaluate their experience of care provision for their relative in the last month of life. 37 nursing care homes in south-east were contact.	A total of 869 questionnaires were posted, with a 42% response rate. Bereaved relatives were satisfied with the care provided. Qualitative responses from family members highlighted some excellent care, although issues in relation to medical input, professional teamwork, last	20/22 18/20

				days of life and spiritual care remain problematic.	
Lee et al. (2016)	Aim: To understand the views of those service managers and frontline staff who organise and provide end of life care.	Qualitative	Semi-structured interviews and focus groups with 33 managers, 54 staff involved in frontline EoLC which included nurses and doctors and care assistants.	The current skills and knowledge of care assistants was highlighted as a challenge to providing high quality EoLC.	16/20
Bamford et al. (2018)	Aim: To understand the factors that facilitate good EoLC in dementia in England.	Qualitative	Semi-structured interviews, focus groups, discussions and observations of routine care with frontline staff, national experts and managers.	timely planning discussions and recognition of end of life were identified as key factors in the delivery of EoLC for those with dementia.	16/20

* Qualitative studies were scored out of 20. Mixed method studies were scored on their qualitative quality (out of 20) and their quantitative quality (out of 22), and therefore have two scores.


Appendix 3: Systematic Critical realist review, published in the Journal of Nursing and Health Sciences

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REVIEW ARTICLE

 WILEY

Systematic critical realist review of interventions designed to improve end-of-life care in care homes

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Abstract

The demand for high-quality end-of-life care is rising. Frequently evidenced concerns about the provision of end-of-life in care homes relate to inter-disciplinary communication and engagement in advance care planning. A number of interventions employing different mechanisms have been designed to address these issues. Therefore, the aim of this systematic critical realist review was to describe and explain the effectiveness of interventions designed to improve end-of-life care in care homes. Electronic searches were conducted in ScienceDirect, MEDLINE, PubMed, PsycINFO, and CINAHL from January 2000 to August 2018. Forty one studies were included in the review. While most of the evidence identified in this review was not strong, there was evidence to suggest that education and inter-professional collaboration can be effective intervention mechanisms for improving end-of-life care in care homes. High staff turnover was a significant contextual mechanism impacting on the sustainability of interventions. In terms of human agency, it is important to note a consistent finding related to the dedication and enthusiasm of care home staff who deliver end-of-life care.

KEYWORDS

education, home, palliative care residential home, systematic review, terminal care

Appendix 4: Table of included articles and CASP scores (review two)

Author(s), country and objectives	Population, setting and intervention	Design and methodological rigour	Hypothesised intervention mechanisms	Hypothesised contextual mechanisms	Agency	Key outcomes
<p>Aida et al. (2013)</p> <p>USA</p> <p>Objectives: To promote leadership in nursing homes to enhance the implementation of quality EoLC.</p>	<p>Setting: Five nursing homes.</p> <p>Sample: Care home staff and social workers (n=18).</p> <p>Intervention: The intervention consisted of educational sessions in five nursing homes over a ten-month period. The content of education aimed at improving EoLC through evidence-based leadership strategies.</p>	<p>A quantitative study design was used. Pre and post educational session feedback forms were used to rate the effectiveness of the intervention. 12 participants 67% rated the intervention using the 1 to 4-point scale.</p> <p>Quality: 15/22</p>	<p>It was hypothesised that education sessions related to leadership would help improve care home staffs' knowledge and confidence when delivering EoLC.</p>	<p>Lack of time, higher priorities were found to be barriers inhibiting high quality EoLC.</p>	<p>No data on agency was found.</p>	<p>Self-reported improvements in staff confidence and knowledge when delivering EoLC.</p>
<p>Arcand et al. (2009)</p> <p>USA</p>	<p>Setting: One nursing home.</p>	<p>A qualitative study design using (n=27) Semi-structured interviews before the</p>	<p>It was hypothesised that education would improve communication between the care</p>	<p>Information booklets could be taken away and flexibly</p>	<p>No data on agency was found.</p>	<p>Education facilitated communication within the team, and between the team and family members.</p>

<p>Objectives: To assess the effectiveness of a nursing home educational program on end of life care.</p>	<p>Sample: Care home staff and relatives</p> <p>Intervention: The intervention consisted of an educational program on the progression of dementia and its relation to EoLC.</p> <p>Delivery included providing an information booklet to all NH staff, and optionally to families.</p>	<p>intervention and (n=21) after.</p> <p>Quality: 15/20</p>	<p>home team and relatives at the EoL.</p>	<p>accessed by staff and relatives in their own time.</p>		<p>However, the intervention needs to be replicated to confirm these outcomes.</p>
<p>Badger et al. (2012)</p> <p>UK</p> <p>Objectives: To evaluate the effect of a training programme to improve EoLC in nursing homes.</p>	<p>Setting: nursing homes.</p> <p>Sample: Care home staff</p> <p>Intervention: The study explored the GSFCH programme to evaluate how it has influenced collaboration</p>	<p>A mixed methods study using questionnaires (n=79) pre intervention and (n=52) post intervention.</p> <p>Interviews with managers, the interviews and focus</p>	<p>It was hypothesised that implementing the GSFCH would improve collaboration between care homes and external services by enhancing staff knowledge and confidence.</p>	<p>Challenges to collaboration included working with large numbers of general practitioners , out-of-hours services and</p>	<p>It was hypothesised that increased staff confidence resulted in improved communication and collaboration.</p>	<p>Improved collaborations between home staff and health service practitioners were identified by 33% of managers as one of the main programme outcomes.</p>

	between nursing home staff and other health practitioners.	groups with all staff grades. Quality: 18/20 20/22		access to specialist practitioners		
Baron et al. (2015) UK Objectives: To evaluate the success of a programme of Advance Care Planning education.	Setting: 16 Nursing homes Sample: health care assistants (78%), with 12% nurses, 4% managers and < 1% 'other'. Intervention: To evaluate the success of an education programme of ACP education for nursing home staff by examining its effect on staff knowledge, ACP practice within the home and end-of-life hospital admission rates from the nursing home.	A Longitudinal study design using questionnaires (n=80) of staff who had completed the intervention and (n=89) of care home staff who had not, and (n=40) of staff who worked in care homes which had not yet received training. Quality: 18/24	It was hypothesised that delivering education on advanced care planning to care home staff would increase their knowledge and reduce the amount of unnecessary admissions to hospital at the EoL.	This study did not routinely collect data on nursing and health care staff turnover rates, but it did elicit that in at least four of the homes the managers were different at the time the original ACP data were collected	No data on agency was found.	Superior Advance Care Planning knowledge was evident in those staff that had completed the training. There was an increase of 85% in the number of Advance Care Plans completed.

<p>Brännström et al. (2016)</p> <p>Sweden</p> <p>Objectives: To compare the effects of the Liverpool Care Pathway for the Dying Patient and usual care on patients' symptom distress and well-being during the last days of life, in residential care homes.</p>	<p>Setting: 19 residential homes.</p> <p>Sample: bereaved relatives</p> <p>Intervention: During the following 15-months, usual care continued in the control area, while residential care home staff implemented Liverpool Care Pathway for the Dying Patient use in the intervention area.</p>	<p>Exploratory controlled before-and-after study. The intervention was evaluated by family members completing retrospective symptom assessments after the patient's death.</p> <p>71 questionnaires were analysed in intervention group</p> <p>64 questionnaires were analysed in the control group</p> <p>Quality: 19/22</p>	<p>It was hypothesised that the intervention would potential to improve several aspects of the quality of end-of-life care for dying elderly people at residential care homes.</p>	<p>Lack of time, off-hours for GP was noted as inhibiting the intervention outcomes.</p>	<p>No data on agency was found.</p>	<p>Shortness of breath (estimate = -2.46; 95% confidence interval = -4.43 to -0.49) and nausea (estimate = -1.83; 95% confidence interval = -3.12 to -0.54) were significantly reduced.</p>
<p>Braun et al. (2005)</p> <p>USA</p> <p>Objectives: To describe the development and</p>	<p>Setting: 10 nursing homes.</p> <p>Sample: nursing home staff.</p> <p>Intervention: An educational intervention was given to 10 nursing homes.</p>	<p>A qualitative study design using questionnaires (n=88) following completion of the intervention.</p>	<p>It was hypothesised that education consisting of group discussions of scenarios would improve care home staffs knowledge and confidence to deliver EoLC.</p>	<p>A lack of time and funds were found to negatively influence participation in the intervention.</p>	<p>Participation in the training was not required, and the training likely attracted individuals who were among the</p>	<p>Participants significantly improved their scores on knowledge and attitude measures.</p>

testing of an 8-hour curriculum for nursing home staff.	The intervention featured group discussions of scenarios that elicited feelings and emotions.	Quality: 15/20			most interested and motivated.	
Casarett et al. (2005) USA Objectives: To determine whether it is possible to increase hospice utilisation and improve the quality EoLC by identifying residents whose goals and preferences are consistent with hospice care.	Setting: Three nursing homes . Sample: care home residents and their surrogate decision makers Intervention: The intervention consisted of a structured interview identified residents whose goals for care, treatment preferences, and palliative care needs made them appropriate for hospice care.	Randomised Control Trial Of the 205 residents in the study sample, 107 were randomly assigned to receive the intervention, and 98 received usual care. The primary outcome measures were (1) hospice enrolment within 30 days of the intervention and (2) families' ratings of the quality of care for residents who died during the 6-month follow-up period.	It was hypothesised that increasing residents' access/early referral to hospice care would improve their EoLC experiences.	No contextual mechanisms were identified in the study.	No data on agency was found.	Intervention residents had fewer acute care admissions (mean: 0.28 vs 0.49; P = .04) and spent fewer days in an acute care setting (mean: 1.2 vs 3.0; P = .03).

		Quality: 16/22				
Cox et al. (2017) UK Objectives: To evaluate a collaborative intervention in care homes seeking to increase the confidence and competence of staff in EoLC.	Setting: Six care homes Sample: Care home staff Intervention: The intervention consisted of an end of life care toolkit and associated training on EoLC to increase knowledge and confidence of staff in care homes, facilitated by a specialist palliative care team.	A mixed method study design using focus groups with n=24 care home staff. 54 staff attended at least one training session; and pre- and post-intervention questionnaires were completed by 78 and 103 staff. Quality: 16/20 18/22	It was hypothesised that the EoLC toolkit would improve staffs knowledge and confidence to reduce unnecessary admissions to hospital at the EoL.	One of the challenges encountered during this study related to the ability to engage continually with care homes during times of leadership change.	It was hypothesised that reduced confidence in discussing death and dying with residents' post-intervention may indicate a greater awareness after training that EoLC is more complex than they may have first appreciated	Data indicate greater reduction in the number of residents from participating care homes dying in hospital than those from comparison homes.
Cronfalk et al. (2015) Sweden	Setting: 37 nursing homes. Sample: nursing home staff	A qualitative study design. 852 staff from the 37 nursing homes participated in the intervention. Staff from 7 nursing homes partici	It was hypothesised that education would help nursing home staff gain knowledge to build competence to enable improved	Lack of a common language between different professions	Staff experienced difficulties in talking about death due to a lack of	Self-reported staff reported positive experiences as they gained new knowledge and insight into palliative care.

<p>Objectives: To describe nursing home staff's attitudes to educational programs in palliative care.</p>	<p>Intervention: Three different educational programs relevant to EoLC delivery were developed by specialist staff from three local palliative care teams.</p>	<p>parted in 11 focus-group discussions.</p> <p>Quality: 14/20</p>	<p>delivery of EoLC in nursing homes.</p>	<p>caused tension in situations involved in caring for dying people.</p>	<p>theoretical knowledge</p>	
<p>Dobie et al. (2016)</p> <p>UK</p> <p>Objectives: To offer education and support on EoLC to all staff in care homes.</p>	<p>Setting: Unknown number of nursing homes</p> <p>Sample: nursing home staff</p> <p>Intervention: The intervention was a study day in local venues over one day;</p>	<p>Unknown study design. 136 evaluation forms were completed.</p> <p>Quality: Unclear based on unknown study design.</p>	<p>It was hypothesised that the study day would empower nursing home staff with knowledge and tools so that they had a better understanding of what constitutes a 'good death' and ultimately give them the confidence to deliver high-quality personalised EoLC.</p>	<p>One study day was the minimum time required and a period of time managers and staff felt they could accommodate.</p>	<p>Participants also recognised that many less experienced staff may need more support, particularly as the number of deaths in care homes is projected to increase.</p> <p>A belief that care workers are unable to</p>	<p>Increases in staff confidence and knowledge when delivering EoLC.</p>

					relate to certain ideas means they can be excluded from training opportunities open to clinical staff.	
<p>Dowding, and Homer (2000)</p> <p>UK</p> <p>Objectives: To enable health care assistants to improve their daily patient care through awareness of the principles of palliative care.</p>	<p>Setting: One nursing home.</p> <p>Sample: healthcare assistants</p> <p>Intervention: A study day for Health Care Assistants was offered to a care home in the UK. The study day focused on the principles and practice of palliative care for practitioners. Evaluation forms were completed post intervention. Attendance on each of the three days was full, with</p>	<p>A qualitative study design. 46 healthcare assistants completed evaluation forms after the intervention.</p> <p>Quality: 14/20</p>	<p>It was hypothesised that education would nursing home staff answer service users questions about death and dying.</p>	<p>Care assistants had many vocational and emotional needs that were not being met.</p>	<p>It was evident that participants valued the study day and were motivated to deliver high quality EoLC.</p>	<p>Participants valued the study day and feedback showed that the Health Care Assistants, essentially assistants to qualified nursing staff with minimal or no training themselves, had many vocational and emotional needs that were not being met.</p>

	15, 15 and 16 attendees on each respective day.					
Duffy and Woodland (2006) UK Objectives: To describe introduction of the Liverpool Care Pathway in a nursing home.	Setting: One nursing home. Sample: none Intervention: 6 month implementation of the Liverpool Care Pathway took place.	A qualitative descriptive study presenting a descriptive account of the process of implementing the Liverpool Care Pathway into a nursing home. Quality: 12/20	It was hypothesised that introducing the LCP and the anticipatory paperwork would help nursing home staff keep residents in the home rather than admit them to hospital at the EoL.	Limited availability of GPs out of hours to prescribe drugs.	Staff felt that that the pathway was allowing them to prepare ahead and ask the GP to prescribe the necessary drugs in advance.	Increases in staff confidence and knowledge when delivering EoLC.
Farrington (2014) UK Objectives: To evaluate the impact of an educational course on participants' confidence in delivering EoLC .	Setting: Seven nursing homes. Sample: nursing assistants and registered nurses Intervention: The intervention implemented an educational course which consisted of six modules each taking around an	A mixed method study design (n=6) questionnaires, documentary analysis, semi-structured interviews (n= 16) and observations. <i>Sample:</i> Nursing home staff. Quality: 14/20 15/22	It was hypothesised that delivering 6 education modules would enhance nursing home staffs knowledge and confidence thus improve EoLC delivery.	Uneven participation , the absence of mechanisms for disseminating new insights and knowledge within the home	There was a widespread perception that nurses' professional dominance in the nursing home made sustainable change difficult.	Improvements in participants' confidence in delivering end of life care were observed, particularly in the core competency areas of symptom management, communication, and advance care planning.

	hour to complete, with an introductory session on overarching principles of end of life care followed by four modules.					
Finucane et al. (2013) UK Objectives: To sustain a high standard of palliative care in seven UK nursing care.	Setting: Nursing homes Sample: Death audit data Intervention: Thirty-five workshops were carried out during the course of the project. Staff across all care homes were invited to attend each workshop. Each workshop lasted 2.5 h and was facilitated by both nurse specialists. Two palliative care nurse specialists each spent one day per week	Sustainability study using analysing death audit data. Quality: 21/24	It was hypothesised that providing a specialist facilitator (champion) would help sustain high quality EoLC by providing support and education through workshops to enhance the knowledge of the nursing home staff.	Only three of the original 16 key champions remained between the completion of the original project and the start of the sustainability project. Most had left the care homes in the interim.	Nursing home staff were motivated and engaged in the intervention.	In comparison with the initial intervention, there were increases in the proportion of deceased residents with an anticipatory care plan in place. However, overall hospital deaths increased.

	providing support and training to seven care homes.					
Froggatt et al. (2017) UK Objectives: To evaluate the 'Hospice in Your Care Home' intervention in nursing homes.	Setting: Nine nursing homes. Sample: Nursing home staff Intervention: The 'Hospice in Your Care Home' programme involves a number of interventions: role modelling and working alongside staff, responses to urgent referrals, advance care planning and training courses.	The responsive evaluation comprised: • an analysis of secondary service provision data • focus group interviews with care home managers (n=7), care home staff (n=11) and the project team (n=6) • Preliminary analysis of cost (time and finance). Quality: 18/20	It was hypothesised that adopting a hospice approach in care homes would enable reductions in admissions at hospital at the EoL and education provided would improve staffs knowledge and confidence delivering EoLC.	Barriers to the interventions were the ongoing challenges regarding staffing levels and release of staff to attend training	Nursing home staff were motivated and engaged in the intervention.	Hospital admissions were significantly reduced by 25% (p=0.01), between 2015 and 2016.
Froggatt (2000) UK Objectives: To provide education for nursing	Setting: Four nursing homes. Sample: Nursing home staff Intervention: The article evaluates a 2-year palliative	A case study design using qualitative methods. Semi-structured interviews (n=43), participant observations (411 hours), (n=173)	It was hypothesised that education on the core principles of EoLC such as discussing death and dying and pain control would improve the care of	The evaluation did not commence until the education project had run for a	Healthcare assistants particularly gained more confidence in their ability to listen and	Whilst consultation about general care is taking place in the majority of homes surveyed using both formal and informal processes, the number of residents that have

home staff to improve EoLC.	care education project for nursing home staff. 341 individuals attended courses: 151 registered nurses from 54 nursing homes, 115 healthcare assistants from 36 of these nursing homes and 75 ancillary staff from 16 nursing homes.	questionnaires and case note reviews. Quality: 15/20	dying people in nursing homes.	year. Consequently, it was not possible to obtain any pre-intervention data for either the individuals or the nursing homes that participated in the project.	talk with residents.	completed any ACP processes varies.
Garden et al. (2016) UK Objectives: To evaluate the impact of education sessions on EoLC delivery.	Setting: Seven nursing homes. Sample: nursing home staff Intervention: Education sessions (6-8) were delivered within 7 care homes in the UK. These education sessions consisted of guidance on advanced care planning for care	Unknown/unclear study design using questionnaires: 250 staff were trained, of which 124 and 90 completed pre- and post-education evaluation questionnaires respectively. Quality: Unclear based on unknown study design.	It was hypothesised that combining education for care home staff and advance care planning for care home residents with dementia would reduce unnecessary admissions at the EoL and improve staff confidence and knowledge.	This service was implemented in an urban setting where proximity between care homes and acute hospital may favour high admission rates. The reduction observed here might	Nursing home staff were motivated and more confident delivering EoLC following the intervention.	There were improvements in staff confidence in recognition, prevention, management and knowledge of factors associated with delirium and dysphagia. 92% of carers rated the service >9/10. Admissions fell by 37% from baseline in the first year.

	home residents with dementia.			not occur in areas with care homes with lower hospital admission rates, such as rural areas		
Hall et al. (2011) UK Objectives: To explore the perceived benefits of, and barriers to, implementation of the Gold Standards Framework for Care Homes (GSFCH).	Setting: Nine nursing homes. Sample: nursing home staff Intervention: The intervention was the GSFCH. Specifically the 7Cs: communication, coordination, control of symptoms, continuity, continued learning, carer support, and care of the dying.	Qualitative design using semi structured interviews with 9 care home managers, 8 nurses and 9 care assistants, 11 residents and 7 family members. Quality: 18/20	It was hypothesised that the GSFCH would improve EoLC by enhancing communication, increase staff confidence and knowledge and improve symptom control.	Limited resources may result in some aspects of end of life care, such as after death care for staff and families, receiving less attention.	Some staff appeared unwilling/lacking the confidence and knowledge to discuss death and dying as they did not want to upset residents and relatives.	Perceived benefits of the GSFCH included: improved symptom control and team communication; finding helpful external support and expertise; increasing staff confidence; fostering residents' choice; and boosting the reputation of the home .
Hewison, Badger and Swani (2011)	Setting: 22 nursing homes.	Unknown/unclear study design. A brief questionnaire was sent to the participants /	It was hypothesised that	Only 8 participants attended two or more	No data on agency was found.	More consistent use of care plans, increased involvement of clients and their

<p>UK</p> <p>Objectives: To evaluate the impact of the managerial meetings using action learning on EoLC.</p>	<p>Sample: nursing home managers</p> <p>Intervention: The managers of the 22 nursing homes in the local health-care area were invited to participate in four meetings over an eight-month period.</p>	<p>During the Action learning meetings, notes were taken of the discussions that took place.</p> <p>Quality: Unclear based on unknown study design.</p>		<p>meetings as the intervention required too much time.</p>		<p>families in planning end-of-life care, more training for staff.</p>
<p>Hickman et al. (2016)</p> <p>USA</p> <p>Objectives: To describe processes and preliminary outcomes from the implementation of a systematic advance care planning (ACP) intervention in the nursing home setting.</p>	<p>Setting: 19 nursing homes.</p> <p>Sample: nursing home staff/ Residents</p> <p>Intervention: ACP conversations were conducted with residents, families, and the legal representatives of incapacitated residents using a structured ACP interview guide with the goal of</p>	<p>A quantitative design. ACP documentation, and the audit data were analysed using descriptive statistics.</p> <p>Quality: 18/22</p>	<p>It was hypothesised that implementation of an intensive ACP intervention would reduce avoidable hospitalizations of long-stay residents in 19 nursing homes.</p>	<p>nursing home staff who add ACP to their existing roles with minimal to no additional training, lack dedicated time, and do not receive up-front implementation support</p>	<p>It was found that registered nurses were motivated engaging in ACP</p>	<p>During the initial implementation phase, 27% (731/2,709) of residents had participated in one or more ACP conversations with a project nurse, resulting in a change in documented treatment preferences for 69% (504/731). The most common change (87%) was the generation of a Physician Orders for Scope of Treatment form. The most frequently reported</p>

	offering ACP to all residents.					barrier to ACP was lack of time.
Hockley et al. (2005) UK Objectives: To promote quality end-of-life care in eight nursing.	Setting: Eight nursing home Sample: Intervention: action learning as part of the facilitation to improve the critical reflection on issues of concern ¹⁶ when implementing an integrated care pathway (ICP) for the last days of life.	A qualitative design Focus groups and field notes were used to evaluate the intervention Quality: 15/20	It was hypothesised using action learning would empower staff in the practice of quality end-of-life care, and promote sustainable development of end-of-life care once the study finished.	It was an uphill a struggle for many of the trained staff to get their GPs involved in the study, and to prescribe for end-of-life care.	A covert culture surrounding death and dying was found in the majority of the nursing homes	greater 'openness' around death and dying; recognising dying and taking responsibility; better 'teamwork'; critically using palliative care knowledge to influence practice; more meaningful communication.
Watson et al. (2010)	Setting: Seven nursing homes.	Qualitative design using semi-structured interviews with 22 bereaved	It was hypothesised that implementing the GSFCH and the LCP would improve EoLC in	The project's time limitations and the fact	No data on agency was found.	Care home staff changed their attitudes about dying. This enabled more

<p>UK</p> <p>Objectives: To compare the effectiveness of the GSFCH and the LCP in nursing homes.</p>	<p>Sample:</p> <p>Intervention: Two EoLC interventions were implemented in the care homes, namely, the Gold Standards Framework for Care Homes (GSFCH) and an adapted Liverpool Care Pathway for Care Homes (LCP). A model of high facilitation, visiting the homes every 10–14 days with significant in-house staff training, was used to implement the 18-month programme.</p>	<p>relatives/friends before, and 14 bereaved relatives/friends and six care home managers after.</p> <p>Quality: 16/20</p>	<p>care home by equipping care home staff with the knowledge and skills to more effectively deliver EoLC.</p>	<p>that the qualitative evaluator only worked one day a week on it meant that telephone interviews were easier to arrange within the busy schedules of the home managers.</p>		<p>informed end-of-life decision-making involving families/friends, staff and GPs.</p>
<p>Keay et al. (2003)</p> <p>USA</p>	<p>Setting: Five nursing homes.</p> <p>Sample: Nursing home staff</p> <p>Intervention: Half-day adult</p>	<p>A mixed method design using qualitative, pre educational program survey and quantitative analysis of audit data to determine place of</p>	<p>It was hypothesised that the education programme would improve the quality of dying for nursing home residents by increasing staff knowledge and</p>	<p>Participants were targeted with letters and telephone calls, and</p>	<p>No data on agency was found.</p>	<p>No statistically significant changes were found in regard to Chart documentation of recognition of possible death, presence of</p>

Objectives: To determine if an educational intervention improves the quality of EoLC in nursing homes.	educational outreach program, including audit and feedback, targeted at opinion leaders, and quality improvement suggestions	deaths and ACP documentation. Quality: 17/20 19/22	confidence in areas such as documentation.	scheduling the educational intervention at a time convenient for them.		advance directives, pain control, analgesics used, dyspnoea control, control of uncomfortable symptoms during the dying process, documented hygiene, documented bereavement support, and total patient comfort
Kinley et al. (2014) UK Objectives: To evaluate the effects of implementing high facilitation intervention when implementing the GSF.	Setting: 24 nursing homes. Sample: case notes Intervention: Intervention consisted of implementing action learning alongside high facilitation when implementing the GSFCH.	Randomised Controlled Trial 24 nursing homes received high facilitation to enable them to implement the Gold Standards Framework for Care Homes programme. The managers of 12 nursing homes additionally took part in action learning sets. A third group (14 nursing homes) received the 'standard' Gold Standards Framework for Care Homes facilitation	It was hypothesised that action learning alongside high facilitation when implementing the Gold Standards Framework for Care Homes programme will result in an improvement in the care home staff ability to facilitate good EoLC.	Commitment to such a group for nurse managers who already appear to have multiple roles is challenging.	Managers were motivated and attendance to meetings was high.	A greater proportion of residents died in those nursing homes receiving high facilitation and action learning alongside implementing to GSFCH but not significantly so.

		available in their locality. Examination of 2,444 case notes Quality: 20/22				
Kinley et al. (2017) UK Objectives: To describe the implementation of an EoLC programme.	Setting: 23 residential homes. Sample: Audit data from case home residents Intervention: To implement an end-of-life care programme, namely the 'Steps to Success' programme, in residential care homes.	A quantitative design. Measurable outcomes were collected through audit. Number of care home deaths and number of advance care plan discussions and completion of 'do not attempt cardiopulmonary resuscitation' forms. Quality: 20/24	It was hypothesized that that the 'Steps to Success' programme, would empower and enable staff in residential care homes to embed a framework to meet their residents EoLC needs	It was found that ongoing education was better at sustaining outcomes in care home with a high staff turnover.	Residential care home staff had increased confidence to care for dying residents in the residential care home setting.	Over four years audit of all deceased residents' records in the participating homes was collected. This shows an increase of home deaths in 2011/12 to 2014/15 from 44% (n=8/18) within four residential care homes to 64% (n=74/115) in 23 residential care homes with corresponding increase in advance care plan discussions and completion of 'do not attempt cardiopulmonary resuscitation' forms.

<p>Kunte et al. (2017)</p> <p>USA</p> <p>Objectives: To examine whether improvement in EoL knowledge increases the rates of completed advanced care plans.</p>	<p>Setting: Two nursing homes.</p> <p>Sample: nursing home staff</p> <p>Intervention: Nursing staff at each site received 3 weekly 30-minute education sessions. The first 2 sessions, which were held separately for the nurses and the nursing assistants. The third session was a combined nurses and assistants session and included a role play on communication at EOL.</p>	<p>Unknown/unclear study design. Pre-education and post education, knowledge of nursing staff was assessed (using 109-item multiple-choice test) and records of 139 residents were examined for advance directives and hospital transfers.</p> <p>Quality: Unclear based on unknown study design.</p>	<p>It was hypothesised that improvement in EoLC knowledge of nursing home staff, especially nursing assistants, increases the rate of advance directives and decreases the rate of their hospital transfers.</p>	<p>No explicit or implicit data on contextual mechanisms was found.</p>	<p>Included both nurses and care assistants</p>	<p>EOL knowledge of nursing assistants showed greater improvement than that of nurses; all nursing staff rated their knowledge higher. Documentation of resident EOL preferences improved minimally, but the rate of transfers to the hospitals was dramatically reduced.</p>
<p>Letizia and Jones (2012)</p> <p>USA</p>	<p>Setting: nursing homes</p> <p>Sample: 99 nurse practitioners</p> <p>Intervention: An education intervention was</p>	<p>Unknown/unclear study design using Questionnaires and evaluation forms to evaluate the effectiveness of the intervention pre and post-test.</p>	<p>It was hypothesised that three online learning modules would lead to improvements in knowledge</p>	<p>Attendance rates were high to the education sessions as they were online and could be</p>	<p>Nursing home staff were extremely positive towards the intervention.</p>	<p>Statistically significant difference in the mean pre-test and post test scores indicated significant learning gains among the participants. Reported level of confidence in</p>

Objectives: To develop and deliver three learning modules.	implemented. This educational project was based on the well-established End-of-Life Nursing Education Consortium curriculum.	Quality: Unclear based on unknown study design.		accessed flexible despite high workloads of staff.		providing palliative care increased from the beginning to the end of the program.
Livingston et al. (2013) UK Objective: To improve EoLC for people with dementia living in nursing homes by increasing the amount of advanced care plans.	Setting: One nursing home. Sample: nursing home staff, residents and relatives Intervention: The intervention was a ten-session manualized, interactive staff training program. We compared advance care wish	Non-Randomised Study. compared advance care wishes documentation and implementation, place of death for residents who died, and themes from staff and family carers' after-death interviews pre- and post-intervention. Quality: 19/24	It was hypothesised training for nursing home staff would improve their knowledge and ability to deliver EoLC increasing ACP and decreasing unnecessary admissions to hospital.	The intervention was only implemented in one home thus more work is needed to assess impact in diverse contexts.	Staff members were confident about end-of-life planning and implementing advanced wishes	Increases in documented advance care wishes arising from residents' and relatives' discussions with staff about end-of-life.

	<p>es documentation and implementation, place of death for residents who died, and themes from staff and family carers' after-death interviews pre- and post-intervention.</p>					
<p>Mayrhofer et al. (2016)</p> <p>UK</p> <p>Objective: To evaluate the feasibility of using a train the trainer (TTT) model to support EoL care in care homes.</p>	<p>Setting: 18 nursing homes.</p> <p>Sample: nursing and residential care home staff and residents</p> <p>Intervention: Thirty six care home staff, who had completed ABC training, were selected to be 'trainers' in EoL care. The trainers then cascaded knowledge to the wider workforce.</p>	<p>Unknown/unclear study design using: review of care home residents' characteristics and service use ($n = 274$), decedents' notes ($n = 150$), staff interviews ($n = 49$), focus groups ($n = 3$), audio diaries ($n = 28$) and observations of workshops ($n = 3$).</p> <p>Quality: the qualitative element of study was scored 17/20.</p>	<p>It was hypothesised that the trainer could train care home staff to improve their knowledge and confidence when delivering EoLC.</p>	<p>The ability to incorporate the trainer's role into the existing work schedule also had an impact on the uptake of the intervention. Staff often had to create time to carry out training within the</p>	<p>Strong management and leadership in individuals was found to promote the intervention.</p>	<p>positive association between care home stability, in terms of leadership and staff turnover, and uptake of the programme. Care home ownership, type of care home, size of care home, previous training in EoL care and resident characteristics were not associated with programme completion. Working with facilitators was important to trainers, but insufficient to compensate for</p>

				<p>specified timeframe.</p> <p>In six of the care homes the manager left whilst the EoL care intervention was implemented.</p>		<p>organisational turbulence. Variability of uptake was also linked to management support, programme fit with the trainers' roles and responsibilities and their opportunities to work with staff on a daily basis.</p>
<p>McGlade et al. (2017)</p> <p>UK</p> <p>Objective: To identify challenges in</p>	<p>Setting: Two nursing homes and one community hospital.</p> <p>Sample: nursing and residential care home staff</p>	<p>A feasibility study with unknown/unclear descriptions of methods used.</p>	<p>It was hypothesised that providing staff education on advanced care planning would improve completion of advanced care plans.</p>	<p>The considerable logistical challenge of releasing staff for training triggered development of an e-</p>	<p>No data was found on agency.</p>	<p>Over 50% of all residents had completed some form of end-of-life care plan. Of the 70 residents who died in the post-implementation period, 14% had no care plan, 10% (with</p>

<p>implementing an advance care planning programme.</p>	<p>Intervention: This feasibility study had two phases: (1) staff education on advance care planning and (2) structured advance care planning by staff with residents and families.</p>	<p>Quality: Unclear based on unknown study design.</p>		<p>learning programme to facilitate training.</p>		<p>capacity) completed an advance care directive and lacking such capacity, 76% had an end-of-life care plan completed for them by the medical team, following discussions with the resident (if able) and family.</p>
<p>Nash and Fitzpatrick (2015)</p> <p>UK</p> <p>Objectives: To explore and describe the implementation of the Gold Standards Framework (GSF) in nursing homes.</p>	<p>Setting: Three nursing homes.</p> <p>Sample: nursing home staff</p> <p>Intervention: A qualitative descriptive study was conducted with three purposively selected nursing care homes in London. All had implemented the Gold Standards</p>	<p>A qualitative design. Interviews with care home managers (n=3) and in each home, a focus group was conducted with registered nurses (RNs) and health-care assistants (HCAs): focus group 1, n=2 RN, n=2 HCA; focus group 2, n=2 RN, n=3 HCA; focus group 3, n=3 RN, n=3 HCA.</p> <p>Quality: 15/20</p>	<p>It was hypothesised that GSFCH would improve EoLC by enhancing staff confidence and knowledge.</p>	<p>More ongoing support and development to help embed the key tenets of the GSFCH in the culture of caring.</p>	<p>There was a positive regard for the GSFCH from nursing home staff.</p>	<p>RNs, HCAs and managers regarded the training and support afforded by the GSFCH programme to inform EoLC for older residents positively.</p>

	Framework programme.					
O'Brien et al. (2016) UK Objectives: To obtain a detailed account of the impact of Six Steps intervention on care homes.	Setting: Residential and nursing homes Sample: Residential and nursing home staff Intervention: Evaluation of <i>Six Steps</i> with the first cohort of care homes, the <i>Six Steps</i> programme has a workshop format addressing the core phases of EoLC within a six-stage cycle.	The study employed qualitative design using online questionnaire with facilitators (n = 16), interviews with facilitators (n = 9) and case studies of care homes that had completed the programme (n = 6). Quality: 17/20	It was hypothesised that delivering education to champions who would then cascade their knowledge to the wider workforce would improve knowledge thus EoLC.	The programme was flexibly designed so that it could be individually tailored to the geographical location and the individual cohort requirements. Lack of time allocated to champions to devote to additional programme work, sickness/high staff turnover presented	Inappropriate staff selected as 'Champions' and staff who lacked confidence and skills to disseminate knowledge to the wider workforce.	improvement in Advance Care Planning, improved staff communication/confidence when dealing with multi-disciplinary teams, improved end-of-life processes/documentation and increased staff confidence through acquisition of new knowledge and new processes

				challenges to embedding programme values.		
O'Sullivan et al. (2016) Ireland Objectives: To assess the economic impact (gross savings) of the Let Me Decide programme.	Setting: Three nursing homes. Sample: Nursing home staff Intervention: 90 staff were trained in a palliative care educational programme.	A quantitative study design using Economic (gross cost) analysis of systematically implementing a programme of advance care planning. Quality: 15/22	It was hypothesised that providing EoLC education on advanced care planning would facilitate more ACP to be completed.	Gross costs were reduced and scenario analysis projected large annual savings if These results were extrapolated to the wider population.	No data on agency was found.	The uptake of an ACD or end-of-life care post-implementation rose from 25 to 76%. Post implementation, there were statistically significant decreases in hospitalisation rates from baseline (hospitalisation incidents declined from 27.8 to 14.6%, $z=3.96$, $p<0.001$; inpatient hospital days reduced from 0.54 to 0.36%, $z=8.85$, $p<0.001$).
Parks et al. (2005) USA Objectives: To determine if an	Setting: One nursing home. Sample: nursing home staff, social workers,	Unknown/ unclear study design. Thirty-two nursing home staff completed the pre-intervention questionnaires. Twenty-nine nursing home staff completed the post-	It was hypothesised that a staff educational program on end-of-life care for dementia residents can improve end-of-life	Lectures were delivered in service so care home staff did not have to travel	The attitudes of staff towards residents with dementia improved	There was a significant change in the end-of-life knowledge level of the ancillary staff ($P=.0270$). Specifically, there was a significant change in one question dealing with

<p>educational program can improve knowledge and attitude among ancillary staff on EoLC issues in a nursing home.</p>	<p>recreational therapists</p> <p>Intervention: The intervention was a novel educational program consisting of five in-service lectures with accompanying take home self-study modules for ancillary staff in long-term care entitled Dignity in Dementia.</p>	<p>intervention questionnaires (90.6%).</p> <p>Quality: Unclear based on unknown study design.</p>	<p>knowledge and attitudes.</p>	<p>increasing attendance.</p>	<p>after education.</p>	<p>dementia as a terminal disease (P = .006). There were also significant changes in the average attitude scores of the ancillary staff. (P = .0242). One-year follow-up revealed that both knowledge and attitude changes were maintained.</p>
<p>Smith and Brown (2017)</p> <p>UK</p> <p>Objectives: To describe an intervention aimed at supporting staff in nursing care homes for older people to deliver high-quality EoLC.</p>	<p>Setting: three nursing homes</p> <p>Sample: nursing home staff</p> <p>Intervention: The nursing home facilitator and a member of the nursing staff on each unit within each home met on a monthly basis to review the register and assess the</p>	<p>Unknown/unclear study design. Analysis of residents' notes to determine place of death.</p> <p>Quality: Unclear based on unknown study design.</p>	<p>It was anticipated that this proactive approach to care at the end of life would reduce unnecessary crisis admissions to hospital and enable more people to die in their usual place of residence</p>	<p>The nursing home facilitator visited the nursing home every 2 weeks and spent some time working alongside staff, which enabled her to 'walk in the steps' of the staff and gain insight</p>	<p>trusting relationships that had been created</p>	<p>The 25% reduction in hospital deaths equates to a cost saving of £38000. If the results are replicated across the remainder of the homes in the Borough, cost savings could near £500000.</p>

	resident's prognosis. The registers were also reviewed on ward rounds with the GP responsible for the residents on each unit.			into the challenges they faced in delivering quality end-of-life care		
Temkin-Greener et al. (2017) USA Objectives: To examine the efficacy of nursing home -based integrated	Setting: 31 nursing homes. Sample: administrators, directors of nursing, nurses, nursing aides, and social workers. Intervention: facility-level	Randomised controlled trial The Minimum Data Set, vital status files, staff surveys, and in-depth interviews were employed. For each outcome, a difference-in-difference model	It was hypothesised that providing palliative and EOL geriatric training would improve staffs' knowledge and skills and reduce in hospital deaths.	Because of high staff turnover the pre-post intervention assessments of care processes were most likely completed	No data was found on agency.	No statistically significant effect of the intervention. However care homes with working teams had significant reductions in the odds of in-hospital death compared to the other treatment [odds ratio (OR), 0.400; P<0.001),

<p>palliative care teams in improving the quality of EoLC.</p>	<p>intervention involving a multicomponent strategy that included implementing facility based palliative care teams and providing staff with palliative and EOL geriatric training.</p>	<p>compared the pre-post intervention periods using logistic and Poisson regressions.</p> <p>Quality: 19/22</p>		<p>by different individuals.</p>		<p>control (OR, 0.482; P<0.05), and nonrandomized control NHs (0.581; P<0.01).</p>
<p>Thulesius et al. (2002)</p> <p>Sweden</p> <p>Objectives: To evaluate a 1-year learner-centred educational project in EoLC for home care staff in a rural district of Sweden.</p>	<p>Setting: Nursing homes in two districts.</p> <p>Sample: nurses, physiotherapists, assistant nurses, and caring assistants.</p> <p>Intervention: Learner centered education was provided</p>	<p>Unknown/unclear study design using the Hospital Anxiety and Depression (HAD) scale to measure mental wellbeing. <i>pre-intervention</i> questionnaires (n=272) and post intervention (n=187)</p> <p>Quality: Unclear based on unknown study design.</p>	<p>It was hypothesised that a comprehensive educational programme not only improved attitudes towards end-of-life care, but also the mental well-being of the home care staff.</p>	<p>There was no difference in turnover of home care staffing during the studied period in the two districts.</p>	<p>No data was found on agency.</p>	<p>The total HAD score decreased from 8.3 pre-test to 5.3 post-test in the education group (95% CI=2.1–3.7; P<0.001), and was 6.8 for both years in the control group.</p>
<p>Waldron et al. (2008)</p>	<p>Setting: Nursing homes</p>	<p>Unknown/unclear study design using (n=31) questionnaires</p>	<p>It was hypothesised that EOLC education cascaded by designated nursing home staff</p>	<p>Many respondents had not commenced</p>	<p>There was a high satisfaction with course</p>	<p>There was a high satisfaction with course content, facilitation and</p>

<p>UK</p> <p>Objectives: To assess the palliative care education received and consequently cascaded by designated nursing home staff.</p>	<p>Sample: nursing home staff and link nurses</p> <p>Intervention: 33 nursing homes took up an initial training opportunity to develop and enhance their care staff's knowledge and delivery of palliative care. A palliative care education facilitator coordinated and delivered in-house teaching to link nurses, in central venues, who in turn could deliver the training to other staff.</p>	<p>completed by link nurses.</p> <p>Quality: Unclear based on unknown study design.</p>	<p>would enhance the wider workforces' knowledge and confidence when delivering EoLC.</p>	<p>cascading training within their nursing homes due to lack of time.</p>	<p>content and staff were motivated to deliver high quality EoLC.</p> <p>Ongoing support is needed to support less confident staff to cascade information to their colleagues.</p>	<p>benefits accrued from participation. Many respondents (83%) had not commenced cascading training within their nursing homes due to lack of time and competing mandatory demands.</p>
<p>Wen et al. (2012)</p> <p>USA</p>	<p>Setting: Five nursing homes</p> <p>Sample: Nursing home staff</p>	<p>A qualitative design using Questionnaires completed before and after the educational series to evaluate</p>	<p>It was hypothesised that nursing staff who attended the lectures would be better able to apply their palliative care skills in practice.</p>	<p>Limited time of staff to engage in the intervention on top of</p>	<p>Nursing home staff were motivated and engaged</p>	<p>Nursing home staff reported applying palliative care skills significantly more frequently after the intervention. A</p>

<p>Objectives: To examine nursing home staff perceptions of EoLC skills after an educational intervention.</p>	<p>Intervention: The intervention consisted of six lectures on core palliative care concepts for frontline nursing home staff at five community nursing homes.</p>	<p>frequency of application of palliative care skills.</p> <p>Quality: 18/20</p>		<p>existing work schedules.</p>	<p>with the intervention.</p>	<p>significant dose-response association was noted between number of in-service sessions attended and improvement in scores: Scores increased 0.04 points for staff who attended two of the six sessions, 0.12 for four sessions attended, and 0.46 for five to six sessions attended ($p = 0.03$).</p>
<p>Kinley et al. (2018)</p> <p>UK</p> <p>Objectives: To identify the type, role, impact and cost of facilitation when implementing the GSFCH programme.</p>	<p>Setting: 38 nursing homes</p> <p>Sample: nursing home staff</p> <p>Intervention: Staff from 38 nursing care homes undertaking the GSFCH programme. Staff in 24 nursing care homes received high facilitation. Of those, 12 also received action learning. The remaining 14</p>	<p>A mixed method study design using semi-structured interviews, surveys and activity logs.</p> <p>Quality: 17/20 19/22</p>	<p>It was hypothesised that using high facilitation methods would better support care home to implement and sustain the GSFCH.</p>	<p>The cost savings in the study outweighed the cost of providing a 'being present' approach to facilitation.</p>	<p>Without mastery and commitment, from all participants, including the external facilitator, learning and initiation of change failed to occur.</p>	<p>Different types of facilitation are offered to support the implementation of end-of-life care initiatives. However, in this study 'being present' facilitation, when supported by multi-layered learning, was the only approach that initiated the change required.</p>

	nursing care homes received usual local facilitation of the GSFCH programme.					
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Appendix 5: Example interview schedule

Date: 01/12/2017

Version number: version 2

[Headed Paper]

IRAS: 233729

Interview Schedule – Bereaved relatives

Title of research: End of Life Care in Care Homes

Preamble:

- Greet participant and introduce self.
- Introduction to the study explaining why you have been invited and what the results will be used for.
- Written consent will be checked and verbal consent is necessary as the interview will be recorded with your permission as outlined in the participant information sheets and consent form.
- Each interview should only take 30-45 minutes. However the interview may go on as long as you want if you have more to add.
- There are no wrong or right answers and do not feel constrained by the topics.
- Answers are voluntary, you do not have to answer a question or engage in a topic if you do not want to.
- If you feel you need a break or want the interview to stop then just let me know.
- Have you any questions before we start?

Interview questions;

Q1: Can you tell me a little bit about yourself? (For example, your connection to your loved one)

Q2: I am interested in finding out about care for you and your loved one in the last months of life so that we can learn from best practice and look at how things can be better. Can you tell me something about your experiences at that time?

Gently take the person through from when they knew their relative wasn't getting better or from admission to the home (if necessary) to death and after.

Possible prompts (if needed):

Able to visit when they wanted?

Communication with care staff?

Knew what was going on?

Involvement in care planning (and giving)?

How they were supported?

Q3: What do the terms end of life care and palliative care mean to you?

Prompts: Were these terms used in your experience? Tell me about that?

Q4: Thinking back on your experiences, in your opinion did anything get in the way of making your relatives care as good as you would have liked at the end of their life? Examples...

Q5: Please tell me about what sort of things made their care at end of life really good.
Examples...

Q6: If anything, what do you think should be done to improve the delivery of end of life care for you and your loved one?

Q7: Is there anything else you would like to add or any questions they would like to ask?

Ending the interview:

- Is there anything else you would like to say about the topic that we have not covered already?
- Thank you for your contribution

Research Team Contact Details:

Adam Spacey Post Graduate Research student (PhD) Bournemouth University Royal London House Bournemouth BH1 3LT Email: aspacey@bournemouth.ac.uk Tel: 07986 635716	Sam Porter Professor of Nursing Sociology Head of Department of Social Sciences and Social Work Bournemouth University Royal London House R203 Bournemouth BH1 3LT Email: Porters@bournemouth.ac.uk Tel: (0044) 1202 964107
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If you have a concern about any aspect of this study and wish to complain, please contact:

Prof V. Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Care, Bournemouth University. Email: researchgovernance@bournemouth.ac.uk

Appendix 6: NHS ethical approval



**Health Research
Authority**

London - Camberwell St Giles Research Ethics Committee

Level 3, Block B

Whitefriars

Lewins Mead

Bristol

BS1 2NT

Telephone: 02071048044

15 January 2018

Mr Adam Spacey
8 Oak Tree Grove Stockton TS185NG
Stockton
TS185NG

Dear Mr Spacey

Study title:	A Critical Realist Evaluation of End of Life Care in Care Homes.
REC reference:	17/LO/1828
Protocol number:	n/a
IRAS project ID:	233729

Thank you for your reply on the 4th January 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Invitation letter]	version 3	04 January 2018
Copies of advertisement materials for research participants [Invitation letter]	version 3	04 January 2018
Covering letter on headed paper [Cover letter]		
Covering letter on headed paper [Cover letter]	Version 1	11 October 2017

Covering letter on headed paper [Cover letter - written clarification]	version 2	01 December 2017
Covering letter on headed paper [Cover letter - written clarification]	version 3	04 January 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity letter]	Version 1	11 October 2017
Interview schedules or topic guides for participants [Indicative interview schedule - for CI]	Version 1	11 October 2017
Interview schedules or topic guides for participants [Indicative interview schedule - for CI]	Version 1	11 October 2017
Interview schedules or topic guides for participants [Indicative interview schedule - for CI (focus groups)]	Version 1	11 October 2017
Interview schedules or topic guides for participants [Revised interview schedule - bereaved relatives]	version 2	01 December 2017
Interview schedules or topic guides for participants [revised interview schedule - home managers]	version 2	01 December 2017
Interview schedules or topic guides for participants [revised interview schedule care home staff]	version 2	01 December 2017
IRAS Checklist XML [Checklist_04012018]		04 January 2018
Letter from funder		
Letter from funder [Letter from Sponsor]	Version 1	11 October 2017

Letter from sponsor		
Letter from sponsor [Letter from Sponsor]	Version 1	11 October 2017
Letter from statistician		
Letter from statistician [Indemnity letter]	Version 1	11 October 2017
Letters of invitation to participant [Invitation letter]	version 3	04 January 2018
Letters of invitation to participant [Invitation letter]	version 3	04 January 2018
Other [Prof Sam Porter CV]	Version 1	11 October 2017
Other [Dr Janet Scammell CV]	Version 1	11 October 2017
Other [Dr Michele Board CV]	Version 1	11 October 2017
Other [Cover letter - written clarification]	version 2	01 December 2017
Other [Written clarifications version 3]	version 3	04 January 2018
Participant consent form [Revised consent form]	version 2	01 December 2017
Participant information sheet (PIS) [Participant information sheets]	version 3	04 January 2018
Participant information sheet (PIS) [Participant information sheets]	version 3	04 January 2018
Participant information sheet (PIS) [Participant information sheets]	version 3	04 January 2018
REC Application Form [SC_Form_30102017]		30 October 2017
Research protocol or project proposal [Full Ethics Protocol]	Version 1	11 October 2017
Summary CV for Chief Investigator (CI) [CVs for CI and supervisory team]	Version 1	11 October 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flow diagram of study]	Version 1	11 October 2017

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.

Appendix 7: Invitation letters for bereaved relatives

Date: 11/10/2017

Version number: version 3

[Headed paper]

IRAS: 233729

Adam Spacey
Post Graduate Research student (PhD)
Bournemouth University
Royal London House
Bournemouth BH1 3LT
Email: aspacey@bournemouth.ac.uk
Tel: 07986 635716

Study title: A Critical Realist Evaluation of End of Life Care in Care Homes.

Invitation to participate in the study

Dear, (Bereaved relative)

We would like to invite you to participate in a research project exploring end of life care in care home settings. We are a small team of nurse researchers supervising a PhD student (Adam Spacey) who is completing this research at Bournemouth University. You have been invited to take part because we feel it is important to include the views of bereaved relatives in our investigation of end of life care in care homes. This will enable us to evaluate how EoL care is carried out in different contexts from different perspectives. We have outlined below some more information about the project. If after reading this, you would be interested in participating and would like more information please let us know so that we can arrange to meet with you to discuss in person.

What will happen if I decide to take part?

Adam Spacey the chief investigator will arrange a mutually convenient time to visit you in your home to interview you to discuss your recent experiences end of life care in a care home. Or if you prefer, we can arrange the meeting to take place at the university. If you agree we would like to return and interview you again to discuss our findings with you. Each interview should take no longer than 30-45 minutes. With your permission, the interview will be audio recorded for transcription purposes. All the written transcripts will be anonymised and kept confidential, and the recordings destroyed.

In phase one, the interview will explore your experiences of end of life care from the perspective of a relative. There are no right or wrong answers; we are just interested in your views. We will ask you about topics that seem to be important to others as determined from our search of the literature on this topic.

After phase one we would like to return to discuss our findings with you (phase two). The purpose of phase two is to test our findings allowing you to refine what we conclude based your personal experiences of end of life care in the care home.

Purpose of the study

The study will explore current practices in the care home sector to identify the barriers to and opportunities for the provision of appropriate end of life care. It is hoped that the study will disseminate knowledge about factors that tend to inhibit or support effective end of life care in care homes. This will allow us to provide care homes, community care and acute services insight into the factors which are likely to inhibit or promote successful end of life care in care homes. Additionally, the findings will then be incorporated to form interventions and procedural recommendations designed to take account of the social, organisational and economic context within which care homes operate.

If you choose to take part in the study, please contact the chief investigator Adam Spacey (email: aspacey@bournemouth.ac.uk) to discuss your participation further.

If you require further information regarding the study or wish to ask any questions please do not hesitate to contact Adam Spacey and Professor Sam Porter, contact details are provided below.

Thank you for taking the time to read this letter of invitation.

Research Team Contact Details:

<p>Adam Spacey Post Graduate Research student (PhD) Bournemouth University Royal London House Bournemouth BH1 3LT Email: aspacey@bournemouth.ac.uk Tel: 07986 635716</p>	<p>Sam Porter Professor of Nursing Sociology Head of Department of Social Sciences and Social Work Bournemouth University Royal London House R203 Bournemouth BH1 3LT Email: Porters@bournemouth.ac.uk Tel: (0044) 1202 964107</p>
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If you have a concern about any aspect of this study and wish to complain, please contact:

Prof V. Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Care, Bournemouth University. Email: researchgovernance@bournemouth.ac.uk

Appendix 8: Invitation letter for care home staff

Date: 11/10/2017

Version number: version 3

[Headed paper]

IRAS: 233729

Adam Spacey
Post Graduate Research student (PhD)
Bournemouth University
Royal London House
Bournemouth BH1 3LT
Email: aspacey@bournemouth.ac.uk
Tel: 07986 635716

Study title: A Critical Realist Evaluation of End of Life Care in Care Homes.

Invitation to participate in the study

Dear, care home staff

We would like to invite you to participate in a research project exploring end of life care in care home settings. We are a small team of nurse researchers supervising a PhD student (Adam Spacey) who is completing this research at Bournemouth University. We wish to work with those in the care home sector and look at current practice in end of life care.

You have been chosen to take part because we feel it is important to include the views of care home managers in our investigation of end of life care in care homes. This will enable us to evaluate how EoL care is carried out in different contexts from different perspectives. We have outlined below some more information about the project. If after reading this you would be interested in participating and would like more information please let us know so that we can arrange to meet with you to discuss in person.

What will happen if I decide to take part?

Adam Spacey the chief investigator will arrange a time to visit you in the care home convenient to you to discuss your experiences of end of life care in a care home. If you agree we would like to return and interview you again to discuss our findings with you. Each interview should take no longer than 30-45 minutes. With your permission, the interview will be audio recorded for transcription purposes. All the written transcripts will be anonymised and kept confidential, and the recordings destroyed.

In phase one, the interview will explore your experiences of end of life care from the perspective of a care home manager. There are no right or wrong answers; we are just interested in your views. We will ask you about topics that seem to be important to others as determined from our search of the literature on this topic.

After phase one we would like to return to discuss our findings with you (phase two). The purpose of phase two is to test our findings allowing you to refine what we conclude based your personal experiences of end of delving life care in the care home.

Purpose of the study

The study will explore current practices in the care home sector to identify the barriers to and opportunities for the provision of appropriate end of life care. It is hoped that the study will disseminate knowledge about factors that tend to inhibit or support effective end of life care in care homes. This will allow us to provide care homes, community care and acute services insight into the factors which are likely to inhibit or promote successful end of life care in care homes. Additionally, the findings will then be incorporated to form interventions and procedural recommendations designed to take account of the social, organisational and economic context within which care homes operate.

If you choose to take part in the study please contact the chief investigator Adam Spacey (email: aspacey@bournemouth.ac.uk) to discuss your participation further.

If you require further information regarding the study or wish to ask any questions please do not hesitate to contact Adam Spacey and Professor Sam Porter, contact details are provided below.

Thank you for taking the time to read this letter of invitation.

Research Team Contact Details:

<p>Adam Spacey Post Graduate Research student (PhD) Bournemouth University Royal London House Bournemouth BH1 3LT Email: aspacey@bournemouth.ac.uk Tel: 07986 635716</p>	<p>Sam Porter Professor of Nursing Sociology Head of Department of Social Sciences and Social Work Bournemouth University Royal London House R203 Bournemouth BH1 3LT Email: Porters@bournemouth.ac.uk Tel: (0044) 1202 964107</p>
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If you have a concern about any aspect of this study and wish to complain, please contact:

Prof V. Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Care, Bournemouth University. Email: researchgovernance@bournemouth.ac.uk

Appendix 9: Participant information sheets for bereaved relatives

Date: 04/01/2018

Version number: version 3

[Headed paper]

IRAS: 233729

Participant information Sheet – Bereaved Relatives

This study is being carried as part of a PhD degree that the chief investigator, Adam Spacey, is doing. He is being supervised by a small team of researchers at Bournemouth University. We are working with a group of care homes who have invited us to explore care at the end of life. Below we have outlined the proposed project in more detail. If after reading this, you are interested in participating, please contact Adam Spacey (**phone:** 07986 635716 or **email:** aspacey@bournemouth.ac.uk), the chief investigator; additional contact details can be found at the end of this document.

Title of study:

Title: End of Life Care in Care homes.

Purpose of the study

We would like to have a discussion with you about your experiences of care at the end of life for your relative. We are interested in exploring any aspects of care that you found good and any aspects of care that you think can be improved. It is hoped that this discussion will help inform our study and will provide care homes insight and knowledge into the factors which are likely to promote or inhibit good end of life care.

Why you have been invited

You have been invited because we would like to explore your experiences of care at the end of life for your relative. The home kindly consented to pass on this information to allow you to decide if you would be interested in taking part in the research.

Do I have to take part?

You do not have to take part in the study. It is your choice. Should you choose to participate, you will be asked to sign a consent form prior to the interview(s). You are free to withdraw at any point and, can request that part or all information already collected be destroyed or withheld up until all your personal details (such as your name) have been removed. Your personal details will be removed 1 week following your interview. When all of your personal details have been removed from the information it is not possible to know which specific information belongs to you.

What will happen if I decide to take part?

Adam Spacey the chief investigator will arrange a time to visit you in your home at a time convenient to you. If you prefer we can arrange the meeting to take place at the university. In the interview, we would like to discuss your recent experiences of care at the end of life received by your relative. There are no right or wrong answers; we are just interested in your views.

Following this first interview, we will ask you if you would like to participate in a second optional interview. Again this second optional interview can be arranged at the university or in your home at a time convenient to you. The second interview will be used to share the research findings with you giving you an opportunity to comment should you wish. With your permission, the interview(s) will be audio recorded for transcription purposes.

Each interview should take no longer than 30-45 minutes

Will the information be kept confidential?

The information collected throughout the study will be anonymised, meaning that all personal details such as your name will be removed. Confidentiality will be respected meaning no information will be shared outside of the research team unless you reveal that you are a risk to self and others. You will not be identified in any publications or reports, and the audio recordings will be destroyed. However, it is possible that quotes used in subsequent reports and publications may be recognised, even though all your personal details such as your name will be removed from any quotes used. Additionally, as well as the chief investigator the anonymised information will be shared with the supervisory team.

If at any point you are unable to understand and retain information (lose mental capacity) following the first interview you would not be expected to undertake a second optional interview. However, the research team would retain the information collected and continue to use it confidentially in the study.

What will happen to the results?

They will be compiled in a thesis and may be published in academic Journals, all information presented in these documents will be non-identifiable.

Are there any benefits or disadvantages to taking part?

There is the potential that you may get upset because the interviews will be discussing the sensitive topic of care at the end of life. If you become distressed or upset you will have the opportunity to stop or pause the interview. If necessary you will also be signposted to the relevant support services. One of these services will be '*cruse bereavement care*' (<http://www.cruse.org.uk/>) which is a national charity aimed at supporting bereaved relatives. Cruse bereavement care has been contacted by the researcher and notified about the studies and the potential use of their services. It is hoped that findings from the study will help improve end of life care across the country and internationally in care homes.

PhD Supervisors & Chief investigator

Professor Samuel Porter – Bournemouth University

Dr Janet Scammell – Bournemouth University

Dr Michele Board – Bournemouth University

Adam Spacey – Chief investigator, Bournemouth University

This research study is funded by Bournemouth University.

Thank you for taking the time to read this

A copy of this information sheet will be given to you to keep at the start of the study. You will also be given the chance to read this again and ask questions, before you then sign a consent form to participate in the interviews.

Research Team Contact Details:

If you would like to take part in this research please contact Adam Spacey (**phone:** 07986 635716 or **email:** aspacey@bournemouth.ac.uk), the chief investigator. Supervisor contact details are displayed below.

Samuel Porter Professor of Nursing Sociology Head of Department of Social Sciences and Social Work Bournemouth University Royal London House R203 Bournemouth BH1 3LT Email: Porters@bournemouth.ac.uk Tel: (0044) 1202 964107	Adam Spacey Post Graduate Research student (PhD) Bournemouth University Royal London House Bournemouth BH1 3LT Email: aspacey@bournemouth.ac.uk Tel: 07986 635716
Dr. Janet Scammell, Associate Professor Nursing Research Cluster Lead 01202 962751 jscammell@bournemouth.ac.uk	Dr. Michele Board Principal Academic Nursing Older People Bournemouth University 01202 961786 mboard@bournemouth.ac.uk

If you have a concern about any aspect of this study and wish to complain, please contact:

Prof V. Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Care, Bournemouth University. Email: researchgovernance@bournemouth.ac.uk

Appendix 10: Participant information sheets for care home staff semi-structured interviews

Date: 04/01/2018

Version number: version 3

[Headed paper]

IRAS: 233729

Participant information Sheet – *Care home managers*

This study is being carried as part of a PhD degree that the chief investigator, Adam Spacey, is doing. He is being supervised by a small team of researchers at Bournemouth University. We are working with a group of care homes who have invited us to explore care at the end of life. Below we have outlined the proposed project in more detail. If after reading this, you are interested in participating, please contact Adam Spacey (**phone:** 07986 635716 or **email:** aspacey@bournemouth.ac.uk), the chief investigator; additional contact details can be found at the end of this document.

Title of study:

Title: End of Life Care in Care Homes.

Purpose of the study

We would like to have a discussion with you about your experiences of delivering end of life care in the care home. We are interested in exploring any aspects of care that you think are good and any aspects of care that you think can be improved. It is hoped that this discussion will inform our study and will provide care homes insight and knowledge into the factors which are likely to inhibit or promote good end of life care.

Why you have been invited

You have been invited because you work in 'title of specific care home' which has kindly offered to take part in our study. We feel it is important to include the views of care home staff in our study of end of life care because your experiences can help impact and shape our research findings.

Do I have to take part?

You do not have to take part in the study. It is your choice. Should you choose to participate, you will be asked to sign a consent form prior to the interview(s). You are free to withdraw at any point and, can request that part or all information already collected be destroyed or withheld up until all your personal details (such as your name) have been removed. Your personal details will be removed 1 week following your interview. When all of your personal details have been removed from the information it is not possible to know which specific information belongs to you.

What will happen if I decide to take part?

Adam Spacey the chief investigator will arrange a time to visit you in the care home convenient to you to discuss your experiences of end of life care in a care home. If you agree we would like to return to conduct a second optional interview with you to discuss our findings. Each interview should take no longer than 30-45 minutes. With your permission, the interview will be audio recorded for transcription purposes.

The first interview will explore your experiences of end of life care from the perspective of a care home manager. There are no right or wrong answers; we are just interested in your views. We will ask you about topics that seem to be important to others as determined from our search of the literature on this topic.

After the first interview, we would like to return to discuss our findings with you. The purpose of this second optional interview is to present our findings to you allowing you to refine what we conclude based your personal experiences of End of life care in the care home.

Will the information be kept confidential?

The information collected throughout the study will be anonymised, meaning that all personal details such as your name will be removed. Confidentiality will be respected meaning no information will be shared outside of the research team unless you reveal that you are a risk to self and others. You will not be identified in any publications or reports, and the audio recordings will be destroyed. However, it is possible that quotes used in subsequent reports and publications may be recognised, even though all your personal details such as your name will be removed from any quotes used. Additionally, as well as the chief investigator the anonymised information will be shared with the supervisory team.

If at any point you are unable to understand and retain information (lose mental capacity) following the first interview you would not be expected to undertake a second optional interview. However, the research team would retain the information collected and continue to use it confidentially in the study.

What will happen to the results?

They will be compiled in a thesis and may be published in academic Journals, all information presented in these documents will be non-identifiable.

Are there any benefits or disadvantages to taking part?

There is the potential to get upset because the interviews will be discussing the sensitive topic of care at the end of life. If you become distressed or upset you will have the opportunity to stop or pause the interview. If necessary you will also be signposted to the relevant support services. It is hoped that findings from the study will help improve end of life care across the country and internationally in care homes.

PhD Supervisors & Chief investigator

Professor Samuel Porter – Bournemouth University

Dr Janet Scammell – Bournemouth University

Dr Michele Board – Bournemouth University

Adam Spacey – Chief investigator Bournemouth University

This research study is funded by Bournemouth University.

Thank you for taking the time to read this

A copy of this information sheet will be given to you to keep at the start of the study. You will also be given the chance to read this again and ask questions, before you then sign a consent form to participate in the interviews.

Research Team Contact Details:

If you would like to take part in this research please contact Adam Spacey (**phone:** 07986 635716 or **email:** aspacey@bournemouth.ac.uk), the chief investigator. Supervisor contact details are displayed below.

Sam Porter	Adam Spacey
Professor of Nursing Sociology	Post Graduate Research student (PhD)
Head of Department of Social Sciences and Social Work	Bournemouth University
Bournemouth University	Royal London House
Royal London House R203	Bournemouth BH1 3LT
Bournemouth BH1 3LT	Email: aspacey@bournemouth.ac.uk
Email: Porters@bournemouth.ac.uk	Tel: 07986 635716
Tel: (0044) 1202 964107	
Dr Janet Scammell, Associate Professor	Dr Michele Board
Nursing Research Cluster Lead	Principal Academic Nursing Older People
01202 962751	Bournemouth University
jscammell@bournemouth.ac.uk	01202 961786 mboard@bournemouth.ac.uk

If you have a concern about any aspect of this study and wish to complain, please contact:

Prof V. Hundley, Deputy Dean for Research & Professional Practice:, Faculty of Health and Social Care, Bournemouth University. Email: researchgovernance@bournemouth.ac.uk

Appendix 11: Participant information sheets for care home staff focus groups

Date: 04/01/2018

Version number: version 3

[Headed paper]

IRAS: 233729

Participant information Sheet - *Professional nursing care home staff (both registered and non-registered)*

This study is being carried as part of a PhD degree that the chief investigator, Adam Spacey, is doing. He is being supervised by a small team of researchers at Bournemouth University. We are working with a group of care homes who have invited us to explore care at the end of life. Below we have outlined the proposed project in more detail. If after reading this, you are interested in participating, please contact Adam Spacey (**phone:** 07986 635716 or **email:** aspacey@bournemouth.ac.uk), the chief investigator; additional contact details can be found at the end of this document.

Title of study:

Title: End of Life Care in Care homes.

Purpose of the study

We would like to have a group discussion with you and your colleagues about your experiences of delivering end of life care in the care home. We are interested in exploring any aspects of care that you think are good and any aspects of care that you think can be improved. It is hoped that this discussion will inform our study and will provide care homes insight and knowledge into the factors which are likely to inhibit or promote good end of life care.

Why you have been invited

You have been invited because you work in 'title of specific care home' which has kindly offered to take part in our study. We feel it is important to include the views of care home staff in our study of end of life care because your experiences can help impact and shape our research findings.

Do I have to take part?

You do not have to take part in the study. It is your choice. If you do decide to take part, you will be asked to sign a consent form before you take part. Also, if you do take part you are free to withdraw at any point. However, due to the nature of focus groups your information cannot be removed following commencement.

What will happen if I decide to take part?

Adam Spacey (chief investigator) and a supervisor will arrange a time to visit you in the care home to discuss your experiences of end of life care in a care home. With your permission, we would like to conduct two focus group discussions. The second focus group is optional; therefore you can decide to only take part in the first focus group should you wish. Each focus group will last a maximum of one hour. With your permission, the interview will be audio recorded for transcription purposes.

The first focus group discussion will explore your experiences of end of life care from the perspective of care home staff. There are no right or wrong answers; we are just interested in your views. We will ask you about topics that seem to be important to others as determined from our search of the literature on this topic.

After the first focus group discussion, we would like to return to discuss our findings with you. The purpose of this second optional focus group discussion is to present our findings to you allowing the focus group to refine what we conclude based their personal experiences of end of life care in the care home.

Will the information be kept confidential?

The information collected throughout the study will be anonymised, meaning that all personal details such as your name will be removed. Confidentiality will be respected meaning no information will be shared outside of the research team unless you reveal that you are a risk to self and others. You will not be identified in any publications or reports, and the audio recordings will be destroyed. However, it is possible that quotes used in subsequent reports and publications may be recognised, even though all your personal details such as your name will be removed from any quotes used.

However, it must be understood that the focus group discussion is confidential to the participants in the room and so the ground rule is that what is discussed is not shared outside with others. Additionally, as well as the chief investigator the anonymised information will be shared with the supervisory team.

If at any point you are unable to understand and retain information (lose mental capacity) following the first focus group discussion you would not be expected to undertake a second optional focus group discussion. However, the research team would retain the information collected and continue to use it confidentially in the study.

What will happen to the results?

They will be compiled in a thesis and may be published in academic Journals, all information presented in these documents will be non-identifiable.

Are there any benefits or disadvantages to taking part?

There is the potential to get upset because the interviews will be discussing the sensitive topic of end of life care. If you become distressed or upset, you will have the opportunity to stop or pause the interview. If necessary, you will also be signposted to the relevant support services. It is hoped that findings from the study will help improve end of life care across the country and internationally in care homes.

PhD Supervisors & Chief investigator

Professor Samuel Porter – Bournemouth University

Dr Janet Scammell – Bournemouth University

Dr Michele Board – Bournemouth University

Adam Spacey – Chief investigator, Bournemouth University

This research study is funded by Bournemouth University.

Thank you for taking the time to read this

A copy of this information sheet will be given to you to keep at the start of the study. You will also be given the chance to read this again and ask questions, before you then sign a consent form to participate in the interviews.

Research Team Contact Details:

If you would like to take part in this research please contact Adam Spacey (**phone:** 07986 635716 or **email:** aspacey@bournemouth.ac.uk), the chief investigator. Supervisor contact details are displayed below.

Sam Porter	Adam Spacey
Professor of Nursing Sociology	Post Graduate Research student (PhD)
Head of Department of Social Sciences and Social Work	Bournemouth University
Bournemouth University	Royal London House
Royal London House R203	Bournemouth BH1 3LT
Bournemouth BH1 3LT	Email: aspacey@bournemouth.ac.uk
Email: Porters@bournemouth.ac.uk	Tel: 07986 635716
Tel: (0044) 1202 964107	
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If you have a concern about any aspect of this study and wish to complain, please contact:

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Appendix 12: Consent form

Date: 11/10/2017

Version number: Version 1

[Headed paper]

IRAS ID: 233729

CONSENT FORM

Study title: A Critical Realist Evaluation of End of Life Care in Care Homes.

Details of Researcher: Adam Spacey, Post Graduate Research student (PhD), Bournemouth University, Royal London House, Bournemouth BH1 3LT

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1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand and consent that I will be audio recorded during the data collection.
4. (If appropriate) I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.
5. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person	Date	Signature

Appendix 13: Lone working policy

Title:	Lone Working Policy
Keywords:	Alone, Remote, Unaccompanied, Health and Safety
Description:	Guidance on Lone Working
Publish Date:	1st July 2015

10.1.1 Lone Working Policy – Bournemouth University

It is the University's responsibility under the Health & Safety at Work Act 1974 to ensure, so far as is reasonably practicable, the Health and Safety of its employees and individuals undertaking activities when working alone.

This policy deals both with individuals who may be required to work by themselves on or off campus or who work outside normal working hours on campus unaccompanied or without immediate access to another person/s for assistance. Also, any individual (e.g. student) undertaking fieldwork, or practical projects without direct supervision and who are exposed to a significant risk of the hazards associated with lone working.

'Normal Working Hours' are defined as the University's core working hours 08:30 – 17:00 Monday to Friday, with 'Out of Hours' defined as anytime outside of the University's normal working hours, including weekends and all public holidays.

In most instances the University considers the carrying out of normal office work to be low risk, especially where there is ready access to either a land phone or mobile phone which an individual can use to summon assistance – either using the '222' emergency number, or the equivalent external line number **(01202) 9 62222**.

Working alone by definition means there will be no direct supervision and/or contact. As with other health and safety risks, BU policy therefore requires this to be proactively managed by carrying out a risk assessment of activities (particularly where there are identified risks) and adopting safe working arrangements to control risks.

Apart from ensuring individuals are sure that they are capable of doing the job/activity safely on their own, it is also important that managers ensure;

- That lone working is considered in all risk assessments carried out in their area of responsibility, and that appropriate formal records are kept.
- Lone working is avoided wherever possible.
- The lone worker knows about the hazards & risks present in the work to be undertaken, and the controls to be followed to reduce the risk.
- The lone worker knows what to do if something goes wrong.
- The lone worker is instructed to formally report any incident.
- Someone else knows the whereabouts of a lone worker and what he or she is doing.
- Consideration is given to the need for effective communication systems for assistance to be summoned.

Individual responsibilities include;

- Avoiding lone working wherever possible (outside of a normal working environment).
- Comply with all control measures as identified through the risk assessment.
- Ensure that agreed control measures are adhered to, and that plans are not deviated upon without prior agreement, or the knowledge of a manager.

Risk Assessments

The assessment of the risks to which a lone worker may be exposed must take into account and consider:

- An individual's ability to carry out their activities safely on their own.
- The potential for the individual to be subject to violence or allegations of inappropriate behavior.
- The individual's ability to request assistance or to withdraw safely from a volatile situation.
- The individual's fitness or ability to work alone.
- Sudden illness or emergency (e.g. accidents, ability to raise the alarm).
- Effects of social isolation
- Fire safety and/or access to fire protection
- Any existing precautionary measures and emergency arrangements.

This list is not intended to be exhaustive, every situation is different and individual controls for those situations must be considered based on their own merits.

Examples of control measures for lone working include;

- Prevention of lone working wherever possible.
- 'Buddy' systems
- Suitable training
- Suitable emergency equipment and emergency arrangements
- Adequate supervision
- Defined work activities and working processes, including written safe systems of work.

Appendix 14: Reflection publication, published in Sage Research Methods



Work: SAGE Research Methods Cases: Medicine and Health

Editor: Figiel, Kasia

Contribution Provisional Title or Description: The Challenges and Benefits of Conducting a Systematic Literature Review of End of Life Care in UK Care Homes

Number of Words: 5000

Illustrations: N/A

Draft Delivery Date: 1/1/2020

<i>All contact information is required</i>	Address --NO P.O. BOXES--	City, State/Province, Zip, Country	Email	Phone	Fax	Affiliation
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Work: SAGE Research Methods Cases: Medicine and Health

Editor: Figiel, Kasia

Contribution: The Challenges and Benefits of Conducting a Systematic Literature Review of End of Life Care in UK Care Homes

CONTRIBUTOR

Signed By: Adam Spacey
Spacey, Adam

Date: 9/17/2019 6:53:32 AM

SAGE PUBLICATIONS, LTD.

Signed By: 
Delia Martinez-Alfonso, Publisher

Appendix 15: Conference abstract

Dear author,

Your communication entitled "A Critical Realist Evaluation of End of Life Care in Care Homes" was accepted for presentation at the STTI 5TH BIENNIAL EUROPEAN CONFERENCE: Nursing's innovation, influence and impact on global health: looking back and moving forward" to be held at Coimbra, Portugal during May 27-30, 2020.

The type of communication approved by the jury is:
Oral presentations

The authors of this communication are:
Adam Spacey

The presenter of this communication is:
Adam Spacey

The theme of this communication is:
3 - Nursing and health education

Thematic axis: Nursing and health education.

Title: A Critical Realist Evaluation of End of Life Care in Care Homes

Introduction: Numbers of advance care plans and unnecessary admissions to hospital at the end-of-life are outcomes commonly used to determine the quality of end-of-life care in UK care homes (Mason et al, 2016; Thwaites et al, 2017; Spacey et al., 2018). However, there is currently a sparsity of research exploring the underlying processes behind these outcomes. This gap in knowledge has limited the effectiveness of interventions designed to improve end-of-life care in care homes (Spacey et al., 2019).

Objectives: The study aim was therefore to inform the design and development of interventions capable of supporting the delivery of high-quality end-of-life care in UK care homes.

Methodology: A two-phased study design using critical realist evaluation was used to address this gap in knowledge and achieve the study aim. Qualitative data was collected (using focus groups and semi-structured interviews) from three care homes in the South West of England from participants which consisted of registered nurses and non-registered care home staff and bereaved relatives.

Results: A current educational focus on gathering information, combined with some care home staff's emotional reluctance to discuss death and dying, and a taboo culture within commercial sector associated with death and dying impacted on the quality of advance care planning discussions. In relation to unnecessary admissions to hospital at the end of life, findings suggest that medically focused education mechanisms, a sparsity of support during out of

hour shifts, and emotional pressure from relatives led to some care home staff overlooking residents documented wishes and preferences and contributing towards unnecessary admissions at the end of life.

Conclusion: Findings were used to develop interventions theories which act as recommendations for practice accounting for the diverse social, economic and organisational contexts of care homes in their design. These intervention theories provide the foundational components and rationale for the development of an evidence-based multicomponent end of life care education intervention.

Keywords: Terminal care, palliative care, nursing homes, residential facilities, critical realism, intervention.