Length of stay and palliative care:
Understanding long-term care facility residents in Europe

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

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ABSTRACT

Doctor of Philosophy

Length of stay and palliative care: understanding long-term care facility residents in Europe

By Danni Collingridge Moore

Background: A key consequence of population ageing will be an increase in the number of care-dependant older adults, unable to remain living in the community until death. The importance of developing long-term care systems to meet the care needs of this group has been recognised in international health policy on ageing; however, the role of long-term care facilities (LTCFs) has received less attention. An understanding of the variation in how long older adults reside in such facilities after admission, the implications of length of stay for palliative care provision, and how palliative care can be implemented successfully in these settings, is urgently needed.

Aim: The overarching research question of this thesis is 'How are resident length of stay and palliative care in long-term care facilities associated?' Firstly, it aims to systematically identify, synthesise and quality assess factors associated with resident length of stay in LTCFs. Secondly, to explore the association of resident, facility and country characteristics with length of stay in LTCFs. Thirdly, to explore the relationship between length of stay and care at end of life in LTCFs, and fourthly to identify facilitators and barriers to implementing palliative care interventions in LTCFs.

Methods: A systematic review was conducted to identify factors associated with length of stay until death in LTCFs, and data assessed and synthesised using an existing tool adapted specifically for this review. Time to event analysis was conducted on internationally comparable data collected in a mortality follow-back study of 1,707 deceased LTCF residents in six European countries. Using the same dataset, generalised linear mixed models were used to explore the relationship between length of stay and five indicators of care at end of life. Finally, a scoping review of implementation strategies used in organisational level interventions that aimed to improve palliative care in LTCFs was conducted, using thematic synthesis to analyse the data.

Results: The thesis identified heterogeneity in the length of stay of LTCF residents, explained by the "theoretical framework of deferred admission". It found that longer stay residents were more likely to experience better outcomes on indicators of palliative care, and produced a three-stage framework of implementation for palliative care interventions in LTCFs.

Conclusion: In applying the theoretical framework of deferred admission, the thesis argues that length of stay is explained though the interplay of a resident's intrinsic capacity and their environmental resources. These findings can guide the implementation of palliative care for all LTCF residents by identifying subgroups likely to experience poorer indicators of palliative care.

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Abbreviations

ACP - Advanced Care Planning

ANOVA - Analysis of Variance

BMI - Body Mass Index

CQC - Care Quality Commission

EAPC - European Association of Palliative Care

ENRICH - Enabling Research in Care Home

ENTRQ - Enhancing transparency in reporting the synthesis of qualitative research statement

EOLD-CAD - End-of-Life in Dementia Scale Comfort Assessment While Dying Scale

GLM - Generalised Linear Model

LTCF - Long-Term Care Facility

MeSH - Medical Subject Headings

MDS - Minimum Data Set

MLE - Maximum Likelihood Estimation

MOOC - Massive Open Online Course

OECD - Organisation for Economic Co-operation and Development

PACE - Palliative Care for Older People in care and nursing homes in Europe

PICOS - the ‘Patient, Intervention, Control, Outcome and Study Design’ approach to developing inclusion criteria

PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PRISMA-ScR - Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews

QoD-LTC - Quality of Dying in Long-Term Care

RETREAT - the ‘Review question, Epistemology underpinning the review, Time frame, Resources, team Expertise, Audience and Type of data being synthesized’ approach to identifying an appropriate approach to qualitative synthesis (Booth et al., 2016).
RCT - Randomised Controlled Trial

SALSA - Search, Appraisal, Synthesis, and Analysis (SALSA) framework (Grant and Booth, 2009).

SHELTER - Services and Health for Elderly in Long-term care study

STROBE - Strengthening the Reporting of Observational Studies in Epidemiology

WHO - World Health Organisation

Authors Declaration

I declare that this PhD is the result of my own work and has not been submitted for the award of any other higher degree at Lancaster University or any other institution.

DCM

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This thesis is dedicated to Dr Naomi Fisher.

Preamble

My interest in long-term care for older adults began in 2013, as a researcher at the University of York. The first study I worked on identified epidemiological sources of data on the health and wellbeing of older adults residing in LTCFs in the UK and Ireland. The study concluded that the majority of longitudinal and nationally representative cross-sectional sources identified either excluded or did not follow-up older adults in LTCFs. I called the subsequent publication “Out of sight, out of mind? A review of data available on the health of care home residents in longitudinal and nationally representative cross-sectional studies in the UK and Ireland”, to reflect the lack of data available (Collingridge Moore and Hanratty, 2013).

Working in this field in the decade since this publication, I have witnessed, and at times had the pleasure of being involved in, research that aimed to improve our understanding of the health and wellbeing of LTCF residents. As a researcher for five years on the PACE study, I had the opportunity to work with an international consortium of researchers focused on improving palliative care for LTCF residents. At international conferences, including the International Association of Gerontology and Geriatrics and the European Association of Palliative Care, I have seen the importance of LTCFs as settings of care for some of the most vulnerable older adults in society advocated in the high quality research presented.

Despite this, the COVID-19 pandemic has shown that LTCFs and their residents continue to be arguably ‘out of sight, out of mind’. In June 2020, I was seconded to the COVID-19 taskforce, based in the Cabinet Office, to prepare and present data on the impact of COVID-19 in LTCFs. As of December 2020, 19,568 care home residents have died of suspected or confirmed COVID-19 in England and Wales, although the number of excess deaths in this setting resulting indirectly from the pandemic is likely to be far more (Office for National Statistics, 2020).

The motivation behind this thesis was to demonstrate the need for, and capabilities of good quality data on LTCF residents. The needs of this group now, more than ever, need advocating.

Chapter 1: Introduction

This thesis focuses on the length of stay of older adults in long-term care facilities (LTCFs) in Europe, the palliative care provided to older adults residing in these settings, and how such care can be improved. The introduction aims to explore the role of LTCFs in providing care to care-dependant older adults, within the broader ageing population, and LTCFs as places of end of life and death for their residents. It will begin by discussing the implications of an ageing population, locating LTCFs within the World Health Organisation (WHO) Global Strategy and Action Plan on Ageing and Health (2016-2020) (World Health Organisation, 2017). It will go on to explore the epidemiology of older people living in LTCFs, in terms of admission, length of stay and death. Palliative care, in the context of older adults and within LTCFs, will be defined, and the methodological challenges of conducting research in this setting discussed. Finally, the PACE (Palliative Care for Older People in care and nursing homes in Europe) programme of research is introduced. The chapter will conclude with the rationale and aims of this thesis.

An ageing population

The world population is experiencing a demographic change, unlike any that has been witnessed before. Across the world, fertility rates are continuing to decline; in Europe, Northern America and parts of Asia, Latin America and Oceania, fertility rates have fallen, resulting in 46% of the world population living in low-fertility countries where the number of births is lower than that needed to maintain the population at its current level (around 2.1 births per woman) (United Nations, 2019).

Concurrently, life expectancy continues to increase, allowing today's older adults to survive to much older ages than their counterparts fifty years ago. By 2040, life expectancy is projected to increase by an additional 4.4 years, which will result in over 25% of countries having an average life expectancy that either meets or exceeds 80 years (Foreman et al., 2018). In resource rich countries, where life expectancy is increasing at a faster rate, improvements in healthcare have increased survival at older ages; between 1970 and 2017 alone, average life expectancy across Organisation for Economic Co-operation and Development (OECD) countries increased by over 10 years (Organisation for Economic Co-operation and Development, 2019).

Combined, the effect of declining fertility rates and longer life expectancy will continue to increase the proportion of older adults in the population compared to younger, commonly referred to as an 'ageing population'. Current projections indicate that by 2050, with the exception of Africa, all regions of the world will have nearly a quarter or more of their population aged 60 years or over (United Nations Department of Economic and Social Affairs Population Division, 2017a, United Nations Department of Economic and Social Affairs Population Division, 2017b). Geographically, the population aged over 65 years will remain relatively stable in resource rich regions, such as Europe and North America, where population ageing is already a reality. The most significant increases are being experienced by Asia and Africa, reflecting a delayed demographic transition of a relatively large population. As the baby boomer generation, those born in the surge of births after World War II in the 1940s to 1960s, begins to enter older ages, this demographic change will become even more apparent.

Increases in the proportion of older adults within the broader population are disproportionately higher among the very old and among women. Survival at older ages has outpaced that of younger generations, resulting in a greater proportion of older adults entering advanced old age. The term ‘oldest old’ is commonly used to refer to older adults aged over 85 years, although delimitation varies (Cohen-Mansfield et al., 2013; He et al., 2014). In addition, gains in life expectancy at 65 years have been disproportionately higher in women compared to men, especially among the oldest old (Kontis et al., 2017).

There is no predefined criteria to define who is and who is not considered an ‘older adult’, however, the term commonly refers to a person who has reached the age at which they can retire or receive a pension in their country of residence. The United Nations refer to older adults as aged over 60 years, however longitudinal studies on ageing may include adults aged over 50 years to allow for international comparison (Borsch-Supan et al., 2013; Kowal et al., 2012; Sonnega et al., 2014; Steptoe et al., 2013). Studies conducted in resource poor countries may include adults aged over 45 years (Arokiasamy et al., 2015; Zhao et al., 2014) or even 40 years (Gomez-Olive et al., 2018), reflecting international variation in the sociological and cultural construction of old age. In this thesis, adults aged 65 years and older will be referred to as older adults, reflecting the European focus of the research.

Health and wellbeing in older adults

The extent to which improvements in health and wellbeing have accompanied improvements in the longevity of older adults is debatable. Compared to younger age groups, differences in older adults' physical and mental functioning of the same chronological age can vary substantially (Peeters G et al., 2015).

In some older adult populations, increases in life expectancy are characterised by a ‘compression of morbidity’, resulting in long periods of relatively good health and a postponed onset of poorer health, experienced for a relatively short time before death (Chatterji et al., 2015b; Fries, 2003). In contrast, others are characterised by an ‘expansion of morbidity’, whereby gains in life expectancy are offset by a greater number healthy years lost due to disability and the effects of multiple chronic conditions (Rechel et al., 2009; Salomon et al., 2012).

Independent of whether morbidity in older ages is compressed or expanded, nearly all older adults will experience some form of decline in health as they age, most likely the onset of one or more chronic conditions, frailty, geriatric syndrome and impairments in cognitive functioning, including dementia or Alzheimer’s disease. The likelihood of developing a chronic condition, such as cardiovascular diseases, chronic obstructive pulmonary disease, and cancer, increases with age, and it is common for older adults to suffer from two or more chronic conditions concurrently, known as “multi-morbidity” (Garin et al., 2016; Nichols et al., 2019; Sleeman et al., 2019). Frailty is a state of increased vulnerability associated with ageing, characterised by a decline in physical and cognitive functioning, compromising an individual’s ability to cope with every day or acute external stressors (Xue, 2011). Frailty can be operationally defined as age-related deterioration in physiological systems, increasing vulnerability through the presence of symptoms such as low grip strength, limited physical activity, decreased walking speed or unintentional weight loss (Fried et al., 2001; Khezrian et al., 2017). Similarly, geriatric syndrome refers to a set of clinical conditions, such as pressure ulcers, incontinence, falls, dizziness, functional decline and delirium, which although not related to specific diagnoses, potentially have a significant impact on health and wellbeing (Inouye et al., 2007).

The biggest threat to a global ageing population is arguably from dementia and Alzheimer’s disease; the diagnoses of which have increased from 20.2 million in 1990 to 43.8 million in 2016, becoming the fifth leading cause of death globally (Nichols et al., 2019). Modifiable risk factors and interventions across the life course for dementia prevention are gaining traction; however, the impact of such policy developments will be delayed and unlikely to prevent the high cost of dementia in the current ageing population for those affected, their families and the health systems that support them (Livingston et al., 2020).

Approaches to caring for older adults

Since the 1980s, addressing the challenges presented by an ageing population has been an area of priority for internationally adopted policies and programmes (United Nations, 1982; United Nations, 1991; United Nations, 2002). Initially, the challenges presented by population ageing in resource poor countries, the establishment of national approaches to developing appropriate social services and healthcare systems and understanding the implications of changes to traditional family structures on caring roles, were the foci of such discussions. The World Health Organisation (WHO) World Report on Ageing, published in 2015, built on these foundations to develop the WHO Public Health Framework for Healthy Ageing, loosely based on the model of successful ageing proposed by Rowe and Kahn (Rowe and Kahn, 1997; World Health Organization, 2015). Within the conceptual model, 'healthy ageing' is defined as

> *"the process of developing and maintaining the functional ability that enables wellbeing in older age".*
>
> (World Health Organisation, 2019a)

Healthy ageing is a central theme of the WHO's work on ageing. This process is underpinned by optimising intrinsic capacity, the sum of an individual's mental and physical ability, and compensating for any loss of capacity by providing the environmental support and care necessary to maintain functional ability (World Health Organization, 2015). Functional ability is determined by combining the individual's intrinsic capacity and their interactions with their environment and can be viewed as the ability to live a good quality of life, as judged by the individual. An older adult with low intrinsic capacity, through poor mobility, could maintain functional ability through supportive characteristics in their environment, i.e. home modifications or informal care. External to the WHO, there is no consensus on a definition of healthy ageing that intersects research, clinical practice and policy. It is common for the terms ‘healthy ageing’, ‘successful ageing’ and ‘active ageing’ to be used interchangeably with little further clarification on underlying concepts.

Prior to Rowe and Kahn, chronological age was the predominant construct on which an individual’s health was determined, based on average losses in capacity across age groups (Rowe and Kahn, 1987). Although logical, this approach devalues the heterogeneity in intrinsic capacity experienced by older age groups, as shown by Peeters G et al, and ignores wider domains of health, including psychological and social dimensions (Peeters G et al., 2015). Rowe and Kahn’s updated definition of successful ageing focuses on three areas, low levels of disease and disability, high levels of cognitive and physical functioning and active engagement with life (Rowe and Kahn, 1997).

In addition to the work of Rowe and Kahn, other theories of optimal ageing have been developed. An alternative theory of ‘successful ageing’ is proposed by Baltes and Baltes (1990), using selective optimisation with compensation. The theory is based on the idea that older adults will selectively prioritise capabilities to adapt to their losses in functional ability associated with ageing. In doing so, older adults take advantage of and maximise their remaining functional capacity, utilizing external compensatory resources. Such resources could be environmental, such as support networks, or technological, such as walking aids. Alternatively, Kuh et al (2014) offer a definition of healthy ageing that focuses on three areas; surviving to old age, delaying chronic disease and associated disability and maintaining functioning (Kuh et al., 2014).

The variety in definitions of healthy ageing has led to multiple approaches and tools used to measure the concept. In a systematic review of outcome measures used in studies exploring healthy ageing, measures of physical, capabilities, cognitive functions and metabolic and physiological health remain the most commons domains explored (Lu et al., 2018). The underrepresentation of psychological wellbeing, social wellbeing and security domains highlights whether all the constructs that comprise healthy ageing have been completely understood.

There are three criticisms of the definition used by the WHO offered in this thesis. Firstly, the definition is at risk of creating a binary understanding of ageing, with older adults split into those who are achieving ‘healthy ageing’ and those whose are not. This has been referred to already by Rowe and Kahn in their discussion of usual versus successful ageing; such a division is unhelpful and has the potential to lead to a divergence in health and long-term care systems which offer few services for older adults who are somewhere between these two extremes.

Secondly, the emphasis on maintaining individual intrinsic capacity refocuses the ability to age successfully on the individual, which realistically is not achievable for the majority of older adults. In doing so, the importance of national development and resourcing of appropriate systems to support ageing populations is reduced, and a reliance on personal autonomy to age ‘healthy’ emphasised.

Finally, the WHO choice of definition has arguably been guided by the need for a standardised understanding of healthy ageing to be used across international and national policy. The fifth objective of the WHO, for example, focuses on improvement of checking, monitoring and studying of the topic of healthy ageing, which requires a simplified applicable aim that can be adopted across nations (World Health Organisation, 2017). The extent to which this definition is applicable across countries and can be successfully utilised in the development of new policies, and updating of existing policies, is unclear (Rudnicka et al., 2020).

The need for consensus in a definition in healthy ageing has been highlighted elsewhere, both to evaluate the effect of policies and interventions to improve ageing, and also from an epidemiological perspective to monitor the prevalence of healthy ageing (Fuchs et al., 2013; Peel et al., 2004). Not only is consensus in a definition of healthy ageing lacking, there is also inconsistency in the composite elements that make up the construct. For example, intrinsic capacity, although defined, is still a largely theoretical construct and tools for measuring intrinsic capacity are yet to be fully developed and validated (Belloni and Cesar, 2019).

On application to a varying and diverse older adult population, the healthy ageing framework can be adapted to the needs of those with relatively high and stable capacity, those with declining capacity, and those with significant losses of capacity. The boundaries of these populations are porous, and the trajectories of many older adults will pass through all three stages of capacity at least once at varying points before death, as shown in the compression and expansion of morbidity hypotheses. The implications of each level of intrinsic capacity for environments, health services and long-term care are shown in figure 1.1.

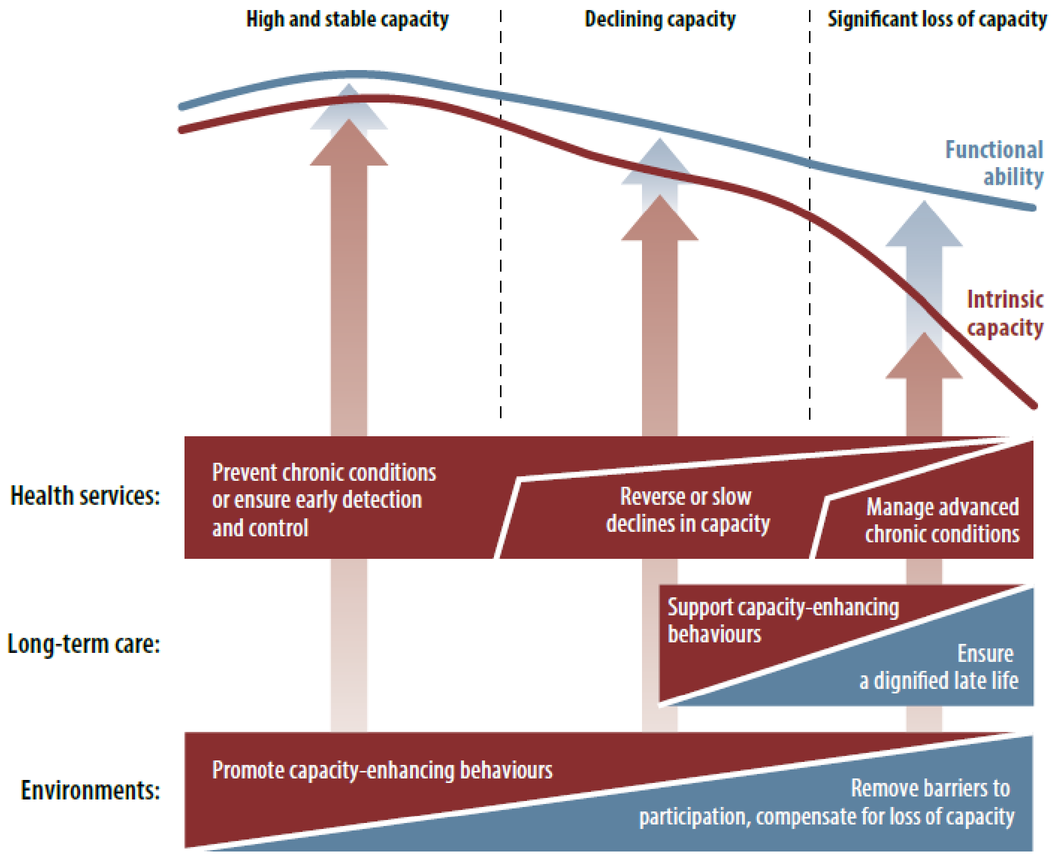

Figure 1.1. The WHO Public Health Framework for Healthy Ageing for health services, long-term care and environments, mapped against varying levels of intrinsic capacity and functional ability (World Health Organization, 2015).

A central component of the healthy ageing approach is the active promotion of ageing in place, whereby an older adult remains in their own home or community as they age until death, in the context of a wider, supportive environment (Wiles et al., 2012). Ageing in place of residence until death is a common preference among older adults (Fleming et al., 2016; Higginson et al., 2017; Ohmachi et al., 2015; Wiggins et al., 2019), however, the development of age-friendly environments that are accessible and inclusive to all older adults, while recognised as a priority, is ongoing and, at present, not adequate in most countries (World Health Organization, 2007). In practice, the achievement of an acceptable quality of life in the community for many older adults is dependent on the availability of either formal or informal care, which may be either unavailable or inaccessible. As levels of capacity decline over time, either such care may no longer meet an older adult's needs, or the level of care required may not be sustainable for those providing long-term care.

Building on the healthy ageing model, the Global Strategy and Action Plan on Ageing and Health (2016-2020) highlighted the need for the provision of long-term care, by developing sustainable and equitable systems for long-term care and ensuring that older adults with reduced intrinsic capacity receive their right to care and support (World Health Organisation, 2017). Few countries have an adequately equipped long-term care systems capable of supporting increasing numbers of “care-dependant” older adults, who have significant ongoing losses in intrinsic capacity (World Health Organisation, 2019b). In addition, the current older adult population is unlikely to fully benefit from the upstream interventions designed to prevent or delay the onset of chronic conditions, the effect of which may not be seen for at least another ten years from implementation.

Increasingly, care-dependant older adults who cannot access appropriate informal or formal caregivers or have needs that can no longer be met by the support available, are unable to remain in their own homes. Despite this, there is little discussion of the role of long-term care settings outside the home; LTCFs, and the older adults who reside within them, are largely missing from the global health policy narrative.

What is a long-term care facility?

The WHO does define a LTCF; however, the term is included within its definition of an institutional care setting, alongside community centres, assisted living facilities, nursing homes, hospitals and other health facilities, which may provide long-term care (World Health Organization, 2015). In practice, the terminology used to discuss LTCFs varies between countries, and can refer to care homes, nursing homes, residential homes, assisted living facilities and homes for the aged, in addition to country-specific terms or terms in other languages.

In research publications, it is common for LTCFs not to be clearly defined, or for little distinction to be made between types of LTCFs, with the term ‘nursing home’ often being used synonymously with all other variations of LTCF. Ribbe et al define a nursing home as an institution providing twenty-four-hour nursing care, assistance with activities of daily living, mobility, psychosocial and personal care, as well as room and board (Ribbe et al., 1997). Sanford et al define a nursing home as a facility that provides twenty-four-hour functional support for people who require assistance with activities of daily living and have identified health needs (Sanford et al., 2015). The publication goes on to state that a nursing home may or may not be staffed with health care professionals, provide long-term care and/or rehabilitation as part of hospital avoidance or to facilitate early hospital discharges, and may play a role in providing palliative care at the end of life. Both these definitions potentially exclude LTCFs that have nursing care provided externally, such as residential care homes in the UK. Country specific terminology can be locally determined, such as 'special homes for the aged' or 'health facilities for the elderly' (Japan), 'assisted living facilities' (USA) and 'residential care facilities' (Australia), adding further ambiguity (Ghavarskhar et al., 2018; Ribbe et al., 1997).

In this thesis, the definition provided by Froggatt et al and adopted by the European Association of Palliative Care (EAPC) will be used (Froggatt and Reitinger, 2013a). An LTCF is defined as a collective institutional setting where care is provided for the older people who live there, 24 hours a day, seven days a week, for an undefined period. The care provided includes on site provision of personal assistance with activities of daily living; nursing and medical care may be provided on-site or by nursing and medical professionals working from an organisation external to the setting. Compared to hostels and sheltered, supported or extra care housing, residents of LTCFs neither own nor rent their accommodation in the facility. Unlike rehabilitative care, which aims to provide a period of rehabilitation after an acute event or post hospitalisation only, LTCFs provide ongoing care until discharge or death.

Long-term care facilities and their residents

The availability, structure and demand for LTCFs internationally varies substantially, depending on the national context of long-term care funding, availability of familial support systems and societal attitudes towards ageing. In previous generations, family members often provided care for older adults within the home until death, which is still common in Asian and African countries (Organisation for Economic Co-operation and Development, 2014). However, in recent years, as families have become smaller and more geographically dispersed, and women, traditionally the primary caregivers for older parents, have entered the workforce, more care for older adults is being provided by LTCFs to meet increasing demand.

Internationally, there is little correlation between the number of potential LTCF users and provision of beds per 1,000 population aged over 65 years, as shown in figures 1.2 and 1.3 (Organisation for Economic Cooperation and Development, 2019). Differences in the availability of care in other settings, i.e. home care, assisted living, hospices, payment of care and the requirement of an assessment of need prior to placement, may go some way to explaining such variation (Ribbe et al., 1997).

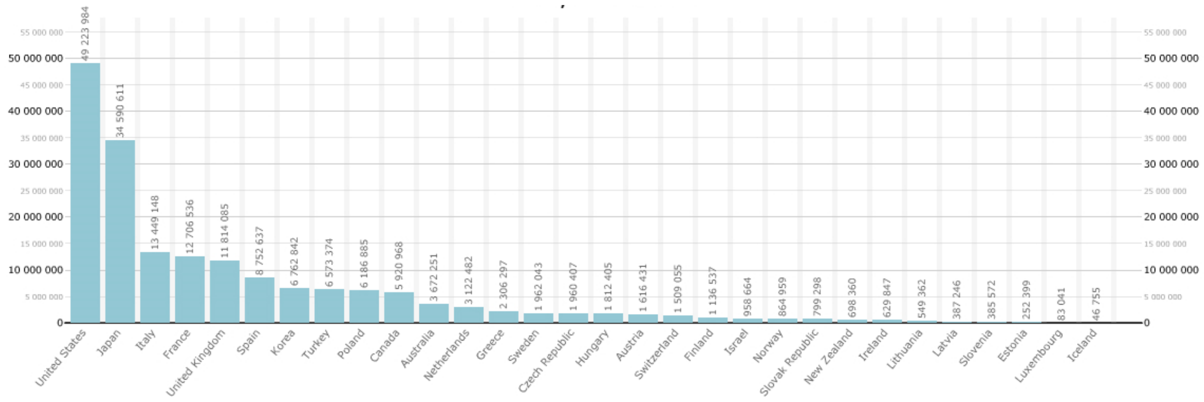

Figure 1.2. Total population aged 65 years and over in 30 countries in 2016.

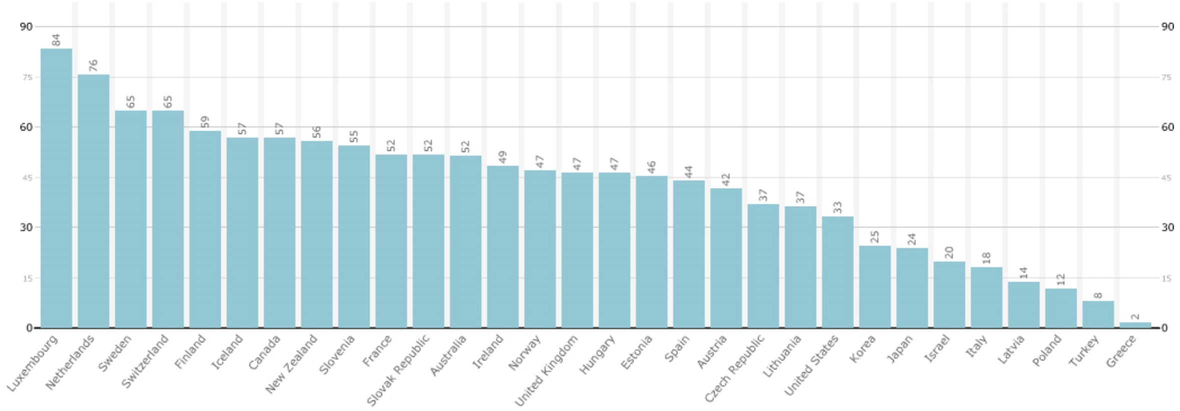

Figure 1.3. Beds in long-term care facilities, per 1,000 population aged 65 years and over in 30 countries in 2016.

A typology of three LTCFs has been proposed by Froggatt et al (Froggatt et al., 2016). Type 1 facilities provide on-site physicians, nurses and care assistants, and are available in the Netherlands, Italy and Finland, usually providing care for the most dependant older adults. Type 2 facilities provide nurses and care assistants on-site, however, medical provision is provided externally, such as those found in Ireland, Austria and France. Type 3 facilities provide on-site care from care assistants only, with nursing and medical provision provided by local primary care services, such as those available in the UK, Denmark and Hungary. In many countries, more than one type of facility is present, to provide a range of care for people with varying dependencies. Irrespective of typology, LTCFs vary in the organisation of care, size, assessment of the quality of care and financing (Kraus et al., 2010; Riedel and Kraus, 2011; Siegel et al., 2019., Tolson et al., 2013).

In terms of the characteristics of older adults who reside in LTCFs, the availability of internationally comparable resident level data is limited, but what data is available shows a population with an average age of over 80 years, that is disproportionately female and has high levels of disability, cognitive impairment and multi-morbidity (Honinx et al., 2019b; Onder et al., 2012a). Unsurprisingly, older adults who reside in LTCFs have relatively poor health compared to those living at home in the community, and contact with health services, including hospitalisations, emergency department use and polypharmacy, can be high (Carron et al., 2017; Graverholt et al., 2011; Onder et al., 2012b).

In many countries, living in an LTCF is viewed negatively, associated with poor quality care and the potential for neglect or abuse, a perception of that has led many older adults and their families to delay or avoid LTCF admission, choosing to age in their homes even when the care available is no longer able to meet their needs (Lillo-Crespo and Riquelme, 2018). Admission to a LTFC is often viewed as the least favourable outcome, synonymous with the fears older adults voice regarding end of life; becoming dependant on other, loss of dignity, losing quality of life, becoming isolated or alone and a lack or appropriate care, specifically pain management (Hanson et al., 2019). The proportion of residents with disability, multi-morbidity and dementia have increased within the LTCF population over the last decade, indicating that older adults are potentially being admitted later closer to death than in previous years (Goodman et al., 2013; Iliffe et al., 2016; Matthews et al., 2013;

The extent to which LTCF residents receive poorer quality care than those residing in the community is debatable; joint working between LTCFs and wider health services vary, with residents depending on LTCF staff to monitor changes in health and determine when referral to external health professionals is required (Goodman et al., 2016; Shah et al., 2011, Victor et al., 2018). Despite this, some research has found that while LTCF residents have worse outcomes than community dwelling residents on physical functioning, social functioning and pain, aspects of health-related quality of life are better (O'Neill et al., 2020).

Admission to long-term care facilities

The transition of older adults from living in the community to admission to an LTCF is highly individual, often complex and seldom due to one reason alone. For some older adults, the trajectory to admission may follow a period of decline in health, where living independently in the community is no longer possible. A higher level of care than that available in the community may be required, or the burden on informal caregivers may become unmanageable. For others, a trigger event, such as a stroke or a fall, which may require hospitalisation, can increase care needs to a point where returning to the community is no longer appropriate (Harrison et al., 2017). In the past ten years, six systematic reviews of predictors of LTCF admission, two focusing on community populations and four on populations specifically with a dementia diagnosis, have explored factors associated with either the likelihood of LTCF admission or hastened admission, the findings of which are shown in table 1.1.

	(Gaugler et al., 2007) USA studies only	(Luppa et al., 2008) dementia populations only	(Gaugler et al., 2009) dementia populations only	(Luppa et al., 2010)	(Cepoiu-Martin et al., 2016) dementia populations only	(Toot et al., 2017) dementia populations only
Number of studies included in review	77	42	80	36	59 (37) *	26
Increased age	X	X		X	X	
Being a man	X	X				
Non-white ethnicity		X			X	X
Cognitive impairment/severity	X	X	X	X	X	X
Limited physical functioning/self-rated health	X		X	X	X	X
Number of prescriptions				X		
Prior hospitalisation	X					
Prior LTCF admission	X			X		
Unmarried/spouse not present	X	X			X	
Lives alone	X	X			X	
Not owning a home				X		
Caregiver burden			X		X	X
Non spouse caregiver		X				

Table 1.1. Overview of systematic reviews exploring predictors of admission to a LTCF (*37 in meta-analysis).

The likelihood of LTCF admission has been found to increase with older age; however, the effect of gender had inconsistent evidence to support increased likelihood among either men or women (Aguero-Torres et al., 2001; Martikainen et al., 2009; McCann et al., 2012a). The collated findings show that older adults with cognitive impairment are more likely to enter an LTCF than their cognitively intact counterparts, independent of additional comorbidities (Braunseis et al., 2012; Eaker et al., 2002). Combining co-existing limitations in physical and cognitive capacity significantly increases the likelihood of entering an LTCF, as does contact with wider health services, i.e. hospitalisations (von Bonsdorff, 2006). The associated deteriorations in physical capacity that occur in older adults with dementia can lead to methodological challenges in identifying the individual impact of physical and cognitive predictors of LTCF admission. If older adults with dementia are included in community samples, separating the effects of dementia or cognitive impairment reduces the predictive value of other factors, such as physical impairments (Luppa et al., 2008).

The availability of wider support, i.e. through a spouse or another person residing in the home, and low levels of caregiver burden, reduce the likelihood of admission (Kersting, 2001; McCann et al., 2011; Steinbach, 1992). The influence of socio-economic factors are less understood, however research indicates that older adults who own a home are less likely to enter an LTCF than those who rent, with homeownership reducing the likelihood of admission regardless of the value of the home (McCann et al., 2012b; Wang et al., 2001). Without wider contextual data on the availability and financing of long-term care, these findings are hard to interpret and make cross-national generalisations difficult.

The findings of such reviews are useful in identifying trends in LTCF admission, however in practice the transition into long-term care, and the underlying processes that lead to the need for relocation, are difficult to capture using observational, quantitative data. Further exploration using a qualitative approach identified changes in the health and care needs of patients, including worsening behavioural symptoms and increased care-dependency, combined with the experience of carers, including increased caregiver burden and the inability of the informal caregiver to care for the patient, as key drivers for LTCF admission (Afram et al., 2014). The little research that has explored cross-national factors found that admission was context specific and supported previous qualitative findings that caregiver burden and dependency in activities of daily life increased the likelihood of admission across countries (Stolz et al., 2019). These characteristics also influence professionals' perceptions of the appropriateness of LTCF admission (Tucker et al., 2016; Verbeek et al., 2015).

Length of stay in long-term care facilities

As predictors of LTCF admission have gained increased attention, the length of time an older adult resides in an LTCF, and the factors associated with this length of stay, are less understood. In the UK, the majority of residents will reside in LTCFs until death, with discharge back into the community much less common. The preference to remain and subsequently die in the home may explain this trend, with LTCF admission being delayed until no other option is viable.

In Europe, length of stay varies between countries, and reliable estimates are difficult to source. The EAPC Taskforce report “Mapping palliative care systems in long-term care facilities in Europe” found that average length of stay in an LTCF ranged from 63 days in Israel to over 1,080 days in Ireland (Froggatt and Reitinger, 2013). However, the data was provided by identified country experts, the extent to which it is nationally representative of the LTCF population is unclear, and variation in the method of data collection makes meaningful comparisons difficult.

In England, two broad groups of LTCF residents have been identified; those residing for a short period before death or discharge and those who had resided in the facility for months or potentially years (Froggatt and Payne, 2006). The characteristics of these two groups, and variation between them, has not yet been explored. It is unclear whether the factors that increase the likelihood of entering an LTCF are also associated with shorter lengths of stay before death, or if the characteristics that delay admission are associated with subsequently shorter lengths of stays. One systematic review has been conducted exploring factors associated with length of stay in LTCF, however the data was limited to short-term mortality on health-related characteristics and only five studies included were conducted in LTCFs (Thomas et al., 2013).

Previous studies have explored factors associated with length of stay, however there has been no synthesis of these findings (Connolly et al., 2014; Heppenstall et al., 2015; Lucchetti et al., 2015; Navarro-Gil et al., 2014; Sund Levander et al., 2016; Sung, 2014) and only one study compared data across countries (Vetrano et al., 2018). Efforts to map the trajectories of dying LTCF residents have been explored; however, these are limited to the final weeks of life and focus specifically on care at the end of life (Barclay et al., 2014). Our understanding of how the characteristics of LTCF residents with shorter and longer lengths of stay differ is relatively limited.

Deaths in long-term care facilities

The majority of older adults will die in one of three settings; in their home, in a hospital or in some form of LTCF. The proportion of the older adult population dying in each setting varies between countries, for example in an international study of place of death in older adults with dementia, deaths in hospital were most frequent in South Korea (73.6%), Hungary (62.3%), and France (35.9%), in the home in Italy (42.2%), Spain (46.1%), and Mexico (69.3%) and in a long-term care setting in the other eight countries investigated, ranging from 8.9% in Wales to 93.1% in the Netherlands (Reyniers et al., 2014).

As well as being the preferred place of death for those approaching end of life and their families, death at home is consistent with the ageing in place approach (Gomes et al., 2013). The perceived achievement of a home death is dependent on the interplay of clinical characteristics; diagnoses, dying trajectory and pain and symptom management, individual characteristics; demographic variables and patient preference; and environmental characteristics; availability of home care and inpatient beds and provision of social support (Gomes and Higginson, 2006).

Despite this preference, there has been a reduction in the proportion of older adults dying in hospital or at home, and an increase in those dying in LTCFs in the past twenty years, although the proportion of deaths differs significantly between countries (Broad et al., 2013; Houttekier et al., 2010). In England and Wales, LTCFs are projected to become the most common place of death for older adults by 2040 (Bone et al., 2018).

Trajectories of death in older adults

As death is a natural progression for adults approaching older ages, it would be expected that end of life in older adults can be easily recognised and timely, appropriate care provided. In practice, identifying the onset of end of life can be difficult, and the term 'end of life' can refer to the last years, months, weeks, days or potentially hours of life depending on the context and setting. Figure 1.4, 1.5 and 1.6 show three simplified examples of trajectories common in older adults; rapid functional decline, intermittent functional decline and gradual functional decline, alongside the psychological, social and spiritual impacts associated with these trajectories, depicted by Murray et al (Murray et al., 2017). A fourth trajectory, the catastrophic event trajectory (not shown here), has been suggested depicting sudden health events such as a stroke, heart attack or hip fracture, characterised by a rapid decline in health, followed by a prolonged state of dependence (Ballentine, 2013; Ballentine, 2018)

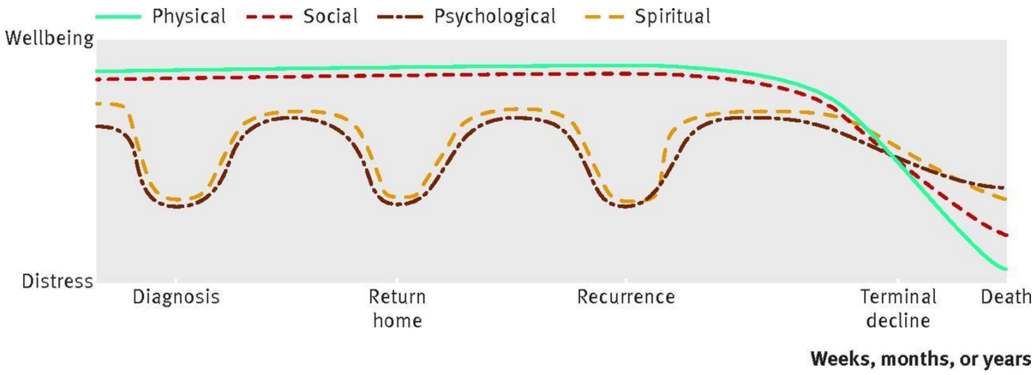

Figure 1. 4. Simplified trajectory of a patient experiencing rapid functional decline (Murray et al., 2017).

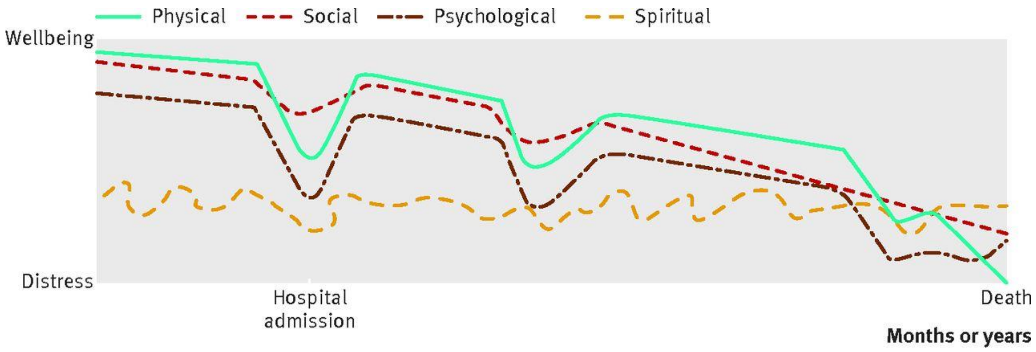

Figure 1. 5. Simplified trajectory of a patient experiencing intermittent decline (Murray et al., 2017).

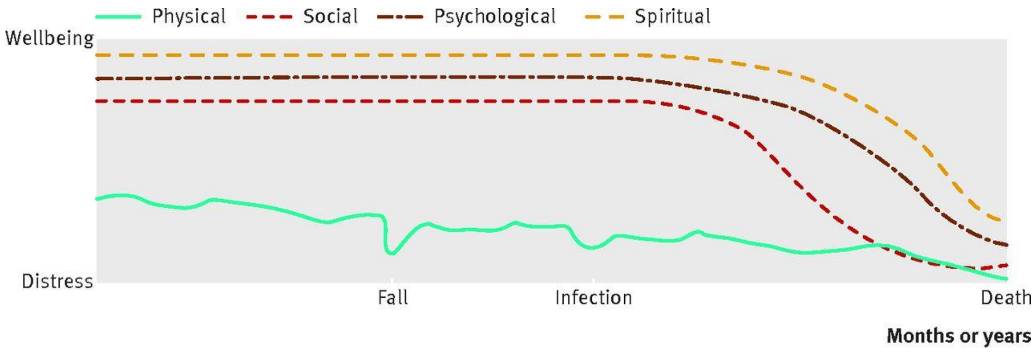

Figure 1. 6. Simplified trajectory of a patient experiencing gradual decline (Murray et al., 2017).

The trajectory of gradual decline is common in older adults experiencing cognitive impairment, frailty and geriatric conditions. As illustrated in figure 1.6, the onset of end of life is less defined, characterised by periods of decreased and increased rates of deterioration. It is also common for older adults approaching end of life to have either no specific diagnoses or multiple diagnoses; making the identification of underlying and contributory causes of death complex, especially among older adults with dementia (Gao et al., 2018). The setting in which death occurs, and the trajectory of dying, have implications for the palliative care is provided.

Definitions of palliative care and end of life care

Palliative care aims to improve quality of life and reduce the suffering in people with advanced and life-limiting conditions. The World Health Organisation offers the following definition:

> *"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"*
>
> (World Health Organization, 2018)

Palliative care is focused on the person and their family, rather than the disease or diagnosis, it neither hastens nor delays death and it focuses on the quality of life of the patient; alleviating physical, psychological, social and spiritual sufferings (Doyle and Woodruff, 2013). Historically, palliative care has been delayed until curative treatments are either no longer effective, despite evidence that 80% of people could benefit from early palliative care, established at the point of diagnosis (Murtagh et al., 2014).

In the UK, and throughout this thesis, the term palliative care is used synonymously with the term end of life care; care provided one to two years before death where the life-limiting nature of the patient's illness or condition becomes apparent to the patient, their family and health professionals involved in providing care (Radbruch and Payne, 2009). Internationally, the term end of life is used to describe a much shorter time frame before death, usually the last weeks, days or hours of life.

Palliative care is delivered on three levels of specialisation, as discussed by Radbruch and Payne (Radbruch and Payne, 2009., Worldwide Palliative Care Alliance, 2014). Firstly, a palliative care approach, or the application of palliative care principles, can be practised by all staff involved in providing care to those approaching end of life, with no specialist training necessary. Secondly, general palliative care can be provided by those who have undergone additional training in palliative care and are routinely working with patients approaching end of life, usually in non-specialist settings such as hospitals or in the community. Finally, specialist palliative care refers to palliative care provided by those who have undergone recognised specialist palliative care training, and whose primary role is to deliver specialist palliative care to patients with complex needs. Although palliative care has usually been provided within an in-patient setting in the UK such as hospices, such care is now provided across settings, including in LTCFs, hospitals, and the community.

Palliative care for older adults

The trajectory of patients with rapid functional decline, as shown in figure.1.4, where end of life is both predictable and anticipated, is consistent with the traditional model of the late involvement of palliative care provided in hospices, provided in the last weeks or months of life when curative treatments have been exhausted (Murray et al., 2005). For the majority of older adults, this model is not compatible with their illness trajectory. The figures shown in 1.7 illustrates three conceptual models of palliative care as compared by Bede et al., described as the traditional, early and dynamic involvement of palliative services model (Bede et al. 2009). In the traditional model of late involvement of palliative services, palliative care begins only when curative treatments have been exhausted. The second model, based on early palliative care involvement, integrates palliative care with disease-modifying treatment from an early stage and is delivered concurrently with other potentially curative or disease-modifying treatments. Finally, the current model of dynamic palliative care involvement is based on the individual patient's needs and their experience of triggers for palliative care (Murray et al., 2017). The dynamic model may be more appropriate to the needs of older adults at end of life, removing the requirement for a specific diagnosis or prognosis to "begin" palliative care, allowing earlier delivery of palliative care and including older adults who could benefit from receiving palliative care alongside treatment for multiple chronic conditions. However, these models are simplified, and the applicability of the models presented to older adults and to LTCF residents has yet to be explored.

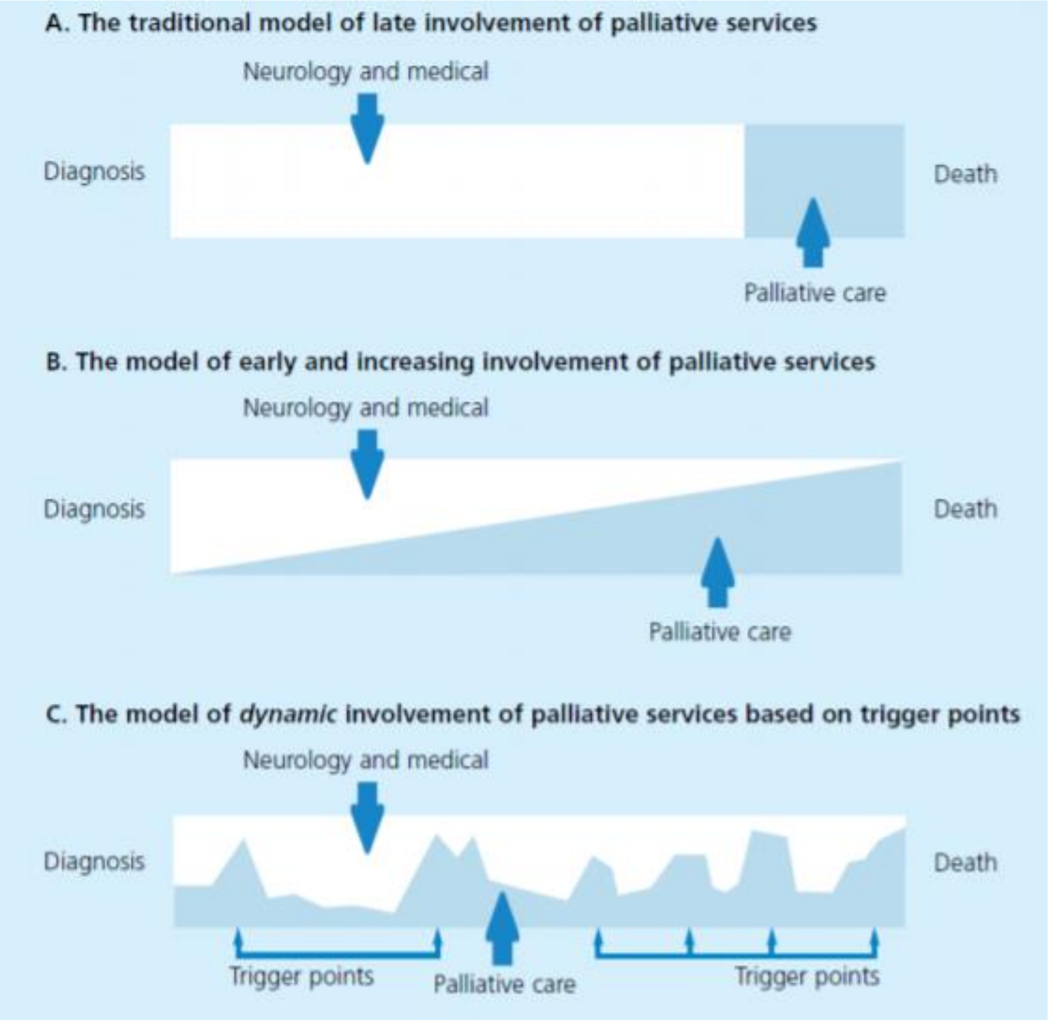

Figure 1.7. The traditional, early and dynamic involvement models of palliative care (Bede et al. 2009).

In practice, providing palliative care to a care-dependant older adult population can be complex. As discussed, palliative care ideally provides appropriate symptom assessment and management to relieve suffering to maximise the quality of life by incorporating psychological, emotional and spiritual care in addition to physical care needs. However, health professionals may view symptoms such as pain in older adults as inevitable consequences of ageing, leading to either a delay in recognising a need for palliative care or under-treatment of symptoms (Collingridge Moore and Payne, 2019). Alternatively, pursuing potentially curative treatment can lead to overtreatment, which may provide little benefit to the patient and unnecessarily reduce quality of life. In older adults with dementia, symptom identification and assessment have the additional challenge of patients who may be unable to communicate their needs (van der Steen et al., 2014).

The discussion and, where possible, enacting of preferences related to end of life, is referred to as advanced care planning (ACP) It allows a patient to define goals and preferences for the care they receive in the future at which time they may lack the capacity to make crucial decisions (Rietjens et al., 2017). While it may be assumed that older adults at end of life will have accepted that they are dying, many older adults may find it challenging to reflect on death and to engage in conversations about their preferences or identify appropriate health professionals with whom to discuss treatment preferences (Piers et al., 2013; Simon et al., 2015). Despite this, ACP has the potential to avoid unnecessary or inappropriate transitions, reduce unwanted treatments and improve quality of life (Brinkman-Stoppelenburg et al., 2014; Seymour et al., 2004).

The provision of support to family carers of older adults both before and after death can also be problematic. Caregivers may be older adults themselves and may find the experience of providing care both physically and emotionally challenging, including feelings of vulnerability, isolation, and anxiety and being unaware of how to access appropriate support (Turner et al., 2016). Palliative care may be a new and potentially worrying concept to caregivers, many of which may have little knowledge or training on what happens to a person as they approach end of life, or what care is available (Collingridge Moore and Payne, 2019).

The extent to which older adults currently receive appropriate palliative care relative to their needs is debatable. Compared to younger counterparts, older adults receive less adequate pain relief, emotional and spiritual support, and are less likely to have their preferences for place of death either recorded or achieved (Gomes and Higginson, 2006; Higginson and Gao, 2012; Hunt et al., 2014). Older adults are also less likely to receive hospice care, and those that do receive a much shorter period of care prior to death (Allsop et al., 2018).

Palliative care for older adults in long-term care facilities

As LTCFs continue to be a place of death for care-dependant older adults, palliative care must be available in this setting. The EAPC has recognised the importance of LTCFs as settings in which of end of life occurs; in 2012, the ‘Palliative Care in Long-Term Care Settings for Older People’ Task Force was established to identify and map the development of palliative care in LTCFs (European Association of Palliative Care, 2020).

In 2019, the EAPC Atlas of Palliative Care in Europe included LTCFs for the first time, reporting the integration of palliative care in LTCFs internationally (Arias-Casais et al., 2019). In the eighteen out of fifty-four countries that provided data for the Atlas, collaboration between palliative care teams and LTCF staff, funding and regulation of palliative care provision in LTCFs, and palliative care training of LTCF staff varied substantially between countries. Despite this growing recognition, palliative care in LTCFs is seldom supported at a national level; in Europe, few countries have national policies which specifically address palliative care in LTCFs (Froggatt et al., 2016) and just over half of countries have national funding available to support the provision of palliative care in these settings (Arias-Casais et al., 2019).

In most countries, the majority of care in LTCFs is provided by a combination of registered, qualified nurses and health care assistants, although staff turnover can be high (Cavendish, 2013). Health care assistants may have little formal training in clinical care, limited knowledge of end of life in older adults and may lack clarity on their role or responsibility in providing palliative care within the facility (Froggatt and Payne, 2006; Smets et al., 2018b). Engagement with health professionals external to the setting, including providers of specialist palliative care services, may be limited, and regulations regarding access to and administration of medications may provide additional barriers to providing palliative care. Despite this, there is evidence to suggest that a palliative care approach can be beneficial to this population by reducing end of life transitions including hospitalisations, achieving preferred place of death and improving compliance with a residents preferences at end of life (Martin et al., 2016; Miller et al., 2016).

At an organisational level, initiatives aimed to improve palliative care in LTCFs have been developed, consisting of staff education (Aasmul et al., 2018; Ampe et al., 2017), inter-professional collaborations and care coordination (Agar et al., 2017; Luckett et al., 2017). Multicomponent interventions to improve the quality of end of life, specifically adapted for use in LTCFs, are also available, such as the Liverpool Care Pathway (Brannstrom et al., 2016) and the Gold Standards Framework for Care Homes (Finucane et al., 2013). The success of such interventions is mainly dependent on their implementation within individual LTCFs; however, the barriers and facilitators to implementing such interventions are not fully understood (Smets et al., 2018a). Systematic reviews of interventions that focused on improving palliative care in such settings, either through changing staff practices or implementing advance care planning, identified a lack of involvement from wider healthcare professionals, the reluctance of staff and relatives to participate, and high staff turnover and workload (Flo et al., 2016; Low et al., 2015). Few studies describe implementation strategies in detail, if at all, and the reporting of contextual information about the intervention and setting is often lacking. The time point at which these interventions aim to improve the care provided to a resident varies from the point of admission to the last few days of life. In the case of residents who die shortly after admission, such activities may coincide, if at all.

Palliative care and length of stay in long-term care facilities

The point at which an older adult is admitted to an LTCF in terms of their illness trajectory varies substantially and is highly dependent on individual circumstances. In nearly all cases, older adults who enter an LTCF do so in response to a combined loss in intrinsic capacity, due to the health implications of ageing, and a lack of adequate support in the environment to compensate for reductions in functional ability, as illustrated in figure 1.1. Combined with the illness trajectories shown in figures 1.4, 1.5 and 1.6, LTCFs are potentially admitting a varied case mix of older adults, some of whom will experience a relatively rapid decline, allowing little time for LTCF staff to recognise, assess and address palliative care needs, and others who experience a gradual decline, potentially requiring palliative care over a more extended period.

At present, little published research has explored explicitly whether there is variation in the palliative care that residents with shorter or longer lengths of stay experience, despite the characteristics of these populations potentially being very different. Previous studies exploring the provision of palliative care in LTCFs have found that residents with longer length of stay before death had fewer hospitalizations, were more likely to receive palliative drug therapy and less likely to be undertreated for non-pain symptoms (Jansen et al., 2014; Porell and Carter, 2005; Rodriguez et al., 2010). As specific guidelines exist for older adults with dementia and their family caregivers, the guidance needed to achieve good palliative care may differ between shorter and longer stay residents, in addition to the specific guidance published on providing palliative care in LTCFs (Payne, 2010; van der Steen et al., 2014).

Methodological challenges in conducting research on palliative care in LTCF

Comparative international data on LTCFs is sparse and attempts to collate country-specific data usually rely on a combination of government reports, journal articles and expert input. Internationally comparable data, such as that collected in the Services and Health for Elderly in Long-term care study (SHELTER), which aimed to implement the interRAI instrument in LTCFs, is available but is not routinely collected on an ongoing basis (Onder et al., 2012a).

The availability, reporting and accessibility of data collected by LTCFs themselves, varies between countries, as shown by comparing practices in the USA and the UK. In the USA, extensive data on LTCF residents is collected through the national Minimum Data Set (MDS), which, since 1998, has collected information on all residents in Medicare or Medicaid LTCFs, and informs insurance payments for long-term care (Mor et al., 2011). The availability of such data has been utilised for multiple research studies and to routinely monitor the quality of care provided to residents (Gambassi et al., 1998; Hirth et al., 2014; Li et al., 2013).

In comparison, in the UK there is no mandate for the clinical assessment or reporting of LTCFs for insurance or funding purposes, and there is no national, routinely available data on the health of LTCF residents. The feasibility of establishing an MDS in the UK and using standardised assessment tools is underway, however at present the scope of data collected on a residents medical history and care is locally determined by individual facilities or organisations (Chadborn et al., 2019; Musa et al., 2020).

The majority of longitudinal and cohort studies either do not include or follow-up older adults in LTCFs (Collingridge Moore and Hanratty, 2013). The identification of LTCFs residents from existing datasets, such as primary care data, has been achieved through postcode matching however this approach can be complex, time-consuming and potentially inaccurate (Burton et al., 2019). The majority of epidemiological studies of LTCF residents in the UK are limited either geographically to LTCFs in one region, to LTCFs from one organisation or care provider, or are dependent on data collected for a specific research study (Bowman et al., 2004; Gordon et al., 2014; Stewart et al., 2014).

In addition to the complexities of conducting research on older adults, such as minimising participant burden, withdrawal from deterioration in health, and engaging family gatekeepers, conducting research in LTCFs presents additional challenges (Davies et al., 2010). Researchers collecting data in LTCFs may encounter gatekeeping from LTCF owners and managers, additional complications in gaining consent from residents who may lack the capacity to consent to participate in research and issues with staff recruitment and retention (Collingridge Moore et al., 2019; Lam et al., 2018). Research on the health of LTCF residents in the UK has yet to benefit from the potential of big data to the same extent other areas of health research have, partly due to the identification of patients by diagnostic groups rather than by care setting.

Combined with the challenges inherent to conducting research in LTCFs, research in the area of palliative care adds further complexity. There may be a perceived unwillingness of patients and staff to engage with research conducted at end of life, concerns over causing unnecessary distress and ethical concerns regarding approaching and recruiting patients at end of life and their family carers (Collingridge Moore et al., 2019). Guidance on researching palliative care is emerging, although it is not specific to LTCFs (Evans et al., 2013).

Research conducted on length of stay and palliative care, in particular, is open to several methodological limitations, which make the interpretation of findings problematic. Residents are often separated into groups based on their length of stay; such as under six months, up to one year or over one year before death, leaving the experience of residents with longer lengths of stay unexplored (Pivodic et al., 2018). At present, no research has analysed length of stay as a primary explanatory variable, and none have reported conducting any preliminary analysis to identify confounding factors associated with length of stay in the data, such as age, gender, dementia diagnosis or marital status. The associations between length of stay and the provision of palliative care remains unexplored.

The PACE Study

The PACE (Palliative Care for Older People in care and nursing homes in Europe) consortium is an example of an international collaboration that aimed to improve palliative care in LTCFs (PACE Consortium, 2018). The consortium involved seven countries; Belgium, Finland, Italy, the Netherlands, Poland, Switzerland, and England and comprised of three phases.

The first phase mapped, defined and classified different structures, organisational models, and policies related to palliative care provision in LTCFs in Europe (Froggatt et al., 2016). In doing so, the study updated the EAPC Taskforce on Palliative Care in Long-term care settings for older people, published in 2013, and included data on twenty-nine European countries (Froggatt and Reitinger, 2013).

The second phase conducted a cross-sectional, mortality follow-back study of residents’ deaths over a retrospective three-month period (Van den Block et al., 2016). It aimed to explore the effectiveness of health care systems with and without formal palliative care structures, in terms of quality of dying, quality of life, quality of palliative care, cost-effectiveness, and staff knowledge, practices, and attitudes, using data collected from LTCF staff, physicians and relatives.

The third phase was a cluster randomised controlled trial (RCT) of the 'PACE Steps to Success' intervention, delivered over twelve months (Smets et al., 2018a). The trial outcomes included an evaluation of the implementation process of the intervention in LTCFs in each country, and facilitators, barriers, and challenges to this (Oosterveld-Vlug et al., 2019).

The PACE programme generated three principal outputs: the PACE Steps to Success programme, the EAPC White Paper on Palliative care implementation in long-term care facilities, and the “Improving palliative care in care homes” Massive Open Online Course (MOOC). The previous PACE work packages informed the refinement of the PACE Steps to Success programme, which is a freely available resource for LTCF managers and facilitators, and to date has been translated into six languages (Payne et al., 2018). The final publication, “Palliative care implementation in long-term care facilities: European Association for Palliative Care White Paper”, was published in Journal of the American Medical Directors Association (Froggatt et al., 2020). It combined the findings of an international scoping review of implementation strategies of palliative care interventions in LTCFs (chapter six), the results of the PACE cluster RCT, and a transparent expert consultation to develop a framework of twenty recommendations to guide implementation of improvements in palliative care in LTCFs. The PACE Steps to Success programme was the basis for the “Improving palliative care in care homes” MOOC, a three-week course delivered in 2019 and repeated in 2020, attracting over 3,295 students internationally (Payne et al., 2019).

Research aims of this thesis

The topic of this thesis is the relationship between resident length of stay and palliative care in LTCFs for older adults in Europe. This section will discuss the rationale for this work in this thesis, and the research questions it aims to answer.

Rationale for this thesis

Population ageing has led to an urgent need to ensure that care-dependant older adults unable to remain in the community until death receive appropriate palliative care. LTCFs are increasingly becoming a place of care and of death for this population, occupying a unique and increasingly important role within long-term care systems (Bone et al., 2018). For many LTCF residents, especially those with dementia, those who cannot express their needs or preferences, or those with little support from family caregivers, LTCFs are integral in ensuring quality of life, and quality of death.

Despite this, the experience of older adults in LTCFs is mostly absent from public health policy on healthy ageing. Compared to community samples of older adults, relatively little is known of how the LTCF resident population varies, whether such variation is associated with subsequent variation in care at end of life, or how such care can be delivered in these settings. Any approach to meeting the care needs of older adults that excludes the experience of those who are care-dependant and lack the functional ability to age in place, could increase inequalities within an ageing population. The development and delivery of appropriate health services to meet the challenges of an ageing population require a greater understanding of how older adults utilise LTCFs, including differences within this population, the relationship with palliative care indicators, and how interventions to improve palliative care can be implemented successfully.

Research question and aims

The principal research question is “How are resident length of stay and palliative care in LTCFs associated?” The relationship between resident length of stay and palliative care will be explored in four stages, as shown in table two, breaking down the research question into four aims:

1. To systematically identify, synthesise and quality-assess data on factors associated with resident length of stay in LTCFs.
2. To explore any association of resident, facility and country-level factors with length of stay in LTCFs, using internationally comparable data.
3. To explore the relationship between length of stay and care at end of life in LTCFs, using internationally comparable data.
4. To identify facilitators and barriers to implementing palliative care interventions in LTCFs.

Format and structure of this thesis

This section will give an overview of the thesis and an outline of each of the chapters. In addition to outlining the research questions and methodology used, it will describe my role in the development of each paper. This thesis is presented as alternative format and includes four papers published in peer-reviewed journals.

Outline of the chapters

Four studies were conducted to answer the four research questions. These were a systematic review, two empirical studies of data collected in the PACE study, and a scoping review, illustrated in table 1.2.

Chapter 2: Methodology

The methodology chapter introduces literature review methodology, with a specific focus on the development and application of systematic reviews and scoping reviews, to meet the aims of chapters three and six. The chapter discusses the PACE study, and how data from the study is used in chapters four and five, before exploring the application of mixed generalised linear models, in particular time to event analysis.

Chapter 3 (Paper 1): Factors associated with length of stay in care homes. A systematic review of international literature

The first paper forms the foundation of this thesis, upon which subsequent chapters are built. It is a systematic review that addresses the first aim of the thesis; to systematically identify, synthesise and quality assess data on factors associated with length of stay in LTCFs.

I defined the research question and developed the review protocol, including designing the search strategy, conducted the literature search, applied inclusion and exclusion criteria, performed data extraction and quality assessment, synthesised the data, and prepared the manuscript.

Chapter 4 (Paper 2): Length of stay in long-term care facilities – a comparison of residents in six European countries. Results of the PACE cross-sectional study

The second paper applies the findings of paper one to an international dataset of deaths in LTCFs, collected in the PACE study. The analysis meets the second aim of the thesis; to explore the association of resident, facility and country-level factors with length of stay in LTCFs, using internationally comparable data.

As part of my employment as a researcher on the PACE study, I was responsible for managing the England arm of the PACE study, including recruitment, data management and data cleaning, providing an opportunity to contextualise the data in the broader public health policy on global ageing. To explore length of stay in the residents included in the PACE study, I prepared the variables required for the research, conducted time to event analysis on the data, interpreted the results and prepared the manuscript.

Chapter 5 (Paper 3): Associations between length of stay in long-term care facilities and provision of palliative care. Analysis of the PACE cross-sectional study

The third paper explores whether indicators of palliative care vary between shorter and longer stay residents. It aims to answer the third aim of the thesis; to explore the relationship between length of stay and palliative care in long-term care facilities, using internationally comparable data. The analysis incorporates the findings of chapter four to identify factors to be controlled for to allow the accurate exploration of the relationship between length of stay and five indicators of palliative care. These measures are quality of care in the last month of life, comfort in the last week of life, contact with health services at end of life, the presence of advance directives and consensus in care among relatives and staff members. In addition to my employment as a researcher on the PACE study, I prepared the variables required for the research, conducted multivariate regression on the data, interpreted the results and prepared the manuscript.

Chapter 6 (Paper 4): Strategies for the implementation of palliative care education and organisational interventions in long-term care facilities: A scoping review

The fourth paper in this thesis focuses on how palliative care interventions can be implemented successfully in LTCFs, and in doing so proposes possible explanations for the findings of the previous three chapters. It seeks to address the final aim of the thesis, to identify facilitators and barriers to implementing palliative care interventions in LTCFs.

The paper is a scoping review of studies reporting organisational level interventions to improve palliative care in LTCFs, using a thematic synthesis approach to data analysis.

I defined the research question and protocol for the review, conducted the literature search, applied inclusion and exclusion criteria to the identified papers, performed data extraction, synthesized the data and prepared the manuscript. The review was subsequently used in conjunction with wider findings from the PACE study to inform the “Palliative care implementation in long-term care facilities: European Association for Palliative Care White Paper”, published in Journal of the American Medical Directors Association (Froggatt et al., 2020).

Chapter 7: Discussion

The discussion chapter of this thesis reflects on the research question posed in the introduction chapter, “How are resident length of stay and palliative care in long-term care facilities associated?” It will discuss the knowledge that has been contributed to the wider research area in the construction of this thesis and summarise how each of the pre-specified research aims have been met. The main findings of each chapter will be summarised and the strengths and limitations of the four methodological approaches used, and of the thesis, are discussed.

Chapter 8: Conclusion

The concluding chapter of this thesis will discuss priorities for further research, clinical practice implications, and policy recommendations.

Research question	**How are resident length of stay and palliative care in long-term care facilities associated?**			
Chapter	Chapter 3	Chapter 4	Chapter 5	Chapter 6
Paper	Collingridge Moore, D., Keegan, T. J., Dunleavy, L. & Froggatt, K. (2019) Factors associated with length of stay in care homes: a systematic review of international literature. Syst Rev, 8(1), 56.	Collingridge Moore, D., Payne, S., Keegan, T., Van Den Block, L., Deliens, L., Gambassi, G., Heikkila, R., Kijowska, V., Pasman, H. R., Pivodic, L. & Froggatt, K. (2020) Length of stay in long-term care facilities: a comparison of residents in six European countries. Results of the PACE cross-sectional study. BMJ Open, 10(3), e033881.	Collingridge Moore, D., Keegan T, Payne S, Deliens L, Smets, T., Gambassi G, Kylänen, M., Kijowska V, Onwuteaka-Philipsen, B. & Van Den Block L (2020) Associations between length of stay in long-term care facilities and palliative care. Analysis of the PACE cross-sectional study. International Journal of Environmental Research and Public Health, 17(8), E2742.	Collingridge Moore, D., Payne, S., Van Den Block, L., Ling, J. & Froggatt, K. (2020) Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review. Palliat Med, 34(5), 558-570.
Research aim	To systematically identify, synthesise and quality-assess data on factors associated with resident length of stay in LTCFs.	To explore the association of resident, facility and country-level factors with length of stay in LTCFs, using internationally comparable data.	To explore the relationship between length of stay and care at end of life in LTCFs, using internationally comparable data.	To identify facilitators and barriers to implementing palliative care interventions in LTCFs.
Hypothesis	N/A	There is no variation in length of stay between LTCF residents.	There is no association between length of stay and care at end of life in LTCFs	N/A
Design	Systematic literature review	Mixed time to event analysis of data from mortality follow-back study	Generalised linear mixed model of data from mortality follow-back study	Scoping literature review with thematic analysis
Focus of analysis	Identification and assessment of factors associated with resident length of stay	Application of factors associated with resident length of stay to internationally comparable data	Exploration of relationship between resident length of stay and indicators of palliative care, using internationally comparable data	Identification of facilitators and barriers to the implementation of palliative care interventions

Table 1.2. Framework of the structure of the thesis to answer the research question.

Chapter 2: Methodology

The aim of this section is to discuss the methodologies used in this thesis.. Firstly, it will explore the methodological approach of literature reviews, focusing specifically on systematic and scoping reviews. Secondly, it will provide an overview of the PACE study. Thirdly, the use of generalised linear mixed models will be introduced, with a focused discussion on the development and application of time to event analysis. The chapter will conclude with an overview of the methodologies used in this thesis.

Review methodology

Literature reviews are used as the chosen methodological approach in chapters three and six. In chapter three, the first aim of the thesis is addressed; to systematically identify, synthesise and quality assess data on factors associated with length of stay in LTCFs. In chapter six, the final aim of the thesis is addressed, to identify facilitators and barriers to implementing palliative care interventions in long-term care facilities.

A literature review aims to source, combine and synthesise the findings of multiple studies into a critical summary of key findings. A literature review can be defined as

"an analysis and synthesis of work that has been undertaken in a particular area"

pp 1 (Aveyard et al., 2016)

An effective literature review should provide support to a well-defined, pre-specified research topic (Samnani et al., 2017). It should adopt clear inclusion criteria, an appropriate approach to searching the literature and, if required, an assessment of the quality of the data. In addition, it should contribute to the development of new practice, including informing policymaking and identifying what is known and what remains unknown in a specific research area (Aveyard et al., 2016).

A typology of literature reviews has been developed to meet the needs of researchers; however, the key characteristics of their conduct are largely consistent. Prior to starting a literature review, the area of interest, objectives and methodology are established. Pre-specification of how the review will be conducted provides focus, guides the search strategy, clarifies inclusion criteria prior to application, ensures consistency between reviewers and reduces bias (Denison et al., 2013).

The development of inclusion criteria ensures that relevant studies are identified and included to meet the objectives of the review, deliminating the boundaries of the review. Establishing appropriate, comprehensive inclusion criteria allows for the development of the search strategy, including the use of free text words and Medical Subject Headings (MeSH) where available, to identify potential studies for inclusion (Centre for Reviews and Dissemination, 2008; Higgins and Green, 2011). The process also informs the choice of sources to search, including electronic databases, grey literature and relevant websites. Additional papers can be identified through reviewing the reference lists of publications that meet the inclusion criteria, reverse citation searches and sourcing studies included in previously systematic reviews, if available. Inclusion criteria are applied to all publications identified, at abstract and full paper stage, and two reviewers on at least 10% of the sample to ensure reproducibility and consistency in application of the review protocol; minimising selection bias and random error conduct screening.

Once appropriate studies have been identified, data is extracted using a predefined, consistent approach, allowing relevant evidence to be summarised and findings within the studies to be compared and located within the wider literature. If required, studies are assessed based on their quality, allowing the strengths and limitations of the research conducted to be appraised, and, where appropriate, incorporated in data synthesis. Quality assessment aims to assess the risk of bias in relation to the review question, based on the flaws in the design or conduct of the study (Denison et al., 2013). Finally, data synthesis combines data from individual studies to conduct an analysis on the combined. The choice of the approach to data synthesis is dependent on the nature of the data being synthesised, and the aim of the review.

The choice of methodology used in conducting a literature review is guided by the aims and objectives of the review and the research question of interest. Although systematic reviews are arguably the most widely used approach due to the methodological refinement and guidance developed by the Cochrane Collaboration (Higgins and Green, 2011), the need for different types of review methods, both in the approach to searching the literature (which may or may not be systematic) and the synthesis of identified data, has created multiple variations. A typology of frequently used reviews in health research is shown in table 2.3, alongside their aims, strengths and weaknesses.

Review type	Aim	Strengths	Weaknesses
Systematic review	Aims to systematically search, collate, and synthesise evidence using pre-specified eligibility criteria to answer a research question	▪ Follows a rigorous, standardized methodology, informed by internationally agreed guidance (Centre for Reviews and Dissemination, 2008; Higgins and Green, 2011) ▪ Replicable, due to predefined, standardised protocol ▪ Incorporates a quality assessment of included studies, reducing bias ▪ Emphasis is on identifying all relevant studies in the area.	▪ Selection bias towards published research – grey literature may be missed ▪ Stringent inclusion criteria may exclude informative studies that provide wider context.
Scoping review	Aims to map the breadth of evidence available, including the main sources and types of evidence, underpinning a research area (Arksey and O'Malley, 2005)	▪ Shows the breadth or "scope" on a specific research topic ▪ Includes ongoing research ▪ Can identify area for further research ▪ Useful for policymakers in providing an overview of a research area ▪ Can provide a basis to inform the protocol for a systematic review	▪ Systematic approach to search strategy not inherent. ▪ Lacks quality assessment ▪ Recommendations from the findings can be limited
Critical review	Aims to critically evaluate the quality of the literature identified, often resulting in a theory, hypothesis or model (Grant and Booth, 2009)	▪ Critically evaluates the included studies ▪ In depth discussion of the strengths and weaknesses of individual studies ▪ Results in a hypothesis or model	▪ Lacks quality assessment ▪ Systematic approach to search strategy not inherent.
Mapping review	Aims to identify gaps in knowledge and identify future research needs, which are presented visually (Miake-Lye et al., 2016)	▪ Provides a contextualised overview of the research area ▪ Visual representation of mapped literature ▪ Identifies gaps in research (Schmucker et al., 2013)	▪ Lacks quality assessment ▪ Underlying trends may not be fully explored ▪ No specific guidelines on conduct available at present
Review of reviews	Aims to create a summary of evidence from multiple systematic reviews (Higgins and Green, 2011).	▪ Synthesises evidence in areas where multiple systematic reviews have been conducted ▪ Incorporates and explores inconsistencies and differences in conclusions between reviews (Smith et al., 2011) ▪ Includes an assessment of quality	▪ Suitable only in research areas that already have systematic reviews conducted
Rapid review	Aims to use strategies to streamline and accelerate the review process, usually to inform decision making (Khangura et al., 2012; Tricco et al., 2015)	▪ Conducted in a shorter time frame than other reviews. ▪ Usually context specific, i.e. relevant to a specific region (Ganann et al., 2010) ▪ Can provide a basis to inform the protocol for a systematic review	▪ No specific guidelines on conduct available at present ▪ Accelerated methodology may lead to missing information ▪ Not appropriate for areas with a large number of publications

Table 2.1. Typology of frequently used review methods in health research, including aim, strengths and weaknesses, adapted from Grant and Booth, 2009 (Grant and Booth, 2009).

In chapters three and six, the choice of methodological approach used to inform the development, implementation and reporting of the literature review was guided by the Search, Appraisal, Synthesis, and Analysis (SALSA) framework, which defines different types of review based on their approach to the search, appraisal, synthesis and analysis of the evidence (Grant and Booth, 2009). Table 2.4 applies the SALSA framework to the research requirements of chapters three and six, in addition to the current evidence base in the area.

	Chapter three	Chapter six
Research requirements	Systematic identification of all published studies exploring the association of more than one factor with length of stay of LTCF residents prior to death, allowing synthesis of quantitative data combined with an assessment of study quality.	Identification of facilitators and barriers to implementing reported in palliative care interventions in LTCFs, to underpin the creation of a conceptual model.
Evidence base	Observational studies in diverse contexts – no existing literature review conducted specifically in LTCFs.	Intervention and evaluation studies reporting implementation – no existing review conducted.
Search	Systematic, rigorous, replicable search, identifying all relevant primary studies in the field.	Systematic, replicable search to identify studies reporting implementation, aiming for breadth of evidence, focusing on examples of implementation.
Appraisal	Quality assessment required to inform the relative strength of study findings and incorporated in the synthesis of the findings.	Quality assessment not required – focus is on implementation strategies rather than outcomes of the study.
Synthesis	Synthesis of quantitative data, specifically hazard ratios and odds ratios, allowing for an assessment of the strength of evidence for each factor identified.	Reporting of implementation strategies for simple numerical synthesis, qualitative analysis of facilitators and barriers to implementation as discussed by study authors within the paper.
Analysis	Numerical analysis of data identified, synthesising the direction and signification of the reported association between the factor and length of stay and incorporating the assessed quality of the study overall.	Analysis of qualitative data to identify commonalities across the literature, interpreting the themes emerging to create a conceptual model.
Methodological approach used	Systematic review, applying a method of data synthesis used by Luppa et al in a systematic review of predictors of LTCF admission (Luppa et al., 2010).	Scoping review, applying a systematic search strategy and guidance developed by (Arksey and O'Malley, 2005).

Table 2.2. Research requirements mapped against the SALSA framework (Grant and Booth, 2009).

In chapter three, a systematic review was chosen as the methodology most appropriate to meet the objectives specified. A systematic review allows for the identification of all primary studies of factors associated with length of stay in a LTCF. An assessment of the quality of the data is also required, synthesising the quantitative data reported in the context of the quality of the study. In addition, a systematic review will identify the methodological approaches used to explore the association between length of stay and resident and facility factors.

In chapter six, a scoping review method was chosen to meet the research aims and requirements specified. A scoping review allows for the identification of a range of studies reporting organisational level palliative care interventions in LTCFs, which may report implementation in addition to the main study outcomes. An assessment of quality is not required, as the efficacy of the intervention is not the outcome of interest, and the exclusion of poor-quality studies could exclude discussion of important barriers to implementation.

Systematic reviews

A systematic review aims to identify all evidence relevant to a specific research question and synthesise the evidence and can be defined by a clearly stated set of objectives with pre-defined eligibility criteria for studies, an explicit, reproducible methodology, a systematic search strategy, an assessment of the validity of the findings of the included studies, and a systematic presentation, and synthesis, of the characteristics and findings of the included studies (Denison et al., 2013; Higgins and Green, 2011).

Systematic reviews of epidemiological studies have inherent challenges, as encountered in this review. The PICOS (patient, intervention, control, outcome, study design) approach to developing inclusion criteria was not appropriate to the review aims, as there is no intervention or control criteria to apply, and further contextual criteria, such as setting or exposure, were required (Centre for Reviews and Dissemination, 2008). The approach was adapted for this review to include the setting (LTCFs), participants (older adults) outcome (length of stay) and study design (observational studies).

The identification of epidemiological studies can be problematic, as there is greater variability and inconsistency in the terminology used to report study designs, which can lead to poor indexing (Li L et al., 2019). In addition, this systematic review focused on multiple explanatory variables, compared to one. Studies that explored the role of one factor on length of stay only, such as depression or malnutrition, were excluded from this review. Firstly, it would be impossible to develop a search strategy that could identify all factors associated with length of stay without first having a basis on which to justify the inclusion of search terms for each factor. Secondly, the number of studies identified would be very large and difficult to synthesize within the time and resource constraints of the thesis.

Data extraction of epidemiological studies has the additional complexity of the results of multiple analyses being reported, i.e. adjusted and unadjusted, or as separate analyses by cohorts, such as by gender, or by follow up period (Mueller et al., 2018), which requires a decision on which results would be most appropriate to use for comparison between studies.

The choice of data to extract was based on the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement, which provides a checklist of recommendations for the reporting of observational research (Vandenbroucke et al., 2007). The recommendations outlined in the STROBE statement, in addition to background knowledge of the research area, provided a clear, comprehensive approach to extracting the aims, methodology and findings for each study, allowing comparison between studies.

Quality assessment is the critical appraisal of the literature; its strengths, weaknesses and the relative value of the evidence and its contribution to the literature review (Aveyard et al., 2016). Compared to randomised controlled trials, there are substantially fewer tools designed to assess the methodological quality and risk of bias in observational studies. The characteristics that constitute quality vary between studies, dependant on their aims and methodology, however commonalities can be identified. In a systematic review of eighty-six tools to assess quality and susceptibility to bias in observational studies, assessment criteria were based on study selection methods (92%), choice of variables (86%), sources of bias (86%), confounding (78%) and statistical analysis (78%) (Sanderson et al., 2007). In practice, the application of any of these tools may not be appropriate to the research question or the evidence included, and bespoke tools developed to meet the specific needs of individual reviews are common. The Newcastle Ottawa Scale, for example, is a quality assessment for case control studies and cohort studies however would not be appropriate for assessing other epidemiological study designs, such as mortality follow-back studies, where deaths do not constitute loss to follow up (Peterson et al., 2011).

In systematic reviews of RCTs, a meta-analysis would be the standard approach to synthesising quantitative data. Meta-analysis is the process of combining numerical data from multiple studies exploring the same question to summarise the totality of evidence (Spector and Thompson, 1991). In systematic reviews of epidemiological studies, conducting meta-analysis on the data collated can be more challenging. There is wider potential for heterogeneity in settings, independent variables and study designs, meaning that pooling data may not be appropriate. Some studies have based the decision to pool the results by using the I^2 statistic; a random-effects model to make a statistical assessment of heterogeneity, by basing the decision on clinical considerations and an assessment by the reviewer on whether a meta-analysis is needed to meet the objectives of the review (Mueller et al., 2018). In addition, in reviews of more than one explanatory variable, a separate meta-analysis would need to be conducted for each independent variable, i.e. pneumonia, dementia or cancer, would be required.

The quality assessment and data synthesis applied in this review replicated that of Luppa et al, allowing for findings on length of stay to be comparable to factors associated with LTCF admission (Luppa et al., 2010). The review adopted a modified quality assessment appropriate for appraisal of observational studies conducted in LTCFs (Appendix B). The approach to data synthesis for each factor combined the quality assessment of each study with the direction of the variables effect on length of stay and their significance. The process resulted in an assessment of the strength of the evidence for each risk factor as either strong, moderate, weak or inconclusive.

Reporting guidelines

The reporting of the systematic review used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines, which were developed to standardize the conduct and reporting of systematic reviews, enhancing transparency (Moher et al., 2009). The PRISMA statement consists of a twenty seven-item checklist, related to a description of the review rationale, specification of study characteristics, presentation of a full electronic search strategy for at least one database, description of the methods of handling data and combining results of studies and assessment of risk of bias.

Scoping reviews

A scoping review aims to map the breadth of evidence available, including the main sources and types of evidence, underpinning a research area (Arksey and O'Malley, 2005). As discussed by Davis et al, a scoping review

> *"involves the synthesis and analysis of a wide range of research and non-research material to provide greater conceptual clarity about a specific topic or field of evidence"*
>
> **pp 1386** (Davis et al., 2009).

The relative strength of a scoping review is its ability to explore a breadth of literature, potentially including different study designs, and rejection of the requirement for a quality assessment. If applied correctly, the wider mapping of the research area can outweigh the lack of in depth analysis found in a systematic review (Aveyard et al., 2016).

The aim of this scoping review focuses on the exploration of how palliative care interventions are implemented in LTCFs, rather than the effectiveness of the strategies used. Relevant evidence could include various types of intervention investigated using a range of study designs, including multiple quantitative and qualitative outcomes. The application of an in-depth analytical approach could potentially limit the findings, especially as the majority of reporting of the experiences of implementation are reported within the discussion section of publications.

Arksey and O'Malley have proposed a five-step methodological framework for the conduct of scoping reviews (Arksey and O'Malley, 2005), shown in table 2.5. In the scoping review conducted in chapter six, two review questions were identified; what implementation strategies were used to support the delivery of palliative care interventions in long-term care facilities, and what are the facilitators and/or barriers to successful implementation. A systematic search strategy was developed but restricted to 2007 to focus the review on current literature. In addition to the study design and intervention, data charting was restricted to four key, predefined areas of implementation; facilitation, training or education, internal engagement and external engagement, to focus the review.

Framework stage	***Purpose***
Identifying the research question	To identify the primary research question of the review and its objectives, by clarifying the parameters of the research and assigning definitions of key concepts.
Identifying relevant studies	To conduct a comprehensive search and identification of evidence relevant to the research question, within the parameters determined. Achieved using electronic database searches, reference lists, hand searching and networks, where appropriate.
Study selection	To apply inclusion criteria to identified studies, which can be refined ad hoc as familiarity with the evidence increases.
Charting the data	To chart key information from included studies, or sifting, sorting and mapping evidence into key themes and concepts (Spence, 1994), equivocal to data extraction in a systematic review.
Collating, summarizing and reporting the results	To present a narrative overview of the evidence identified, using some form of analytical framework appropriate to the objectives of the review. In comparison to a systematic review, there is no assessment of quality or to aggregate the data for generalizability.
Consultation exercise (optional)	To involve wider stakeholders in the interpretation of the data and identify other sources of evidence

Table 2.3. The five-step methodological framework for the conduct of scoping reviews (Arksey and O'Malley, 2005).

The first four stages discussed in the framework are similar to those conducted in the majority of literature reviews; however, the final stage requires further discussion. Levac et al. recommend breaking this final stage into three parts; analysis of the data (either using descriptive statistics or qualitative analysis), reporting of the results in the context of the research question and consideration of the wider meaning of the findings, such as implications for further research or for policy and practice (Levac et al., 2010).

In chapter six, quotes on facilitators and/or barriers to implementation of the intervention were extracted, primarily in the author's discussion of their study findings. The process of collating, summarizing and reporting such data was guided and enhanced through qualitative evidence synthesis. The choice of qualitative evidence synthesis used in stage five of the scoping review, to collate and summarise the results, was guided by the RETREAT criteria for selecting methods for qualitative evidence synthesis (Booth et al., 2016). The RETREAT criteria use the review question, the epistemology underpinning the review, time frame, resources, team expertise, audience and type of data being synthesized to identify an appropriate approach to qualitative synthesis.

The scoping review used thematic synthesis to analyse the findings of the scoping review (Thomas and Harden, 2008). Thematic synthesis was applied in three stages; firstly, the quotes extracted from each paper were coded line by line, secondly, the free codes were organised into related areas, to construct 'descriptive' themes; and finally the themes were developed into 'analytical' themes. Such an approach allows for the translation of concepts between studies and uses a cyclical process to create analytical themes that describe and explain the descriptive themes identified (Thomas and Harden, 2008).

As further scoping reviews have been published, proposed enhancements to the five-step methodological framework have been developed. Levac et al recommended combining a broad research question with a clear scope of inquiry to guide the review, including defining key populations, outcomes and concepts early on to establish an effective search strategy (Levac et al., 2010). The review defined LTCFs, implementation strategies and palliative care early in the review, to inform the search strategy. In addition, Daudt et al. discuss the enhancement provided by prioritizing aspects of the literature based on the implications for future research, notable gaps and areas of interest based on the research teams' experience, to add meaning to the data (Daudt et al., 2013).

Reporting guidelines

As the scoping review methodology is still a developing approach, there have been concerns regarding the quality of methodological rigour, potential for poor reporting and a lack of clarity in the terminology used to identify scoping reviews (Pham et al., 2014). In response to these challenges, the PRISMA Extension guided the scoping review reporting for Scoping Reviews (PRISMA-ScR), which provides guidance on the reporting of scoping reviews (Tricco et al., 2018). In addition, the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement was used to guide the reporting of the approach used for qualitative evidence synthesis, and to ensure transparency in methodological rigour (Tong et al., 2012).

The PACE Study

This thesis uses data collected in the PACE study. As discussed in the introduction, the PACE programme of research included a mortality follow-back study of all resident deaths in LTCFs in six countries during three-month retrospective period between 2015 and 2016. The protocol for the study includes further information on the methodology used and ethical approvals obtained (Van den Block et al., 2016), however the key methodological approach used is discussed below.

Mortality follow-back studies are a common approach to exploring end of life, and have been used previously to collect data on care costs and quality, decision making, emergency department attendance and referral to specialist palliative care services (Bone et al., 2019; Vanbutsele et al., 2019; Wendrich-van Dael et al., 2019; Yi et al.). The use of retrospective data collection in palliative care research allows the inclusion of all deceased participants, rather than those who die in a specified timeframe, as is the case in prospective studies. Collecting data retrospectively removes the need to specify the onset of end of life, which can be difficult in older adults, and does not require identification of those at risk of dying (Teno, 2005). In addition, it reduces the risk of withdrawal or exclusion of participants whose health restricts their participation (Lawson et al., 2013).

The study was conducted in LTCFs in six Europeans countries; Belgium, Finland, Italy, the Netherlands, Poland and England. The study used the same definition of LTCFs as used throughout this thesis (Froggatt and Reitinger, 2013). Each country involved in the study created a proportional random sampling framework based on national lists of LTCFs. In Italy, no national list of LTCFs was available; therefore, a previously identified source of nursing homes interested in research was used (Onder et al., 2012a). In England, a dataset collated by the Care Quality Commission (CQC) was used, and additional LTCFs were recruited from Enabling Research in Care Homes, a network of LTCFs with an interest in research participation, in addition to those identified and approached through the sampling framework (Enabling Research in Care Homes Network, 2016). The sampling framework was based on the following criteria, with an example from England:

1. Region – each country was split into regions, East Midlands East of England, London, North East, North West, South East, South West, West Midlands and Yorkshire and the Humber.
2. Type – LTCFs were subsequently categorized as type 1: a facility where on-site care is provided by physicians, nurses and care assistants and is either a standalone facility or a unit within a hospital (present in Italy, the Netherlands, Poland); type 2: a facility where on-site care is provided by nurses and care assistants with medical provision provided by local, external primary care services when required and is a standalone facility (present in all countries); type 3: a facility where on-site care is provided by care assistants and nursing with medical provision provided by local, external primary care services when required and is a standalone facility (present in England).
3. Size – LTCFs were categorized as either small or large was based on the median number of beds in each country, for example in England LTCFs with under 30

beds were classed as small and facilities with 30 beds or over were classed as large.

4. Funding status – LTCFs were categorized as either the public sector, the private for profit sector or the not for profit sector. As with LTCF type, not all types are present in each country; in England, LTCF were classed as either not for profit or privately funded (Van den Block et al., 2016).

The managers of the LTCFs identified were contacted by post or e-mail with an information pack about the study and an invitation to take part. LTCFs that agreed to take part in the study were visited by the research team and asked to provide data on the facility, all resident deaths in a retrospective three-month period and staff knowledge and attitudes to palliative care.

Residents were included if they had died in the LTCF, or after transfer to another facility, i.e. to hospital. Several trajectories were possible, a resident may have been admitted many years before the three-month period prior to the research visit or may have been admitted during this period. The start and end date of the three-month period varied by LTCF. An example of nine possible trajectories for residents in three LTCF is shown in figure 2.1.

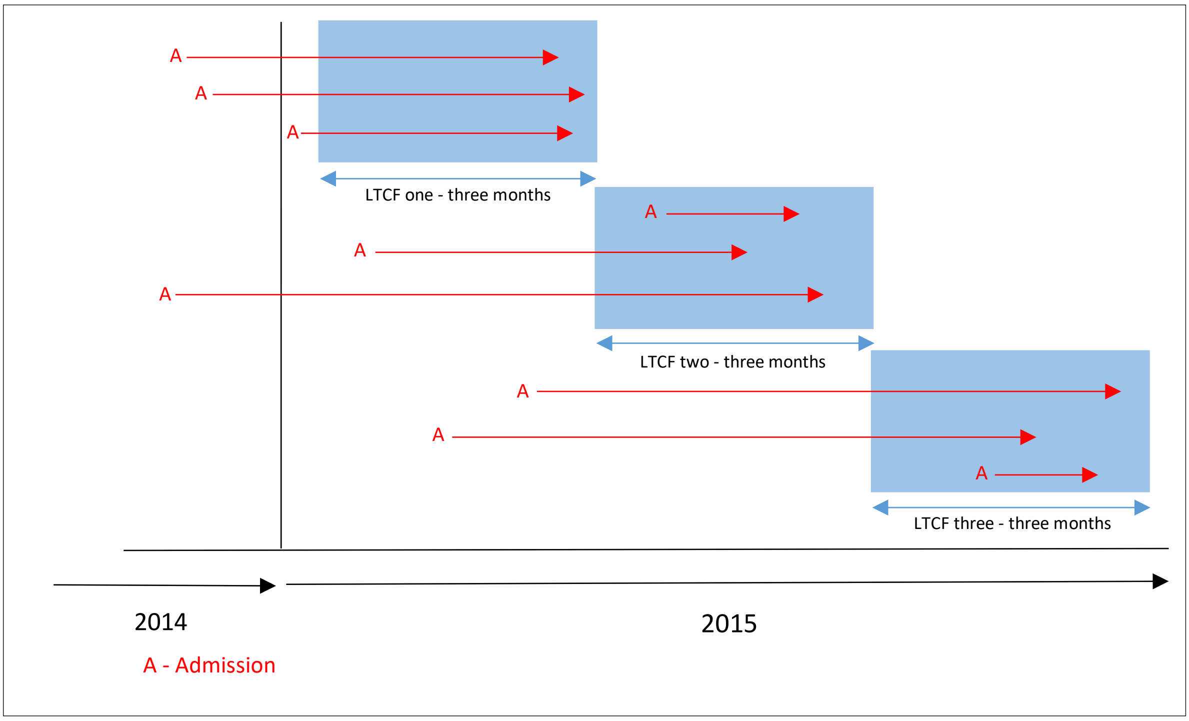

Figure 2.1: Nine examples of possible resident trajectories from three LTCFs.

Data was collected using five questionnaires; a facility questionnaire, completed by either administrative staff or the facility manager; and a demographic questionnaire completed by either administrative staff or the facility manager, were collected during the research visit. A postal questionnaire was sent to the LTCF staff member who knew the resident, to the resident's general practitioner and to the resident's relative, identified by the LTCF using resident administrative records.

The response rate for each questionnaire is shown in table 2.6. This thesis will concentrate on facility and resident data collected from facility managers and the facility staff member who knew the resident only. The facility questionnaire collected data on the funding status of the facility, number of beds, staffing levels, physician involvement, and the provision of generalist and specialist palliative care. The demographic questionnaire collected data including age, gender, marital status, date and place of admission and date and place of death. The LTCF staff member questionnaire collected data on health status and treatments, dying experience, resource use, care during the last month of life, communication and advance care planning and background of the LTCF staff member. Data collected in each country was inputted into an online portal and cleaned by the research team in Belgium. A linked database was created and shared with the wider PACE consortium for individual analysis.

Total sample:
1,707 resident deaths from 322 care homes

Country	**BELGIUM**	**ENGLAND**	**FINLAND**	**ITALY**	**NETHERLANDS**	**POLAND**
LTCF recruited n/LTCFs contacted	46/184 (25.0%)	49/365 (13.4%)	91/185 (49.2%)	36/112 (32.1%)	50/276 (18.1%)	50/176 (28.4%)
Facility questionnaire completed	43/46 93.5%	48/49 98%	88/91– 96.7%	33/36 91.7%	44/50 88%	49/50 98%
Resident deaths	342	168	283	229	329	356
Demographic questionnaire completed	322/342 94.2%	162/168 96.4%	279/283 98.6%	221/229 96.5%	298/329 90.6%	352/356 98.9%
LTCF staff questionnaire completed	291/342 85.1%	91/168 54.2%	269/283 95.1%	200/218 91.7%	222/329 67.5%	311/356 87.4%
Physician questionnaire completed	228/341 66.9%	40/168 23.8%	223/278 80.2%	167/189 88.4%	205/325 63.1%	269/356 75.6%
Relatives questionnaire completed	216/326 66.3%	26/114 22.8%	158/263 60.1%	107/137 78.1%	200/325 61.5%	113/290 45.9%
Staff knowledge and attitudes questionnaire completed	559/715 78.2%	152/485 31.3%	559/673 83.1%	166/240 69.2%	440/851 51.7%	416/428 97.1%

Table 2.4. Recruitment and response rates, by country, in the PACE Study.

Country	BELGIUM	ENGLAND	FINLAND	ITALY	NETHERLANDS	POLAND
Population over 65 (as of 2019)	19%	19%	22%	23%	20%	18%
Number of nursing and elderly home beds	137,069, (2012)	548,397 (2015)	63,111 (2014)	234,008 (2013)	177,966 (2012)	70,277. (2014)
Staff in LTCFs trained in palliative care	40-60%	40-60%	No trained staff	<20%	60-90%	60-90%
Collaboration between palliative care teams and LTCFs staff (experts' estimation)	Most of the time	Sometimes	N/A	Very rarely	Sometimes	Sometimes
Funding for palliative care provision in LTCFs	Y	Y	N/A	Y	Y	N/A
Official documents regulating palliative care provision in LTCFs.						
National strategy	Y	Y	N	Y	N	N
Standards	Y	Y	N	Y	N	N
Guidelines	Y	Y	N	Y	Y	N
Protocols	N	Y	N	N	Y	N

Table 2.5. Indicators of palliative care, by country, in the PACE Study (World Bank Group, 2021; World Health Organisation, 2019c; Arias-Casais et al., 2019).

It should be noted that much of the data synthesised in the EAPC Atlas of Palliative Care in Europe is reported by experts within each country and may not be an accurate reflection of the situation on the ground. In addition to the differences illustrated in table 2.5, developments within countries that affect the provision of palliative care in LTCFs are occurring at national and regional levels (Arias-Casais et al., 2019). In Italy, agreement on the definition of palliative care was reached by national and regional agreements in 2012. In Belgium, regulations on the responsibility to provide palliative care in LTCFs have been definedby regional governments. There are also differences between countries in the extent for the need for palliative care in LTCFs is recognised (Arias-Casais et al., 2019). In the Netherlands, many LTCFs have specialist palliative care units and physicians who specialise in palliative care, where as in Poland there are no specific guidance for palliative care in LTCFs, and patients in LTCFs cannot access or receive care from specialist palliative care services.

Generalised linear models

Generalised linear models were chosen as the methodological approach used to test the hypotheses presented in chapters four and five of this thesis. In chapter four, the association between resident, facility and country level factors with length of stay in LTCFs, using internationally comparable data, was explored. In chapter five, the relationship between length of stay and care at end of life in LTCFs, using the same dataset, was explored.

In both chapters four and five, the choice of methodological approach used to test the stated hypotheses was informed by comparing the characteristics of the explanatory and outcome variables to guidance on the choice of generalised linear models as outlined in table 2.7.

Type of outcome	Suggested type of generalised linear model
Continuous numerical	
One explanatory variable	Simple linear regression
More than one explanatory variable	Multiple linear regression
Incidence or disease or binary outcome	Logistic regression
Categorical with more than 2 categories	Multinomial or ordinal logistic regression
Event rate or count	Poisson regression
Time to event	Cox Proportional Hazards Regression OR Exponential, Weibell or Gompertz model.

Table 2.6. Choice of appropriate type of GLM depending on outcome, adapted from Petrie and Sabin, 2005 (Petrie and Sabin, 2005).

In chapter four, a time to event analysis with a random-effect term added was applied to the data to test the stated hypothesis; that there is no variation in length of stay between LTCF residents. Time to event analysis is an appropriate analytical approach to test this hypothesis for three reasons. Firstly, the data is characterised by the movement of LTCF residents through several states: alive or dead, over time. Secondly, the change in state, from alive to dead, can occur at any point in time post-admission. Thirdly, multiple factors may influence the movement between these states as identified in the systematic review conducted in chapter three, including age, gender and diagnoses.

In chapter five, generalised linear mixed models were applied to the data to test the stated hypothesis; that there is no association between length of stay and care at end of life in LTCFs. Generalised linear models allow for the effect of multiple explanatory variables on an outcome variable to be explored, adjusting for the influence of all other explanatory variables in the model. As the model will include multiple resident, facility and country level factors, univariate analysis, where the effect of each explanatory variable is explored in isolation, would reduce the explanatory value of the findings. Finally, generalised linear mixed models are an appropriate approach for continuous and categorical variables, either as explanatory or outcome variables.

The inclusion of a random-effects term was used to control for any effects associated with residing in a specific facility. As the data includes observations from multiple residents residing in the same facility, the effect of unknown random, facility level characteristics that are not included as explanatory variables within the model, can be controlled for.

Generalised linear models

A generalised linear model (GLM) is a statistical model that aims to describe the relationship between an outcome variable and at least one explanatory variable (Petrie and Sabin, 2005). It is a type of linear regression where dependant variables with distributions that are other than normal are allowed. The equation for a GLM is:

$$g(Y) = a + b_1 x_i + b_2 x_{ii}$$

where Y is estimated value of the outcome variable which follows a known probability distribution, and $g(Y)$ is the transformation of Y that produces a linear relationship with the explanatory variables included in the model, a is the predicted value of Y when x_i equals 0, the estimated intercept, b_1 is the coefficient estimate describing the relationship between x_i and Y and x_i is an explanatory variable.

Generalised linear models estimate parameters using Maximum Likelihood Estimation (MLE) (Petrie and Sabin, 2005). In MLE, the regression coefficients in a given model are estimated based on the values that maximize the likelihood that the values predict the observed value of the outcome variable. The adequacy of the fit of a GLM can be improved by adding additional explanatory variables and assessed using the likelihood ratio.

The use of GLMs is advantageous in that they can be used to explore the influence of variables with multiple distribution types, on outcome variables within this analysis, including numerical, such as age or general health, categorical, such as gender or marital status, count or time to event data outcome variables. In addition, the results allow an interpretation of the relative effect of an explanatory variable, in the context of the effect of multiple explanatory variables included in the model. In addition, large datasets are required to meaningfully apply GLMs; the number of explanatory variables should be less than n/10 (Petrie and Sabin, 2005). In this analysis, there were a maximum of 35 covariates that could be included in the model, with a minimum of 869 events, meeting the requirement.

In chapter five, two types of GLM are used, multiple linear regression and logistic regression. Multiple linear regression explores the effect of numerous explanatory variables simultaneously, allowing for the joint effect of multiple explanatory variables to be identified. Multiple linear regression was performed on the continuous outcomes in the analysis; quality of care in the last month of life (QoD-LTC), comfort in the last week of life (EOLD-CAD) and their subscales (Kiely et al., 2006; Munn et al., 2007). A multiple linear regression equation is shown below:

$$g(Y) = a + b_1x_i + b_2x_{ii} + e_i$$

where Y is estimated value of the outcome variable which follows a known probability distribution, and $g(Y)$ is the transformation of Y that produces a linear relationship with the explanatory variables included in the model, a is the predicted value of Y when x_i equals 0, the estimated intercept, b_1 is the coefficient estimate describing the relationship between x_i and Y, x_i is an explanatory variable and e_i is the error term, the residual difference between values predicted in the regression model and what is actually observed.

Using a multiple linear regression to model data allows the identification and characterisation of a specific variable of interest and its association with the outcome variable, adjusting for the effect of the other variables included in the model. On application to this analysis, the influence of length of stay on the QoD-LTC and EOLD-CAD was explored, adjusting for ten resident and facility characteristics identified as associated with length of stay, including age, gender, place of admission, diagnoses, LTCF ownership and country.

The null hypothesis, that there is no variation in length of stay between LTCF residents, equates that changing the value of the explanatory variable (length of stay) has no effect on the outcome variable (total scores and subscales of the QoD-LTC and EOLD-CAD), and the regression coefficient (b_1) is zero. To test the null hypothesis, the test statistic is calculated and, with a p value <0.05, indicates rejection of the null hypothesis.

Multiple logistic regression can be applied when the outcome of interest is binary and, as with multiple linear regression, multiple explanatory variables can be tested. As the outcome is binary, the third assumption of linear regression, that the residuals of the model are normally distributed, is not met (Katz, 2011). Therefore, a logit transportation of the probability that the outcome variable of an individual equals one (Petrie and Sabin, 2005). Multiple logistic regression was performed on the binary outcomes in the analysis, contact with health services in the last month of life, hospital admissions, emergency department visits, presence of advance directives and consensus in care and treatment. A logistic regression equation is shown below:

$$logit(p) = a + b_1 x_i$$

where p is the estimated value of the probability that an individual is classed as one of the binary outcomes (i.e. an individual had an advanced care plan in place), a is the predicted value of p when x_i equals 0, $b_1$is the coefficient estimate describing the relationship between x_i and p and x_i is an explanatory variable i.e. length of stay).

Logistic regression provides the logit of the conditional probability that the binary outcome variable equals one, over the probability that it equals zero, at a particular value of the predictor variable (Petrie and Sabin, 2005). The output of logistic regression is, like linear regression, a regression coefficient, however it is commonly reported as an odds ratio, the exponential of a logistic regression coefficient. To allow comparability between measures, the results of the logistic regression models are reported as regression coefficients. As a logistic regression is fitted into a log scale, the regression coefficient shows the combined effect of the explanatory variables, rather than an additive effect seen in linear regression. The process for testing of the null hypothesis is the same as in multiple linear regression.

Time to event analysis

The use of retrospective data collection in palliative care research, such as that used in the PACE study, allows the inclusion of all deceased participants, rather than those who die in a specified timeframe, as is the case in prospective studies. Time to event analysis is a type of GLM that is applied when the outcome of interest is the time to an event, also known as "survival analysis". It can be defined as the analysis of the time to an event, using data that describes the length of time from a time origin to an endpoint of interest (Kartsonaki, 2016). This analytical approach is often used in health research to explore the length of time to the onset of a disease or condition, or to death (Lin et al., 2017; Salib and Thompson, 2018; Vossius et al., 2018).

In most studies, the data used in time to event analysis will not be a complete record of every individual in the sample, from baseline to event, with the majority of data containing some form of censoring where the survival time for a participant is unknown. An example of the effect of left and right censoring is shown in figure 2.2 (Emmert-Streib and Dehmer, 2019). Left censoring occurs when data on state of the patient at the beginning of the observation period is unavailable, whereas right censoring occurs when data on whether a patient experienced the event within a specific time frame is unavailable. Right censoring can occur through a participant being lost to follow up, an event not occurring within the observation period, or another event occurring making the occurrence of the event of interest impossible. In the data from the PACE study used in chapter four, there is no left or right censoring of the data, as all residents experience the “event” or death prior to the end of follow up and all were residing in the care home at the start of data collection, as shown in figure 2.1.

In addition, time to event data is rarely normally distributed, comprising typically of many events in the early time periods and fewer events in later time periods, a characteristic also identified in the PACE dataset (Clark et al., 2003).

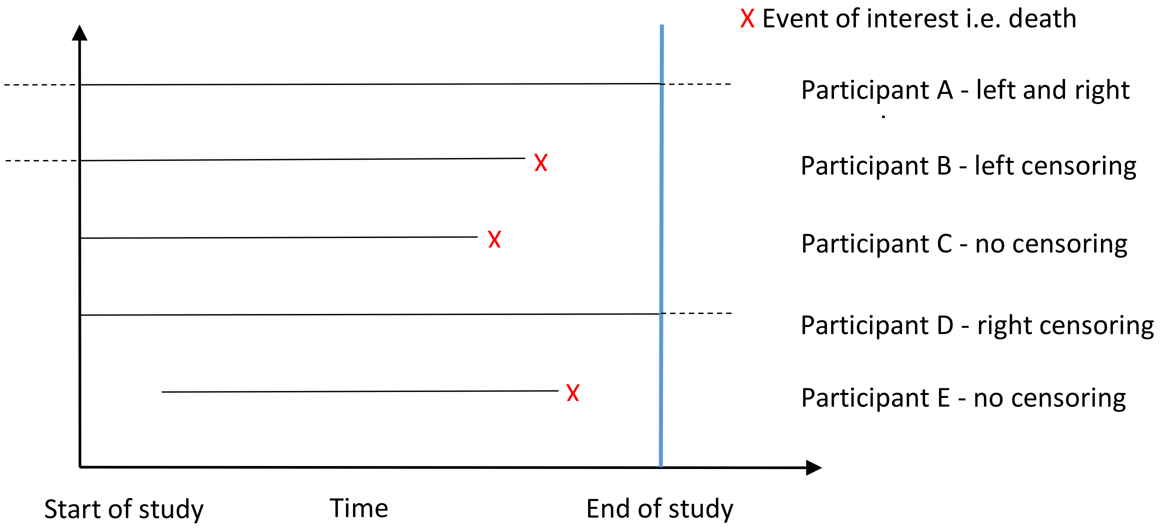

Figure 2.2. Examples of left and right censoring in observational studies.

The first probability used in time to event analysis is the survival probability, applied in this analysis as the probability that an individual survives from time of admission to a LTCF to a death. It can be estimated using a Kaplan-Meier method, where the probability of surviving from one time point to the next sequential time point can be multiplied together to provide a cumulative survival probability, using the equation shown below:

$$S(t_j) = S(t_{i-j})(1 - d_j/n_j)$$

where $S(t)$ is the probability that an individual survives from the original time point to a specified future time, (t_j) is the time at j, $S(t_{i-j})$ is the probability of being alive at t_{i-j}, d_j is the number of events at t_j and n_j is the number of patients alive just before at t_j (Clark et al., 2003).

Figure 2.3 depicts a Kaplan Meier survival estimate for a sample of LTCF residents in the PACE study, where survival probability is plotted against time, from LTCF admission to death. The y axis shows the probability of residents surviving, which can be interpreted as a percentage, and the x axis show length of stay until death.

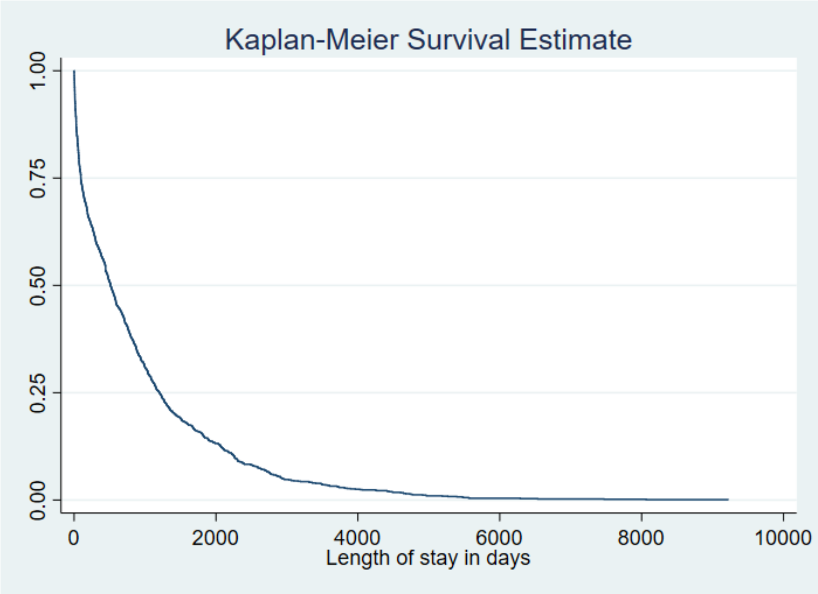

Figure 2.3. Kaplan Meier survival estimate of LTCF resident's survival from admission to death.

The survival probabilities of more than one group can be compared. Figure 2.4 shows two Kaplan Meier survival curves, one for men and one for women using the same sample shown in figure 2.3, plotted on the same graph. To test the null hypothesis, there is no variation in length of stay between LTCF residents, the test statistic, a log rank test, is calculated using observed and expected events in each group at each event time. A p value <0.05 indicates rejection of the null hypothesis; however, size of effect is not estimated.

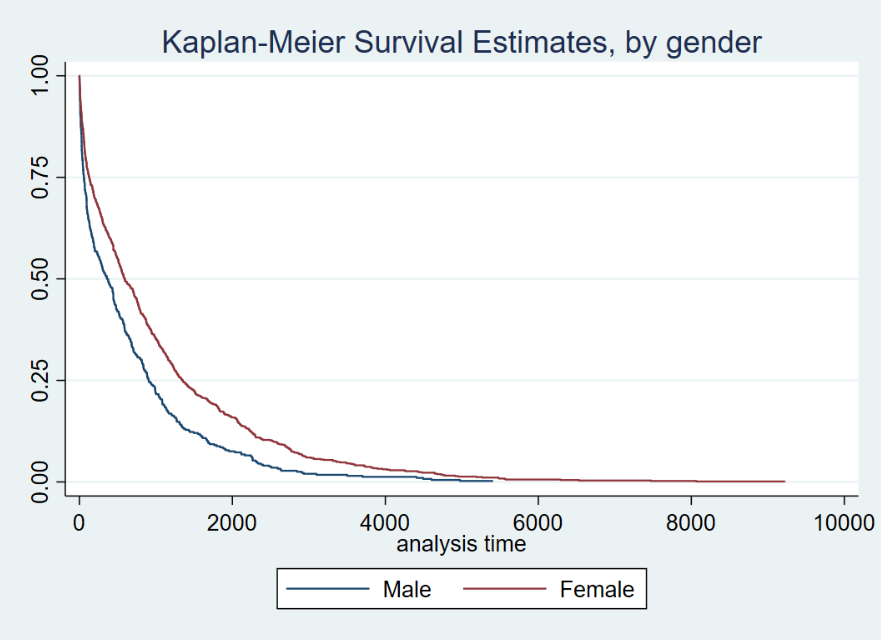

Figure 2.4. Kaplan Meier survival curves, split by gender, of LTCF residents from admission to death.

The second probability used in time to event analysis is the hazard probability. The hazard is the probability that a participant observed as a specific time point will die at that time, based on the participant having survived up to the specified time point, using the equation is shown below:

$$h(t) = -d/d_t\,[\log S(t)]$$

where $h(t)$ is the hazard function, d is the number of events, d_t is the number of events at time t, $S(t)$ is the probability that an individual survives from the original time point to a specified future time (t) (Clark et al., 2003).

As the hazard probability is difficult to estimate, the Nelson–Aalen cumulative hazard function is used. The cumulative hazard can be thought of as the number of events expected for each individual by a specific time point, if the events were repeatable (Clark et al., 2003). Figure 2.5 depicts the Nelson–Aalen cumulative hazard of LTCF residents from admission to death.

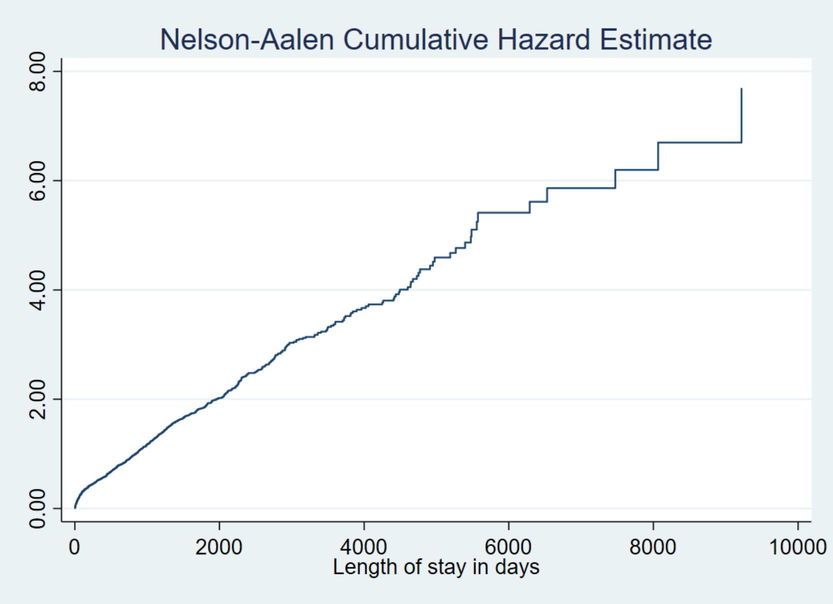

Figure 2.5: Nelson–Aalen cumulative hazard function of LTCF residents from admission to death.

The null hypothesis for the log rank test is that the hazard ratio in both groups is equal to 1, that there is no difference in length of stay between LTCF residents. The hazard ratio measures relative survival, or

$$HR = \frac{O_1/E_1}{O_2/E_2}$$

where HR is the Hazard Ratio, E is the total expected number of events, O is the total observed number of events. A hazard ratio of 1 indicates no difference in survival, a hazard ratio less than one indicates a reduced risk of the death (longer length of stay) and a hazard ratio more than one indicates an increased risk of the death (shorter length of stay).

Proportional-hazards models

Multivariate modelling of time to event data allows for the relative influence of multiple covariates on survival probabilities to be explored. Two main approaches can be used to model time to event data: proportional hazard models and accelerated failure time models.

A proportional hazards model explores the effect of multiple factors on time to an event, and can be semi-parametric or fully parametric (Bradburn et al., 2003a). In a fully parametric proportional hazards model, the hazard is assumed to follow a specific statistical distribution, such as an exponential, Weibull or Gompertz distribution (Emmert-Streib and Dehmer, 2019). The process of specifying a distribution that resembles the data can be difficult, however the use of such models result in more precise estimates. In both the parametric and semi-parametric proportional hazards models, the interpretation of the hazard ratio is the same (Bradburn et al., 2003a). As the hazard of the dying increases, length of survival decreases, therefore if the hazard ratio for a covariate is greater than one, as the value of the covariate increases, the hazard also increases, decreasing length of survival time).

In chapter four, a parametric proportional hazards model using a Weibull distribution was used to investigate the association between the time to death of each resident and predictor variables. The use of a parametric model was appropriate as the hazard function of the data followed the Weibull statistical distribution, resulting in more precise estimates than if a Cox Proportional hazard model had been used (Bradburn et al., 2003a). In addition, the majority of studies identified in chapter three used some form of proportional hazards models; therefore, the use of an AFT model would not produce comparable results to existing literature in this area. In an accelerated failure time model, each covariate in the model either stretches or shrinks the survival curve by a certain amount; the size of effect is reported as a time ratio, as opposed to a hazard ratio, making comparisons to previous findings problematic.

For each variable tested for association with length of stay, univariate analysis was performed, and p values calculated using Pearson Chi^2 and one-way Analysis of Variance (ANOVAs). All factors associated with the outcome at a $p \leq 0.2$ at univariate analysis were entered into a proportional hazards model. Proportionality assumptions were checked for each model using time dependant covariates and Schoenfeld residuals; and goodness of fit was tested using Cox-Snell residuals (Bradburn et al., 2003b).

Mixed modelling of clustered data

The data collected in the PACE study is hierarchical, as the data collected on residents is ‘clustered’ within multiple facilities. The observations collected in the study on each resident are therefore not independent, as there is likely to be some form of correlation between residents within the same facility. To account for clustering within LTCFs, a random-effects term was added to the GLMs used throughout the thesis (Twisk, 2006). A random-effects term attributes differences between clusters to a ‘random factor’, including a random error that accounts for variation between clusters, in addition to the variance within clusters (Petrie and Sabin, 2005).

Conclusion

This chapter has focused on two methodological approaches to the research conducted within this thesis, literature reviews and generalised linear mixed models. The following four chapters illustrate the application of these approaches to uncover knowledge related to length of stay and palliative care in LTCFs.

Chapter 3 - Paper 1: Collingridge Moore, D., Keegan, T. J., Dunleavy, L. & Froggatt, K. (2019) Factors associated with length of stay in care homes: a systematic review of international literature. Syst Rev, 8(1), 56.

Rationale

Chapter three focuses on the identification of factors associated with length of stay of residents from admission to death in a LTCF. A number of studies have explored factors associated with resident length of stay in LTCFs; however, the findings of these studies have not been synthesized. This study provides a systematic review of factors associated with length of stay until death and the strength of evidence supporting each of these factors.

Aim and objectives

The aim of chapter three is to systematically identify, synthesise and quality assess data on factors associated with resident length of stay in LTCFs. To achieve this aim, the chapter has three objectives:

1. To identify studies which explore length of stay in LTCFs.
2. To determine the methodological quality of these studies.
3. To evaluate the evidence supporting each factor identified within these studies.

Overview of methodology

A systematic review was conducted to meet the aim of the chapter. Key databases were searched for studies that met the predefined inclusion criteria. Included studies were data extracted and assessed for quality using an assessment tool adapted specifically for this review. Data synthesis combined the direction and significance of association with the quality of the study, resulting in strong, moderate, weak or inconclusive evidence for each factor identified. The review was developed and reported using criteria established in the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement (Moher et al., 2009).

Overview of my contribution to the publication

I designed and conducted the review, defining the research question, developing the review protocol, including preparing and conducting the search strategy, applying the inclusion and exclusion criteria, performing the data extraction and quality assessment, synthesising the data and preparing the paper for publication. I submitted the manuscript to the journal after incorporating feedback from the other authors and responded to reviewer feedback, where received.

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Systematic Reviews

RESEARCH Open Access

Factors associated with length of stay in care homes: a systematic review of international literature

Danni Collingridge Moore*, Thomas J. Keegan, Lesley Dunleavy and Katherine Froggatt

Abstract

Background: A number of studies have explored factors associated with resident length of stay in care homes; however the findings of these studies have not been synthesized. The aim of this paper is to provide a systematic review of factors associated with length of stay until death and the strength of evidence supporting each of these factors.

Methodology: This is a systematic review; databases included MEDLINE, EMBASE, PsycINFO, CINAHL, Proquest, the Cochrane Library and Web of Science were searched. Observational studies, either prospective or retrospective, that explored multiple factors associated with length of stay until death in care homes were included. Studies that met the inclusion criteria were sourced, data extracted and assessed for quality. Data synthesis combined the direction and significance of association with the quality of the study, resulting in strong, moderate, weak or inconclusive evidence for each factor identified.

Results: Forty-seven studies were identified as meeting the inclusion criteria. After quality assessment, 14 studies were judged to be of a high quality, 31 of a moderate quality and 2 of a low quality. Three factors had strong evidence to support their association with shorter lengths of stay: shortness of breath, receipt of oxygen therapy and admission to a facility providing nursing care.

Conclusions: This review summarized the factors associated with length of stay. It found stronger evidence for physical functioning being associated with shorter lengths of stay than for cognitive functioning. An understanding of expected length of stay for older adults admitted to a care home is important for estimating lifetime costs and the implications of reforming funding arrangements for social care. Further research is needed to explore heterogeneity in this area.

Keywords: Systematic review, Long-term care facility, Care home, Nursing home, Length of stay

Background

The global population is ageing; 35% of the European population and 28% of the North American population are expected to be aged 60 years or over by 2050 [1]. By 2030, the number of older persons in the world is estimated to increase to 1.4 billion, resulting in 2.1 billion in 2050 and potentially 3.1 billion in 2100 [2]. As a consequence of this growth, deaths in this population group will also increase; among those 80 years and older, deaths are projected to rise to over 15 million by 2030 [3]. Providing care for an ageing, and dying, population is, and will continue to be, a novel challenge for healthcare systems around the world.

Older adults are more likely to be frail, have multiple comorbidities and suffer from chronic diseases, including dementia, than younger adults. As end of life approaches, common preference among older adults is to remain in the home until death [4]; however, this may not be possible for those requiring high levels of care or without access to formal or informal care providers. The majority of deaths in older adults with dementia occur in long-term care facilities [5, 6]; in England and Wales, it is estimated that by 2040, care homes will become the most common

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place of death [7]. Although terminology and typology vary between countries, a care home or long-term care facility generally refers to a collective institutional setting where care is provided to older adults, who live there, 24 hours a day, 7 days a week [8]. The provision of care homes, in terms of type (with or without nursing), number of beds and staffing levels, provision of funding and relationship with the wider health care system, also varies between countries [8]. This paper will use the term care home throughout.

Transitions from living in the community to a care home can be varied, and reflective of individual circumstances, such as health status, access to care and financial circumstances. A systematic review by Luppa et al. identified characteristics associated with admission into care homes from 36 prospective observational studies of population samples, which followed older adults in the community to care home admission [9]. Older adults who enter care homes are more likely to be older, have lower self-rated health, functional impairments, cognitive impairments and dementia [9]. In some cases, admission may follow a long period of physical or cognitive decline leaving caregivers unable to provide the level of care required by the resident. In other cases, a trigger event, such as a stroke or fall, may lead to a resident being unable to return to living independently in their own home.

Compared to older adults residing in the community, care home residents have poorer health, including higher rates of dementia, stroke and severe mental illness [10]. An increased use of health services is common; care home residents also have high rates of hospital and emergency department admission, primary care contact and use of out of hours services [11–13]. In 2014, Barclay et al. conducted a prospective study following residents in six residential care homes until death and identified four trajectories towards end of life: anticipated dying, uncertain dying, unexpected death and unpredicted dying [14]. Briefly, the trajectories were based on whether the resident's death was expected and the presence of a sudden illness or an acute event.

Despite these high healthcare needs, the availability of data on care homes and their residents varies internationally. Some countries have minimum datasets, such as Minimum Data Set in the USA [15], which provide a wealth of routinely collected data for potential research. Data on care home residents may also be available in larger cohort studies, such as the English Longitudinal Study of Ageing (ELSA) [16] or the Survey of Health, Ageing and Retirement in Europe (SHARE) [17]. However, care home residents are frequently excluded from datasets focusing on older adults; in the UK few observational studies either include care home residents at baseline or follow up community-dwelling residents into care homes [18]. Methodological challenges of conducting research with older adults in care homes have been described elsewhere, including recruitment barriers, difficulties engaging with staff and adapting to competing demands on time and resources [19].

Length of stay from admission until death is a simple measure that could inform our understanding of care home residents and identify variation in health service use. Length of stay is often reported as an outcome in care home research; however, there is little consensus on the factors associated with length of stay, or how length of stay varies among residents, nationally and internationally. Building on the European Association for Palliative Care Taskforce on Palliative Care in Long-term Care Settings for Older People [20], Froggatt et al. conducted a survey of palliative care provision in long-term care facilities in 29 European countries [21]. Data on average length of stay was returned by 14 countries (48%) and ranged from 63 days (Israel) to over 2000 days (Luxembourg). Using an average to report length of stay can be misleading; a minority of residents residing in care homes for an extended period, sometimes over 10 years, can skew an average measure, eclipsing residents admitted for very short periods of time.

An understanding of length of stay data has several potential benefits: it can inform service planning to accommodate a growing number of residents and, combined with other measures, be used to inform the provision of care within the wider health system. It can be used to identify variation across care homes, highlighting facilities with lengths of stay either below or above the expected based on the resident profile. Residents, their relatives and healthcare professionals could also benefit from this information to inform decision-making regarding relocation into long-term care, and as a guide to support the provision and delivery of palliative care. Unlike mortality prediction tools, which have been developed to aid the identification of residents likely to die within a specified time frame [22–24], an understanding of length of stay within the care home population provides an overview of how care homes are being utilized by the older adults.

One previously conducted systematic review on length of stay in care home residents, conducted in 2013, identified five studies conducted in nursing homes; however, the review was limited to short-term mortality on health-related characteristics [25]. The aim of this paper is to systematically review the factors identified in observational studies as associated with length of stay in care homes.

Methodology

Identification of papers

A protocol for the systematic review was prepared prior to conducting the review. A systematic search strategy was developed and reported using criteria established in the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement

[26]. The search strategy included a combination of free-text terms and subject indexing terms, such as MeSH and EMTREE (Table 1). The search strategy was developed through identification of key terms in the titles and abstracts of relevant studies identified in an initial scoping search of the literature.

The following electronic databases were searched for articles published in peer-reviewed journals, from database inception to September 2016, and were not limited by language or publication restrictions: MEDLINE, EMBASE, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Proquest, the Cochrane Library, including the Cochrane Methodology Register, Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Database of Systematic Reviews (CDSR), Database of Abstracts of Reviews of Effect (DARE), Health Technology Assessment (HTA) database and NHS Economic Evaluation Database (NHS EED), Web of Science, the Campbell Library, SCOPUS and Social Care Online.

In cases where a conference abstract or unpublished research met the inclusion criteria, the lead author was contacted where possible. Additional papers were identified through other sources, including reviewing the reference lists of publications that met the inclusion criteria, reverse citation searches and grey literature. Reverse citation searches were undertaken on included papers using the ISI Web of Science Citation Databases. Grey literature was searched using OpenGrey. Websites were searched using an abbreviated search strategy; these included the World Health Organization, European Association of Palliative Care and Age UK.

Table 1 Example search strategy

Ovid MEDLINE
1. exp. Nursing Homes/
2. exp. Homes for the Aged/
3. "care home*".ti.
4. "nursing home*".ti.
5. "nursing facilit*".ti.
6. "residential home*".ti.
7. "residential care".ti.
8. "residential long term care".ti.
9. "institutionali?ed".ti.
10. "institutional* residen*".ti.
11. "institutional* care*".ti.
12. ("long term" adj1 "care facilit*").ti.
13. ("long term" adj1 "care residen*").ti.
14. ("long term" adj1 "care institution*").ti.
15. ("long term" adj1 "institution* care*").ti.
16. ("institution*" adj1 "long term care*").ti.
17. "survival".ti,ab.
18. "mortality".ti,ab.
19. "death".ti,ab.
20. "length" adj1 "stay".ti,ab.
21. "life" adj1 "expectanc*".ti,ab.
22. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
23. 17 or 18 or 19 or 20 or 21
24. 22 and 23

Inclusion and exclusion criteria

The review focused on older adults, defined as any adult or groups of adults aged 65 years or above. Participants were included in the review if they resided in a care home or long-term care facility. As previously stated, the term "long-term care facility" generally refers to a collective institutional setting where care is provided to older people, who live there, 24 hours a day, 7 days a week, as defined previously [8]. In the review, this definition was also applied to care homes. Studies in hospitals, assisted living facilities, sheltered housing and hospices were excluded.

The review had one outcome measure, length of stay, defined as length of stay within a care home until death. Length of stay could be measured in days, months, years or any other unit of time; and measured from any time point after admission. Studies exploring length of stay until discharge were excluded. The review was restricted to observational studies, including retrospective or prospective cohort studies and case-control studies.

In the first stage of screening, a decision on whether a paper met the inclusion criteria was based on the study title and abstract. In the second stage of screening, a final decision on inclusion was made based on reading the full paper.

In both stages, screening was conducted by one reviewer (DCM), and decisions checked by a blinded second reviewer (LD) on a subsample of 10% of the papers. Discrepancies were discussed, and a final decision was made by a third member of the research team (KF). Reasons for excluding full papers were recorded and reported (Fig. 1).

Data extraction

Data from the included studies were extracted using a data extraction form specifically developed for this review, informed by STROBE statement on the reporting of observational studies [27]. Data was extracted by one reviewer (DCM). The data collected from each study included: information on participants (number of residents, age of residents, gender of residents), the care home (type of care home, number of care homes), the methodology (study setting, type of study, dataset used, data collection period, follow up period, how length of stay was defined, variables included in model, statistical method used) and information on missing data. The results of the paper, including risk measure used and its value, confidence intervals and measure of significance were also extracted.

If a study contained more than one cohort, both cohorts were included as separate groups, such as Engle and Graney [28]. In development and validation studies, data from the development cohort was extracted. In studies where men and women were listed separately, such as Hedinger, Hamming and Bopp, [29], the cohort that

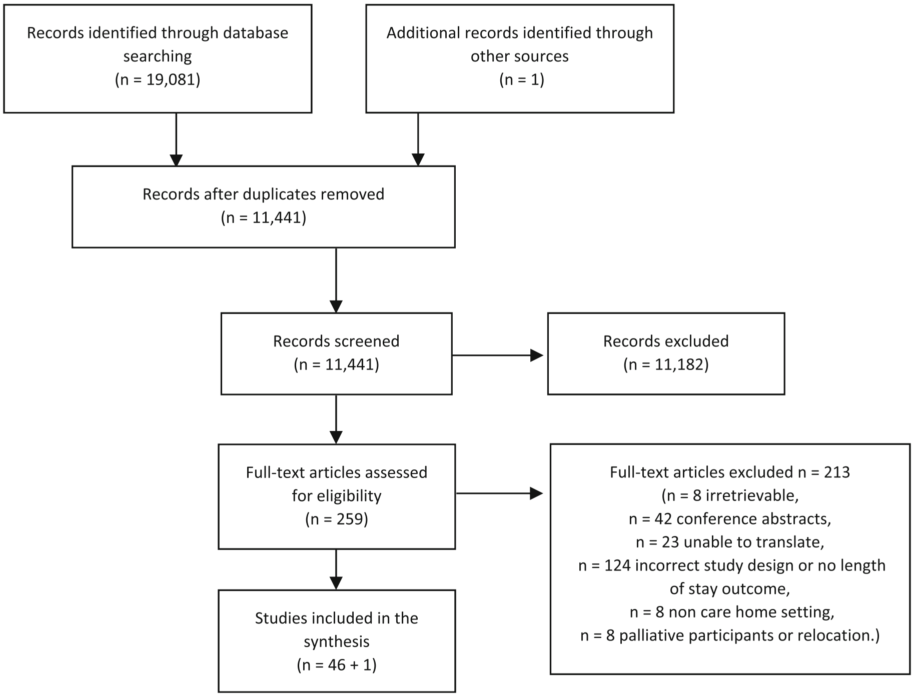

Fig. 1 PRISMA flowchart

reflected the sample majority was used. In cases where the results were significant, either through significance testing or confidence intervals, the result was classed as significant. In cases were no data on an included variable was reported in the results, the result was not significant or the confidence interval indicated none significance, the result was classed as not significant. If a study reported more than one result for the same outcome, i.e. age reported in groups, the result with either the most significant or the largest ratio was used to avoid duplication. Factors included in less than three studies were excluded from the analysis to avoid bias in the evidence synthesis, which required a minimum of three studies to apply the data synthesis.

Quality assessment

There are numerous tools to assess the methodological quality and risk of bias in randomized controlled trials; however, few are designed specifically for observational studies [30]. To ensure that the quality assessment tool was appropriate for the topic area, the review used a modified version of the quality assessment tool used by Luppa et al., adapted for application to studies on factors associated with length of stay in care homes. The adapted tool has 14 items, scored as either 0 (not meeting the criteria) or 1 (meeting the criteria) (see Additional file 1). A score of 75% or more of the assessment criteria was defined as high-quality studies, between 50% and 75% was defined as moderate quality and less than 50% was defined as low quality.

Data synthesis

Due to heterogeneity in the setting, sample and tools used, a meta-analysis was not appropriate to synthesize the data. Data synthesis was split into two stages. Firstly, the characteristics of the study were described, including the study design, sample size and variables reported. Numerical data was tabulated and presented for each factor, showing effect size and direction.

Secondly, in a similar approach used by Luppa et al., all factors identified across the studies were pooled and grouped, alongside the direction of the variables effect on length of stay and their significance (positive, negative and not significant). These findings were then cross-referenced with the quality assessment score for the study (see Additional files 2 and 3).

A judgment was made on the strength of the evidence for each risk factor from this cross tabulation. A factor was classed as being supported by strong evidence if there are consistent findings in at least 75% of studies in at least three high-quality studies. Moderate evidence was classed as consistent findings in at least 50% of studies in at least two high-quality studies. Weak evidence was classed as findings of one high-quality study and of at least two moderate- to low-quality studies or consistent findings (≥ 75%) in at least four or more moderate- to low-quality studies. If a risk factor was not classed as having strong, moderate or weak evidence, it was classed as inconclusive.

Results

The searches of the electronic databases identified 19,081 titles and abstracts, resulting in 11,441 after deduplication. Based on applying the inclusion criteria to the abstract of the paper, 11,182 abstracts were excluded, identifying 259 abstracts for which full papers were sourced. Eight papers could not be sourced, 42 were excluded as they were conference proceedings, 124 were excluded based on study design or did not have a risk measure, 23 were in a language which could not be translated by the research team, 8 were not conducted in care homes and 8 were exclusively in patients approaching end of life or concerned relocation. One paper was identified through other sources.

In total, 47 studies met the inclusion criteria for the review (Additional file 4). Study designs as reported by the papers included prospective studies (16), retrospective studies (13), longitudinal, cohort or follow-up studies (8), secondary analysis, linked observational or population-based studies (4) and case-control studies (2). Four papers did not report study design.

Seven of the 47 papers were split into more than 1 cohort, mostly through reporting follow-up for more than 1 time point; each cohort was included in the synthesis separately resulting in 57 included cohorts from 47 papers. One year follow-up was based on 26 cohorts.

Eighteen studies were conducted in the USA, 10 in Europe, 7 in the UK, 4 in Hong Kong, 2 in New Zealand and 5 elsewhere. Total sample size was 942,626, sample sizes ranged from 49 to 218,088, with 9 studies including residents with dementia, Alzheimer's disease or Parkinson's disease only. The majority of studies included residents aged over 65 years who were newly admitted to the facility. Average age ranged from 76.03 (10.08) to 92.9 (3.0), and the percentage of the sample that was female ranged from 59.6 to 89.7%, where reported. In terms of how the study described the facility in which data were collected, 32 studies were based in nursing homes, 6 in long-term care facilities and 9 in residential homes, care homes or other. Length of follow-up ranged from 1 month to 11 years, with three studies collecting data retrospectively or until death (see Additional file 2).

Methodological quality

Fourteen of the 47 studies were judged to be of a high quality, 31 of a moderate quality and 2 of a low quality. The lowest scores on the methodological quality were on reporting the training and quality control methods for interviewers' technique (reported in 8/47 papers) and the reliability and/or validity of study instruments (reported in 8/47 papers).

Factors associated with length of stay

Factors associated with length of stay, minimum and maximum risk results and strength of evidence have been summarized in Table 2. Three factors had strong evidence to support their association with shorter lengths of stay: shortness of breath, receipt of oxygen therapy and admission to a nursing home. Nine factors had moderate evidence to support their association with shorter lengths of stay: cancer, increased contact with primary care, poor general health, poor mobility, low BMI or malnutrition, poor physical functioning, presence of pressure ulcers, older age and being male.

Weak evidence to support their association with shorter lengths of stay was identified for admission from hospital, behaviour problems, biochemical indicators, poor cognitive function, dementia or Alzheimer's disease, depression, diabetes, poor appetite, presence of a feeding tube, help with feeding or diet, hallucinations, delusions, wandering or delirium, incontinence or catheter use, respiratory disorders or COPD, history of stroke, vision impairment, and being married. History of fractures or falls, being of white ethnicity and vaccinations decreased the risk of shorter lengths of stay.

Subgroup analysis—studies with follow-up periods of 1 year or less

A subgroup analysis was conducted on studies that investigated a follow-up period of 1 year or less (Table 3). Twenty-six papers were included, with the same criteria as applied to the full sample. Within 1 year of follow-up, oxygen therapy remained strongly associated with shorter stays, although residence in a nursing home and shortness of breath were associated with moderate evidence. Increased age, cancer, poor appetite, being male, poor general health, low BMI or malnutrition, poor physical functioning remained supported by moderate evidence, respiratory disorders or COPD increased from weak to moderate evidence.

Discussion

The aim of this study was to identify factors associated with length of stay in care homes; the discussion will focus on factors identified as having strong or moderate evidence and notable exceptions.

Unsurprisingly, shorter lengths of stay were associated with characteristics related to end of life. Shortness of breath is common in dying residents, and oxygen therapy provides symptom relief associated with breathlessness, both of which were supported by strong evidence [31]. Low BMI and malnutrition were supported by moderate evidence, which are also common in residents approaching death [32]. Admission to a facility providing nursing care was associated with shorter lengths of stay compared to a residential-only facility. It is possible that

Table 2 Factors with evidence to support a relation to length of stay

Predictors	Lowest ratio		Highest ratio		Strong evidence	Moderate evidence	Weak evidence
Care home characteristics—nursing	1.14 (1.01–1.30)	HR (CI)	1.85 (1.50–2.23)	OR (CI)	X		
Clinical intervention—oxygen therapy	1.6 (1.4–1.8)	HR (CI)	2.61 (1.30–5.21)	OR (CI)	X		
Shortness of breath	1.5 (1.3–1.9)	HR (CI)	4.88	OR	X		
Age	0.70 (0.53–0.93)	OR (CI)	3.25 (2.39–4.41)	HR (CI)		X	
Cancer	1.36 (1.21–1.53)	HR (CI)	374 (174–804)	OR (CI)		X	
Contact with primary care—number of contacts	1.65 (1.43–1.92)	HR (CI)	1.90 (1.2–3.2)	HR (CI)		X	
Gender—being female[a]	0.49 (0.36–0.66)	HR (CI)	2.10 (1.22–3.60)	RR		X	
General health	0.609 (0.416–0.891)	HR (CI)	16.18 (11.41–22.95)	HR (CI)		X	
Mobility	0.93 (0.84–1.02)	RR (CI)	4.6 (2.3–12.7)	OR (CI)		X	
Nutrition—low BMI or malnutrition	0.81 (0.57–1.16)	HR (CI)	2.26 (1.56–3.28)	RR (CI)		X	
Physical functioning	0.23 (0.10–0.50)	HR (CI)	8.0 (2.2–47.8)	OR (CI)		X	
Pressure ulcers	1.03 (1.00–1.06)	HR (CI)	2.7 (1.37–5.1)	OR (CI)		X	
Admission source—hospital	0.81 (0.43–1.52)	HR (CI)	2.02 (1.2–3.3)	HR (CI)			X
Behaviour problems	0.90 (0.78–1.05)	RR (CI)	3.95	OR			X
Biochemical indicators	0.19 (0.10–0.36)	HR (CI)	3.207 (1.023–0.060)	OR (CI)			X
Cognitive function	0.8	OR	10.5 (1.02–1.08)	HR (CI)			X
Dementia or Alzheimer's disease	0.48 (0.52–1.05)	OR (CI)	1.96 (1.86–2.06)	IRR (CI)			X
Depression	0.91 (0.82–1.01)	RR (CI)	1.26 (1.00–1.58)	HR (CI)			X
Diabetes	0.99 (0.88–1.12)	HR (CI)	3.789 (1.266–1.336)	OR (CI)			X
Ethnicity—white[a]	0.69 (0.57–0.85)	RR (CI)	0.89 (0.76–1.06)	RR (CI)			X
Falls and fractures[a]	0.40 (0.21–0.74)	OR (CI)	1.2	OR			X
Feeding—appetite	1.39 (1.37–1.41)	OR (CI)	2.16 (1.59–2.93)	HR (CI)			X
Feeding—feeding tube or help with feeding or diet	0.53 (0.31–0.90)	HR (CI)	4.05 (1.40–1.73)	HR (CI)			X
Hallucinations, delusions, wandering or delirium	0.74 (0.77–1.15)	RR (CI)	2.97 (1.50–5.88)	RR			X
Incontinence or catheter use	0.93	RR	3.2 (1.46–7.2)	OR (CI)			X
Marital status—not married [a]	0.90 (0.78–1.05)	RR (CI)	1.31 (1.09–1.59)	RR (CI)			X
Respiratory disorders/COPD	1.17 (1.04–1.33)	HR (CI)	3.4 (1.3–8.8)	OR (CI)			X
Stroke	0.79 (0.33–0.70)	OR (CI)	1.79 (1.68–1.90)	IRR (CI)			X
Vaccinations[a]	0.439 (0.208–0.924)	HR (CI)	0.47 (0.28–0.78)	OR (CI)			X
Vision impairment	0.94 (0.84–1.05)	RR (CI)	1.38 (1.20–1.57)	RR (CI)			X

Combined results of evidence rating for each factor identified: strong, moderate, weak and inconclusive evidence

[a] Associated with longer length of stay

older adults admitted to residential care homes are more able to function independently than those requiring nursing care, and those who do require nursing care subsequently have higher health needs on admission [33].

It is understandable that older adults die sooner after admission; increased age is associated with frailty, multiple comorbidities and greater healthcare needs. Shorter lengths of stay were associated with contact with primary care, which could reflect greater general practitioner involvement, either as resident health deteriorates or through the provision of palliative care [34]. There was inconclusive evidence to support an association between admission to hospital and shorter lengths of stay. One explanation could be that residents with a poorer diagnosis at admission may have advance care planning in place, including choosing not to be admitted to a hospital [35]. It could also reflect variation in the services offered by different types of facilities; facilities with onsite geriatricians and nursing facilities may be better equipped to provide care and avoid hospital admissions compared to residential facilities; however, this cannot be explored using the current data.

There was moderate evidence to suggest that men had shorter lengths of stay in care homes than women. In all studies that reported the gender profile of the sample, there were substantially more women in the samples

Table 3 Factors with evidence to support a relation to length of stay up to 1 year

Predictors	Lowest ratio		Highest ratio		Strong evidence	Moderate evidence	Weak evidence
Clinical intervention—oxygen therapy	1.6 (1.4–1.8)	HR (CI)	2.61 (1.30–5.21)	OR (CI)	X		
Age	1.02 (0.98–1.07)	HR (CI)	3.05	HR		X	
Cancer	1.36 (1.21–1.53)	HR (CI)	374 (174–804)	OR (CI)		X	
Care home characteristics—nursing	1.14 (1.01–1.30)	HR (CI)	1.48 (1.36–1.61)	HR (CI)		X	
Feeding—appetite	1.39 (1.37–1.41)	OR (CI)	2.16 (1.59–2.93)	HR (CI)		X	
Gender—being female[a]	0.49 (0.36–0.66)	HR (CI)	2.10 (1.22–3.60)	RR		X	
General health	1.1	OR	6.04 (4.19–8.71)	OR (CI)		X	
Nutrition—low BMI or malnutrition	0.844 (0.766–0.930)	HR (CI)	2.26 (1.56–3.28)	RR (CI)		X	
Physical functioning	0.718 (0.644–0.801)	HR (CI)	8.0 (2.2–47.8)	OR (CI)		X	
Respiratory disorders/COPD	1.17 (1.04–1.33)	HR (CI)	3.4 (1.3–8.8)	OR (CI)		X	
Shortness of breath	1.5 (1.3–1.9)	HR (CI)	2.69 (2.20–3.29)	HR (CI)		X	
Admission source—hospital	0.81 (0.43–1.52)	HR (CI)	2.02 (1.2–3.3)	HR (CI)			X
Biochemical indicators	0.25	PCC	1.55 (1.12–2.13)	OR (CI)			X
Cognitive function	0.8	OR	10.5 (1.02–1.08)	HR (CI)			X
Falls and fractures[a]	0.40 (0.21–0.74)	OR (CI)	1.2	OR			X
Feeding—feeding tube or help with feeding or diet	0.7	OR	4.05 (1.40–1.73)	HR (CI)			X
Incontinence or catheter use	0.93	RR	1.1	OR			X
Pressure ulcers	1.03 (1.00–1.06)	HR (CI)	2.7 (1.37–5.1)	OR (CI)			X

Combined results of evidence rating for each factor identified: strong, moderate, weak and inconclusive evidence—limited to studies with 1 year follow-up or less

[a]Associated with longer length of stay

than men. This finding could reflect a gender imbalance in admission to care homes; women generally live longer than men, and the sample characteristics could reflect widowed women who are unable to live independently after the death of a spouse [36].

Two disease diagnoses were associated with shorter lengths of stay, cancer and, at 1 year follow-up, respiratory disorders or COPD. Functional impairment and characteristics associated with poor functioning, such as poor mobility and pressure ulcers, were identified as having moderate evidence to support them. Poor general health was associated with shorter lengths of stay, indicating that general measures of health and functioning may be more accurate predictors of length of stay than individual diagnoses.

The notable finding of this review is the weak evidence for poor cognitive function and dementia or Alzheimer's disease being associated with shorter lengths of stay. In Luppa et al.'s review of predictors of care home admission, strong evidence was found to support both the association of cognitive impairment or dementia and poor physical functioning with care home admission [9], however post-admission, this review found neither cognitive impairment nor dementia nor Alzheimer's disease to be strongly associated with shorter lengths of stay.

One explanation could be related to life expectancy and disease trajectory. Compression of morbidity in ageing populations is an ongoing trend [37], whereby the onset of chronic illness is occurring later in life, for a relatively short time period before death [38]. However, the median survival time for an older adult with dementia from onset to death is 4.1 years (IQR 2.5–7.6) for men and 4.6 years (IQR 2.9–7.0) for women [39]. Survival varies substantially dependent on age of onset, with those diagnosed younger (between 65 and 69 years) potentially living over 10 years [39]. It is possible that residents with dementia are living longer than those with no cognitive impairment post-care home admission.

Another explanation for these findings could be related to characteristics prior to admission, in particular, caregiver burden. Cognitive impairment is a long-term, chronic condition, which reduces one's ability to live independently. Research suggests that variation in caregiver burden is associated with caregiver characteristics rather than patient characteristics [40], stress among caregivers of those with dementia has been found to be higher than for caregivers caring for older adults without dementia [41]. Although individual experiences vary, caregivers to those with dementia provide more hours per week spent on caregiving tasks and support a higher number of activities of daily living, as well as being affected by negative consequences of caregiving, such as employment complications, caregiver strain and mental and physical health problems [42]. Residents with physical impairment may be surviving in the community longer than those with cognitive impairment due to lower caregiver burden, and are subsequently admitted to care homes later, leading to shorter lengths of stay.

Finally, the availability of formal home care services may explain this finding. Formal home care services provide support for older adults to remain living in their own homes, undertaking domestic and personal care based on individual needs. It is possible that older adults with functional impairments are more able to locate and access services to support their remaining in the community than those with cognitive impairment, further delaying care home admission.

Strengths and limitations

To the authors' knowledge, this is the first systematic review of international literature on factors associated with length of stay in care homes. The review had broad inclusion criteria and was not limited to one type of care home. Efforts to ensure that the studies identified were comparable limited the review to study designs that followed residents until death, meaning that residents who were discharged or moved to another care home were not included. The inclusion of variables related to resident and care home characteristics adds an additional dimension to the review.

The review is potentially limited by the heterogeneity in the terminology used in studies in care homes. Efforts were made to include a multitude of terms related to care homes in the search strategy used to identify studies from a variety of settings; however, it is possible that some studies that included less common terms for care homes were missed. The levels of care provided by different care homes, their admission criteria and the terminology used to define care homes vary between countries making the synthesis of data published on care homes problematic. For example, the definition of long-term care facilities applied in this review excluded studies in assisted living facilities and sheltered accommodation. Further discussion is needed to refine the terms used in this area and improve subsequent reporting. In addition, it is difficult to make meaningful comparisons between countries without considering the national policies and provision of care offered by care homes within a country's wider health care system. The review also does not capture a resident's living arrangement prior to admission that may affect the decision to enter a care home and their subsequent experience.

The focus of the review centered on studies that had explored a number of factors as their aim, without any prior hypothesis. Studies that explored the role of one factor on length of stay, such as depression or malnutrition, were excluded, for two reasons. Firstly, it would be impossible to develop a search strategy that could identify all factors associated with length of stay, without first having a basis on which to justify the inclusion of search terms for each factor. Secondly, the number of studies identified would be very large and difficult to synthesize.

The interpretation of the results is also limited by the limitations of the individual studies. Most studies only collected data at baseline, with follow-up restricted to the outcome measure of time until death. It is possible that changes in time-dependent characteristics, such as cognitive impairment, which may get progressively worse, were missed. There were numerous measures used to assess factors, for example, at least 6 tools were used to assess physical functioning and 12 for cognitive functioning; however, the analytical approach used in this review allowed these findings to be combined and weighted into a meaningful measure of association and methodological quality. Finally, the review did not perform study selection and study extraction in duplicate on the full dataset.

Implications for further research

The study highlighted the varied trajectories of care home residents approaching end of life and the need for flexible, appropriate palliative care provision to accommodate different trajectories. This review has synthesized factors associated with variation in length of stay in care homes, and identified similar homogeneity within the care home population from admission to death, which is not yet fully understood.

Increasingly, care homes are taking on a complex role within the wider health system, catering for the diversities of an ageing population that can no longer live in the community. At one end of the spectrum, care homes are acting as proxy hospices for short-stay residents approaching end of life. At the other end, care homes are accommodating residents with cognitive impairments who may survive for many years post-admission. Supporting care homes in negotiating these two roles; delivering palliative care for short-stay residents while simultaneously providing a residential home for long-stay residents, in the same space, is imperative and requires further research. In addition, further thought should be given to the suitability of care homes in catering for such a wide variation in needs. The potential for other types of services, such as specialist dementia care units and assisted living facilities, in providing care for subgroups of care home residents could be examined, although there is debate as to whether such services provide better care [43, 44].

The findings of this review have identified numerous questions requiring further investigation. Firstly, further research is needed to explore the relationship between factors associated with care home admission and factors associated with length of stay. Longitudinal studies which follow community-dwelling older adults post-admission are required to fully understand this relationship. Secondly, in this review, characteristics related to the care home were only collected in eight studies, further data on variation in length of stay and care home-related factors could identify ways to improve the delivery of care. It is imperative that research on care home residents contextualizes the data within the long-term care setting to inform the generalizability of the findings internationally. Finally, inclusion and identification of care home residents in existing national datasets would allow comparisons within and between countries, and enable time-dependent variables to be monitored.

Conclusion

Care home residents remain a growing, diverse population. An understanding of the factors associated with shorter and longer lengths of residence within care homes can be used to inform residents and their families about their potential use of health care services. Clinicians can use these findings to inform treatment decisions for older residents residing in care homes, and if required, organize palliative care. On a wider scale, policy-makers can use these findings to inform service planning for the future and to identify facilities in which lengths of stay deviate from the expected. Good quality, replicable research on the health needs of care home residents is a priority, now and in the future.

Additional files

Additional file 1: Criteria for assessing methodological quality of studies. (DOCX 34 kb)

Additional file 2: Factors associated with length of stay before death in care home residents in all studies and split between high-, moderate- and low-quality studies. (DOCX 45 kb)

Additional file 3: Factors associated with length of stay before death in care home residents in all studies and split between high-, moderate- and low-quality studies-limited to 1 year follow-up. (DOCX 47 kb)

Additional file 4: Factors associated with length of stay before death in care home residents—data extracted from included papers. (DOCX 349 kb)

Abbreviations

BMI: Body mass index; COPD: Chronic obstructive pulmonary disease

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Availability of data and materials

The search strategies used during the current study are available from the corresponding author on reasonable request.

Authors' contributions

DCM designed the protocol, conducted the search, reviewed the papers for inclusion, extracted and synthesized the data and wrote the paper. LD acted as a second reviewer. Supervising authors interpreted data and critically reviewed the paper. All authors read and approved the final manuscript.

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Contribution to the thesis

The third chapter in this thesis explored factors associated with length of stay in LTCFs, synthesising international evidence from forty-seven studies. The review found shorter lengths of stay to be strongly associated with characteristics related to end of life, i.e. shortness of breath and oxygen therapy, and admission to a facility providing nursing care. The main finding of the review was the weak evidence for the association of poor cognitive function and dementia or Alzheimer's disease with shorter lengths of stay, despite being one of the strongest predictors of admission to a LTCF. The review has built on previous knowledge that identified two subpopulations of residents, short stay and long stay, and defined the characteristics of each group.

The review also identified research gaps in this area; a lack of studies using internationally comparable data, underreporting of facility and country level characteristics, and little data that is collected at a time point other than admission. The limitations of the studies included in the review highlight the need for longitudinal data collected on older adults transitioning from residence in the community to admission to a LTCF.

Chapter three has synthesised current evidence on factors associated with length of stay in LTCFs. In doing so, it has provided a methodologically rigorous approach to identifying the factors associated with length of stay to be included in the analysis of the PACE dataset conducted in the next chapter.

Chapter 4 - Paper 2: Collingridge Moore, D., Payne, S., Keegan, T., Van Den Block, L., Deliens, L., Gambassi, G., Heikkila, R., Kijowska, V., Pasman, H. R., Pivodic, L. & Froggatt, K. (2020) Length of stay in long-term care facilities: a comparison of residents in six European countries. Results of the PACE cross-sectional study. BMJ Open, 10(3), e033881.

Rationale

In chapter three, the systematic review identified factors with evidence to support their association with length of stay in LTCFs. In addition to exploring the characteristics of shorter and longer stay populations, the chapter highlighted a lack of international studies using data comparable between countries, limited use of characteristics related to the LTCF, and studies using data collected at time points post-admission.

Since the publication of the previous chapter, one study has explored length of stay in LTCFs across multiple countries. The Services and Health for Elderly in Long-term care (SHELTER) study aimed to assess the validity and reliability of the InterRAI LTCF, translated for use and implemented in Czech Republic, England, Finland, France, Germany, Italy, The Netherlands and Israel (Onder et al., 2012a). The analysis aimed to investigate the impact on survival of selected health determinants, including smoking status, social participation, immunization practices, with age, sex, disease diagnosis, cognitive status functional status and multi-morbidity included as covariates (Vetrano et al., 2018). The sample included 4,156 residents from 57 nursing homes, who were either residing in the care home at baseline or admitted within three months, with a follow up period of 12 months. However, the study has a number of limitations, in each country ten or fewer nursing homes were recruited, the sample was restricted to nursing homes (with no further definition), facilities were not randomly sampled, or representative of each country, and comparisons between countries were not reported (Onder et al., 2012a). At present, the research gaps identified in chapter three have yet to be met.

The PACE study, a retrospective, cross sectional review of deaths in LTCFs, conducted in six Europeans countries, has the potential to explore these three areas. Data collected in the PACE study can be used to explore the effect of different types of facilities on length of stay; controlling for the effect of specific facilities on multiple residents and utilise data collected at various time points between admission and death.

Aim and objectives

The aim of chapter four is to explore the association of resident, facility and country level factors with length of stay in LTCFs, using internationally comparable data. To achieve this aim, the chapter has two objectives:

1. To compare length of stay from admission to death in LTCFs between countries included in the PACE dataset.
2. To investigate the association of resident, facility and country level factors with length of stay from admission to death in LTCFs within and between countries included in the PACE dataset.

Overview of methodology

Chapter four focuses on applying the findings of chapter three to internationally comparable data collected in the PACE study; a mortality follow-back survey initially collected to compare the effectiveness of health care systems with and without formal palliative care structures. Data were collected on LTCF residents across six European countries: Belgium, England, Finland, Italy, the Netherlands and Poland. The analysis uses multilevel time to event analysis to explore the relationship between length of stay and the factors identified as related to length of stay in chapter three. The study was conducted in line with the STROBE (STrengthening the Reporting of OBservational studies in Epidemiology) statement (Vandenbroucke et al., 2007).

Overview of my contribution to the publication

I led the recruitment of LTCFs in England, collected and cleaned the data for the PACE study. In this PhD study, I prepared the variables required for the analysis, conducted time to event analysis on the data and interpreted the results in the context of the findings of chapter three. I submitted the manuscript to the journal after incorporating feedback from the other authors and responded to reviewer feedback, where received.

BMJ Open

Length of stay in long-term care facilities: a comparison of residents in six European countries. Results of the PACE cross-sectional study

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ABSTRACT

Objectives This paper aims to investigate resident, facility and country characteristics associated with length of stay in long-term care facilities (LTCFs) across six European countries.

Setting Data from a cross-sectional study of deceased residents, conducted in LTCFs in Belgium, England, Finland, Italy, the Netherlands and Poland.

Participants All residents aged 65 years and older at admission who died in a 3-month period residing in a proportional random sample of LTCFs were included.

Primary and secondary outcome measures The primary outcome was length of stay in days, calculated from date of admission and date of death. Resident, facility and country characteristics were included in a proportional hazards model.

Results The proportion of deaths within 1 year of admission was 42% (range 32%–63%). Older age at admission (HR 1.04, 95% CI 1.03 to 1.06), being married/in a civil partnership at time of death (HR 1.47, 95% CI 1.13 to 1.89), having cancer at time of death (HR 1.60, 95% CI 1.22 to 2.10) and admission from a hospital (HR 1.84, 95% CI 1.43 to 2.37) or another LTCF (HR 1.81, 95% CI 1.37 to 2.40) were associated with shorter lengths of stay across all countries. Being female (HR 0.72, 95% CI 0.57 to 0.90) was associated with longer lengths of stay.

Conclusions Length of stay varied significantly between countries. Factors prior to LTCF admission, in particular the availability of resources that allow an older adult to remain living in the community, appear to influence length of stay. Further research is needed to explore the availability of long-term care in the community prior to admission and its influence on the trajectories of LTCF residents in Europe.

Strengths and limitations of this study

- The study sample included a large, representative sample of residents in long-term care facilities (LTCFs) across six European countries.
- The cohort of residents was identified retrospectively after death, meaning that there was no loss to follow-up at the end of the study.
- The study collected data on LTCF characteristics, including LTCF type and size.
- Health-related characteristics were measured either at death or in the last month/week of life, limiting the generalisability of the findings to resident characteristics at LTCF admission.
- The study was limited to data collected from LTCF staff members, increasing the likelihood of recall bias.

INTRODUCTION

As the population ages, the need for accessible, appropriate long-term care provision will become a global priority. Despite being reported as the least preferred place of death, older adults with dementia and multiple, complex conditions often die in long-term care facilities (LTCFs), although the proportion of deaths differs significantly between countries.[1–5] In England and Wales, LTCFs are projected to become the most common place of death for older adults by 2040.[6]

Previous reviews of studies containing community-based samples of older adults have identified numerous factors predictive of future LTCF admission, with older adults with dementia more likely to be admitted to an LTCF than those without.[7 8] Postadmission, the factors associated with shorter and longer length of stay in an LTCF have also been explored[9–14]; a systematic review of these factors identified shorter lengths of stay associated with older age, being male, having a cancer diagnosis, shortness of breath, receipt of oxygen therapy and residence in an LTCF providing nursing care.[15] In particular, the review found stronger evidence for the association of poor physical functioning and shorter lengths of stay, compared with cognitive functioning. The findings of the review were limited as no international studies using data comparable between countries were identified and few studies included characteristics related to the facility or used data collected at time points post-admission. More recently, length of stay in nursing homes across seven countries has been examined using internationally comparable data from the Services and Health for Elderly in Long TERm care (SHELTER) study.[16] The sample was restricted to nursing homes, was neither randomly sampled nor representative of each country, and the findings were not reported between countries.[17]

In this analysis, we have used data from the Palliative Care for Older People in care and nursing homes in Europe (PACE) study, a retrospective, cross-sectional study of deaths in LTCFs, conducted in six European countries, which aimed to explore quality of dying and end-of-life care.[18] The PACE study collected data on nationally representative samples of deaths in multiple types of LTCFs, allowing comparison of length of stay between countries. This paper aims to compare length of stay between countries and to investigate the association of resident, facility and country level factors with length of stay from admission to death in LTCFs. In doing so, it will explore differences in the characteristics of LTCF residents with varying lengths of stay and identify heterogeneity in a relatively under researched population.

METHODS

Study design and setting

The PACE study undertook a retrospective, cross-sectional study of deaths in LTCFs in Belgium, England, Finland, Italy, the Netherlands and Poland. LTCFs were defined as a collective institutional setting where care is provided for older adult residents who reside there, 24 hours a day, 7 days a week, for an undefined period of time.[19] The care provided includes onsite provision of personal assistance with activities of daily living, nursing and medical care may be provided onsite or by nursing and medical professionals working from an organisation external to the setting.[19]

In each country, a proportional random sampling framework of LTCFs was developed using national lists of LTCFs. In Italy, no national list of LTCFs was available, therefore, a cluster of nursing homes interested in research was used.[17] In England, LTCFs were also recruited from Enabling Research in Care Homes, a network of LTCFs with an interest in research participation.[20] The methods used to recruit the LTCF and ethical approvals are discussed in the study protocol and primary outcomes publication.[21 22]

Patient and public involvement

In each country, feedback on questionnaires for relatives was provided by three relatives recruited by the researchers. In England, a research partnership group including carers and volunteers provided feedback on questionnaires for relatives. Patient and public involvement is discussed in detail in the study protocol.[21]

Study population

LTCFs that consented to take part in the study were asked to provide data on the facility and on all resident deaths in a retrospective period between 2015 and 2016. Residents were included in the study if they had died in the facility, or after transfer to hospital, in the past 3 months. For each identified resident, structured questionnaires were sent to the administrative staff (response rate 95.7%), facility manager (94.7%) and a staff member who knew the resident (81.6%). Questionnaires were also sent to the resident's physician and the resident's relative, however, data from these questionnaires are not used in this analysis.

Independent variables

Factors identified in a systematic review as having strong, moderate or weak evidence of being related to length of stay were used to identify variables of interest collected in the PACE study.[15] The construction of each variable is detailed in table 1.

Demographic data were collected on resident age, gender, marital status and source of admission. Data on diagnoses of cancer, severe pulmonary disease or severe diabetes were collected, as was the presence of pressure ulcers or history of a stroke. Shortness of breath, oxygen therapy, assistance with eating or drinking and enteral, parenteral or artificial administration of nutrition during the last week of life were also recorded. Severity of dementia was calculated using a combined score from the Global Dementia Scale (GDS)[23] and Cognitive Performance Scale (CPS).[24]

The general health of the resident during the last week of life was documented using a scale of 0–100, with 0 representing worst health possible and 100 representing the best health possible. Physical functioning was determined using two validated questionnaires, the Bedford Alzheimer Nursing-Severity Scale (BANS-S)[25] and the EuroQol 5 dimensional (EQ-5D).[26] The BANS-S collected data on seven items; ability to dress oneself, sleep cycle, speech, eating, mobility, muscle flexibility and eye contact in the last month of life. The EQ-5D measured quality of life in the last week of life, including anxiety or depression, mobility, self-care, usual activities and pain in the last week of life.

Contact with health services were measured by the number of visits either received or made by a physician, visits to a hospital and admissions to an emergency department. Place of death was determined as the facility, hospice or palliative care unit, or a hospital.

Using the typology developed by Froggatt *et al*, LTCFs were categorised by the type of care offered.[27] These were: type 1; a facility where onsite care is provided by physicians, nurses and care assistants (present in Italy, Netherlands, Poland); type 2: a facility where onsite care is provided by nurses and care assistants with medical provision provided by local, external primary care services (present in all countries); type 3: a facility where onsite care is provided by care assistants, and nursing with medical provision provided by local, external primary care

Table 1 Definition of variables used in the analysis

Variable name	Variable definition
Age	Resident age at the time of admission.
Gender	Resident gender at the time of admission.
Marital status	Marital status at the time of death, grouped into married/in civil partnership or in long-term relationship, or other (divorced, widowed, never married).
Source of admission	Source of admission to the LTCF, grouped into three categories, community, hospital or another LTCF.
Cancer Severe pulmonary disease Severe diabetes	Diagnosis based on the question ‘which of the following conditions was the resident suffering from at the time of death?’
Pressure ulcers	Whether the resident had decubitus during the last week of life.
Stroke	Whether the resident suffered a stroke in the last month of life.
Shortness of breath	Whether the resident experienced shortness of breath during the last week of life, classed as not at all, somewhat or a lot.
Oxygen therapy	Whether the resident received oxygen therapy in the last week of life.
Assistance with eating or drinking	Whether the resident received assistance with eating or drinking in the last week of life.
Enteral, parenteral or artificial administration of nutrition	Whether the resident received enteral,parenteral or artificial administration of nutrition in the last week of life.
Severity of dementia	Very severe or advanced dementia was classed as a GDS score of 7 and a CPS score of 5 or 6. Severe dementia was classed as a GDS score less than 7 and a CPS score of 5 or 6, or a GDS score of seven and a CPS score of less than 5. Mild or moderate dementia was classed as a GDS score less than 7 and a CPS score of less than 5.
General health	The general health of the resident during the last week of life, documented using a scale of 0 to 100, with 0 representing worst health possible and 100 representing the best health possible.
Physical functioning	Scores for each BANS-S item ranged from one to four, with one indicating ability and four indicating dependency, which were grouped into no or mild impairments (scores 1–2) versus moderate to severe impairments (scores 3–4). Scores for each EQ-5D item ranged from 0 to 5, with 0 indicating no problems or independence and 5 indicating severe problems or total dependence. These were grouped into no or mild impairments (scores 1–3) versus moderate to severe impairments (scores 4–5).
Physician visits	The no of visits either received or made by a physician during the last month of life.
Hospital visits	The no of visits to a hospital, geriatric ward, intensive care unit or general ward (for more than 24 hours) during the last month of life.
Emergency department admissions	The no of admissions to a hospital emergency room (for less than 24 hours) during the last month of life.
Place of death	Place of death was determined as the facility, a hospice or palliative care unit, or a hospital; including a general ward, intensive care unit or accident and emergency department.
LTCF type	Each LTCF was categorised by the type of care offered. Type 1; a facility where onsite care is provided by physicians, nurses and care assistants (present in Italy, Netherlands, Poland); type 2: a facility where onsite care is provided by nurses and care assistants with medical provision provided by local, external primary care services (present in all countries); type 3: a facility where onsite care is provided by care assistants, and nursing with medical provision provided by local, external primary care services (present in England).
LTCF funding status	The funding status of the LTCF was either public (non-profit), private (non-profit) or private (for profit).
LTCF size	The size of the facility was classed as either small or large, based on average bed number in each country sample.

BANS-S, Bedford Alzheimer Nursing-Severity Scale; CPS, Cognitive Performance Scale; EQ-5D, EuroQol 5 dimensional; GDS, Global Dementia Scale; LTCF, long-term care facility.

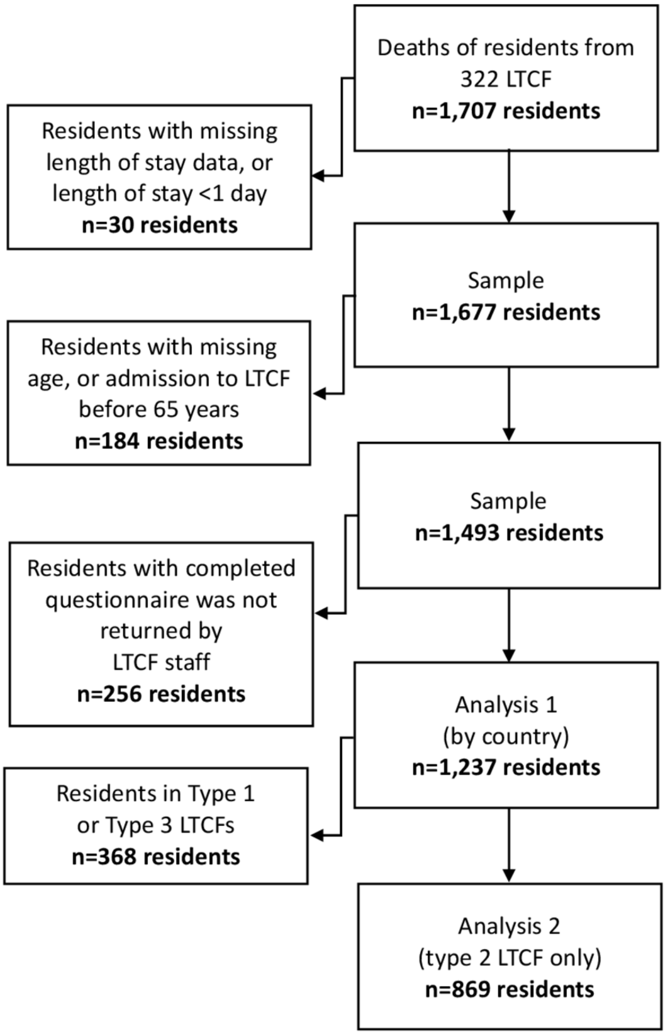

Figure 1 Recruitment to the PACE study and development of the dataset. LTCF, long-term care facility; PACE, Palliative Care for Older People in care and nursing homes in Europe.

services (present in England). The funding status of the LTCF was either public (non-profit), private non-profit or private for profit. The size of the facility was classed as either small or large, based on average bed number in each country sample.

Dependent variable

Date of admission and date of death were used to calculate length of stay in days in the facility.

Data analysis

First, analysis was conducted by country on all LTCFs within the country sample, with LTCF type included as a factor if more than one type was present in the country. Second, analysis was restricted to residents in type 2 LTCFs, providing onsite nursing care and external medical provision, which are present in all six countries, allowing for comparison of similar LTCF types between countries.

The initial dataset contained data on 1707 participants, as detailed in figure 1. Participants were excluded if length of stay could not be calculated or was less than 1 day, if residents were younger than 65 years on admission, were missing data on age, or no questionnaire was returned by LTCF staff (n=470), resulting in a final sample of 1237 participants. Analysis of LTCFs providing onsite nursing care only was conducted on 869 participants.

Univariate analysis of the variables was performed and significance tested using log rank tests and Kaplan-Meir curves were plotted for each factor. All factors associated with the outcome at a p≤0.2 at univariate analysis were entered into a proportional hazards model, including testing for potential interactions between age, gender and marital status. HRs, 95% CIs and p values that reached a statistical significance of p≤0.05 or p≤0.01 are reported. An HR above 1 indicates a greater risk of death, or a shorter length of stay, and an HR of less than 1 indicates a lower risk of death or a longer length of stay. Multicollinearity was checked using variance inflation factors. Proportionality assumptions were tested by exploring time-dependant covariates and Schoenfeld residuals; and goodness of fit was tested using Cox-Snell residuals. A variable to identify each individual LTCF was added as a random, multilevel effect to account for multiple residents within the same LTCF. The final model used was a parametric proportional hazards model using a Weibull distribution. All analyses were performed using v16 Stata.[28]

RESULTS

The characteristics of the sample are described in table 2. The non-response analysis did not identify significant differences in the lengths of stay of residents for whom a staff questionnaire was or was not completed and returned (p=0.356). The median length of stay was 73.4 weeks, ranging from 16 weeks in Poland to 103.9 weeks in Belgium. Average length of stay was 126 weeks (SD 157), ranging from 93 (SD 156) weeks in Poland to 163 (SD 182) weeks in Belgium. The number of deaths within 1 year of admission was 521 (42%), ranging from 85 (32%) in Belgium to 165 (63%) in Poland. The mean age of residents at admission was 83.9 years (SD 7.2), ranging from 82.1 (SD 7.8) in Poland to 85.7 (SD 7.4) in England. The percentage of residents who were female was 67%, ranging from 64% in Belgium to 77% in England.

Analysis of all LTCFs by country

Table 3 shows the results of the proportional hazards model for each of the six countries, results that reached a statistical significance of p≤0.05 or p≤0.01 are indicated.

In Belgium, older age at admission (HR 1.05, 95% CI 1.02 to 1.08), being married/in a civil partnership (HR 2.65, 95% CI 1.68 to 4.16) and admission from hospital (HR 2.62, 95% CI 1.80 to 3.81) or another LTCF (HR 2.14, 95% CI 1.25 to 3.67) were associated with shorter lengths of stay. Moderate or severe mobility problems (HR 0.34, 95% CI 0.14 to 0.86) were associated with longer lengths of stay.

Table 2 Characteristics of deceased LTCF residents all six countries

	Belgium	England	Finland	Italy	Netherlands	Poland	Overall	
	n=262	**n=75**	**n=252**	**n=192**	**n=193**	**n=263**	**n=1237**	**P value**
No of LTCFs (average number of residents/range)	46 (6/1–17)	37 (2/1–7)	88 (3/1–11)	32 (6/1–27)	42 (5/1–32)	46 (6/1–24)	288 (4/1–32)	
Average length of stay—mean/SD (weeks)	163/182	147/153	119/140	102/136	146/153	93/156	126/157	≤0.01
Length of stay—median	103.9	101	83	61.4	101.4	16	73.4	
Deaths within 1 year of admission	85 (32)	27 (36)	93 (37)	87 (45)	64 (33)	165 (63)	521 (42)	
Age at admission								
Mean/SD (years)	84.6/6.5	85.7/7.4	83.9/7.2	84.2/7.4	84.4/6.8	82.1/7.8	83.9/7.2	≤0.01
65–74 years	22 (8)	6 (8)	26 (10)	22 (11)	19 (10)	51 (19)	146 (12)	≤0.01
75–84 years	93 (37)	23 (31)	107 (42)	67 (35)	72 (37)	107 (41)	469 (38)	
85–94 years	136 (52)	41 (55)	107 (42)	90 (47)	94 (49)	96 (37)	564 (46)	
94 years and over	11 (4)	5 (7)	12 (5)	13 (7)	8 (4)	9 (3)	58 (5)	
Gender—female	168 (64)	58 (77)	163 (65)	131 (68)	131 (68)	180 (68)	831 (67)	0.43
Marital status—married or in a civil partnership	61 (23)	14 (19)	58 (23)	47 (24)	50 (26)	30 (11)	260 (21)	≤0.01
Source of admission								≤0.01
Community	96 (37)	39 (52)	75 (30)	92 (48)	94 (49)	136 (52)	532 (43)	
Hospital	81 (31)	18 (24)	86 (34)	59 (31)	28 (15)	93 (35)	365 (30)	
Other LTCF	30 (12)	16 (21)	68 (27)	31 (16)	32 (17)	25 (10)	202 (16)	
Place of death								≤0.01
LTCF	214 (82)	62 (83)	213 (85)	165 (86)	172 (89)	214 (81)	1040 (84)	
Hospice/PCU	1 (0)	0 (0)	23 (9)	0 (0)	11 (5)	48 (18)	83 (7)	
Hospital	47 (18)	12 (16)	2 (1)	23 (12)	6 (3)	1 (0)	91 (7)	
Cancer	36 (14)	14 (19)	36 (14)	36 (19)	34 (18)	25 (10)	181 (15)	0.08
Severe pulmonary disease	40 (15)	8 (11)	20 (8)	30 (16)	27 (14)	35 (13)	160 (13)	0.13
Severe diabetes	20 (8)	2 (3)	23 (9)	27 (14)	12 (6)	30 (11)	114 (9)	0.02
Stroke	24 (9)	6 (8)	12 (5)	25 (13)	9 (5)	42 (16)	118 (10)	≤0.01
Pressure ulcers	49 (19)	7 (9)	44 (17)	72 (38)	33 (18)	91 (35)	296 (24)	≤0.01
General health—mean/SD†	31.7/24.2	33.2/22.9	24.4/21.8	20.1/19.9	29.2/21	26.9/25.1	27.1/23	≤0.01
Dementia								≤0.01
Resident did not have dementia	92 (35)	25 (33)	40 (16)	41 (21)	74 (38)	66 (25)	338 (27)	
Mild or moderate dementia	24 (9)	11 (15)	43 (17)	14 (7)	28 (15)	14 (5)	134 (11)	
Severe dementia	45 (17)	10 (13)	54 (21)	39 (20)	34 (18)	32 (12)	214 (17)	
Very severe or advanced dementia	77 (29)	17 (23)	71 (28)	64 (33)	52 (27)	93 (35)	374 (30)	

Continued

Table 2 Continued

	Belgium	England	Finland	Italy	Netherlands	Poland	Overall	
	n=262	n=75	n=252	n=192	n=193	n=263	n=1237	P value
Assistance with eating or drinking	190 (73)	49 (65)	197 (78)	159 (83)	140 (73)	225 (86)	960 (78)	≤0.01
Enteral, parenteral or artificial administration of nutrition	15 (6)	5 (7)	19 (8)	81 (42)	6 (3)	142 (54)	268 (22)	≤0.01
Shortness of breath								≤0.01
Not at all	120 (46)	43 (57)	83 (33)	86 (45)	90 (47)	72 (27)	494 (40)	
Somewhat	90 (34)	21 (28)	111 (44)	64 (33)	56 (29)	131 (50)	473 (38)	
A lot	39 (15)	8 (11)	44 (17)	30 (16)	43 (22)	44 (17)	208 (17)	
Oxygen therapy	57 (22)	7 (9)	57 (23)	120 (63)	24 (12)	94 (36)	359 (29)	≤0.01
EQ-5D (moderate or severe problems)								
Anxiety or depression	103 (39)	21 (28)	84 (33)	103 (54)	92 (48)	135 (51)	538 (43)	≤0.01
Mobility	237 (90)	70 (93)	237 (94)	182 (95)	174 (90)	250 (95)	1150 (93)	0.01
Self-care	245 (94)	71 (95)	241 (96)	183 (95)	175 (91)	250 (95)	1165 (94)	≤0.01
Usual activities	243 (93)	67 (89)	241 (96)	187 (97)	177 (92)	253 (96)	1168 (94)	≤0.01
Pain	130 (50)	31 (41)	167 (66)	99 (52)	124 (64)	179 (68)	730 (59)	≤0.01
BANS-S (moderate or severe impairment)								
Dressing	231 (88)	68 (91)	235 (93)	185 (96)	164 (85)	232 (88)	1115 (90)	≤0.01
Sleeping	94 (36)	18 (24)	101 (40)	91 (47)	54 (28)	161 (61)	519 (42)	≤0.01
Speech	129 (49)	24 (32)	131 (52)	130 (68)	69 (36)	178 (68)	661 (53)	≤0.01
Eating	144 (55)	43 (57)	176 (70)	163 (85)	104 (54)	210 (80)	840 (68)	≤0.01
Mobility	200 (76)	59 (79)	207 (82)	178 (93)	139 (72)	229 (87)	1012 (82)	≤0.01
Muscle flexibility	123 (47)	29 (39)	189 (75)	142 (74)	104 (54)	197 (75)	784 (63)	≤0.01
Eye contact	71 (27)	13 (17)	55 (22)	79 (41)	35 (18)	108 (41)	361 (29)	≤0.01
Physician visits								≤0.01
None	4 (2)	5 (7)	35 (14)	44 (23)	3 (2)	28 (11)	119 (10)	
One to four visits	75 (29)	47 (63)	116 (46)	40 (21)	62 (32)	56 (21)	396 (32)	
Five or more	49 (19)	15 (20)	54 (21)	34 (18)	101 (52)	97 (37)	350 (28)	
Hospital visits								≤0.01
None	188 (72)	56 (75)	192 (76)	164 (85)	157 (81)	170 (65)	927 (75)	
One or more	62 (24)	19 (25)	53 (21)	19 (10)	31 (16)	49 (19)	233 (19)	
Emergency department admissions								0.02
None	218 (83)	58 (77)	206 (82)	149 (78)	170 (88)	209 (79)	1010 (82)	
One or more	31 (12)	14 (19)	39 (15)	29 (15)	17 (9)	19 (7)	149 (12)	

Continued

Table 2 Continued

	Belgium	England	Finland	Italy	Netherlands	Poland	Overall	
	n=262	**n=75**	**n=252**	**n=192**	**n=193**	**n=263**	**n=1237**	**P value**
LTCF type								≤0.01
Type 1—onsite nursing/onsite GP	0 (0)	0 (0)	0 (0)	46 (24)	105 (54)	165 (63)	316 (26)	
Type 2—onsite nursing/offsite GP	262 (100)	39 (52)	252 (100)	135 (70)	83 (43)	98 (37)	869 (70)	
Type 3—offsite nursing/offsite GP	0 (0)	36 (48)	0 (0)	0 (0)	0 (0)	0 (0)	36 (3)	
LTCF funding status								≤0.01
Public—non-profit	128 (49)	2 (3)	197 (78)	65 (34)	188 (97)	165 (63)	745 (60)	
Private—non profit	117 (45)	9 (12)	24 (10)	44 (23)	0 (0)	92 (35)	286 (23)	
Private—profit	17 (6)	64 (85)	28 (11)	72 (38)	0 (0)	4 (2)	185 (15)	
LTCF size								0.93
Small	138 (53)	40 (53)	131 (52)	96 (50)	107 (55)	137 (52)	649 (52)	
Large	124 (47)	35 (47)	121 (48)	85 (44)	81 (42)	126 (48)	572 (46)	

Unless otherwise stated data is reported as frequencies and percentages.

*Higher scores indicate better general health. Missing data: gender n=8, marital status n=90, source of admission n=138, place of death n=23, cancer n=55, severe pulmonary disease n=55, severe diabetes n=55, stroke n=127, pressure ulcers n=32, general health n=32, dementia n=177, assistance with eating or drinking n=43, shortness of breath n=62, oxygen therapy n=44, EQ-5D: anxiety or depression n=43, mobility n=25, self-care n=26, usual activities n=24, pain n=31, BANS-S: dressing n=26, sleeping n=33, speech n=30, eating n=26, mobility n=26, muscle flexibility n=32, eye contact n=27. Physician visits n=372, hospital visits n=77, emergency department admissions n=78, LTCF type n=16, LTCF ownership n=21, LTCF size n=16. P values calculated using Pearson X^2 two and one-way ANOVAs.

ANOVA, analysis of variance; BANS-S, Bedford Alzheimer Nursing-Severity Scale; EQ-5D, EuroQol 5 dimensional; GP, general practitioner; LTCF, long-term care facility; PCU, palliative care unit.

Table 3 Multilevel proportional hazard model—factors associated with length of stay within each country

	Belgium		England		Finland		Italy		Netherlands		Poland	
	HR	95% CI	HR	95% CI	HR	95% CI	HR	95% CI	HR	95% CI	HR	95% CI
Age at admission	1.05**	1.02 to 1.08	1.09**	1.02 to 1.16	1	0.95 to 1.05	1.04**	1.01 to 1.07	1.04*	1 to 1.08	1.07*	1.03 to 1.12
Gender—female	0.7	0.48 to 1.02	0.12**	0.04 to 0.37	0.69	0.95 to 1.05	0.75	0.48 to 1.17	0.64	0.39 to 1.05	0.42*	0.21 to 0.86
Married/civil partnership#female					6.45*	1.21 to 34.23						
Marital status—married or in a civil partnership	2.65**	1.68 to 4.16			1.01	0.27 to 3.7	1.2	0.73 to 1.96	1.55	0.92 to 2.6	1.93	0.8 to 4.65
Source of admission—community (ref)												
Hospital	2.62**	1.8 to 3.81	2.03	0.74 to 5.59	1.83	0.7 to 4.83			2.58**	1.31 to 5.08	7.04**	3.11 to 15.94
Other LTCF	2.14**	1.25 to 3.67	1.94	0.74 to 5.06	2.27	0.82 to 6.31			2.73**	1.37 to 5.44	0.72	0.28 to 1.86
Place of death—LTCF (ref)												
Hospice/PCU									1.24	0.49 to 3.16	1.06	0.42 to 2.68
Hospital	1.02	0.57 to 1.8							58.66**	4.9 to 702.44		
Cancer			1.1	0.49 to 2.46	1.74	0.52 to 5.86	1.85*	1.12 to 3.06				
Severe pulmonary disease	1.05	0.62 to 1.76			1.79	0.51 to 6.29	0.94	0.57 to 1.54			0.84	0.36 to 1.94
Severe diabetes					0.92	0.29 to 2.85						
Stroke					1.64	0.32 to 8.4					1.05	0.35 to 3.12
Pressure ulcers					1.25	0.48 to 3.22					1.21	0.59 to 2.47
General health	0.97	0.78 to 1.21	1.38	0.85 to 2.22	0.7	0.4 to 1.23	1.08	0.83 to 1.39	0.91	0.67 to 1.23	1.42	0.93 to 2.15
Dementia—resident did not have dementia (ref)												
Mild or moderate dementia			0.23**	0.08 to 0.68	1.64	0.55 to 4.91	0.58	0.28 to 1.21	2.03	0.99 to 4.14	0.59	0.13 to 2.55
Severe dementia			0.56	0.19 to 1.65	0.72	0.21 to 2.55	0.56*	0.32 to 0.99	1.37	0.75 to 2.49	0.44	0.16 to 1.23
Very severe or advanced dementia			0.15**	0.06 to 0.37	1.14	0.37 to 3.52	0.69	0.4 to 1.17	1.56	0.86 to 2.81	0.63	0.27 to 1.46
EQ-5D (moderate or severe problems)												
Anxiety or depression	1.27	0.86 to 1.88			0.77	0.38 to 1.58			1.18	0.74 to 1.86	1.24	0.67 to 2.28
Mobility	0.34*	0.14 to 0.86	19.95*	1.62 to 245.72	0.37	0.04 to 3.72					0.06*	0 to 0.83
Self-care	0.99	0.23 to 4.26	0.57	0.05 to 6.62							2.37	0.19 to 29.46
Usual activities	1.11	0.32 to 3.82										
Pain	1.14	0.77 to 1.67			1.51	0.69 to 3.28					0.83	0.4 to 1.69
BANS-S (moderate or severe impairment)												
Dressing	1.43	0.67 to 3.04			0.12**	0.02 to 0.74	0.32*	0.12 to 0.9				
Speech	0.91	0.62 to 1.33			0.54	0.24 to 1.21						
Eating		to			1.43	0.45 to 4.5					0.66	0.2 to 2.25
Mobility	0.75	0.45 to 1.27			0.63	0.24 to 1.69			0.98	0.59 to 1.64	2.36	0.28 to 19.81
Eye contact											2.17*	1.19 to 3.96

Continued

Table 3 Continued

	Belgium		England		Finland		Italy		Netherlands		Poland	
	HR	95% CI	HR	95% CI	HR	95% CI	HR	95% CI	HR	95% CI	HR	95% CI
Artificial feeding	0.91	0.42 to 1.96	0.86	0.07 to 10.85	1.46	0.36 to 5.99	0.87	0.58 to 1.3	3.36	0.9 to 12.6		
Assistance with eating or drinking	0.83	0.54 to 1.28	1.03	0.45 to 2.33			0.53*	0.3 to 0.92				
Shortness of breath—not at all (ref)												
Somewhat			0.15**	0.05 to 0.46							0.72	0.32 to 1.61
A lot			0.84	0.19 to 3.78							0.55	0.18 to 1.66
Oxygen therapy			9.69*	1.55 to 60.61	0.76	0.28 to 2.08					2.06	0.89 to 4.79
Physician visits—none (ref)												
One to four visits					2.14	0.88 to 5.17					1.48	0.44 to 4.98
Five or more					3.15	0.92 to 10.84					0.99	0.4 to 2.46
Hospital visits—none (ref)												
One or more	1.25	0.8 to 1.94			0.89	0.3 to 2.67			1.63	0.76 to 3.52	2.18*	1.01 to 4.72
Emergency department admissions—none (ref)												
One or more					1.45	0.55 to 3.82						
LTCF type—type 2—onsite nursing/offsiteGP (ref)												
Type 1—onsite nursing/onsite GP	NA		NA		NA				0.87	0.46 to 1.65	4.05**	1.43 to 11.44
Type 3—offsite nursing/offsite GP	NA		0.11**	0.04 to 0.31	NA		NA		NA		NA	
LTCF funding status—public—non-profit (ref)												
Private—non-profit	1.22	0.85 to 1.77									0.22**	0.1 to 0.49
Private—profit	1.88	0.88 to 4.01										
LTCF size—small (ref)												
Large											0.81	0.39 to 1.68

All factors associated with the outcome at a p value of 0.2 at univariate analysis were entered into the multivariate model.
*P<0.05 **P<0.01.
BANS-S, Bedford Alzheimer Nursing-Severity Scale; EQ-5D, EuroQol 5 dimensional; GP, general practitioner; LTCF, long-term care facility; NA, not applicable; PCU, palliative care unit.

In England, older age at admission (HR 1.09, 95% CI 1.02 to 1.16), moderate or severe mobility problems (HR 19.95, 95% CI 1.62 to 245.72) and receipt of oxygen therapy (HR 9.69, 95% CI 1.55 to 60.61) were associated with shorter lengths of stay. Being female (HR 0.12, 95% CI 0.04 to 0.37), moderate or mild dementia (HR 0.23, 95% CI 0.08 to 0.68), very severe or advanced dementia (HR 0.15, 95% CI 0.06 to 0.37), being somewhat short of breath (HR 0.15, 95% CI 0.05 to 0.46) and residing in a type 3 LTCF (HR 0.11, 95% CI 0.04 to 0.31) were associated with longer lengths of stay.

In Finland, the interactions between gender and being married/in a civil partnership (HR 6.45, 95% CI 1.21 to 34.23) were associated with shorter lengths of stay. Moderate or severe impairment in ability to dress oneself (HR 0.12, 95% CI 0.02 to 0.74) was associated with longer lengths of stay.

In Italy, older age at admission (HR 1.04, 95% CI 1.01 to 1.07) and having a cancer diagnosis (HR 1.85, 95% CI 1.12 to 3.06) were associated with shorter lengths of stay. Severe dementia (HR 0.56, 95% CI 0.32 to 0.99), moderate or severe impairment in ability to dress oneself (HR 0.32, 95% CI 0.12 to 0.90) and assistance with eating or drinking (HR 0.53, 95% CI 0.30 to 0.92) were associated with longer lengths of stay.

In Netherlands, older age at admission (HR 1.04, 95% CI 1.00 to 1.08), dying in hospital (HR 58.66, 95% CI 4.90 to 702.44) and admission from hospital (HR 2.58, 95% CI 1.31 to 5.08) or another LTCF (HR 2.73, 95% CI 1.37 to 5.44) were associated with shorter lengths of stay.

In Poland, older age at admission (HR 1.07, 95% CI 1.03 to 1.12), admission from hospital (HR 7.04, 95% CI 3.11 to 15.94), one or more hospital visits (HR 2.18, 95% CI 1.01 to 4.72), moderate or severe eye contact impairment (HR 2.17, 95% CI 1.19 to 3.96) and residing in a type 1 facility (HR 4.05, 95% CI 1.43 to 11.44) were associated with shorter lengths of stay. Being female (HR 0.42, 95% CI 0.21 to 0.86), moderate or severe mobility problems (HR 0.06, 95% CI 0.00 to 0.83) and residing in a not for profit facility (HR 0.22, 95%CI 0.10 to 0.49) were associated with longer lengths of stay.

Analysis of type 2 LTCFs across countries

Table 4 shows the results of the proportional hazards model for type 2 LTCFs across the six countries. Older age at admission (HR 1.04, 95% CI 1.03 to 1.06), being married/in a civil partnership (HR 1.47, 95% CI 1.13 to 1.89), admission from a hospital (HR 1.84, 95% CI 1.43 to 2.37) or another LTCF (HR 1.81, 95% CI 1.37 to 2.40), having a cancer diagnosis (HR 1.60, 95% CI 1.22 to 2.10) and residing in Italy (HR 1.93, 95% CI 1.25 to 3.00), Poland (HR 1.94, 95% CI 1.27 to 2.96), England (HR 2.18, 95% CI 1.21 to 3.95) or Finland (1.42, 95% CI 1.02 to 1.96) compared with Belgium were associated with shorter lengths of stay. Being female (HR 0.72, 95% CI 0.57 to 0.90) was associated with longer lengths of stay.

Table 4 Multilevel proportional hazards model—factors associated with length of stay in type 2 LTCFs across all six countries

	HR	95% CI
Age at admission	1.04**	1.03 to 1.06
Being female	0.72**	0.57 to 0.90
Being married/in a civil partnership	1.47**	1.13 to 1.89
Source of admission—community (ref)		
Hospital	1.84**	1.43 to 2.37
Other LTCF	1.81**	1.37 to 2.40
Place of death—LTCF (ref)		
Hospice/PCU	1.15	0.75 to 1.78
Hospital	1.30	0.81 to 2.07
General health	0.95	0.84 to 1.08
Cancer	1.60**	1.22 to 2.10
Severe pulmonary disease	1.19	0.89 to 1.61
EQ-5D (moderate or severe problems)		
Anxiety or depression	1.10	0.87 to 1.37
Pain	0.93	0.74 to 1.18
Mobility	1.03	0.77 to 1.37
BANS-S (moderate or severe impairment)		
Speech	0.97	0.76 to 1.25
Dementia—resident did not have dementia (ref)		
Mild or moderate dementia	0.87	0.62 to 1.22
Severe dementia	0.85	0.63 to 1.14
Very severe or advanced dementia	0.78	0.57 to 1.05
Oxygen therapy	1.09	0.85 to 1.40
Hospital visits—none (ref)		
One or more	1.29	0.97 to 1.72
Emergency department admissions—none (ref)		
One or more	0.94	0.66 to 1.33
LTCF funding status—public—non-profit (ref)		
Private—non-profit	1.28	0.95 to 1.74
Private—profit	1.10	0.74 to 1.65
Country—Belgium (ref)		
Finland	1.42*	1.02 to 1.96
Italy	1.93**	1.25 to 3.00
Netherlands	1.24	0.83 to 1.84
Poland	1.94**	1.27 to 2.96
England	2.18**	1.21 to 3.93

All factors associated with the outcome at a p value of 0.2 at univariate analysis were entered into the multivariate model.
*P<0.05 **P<0.01.
BANS-S, Bedford Alzheimer Nursing-Severity Scale; EQ-5D, EuroQol 5 dimensional; LTCF, long-term care facility; PCU, palliative care unit.

DISCUSSION

Summary of findings

In this study, we have examined the association between resident, facility and country-level factors with length of stay in an LTCF. The results show a large variation in length of stay between residents in the same country and between countries. The analysis identified four factors that are consistently statistically significant across all six countries and between countries; older age at admission, being admitted from a hospital or another LTCF, being married/in a civil partnership and being female.

Strengths and limitations

This is the first study that the research team are aware of that compared length of stay until death in multiple types of LTCFs internationally. The data were collected across six European countries, using a standardised collection method within a representative, random, relatively large sample of LTCFs. It would be difficult to achieve a similar dataset in scope and size by combining nationally collected routine data, if such data were available. Previous epidemiological studies of different types of LTCFs have been restricted to nursing homes as one particular type of LTCF or facilities from one organisation[17 29 30] potentially limiting the wider applicability of findings.

The main limitation of this analysis that the PACE study was developed to compare the outcomes, quality and costs of palliative and end-of-life care between countries.[22] Consequently, much of the data collected were related to either the last month or week of life. Although the data were not collected to explore length of stay in LTCFs, they do allow for such an analysis. The majority of previous research in this area were prospective studies collecting data on explanatory variables at baseline and outcome data on death within a prespecified follow-up period.[10–14] In both approaches, changes in the resident's well-being during residence in the LTCF are potentially missed; however, this analysis is novel in its use of data collected at end of life rather than on LTCF admission. Future research would benefit from collecting data at multiple time points from LTCF admission to death to further explore how changes in resident health are associated with length of stay.

The use of retrospective data is a common approach in palliative care research, with the last 3-month of life commonly used.[31–35] The data used in this analysis were reported by LTCF staff, rather than retrieved from medical records, increasing the likelihood of measurement error and recall bias.

Interpretation of findings

The findings indicate that length of stay in an LTCF is associated with pre-existing factors prior to admission. All four characteristics indicate that length of stay in an LTCF is influenced by factors prior to admission, in particular the availability of resources that allow an older adult to remain living in the community. Older adults with care needs in the community commonly receive care from spouses, where available.[36] As women generally live longer than men, it is possible that partnerless older women are living in LTCFs longer than older, married men, due to lack of a spousal carer. The findings in Finland indicate that being married reduces the length of stay in women, however, this was not replicated in other countries. In addition to being more likely to enter an LTCF,[37] this study indicates that partnerless, older women are also likely to live in an LTCF for longer

Admission to an LTCF often follows a period of hospitalisation or other enhanced care, where return to living in the community is no longer possible.[38] In areas where integrated services for older people are well developed, emergency admission to a hospital is lower,[39] supporting the idea that while older adults are remaining in the community for as long as possible before LTCF admission, their care needs may not necessarily be being met.

The relationship between physical functioning, cognitive functioning and length of stay is less clear. In two countries, mobility problems were associated with longer lengths of stay, however, in England mobility problems were related to shorter lengths of stay. The relationship between poor mobility and longer lengths of stay could reflect a deterioration from admission to death; on admission, a resident may have few problems with mobility, subsequently declining over time, reflecting poor mobility before death in longer stay residents. It is less clear why residents with better mobility before death would have shorter lengths of stays. One diagnosis, cancer, was associated with shorter lengths of stay in the between country analysis, possibly reflecting the relatively fast period of decline experienced in this condition.[40]

Dementia was related to longer lengths of stay in Italy and England. Although a diagnosis of dementia has been identified as the strongest predictor of care home admission,[8] in this study, it has not been associated with shorter lengths of stay. The differences found here could be explained by the availability of other services; in England and Italy, it may be more difficult to live independently in the community with dementia; therefore, older adults may be admitted to an LTCF earlier, leading to a longer length of stay. Neither physical nor cognitive functioning was associated with shorter lengths of stay in the between country analysis, indicating that factors prior to admission have a greater influence on length of stay.

The findings also provide some evidence to indicate that older adults use services which provide the minimum available care to meet their needs. In Poland and England, shorter lengths of stay were significantly associated with the highest level of care available (type 1 and type 2, respectively). A possible explanation for this could be that admission criteria for facilities providing higher levels of care require residents to have greater health needs, resulting in shorter lengths of stay before death. Further research is needed to explore how the availability of different types of LTCF provision is utilised by the older adult population. In future, research conducting international comparisons in this area may benefit from comparing countries with similar long-term care provision.

CONCLUSION

Older adults residing in LTCFs are a diverse population with multiple, often complex, healthcare needs. This study has highlighted the need for further research on the trajectories of older adults admitted to LTCFs, and their length of stay. In particular, further attention should be given to ensuring groups likely to have longer lengths of stay, namely partnerless older women, receive appropriate long-term care or other options to remain living in the community are available.

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Contribution to the thesis

The fourth chapter of this thesis has explored factors associated with length of stay in LTCFs, using internationally comparable data from six European countries. The findings indicate that factors prior to LTCF admission, in particular the availability of resources that allow an older adult to remain living in the community, appear to influence length of stay. Older age at admission, being married or in a civil partnership at time of death, having cancer at time of death and admission from a hospital or another facility were associated with shorter lengths of stay across all countries; where as being a woman was associated with longer lengths of stay. The findings of this chapter have further informed and adapted the model of long-term care facility use presented in chapter three.

Chapter four has also, in the process of conducting the analysis, explored the applicability of using mortality follow-back studies to investigate length of stay, and its potential limitations. The findings of this chapter will now be used in chapter five to explore the relationship between length of stay and palliative care, allowing for the characteristics of shorter and longer stay populations to be controlled for.

Chapter 5 - Paper 3: Collingridge Moore, D., Keegan T, Payne S, Deliens L, Smets, T., Gambassi G, Kylänen, M., Kijowska V, Onwuteaka-Philipsen, B. & Van Den Block, L. (2020) Associations between length of stay in long-term care facilities and palliative care. Analysis of the PACE cross-sectional study. International Journal of Environmental Research and Public Health, 17(8), E2742.

Rationale

Chapter five focuses on the relationship between length of stay and indicators of palliative care. Using data collected in the PACE study, it will explore whether length of stay is related to five measures of the quality of palliative care, when factors associated with length of stay are controlled for. The findings of the previous chapter will be used to guide the choice of factors, included in the analysis.

Aim and objectives

The aim of chapter five is to explore the relationship between length of stay and palliative care in LTCFs, using internationally comparable data. To achieve this aim, the chapter has five objectives, to explore whether length of stay in LTCF residents is associated with:

a) Quality of care in the last month of life.

b) Comfort in the last week of life.

c) Contact with health services at end of life.

d) Presence of advance directives

e) Consensus in care among LTCF staff and relatives

Overview of methodology

Chapter five uses the same data as chapter four, sourced from the PACE study. In addition to the factors identified in chapter four, chapter five includes data on the experience of residents at end of life, including two validated measures; the Quality of Dying in Long-Term Care (QoD-LTC) scale and the End-of-Life in Dementia Scale Comfort Assessment While Dying (EOLD-CAD) scale (Kiely et al., 2006; Munn et al., 2007), completed by LTCF staff. The analysis uses generalised linear mixed models to explore the association. The study was conducted in line with the STROBE (STrengthening the Reporting of OBservational studies in Epidemiology) statement (Vandenbroucke et al., 2007).

Overview of my contribution to the publication

Similar to chapter four, I prepared the variables required for the research, conducted multivariate regression on the data, and interpreted the results in the context of the previous chapters and wider literature on palliative care in LTCFs. I submitted the manuscript to the journal after incorporating feedback from the other authors and responded to reviewer feedback, where received.

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Article

Associations between Length of Stay in Long Term Care Facilities and End of Life Care. Analysis of the PACE Cross-Sectional Study

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Abstract: Long term care facilities (LTCFs) are increasingly a place of care at end of life in Europe. Longer residence in an LTCF prior to death has been associated with higher indicators of end of life care; however, the relationship has not been fully explored. The purpose of this analysis is to explore associations between length of stay and end of life care. The analysis used data collected in the Palliative Care for Older People in care and nursing homes in Europe (PACE) study, a cross-sectional mortality follow-back survey of LTCF residents who died within a retrospective 3-month period, conducted in Belgium, England, Finland, Italy, the Netherlands and Poland. Primary outcomes were quality of care in the last month of life, comfort in the last week of life, contact with health services in the last month of life, presence of advance directives and consensus in care. Longer lengths of stay were associated with higher scores of quality of care in the last month of life and comfort in the last week of life. Longer stay residents were more likely to have advance directives in place and have a lasting power of attorney for personal welfare. Further research is needed to explore the underlying reasons for this trend, and how good quality end of life care can be provided to all LTCF residents.

Keywords: long-term care facility; care home; nursing home; length of stay; palliative care; end of life care; epidemiology

1. Introduction

Long-term care facilities (LTCFs) are becoming a common place of death for older adults [1–3], especially those with dementia [4,5]. Although terminology and typology varies between countries, a LTCF, including care homes and nursing homes, generally refers to a collective institutional setting where care is provided to older adults, who live there, 24 h a day, seven days a week [6].

Ensuring LTCF residents approaching end of life receive appropriate care is challenging; residents may be frail, with multiple, complex care needs, and may be unable to either establish or communicate their preferences at end of life. Long term care facilities are often staffed by a combination of registered, qualified nurses and care assistants, who may have limited knowledge of end of life care for older adults and limited access to specialist services to support end of life care [7]. In addition, LTCF managers and their staff may lack clarity in defining and identifying end of life, or their role or responsibility in providing subsequent care within the facility [8]. In many European countries, end of life care in LTCFs in not well supported at a national level; in a review of 29 countries only eight had national policies which specifically addressed end of life care in LTCFs [9].

Palliative care is defined as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [10]. The term "end of life care" is often used synonymously with palliative care in the UK, and refers to "an extended period of 1 to 2 years during which the patient/family and health professionals become aware of the life-limiting nature of their illness" [11]. Previous studies have found that the adoption of a palliative care approach in LTCFs led to a reduction in deaths outside the LTCF [12], an increase in the numbers of completed advance directives [13], improvements in end-of-life communication between residents, relatives and health professionals [14–16] and improvements in staff knowledge [17–19].

Numerous interventions have been developed to improve the provision and quality of end of life care in LTCFs, including staff education [20,21], inter-professional collaborations and care coordination [22,23], either through individual initiatives or as part of multicomponent interventions, such as the Liverpool Care Pathway [24], Gold Standards Framework for Care Homes [25] or the Steps to Success intervention [26]. The time point at which these initiatives aim to change the care provided to a resident varies; whereas the Liverpool Care Pathways focuses on care in the last days of life [24], interventions focusing on communicating preferences at end of life may be introduced either at admission or four to six weeks post admission. For residents who die shortly after admission, such activities may occur simultaneously.

Although specific guidelines exist for providing end of life care specifically to older adults [27] and those with dementia [28], less research has explored variation in the palliative care delivered to specific subgroups, such as women or older adults with little support from family carers. In particular, it is unclear whether the end of life care received by residents admitted shortly before death differs from the care for those who have lived in a facility for many months or even years [29]. Previous studies exploring care at end of life have found that residents with longer length of stay before death had fewer hospitalisations, were more likely to be receive palliative drug therapy, less likely to be undertreated for non-pain symptoms and more likely to have documented do-not-resuscitate (DNR) orders in place [30–33].

At present, no published research has specifically explored the association between length of stay in a LTCF and the experience of residents at end of life, collected either directly from the resident or by proxy measures. None of the research previously discussed included length of stay as a primary explanatory variable of the end of life care indicators investigated, and none report conducting any prior analysis to explore factors associated with length of stay in the data. Therefore, previous research findings may not control for all characteristics associated with longer lengths of stay, leading to associations between end of life care and resident characteristics, such as age, gender, dementia diagnosis or marital status, being confused with associations with length of stay. In addition, it is common for LTCF residents to fall into one of two broad populations, those with relatively short stays before death and those who have resided in the facility for many years [8]. In previous analysis of length of stay and end of life care in LTCFs, residents with different lengths of stay have commonly been separated into residents residing in the facility either 6 months, 1 year or 2 years before death, leaving the experience of residents with longer lengths of stay unexplored.

A greater understanding of how the experience of residents at end of life varies is a research priority, and can inform the development of interventions aiming to improve the provision and quality of end of life care in LTCFs, and explore variation within a heterogeneous population. In this analysis we used data from the Palliative Care for Older People in care and nursing homes in Europe (PACE) cross-sectional study, which aimed to compare quality of dying and end of life care in deceased residents of LTCFs in six European countries [34]. The purpose of this analysis is to explore whether length of stay in LTCF residents is related to five indicators of end of life care; quality of care in the last month of life, comfort in the last week of life, contact with health services in the last month of life, presence of advance directives and consensus among those involved in care and treatment, using staff-reported data on deceased residents from LTCFs in six European countries.

2. Materials and Methods

2.1. Study Design and Setting

The data used in this analysis are from a cross-sectional, mortality follow back survey of deceased residents; the PACE study [35]. The PACE study was conducted in a sample created, where possible, using national lists of LTCFs in Belgium, England, Finland, Italy, the Netherlands and Poland, recruited using a proportionally stratified random sampling framework [36].

In LTCFs that consented to take part in the study, data were collected on residents who had died in a 3-month retrospective period during 2015. Residents were included in the study if they had died in the facility or after transfer to hospital. For each identified resident, demographic information was collected from either administrative staff or the facility manager (response rate 95.7%), and a postal questionnaire sent to a LTCF staff member regarded as most involved in the resident's care (81.6%). A full description of the study methodology, including ethical approvals, are described elsewhere [35].

2.2. Measurements

A LTCF staff member (nurse or care assistant), identified by a key person appointed by the LTCF manager as most involved in the residents' care, self-reported the main outcomes used in this analysis. Data were collected on (i) quality of care in the last month of life, (ii) comfort in the last week of life, (iii) contact with health services in the last month, (iv) presence of advance directives, and (v) consensus among those involved in care and treatment.

Quality of care in the last month of life (i) was measured using the Quality of Dying in Long-Term Care (QoD-LTC) scale [37]. The questionnaire has 11 items, with higher scores indicating better quality of care. Three subscales, personhood, closure and preparatory tasks, can be generated. Comfort in the last week of life (ii) was measured using the End-of-Life in Dementia Scale Comfort Assessment While Dying (EOLD-CAD) scale [38]. The questionnaire has 14 items, with higher scores indicating higher levels of comfort. Four subscales, physical distress, dying symptoms, emotional distress and wellbeing, can be calculated.

The data on contact with health services at end of life (iii) were number of visits either received or made by a physician during the last month of life, number of admissions to a hospital, geriatric ward, intensive care unit or general ward (for more than 24 h) during the last month of life, and the number of visits to a hospital emergency room (for less than 24 h) during the last month of life. Resident's place of death was categorised as either death in a LTCF or in a hospital.

The presence of advance directives (iv) was determined using four outcomes. Firstly, whether the resident had any written advance directives in place, including a do not resuscitate in case of a cardiac or respiratory arrest order, do not transfer to a hospital order, a request to discontinue the use of, or do not use, other treatments, or a request to try all life sustaining measures. Secondly, whether the resident had a lasting power of attorney for personal welfare. Thirdly, whether a staff member ever spoke with the resident about medical treatments he or she would or would not want in the last phase of life or about the preferred course of care in the last phase of life. The final outcome was whether a staff member spoke with a relative of the resident about medical treatments he or she would or would not want in the last phase of life or about the preferred course of care in the last phase of life, prior to a decision being made.

The degree to which those involved in care were in agreement (consensus) on care and treatment in the last month of the resident's life (v), from the perspective of staff members, was measured among LTCF staff, among representatives/family and among all those involved in the resident's care. Staff members were asked to select one of three choices for each question; full consensus, consensus on major issues or no consensus. In this analysis, the answers were categorised as consensus (full consensus or consensus on major issues) or no consensus (no consensus).

Length of stay was calculated in days using date of admission to the LTCF and date of death. Residents were grouped based on their lengths of stay in seven groups: under 1 month, 1 to 3 months, 3 months to 1 year, 1 to 2 years, 2 to 3 years, 3 to 5 years and over 5 years. The groups were demarcated to ensure relatively similar sample sizes in each group, and to allow analysis of longer stay residents. Ten variables previously identified as associated with length of stay in the dataset were included in the analysis to control for resident, LTCF and country characteristics [39]. These were age, gender, marital status, place of admission, presence of cancer, presence and severity of dementia, physical functioning, LTCF type, LTCF funding status and country.

Age and gender were determined at the time of admission. Severity of dementia was calculated using a combined score from the Global Dementia Scale (GDS) [40] and the Cognitive Performance Scale (CPS) [41]. The Bedford Alzheimer Nursing-Severity Scale (BANS-S) [42] was used to measure physical functioning.

Each LTCF was categorised by the type of care offered, as type 1, 2 or 3 [9]. Type 1 facilities offer on-site care provided by physicians, nurses and care assistants (available in Italy, the Netherlands, and Poland). Type 2 facilities offer on-site care provided by nurses and care assistants with medical provision provided by local, external primary care services (available in all countries). Type 3 facilities offer on-site care provided by care assistants, with nursing and medical provision provided by local, external primary care services (available in England). Funding status of the LTCF was classed as either public (non-profit), private (non-profit) or private (for profit).

2.3. Statistical Analysis

Data were collected on 1707 deceased residents from 322 LTCFs. Residents were excluded from the sample if length of stay was less than one day or could not be calculated, if a resident was missing data on age or was younger than 65 years of age on admission, or no questionnaire was returned by LTCF staff (n = 470), resulting in a final sample of 1237 residents. Non-response analysis was conducted on residents for whom staff returned questionnaires and for those whom staff did not return questionnaires, based on the length of stay. Sample characteristics and frequencies for each of the outcomes are reported by length of stay.

For continuous outcomes, associations between length of stay and quality of care in the last month of life (QoD-LTC), comfort in the last week of life (EOLD-CAD) and their subscales were determined using generalised linear regression models. In each model, total scores of the QoD-LTC, EOLD-CAD and their subscales were added as the dependent variable, with length of stay added as a covariate. Resident, facility and country level characteristics previously identified as varying by length of stay were also added to each model as covariates; these were age, gender, marital status, place of admission, cancer, dementia, physical functioning, LTCF type, LTCF funding status and country. A variable identifying each LTCF was added as a random factor. Goodness of fit for each model was assessed using the Akaike information criterion.

For binary outcomes, associations between length of stay and the presence of advance directives, contact with health services and consensus on care and treatment were determined using logistic regression models. In each model, the outcome was added as a dependent variable, with length of stay added as a covariate along with resident, facility and country level characteristics. A variable identifying each LTCF was added as a random factor. The adequacy of the model was assessed using the Hosmer and Lemeshow's goodness-of-fit test. Interactions between age and gender were tested and added to the model where appropriate. Multi-collinearity was checked using variance inflation factors [43].

A positive coefficient indicates that an increase in the value of the dependant variable is associated with an increase in the value of the independent variable. A negative coefficient indicates that a decrease in the value of the dependant variable is associated with a decrease in the value of the independent variable. Statistical significance was set as $p < 0.05$. All analyses were performed using Stata (version 16) [44].

3. Results

The final sample included 1237 residents; 262 in Belgium, 252 in Finland, 192 in Italy, 193 in the Netherlands, 263 in Poland and 75 in England. No significant differences were identified in the lengths of stay of residents for whom a staff questionnaire was or was not completed and returned ($p = 0.356$). The median length of stay was 73.4 weeks (range 16–103.9 weeks) and average length of stay was 126 weeks (SD 157), ranging from 93 (SD 156) to 163 (SD 182) weeks. The mean age of residents at admission was 83.9 years (SD 7.2), ranging from 81.56 (SD 7.12) in residents with length of stay over 5 years to 85.45 (SD 7.2) in residents with a length of stay of 3 months to 1 year. The percentage of residents who were female was 67.6%, ranging from 55.8% in residents with length of stay of 1 to 3 months and 81.1% in residents with length of stay over 5 years. Characteristics of the sample and main outcomes are shown in Tables 1 and 2.

3.1. *Quality of End of Life Care in the Last Month of Life (QoD-LTC)*

Associations between end of life care and length of stay are shown in Table 3. Length of stay was associated with quality of care in the last month of life in the multivariate model. Total scores on the QoD-LTC were significantly higher in residents with a length of stay of 3 months to 1 year compared to under 1 month ($p = 0.002$); and increase significantly up to and over 5 years ($p < 0.001$). Scores on the personhood subscale were significantly higher in residents with a length of stay of 3 months to 1 year compared to under 1 month ($p = 0.010$); and increase significantly up to and over 5 years ($p = 0.001$). Scores on the closure subscale were also significantly higher in residents with a length of stay of 1 to 3 months compared to under 1 month ($p = 0.014$); and increase significantly up to and over 5 years ($p < 0.001$). Scores on the preparatory tasks subscale were significantly higher between 1 to 2 years ($p = 0.027$), 2 to 3 years ($p = 0.002$) and 3 to 5 years ($p < 0.001$), and approached statistical significance at over 5 years ($p = 0.052$).

3.2. *Comfort in the Last Week of Life (EOLD-CAD)*

Total scores on the EOLD-CAD were higher in residents with longer lengths of stay, however length of stay was significantly associated with comfort in the last week of life at only over 5 years compared to under 1 month ($p = 0.005$) in the multivariate model. Scores on the physical distress subscale were significantly higher in residents with a length of stay between 1 to 2 years ($p = 0.040$), 3 to 5 years ($p = 0.027$) and over 5 years ($p < 0.001$). Scores on the emotional distress subscale were significantly higher in residents with a length of stay of 3 to 5 years ($p = 0.007$) and over 5 years ($p = 0.001$) and on the wellbeing subscale at over 5 years ($p = 0.001$). Scores on the dying symptoms subscale were not significantly associated with length of stay.

Table 1. Characteristics of deceased long term care facility (LTCF) residents by length of stay in a LTCF until death.

	Under 1 month	**1 to 3 months**	**3 months to 1 year**	**1 year to 2 years**	**2 year to 3 years**	**3 year to 5 years**	**5 years +**	**Total**	***p* value**
	***n* = 163**	***n* = 135**	***n* = 223**	***n* = 208**	***n* = 162**	***n* = 160**	***n* = 186**	***n* = 1237**	
Age at admission—mean (SD)	83.8 (8.1)	83.7 (7.7)	85.5 (7.2)	84.56 (6.7)	84 (7.1)	83.67 (6)	81.6 (7.2)	83.9 (7.2)	**<0.001**
Gender—female (%)	91 (55.8)	87 (64.4)	142 (64.3)	132 (64.4)	110 (68.8)	119 (74.4)	150 (81.1)	831 (67.6)	**<0.001**
Marital status—married or in a civil partnership	47 (34.8)	37 (31.6)	47 (22.7)	47 (24.1)	35 (22.3)	27 (17.4)	13 (7.2)	253 (22.1)	**<0.001**
Place of admission (%)									
Community	54 (34.6)	49 (39.8)	87 (43.9)	82 (45.1)	68 (47.9)	80 (58.4)	112 (69.6)	532 (48.4)	**<0.001**
Hospital	78 (50)	52 (42.2)	75 (37.9)	59 (32.4)	39 (27.5)	30 (21.9)	32 (19.9)	365 (33.2)	**<0.001**
Other LTCF	24 (15.4)	22 (17.9)	36 (18.2)	41 (22.5)	35 (24.7)	27 (19.7)	17 (10.6)	202 (18.4)	**0.036**
BANS-S—total score—mean (SD) *	20.51 (5.4)	20.00 (4.9)	19.47 (4.8)	19.39 (4.7)	19.46 (4.5)	20.15 (4.3)	19.68 (4.9)	19.77 (4.8)	0.239
Cancer (%)	26 (16)	29 (21.5)	39 (17.5)	31 (14.9)	21 (13)	17 (10.6)	18 (9.7)	181 (14.6)	**0.046**
Dementia (%)									
Resident did not have dementia	63 (48.5)	39 (34.2)	56 (29)	57 (31.5)	33 (23.1)	38 (27.9)	52 (31.9)	338 (31.9)	**0.001**
Mild or moderate	11 (8.5)	24 (21.1)	31 (16.1)	25 (13.8)	17 (11.9)	11 (8.09)	15 (9.2)	134 (12.6)	**0.014**
Severe, very severe or advanced dementia	56 (43.1)	51 (44.8)	106 (54.9)	99 (54.7)	93 (65.1)	87 (64)	96 (58.9)	588 (55.5)	**0.001**
LTCF type (%)									
Type 1—onsite nursing/onsite physician	79 (48.8)	53 (39.6)	60 (27.7)	39 (19.2)	36 (22.4)	22 (13.9)	27 (14.6)	316 (25.9)	**<0.001**
Type 2—onsite nursing/offsite physician	81 (50)	79 (59)	153 (70.5)	158 (77.5)	123 (76.4)	129 (81.7)	146 (78.9)	869 (71.2)	**<0.001**
Type 3—offsite nursing/offsite physician	2 (1.2)	2 (1.5)	4 (1.8)	7 (3.4)	2 (1.2)	7 (4.4)	12 (6.5)	36 (3)	**0.023**
LTCF ownership (%)									
Public—non profit	91 (56.2)	88 (65.7)	129 (60)	120 (59.1)	95 (59.8)	101 (63.9)	121 (65.4)	745 (61.3)	0.497
Private—non profit	45 (27.8)	26 (19.4)	53 (24.7)	46 (22.7)	44 (27.7)	32 (20.3)	40 (21.6)	286 (23.5)	0.427
Private—profit	26 (16.1)	20 (14.9)	33 (15.4)	37 (18.2)	20 (12.6)	25 (15.8)	24 (13)	185 (15.2)	0.790
Country (%)									
Belgium	17 (10.4)	19 (14.1)	49 (22)	46 (22.1)	40 (24.7)	35 (21.9)	56 (30.1)	262 (21.2)	**<0.001**
Finland	25 (15.3)	27 (20)	41 (18.4)	53 (25.5)	35 (21.6)	43 (26.9)	28 (15.1)	252 (20.4)	**0.029**
Italy	29 (17.8)	19 (14.1)	39 (17.5)	37 (17.8)	26 (16.1)	25 (15.6)	17 (9.1)	192 (15.5)	0.228
Netherlands	14 (8.6)	16 (11.9)	34 (15.3)	35 (16.8)	30 (18.5)	25 (15.6)	39 (21)	193 (15.6)	**0.045**
Poland	71 (43.6)	47 (34.8)	47 (21.1)	25 (12)	22 (13.6)	20 (12.5)	31 (17)	263 (6.1)	**<0.001**
England	7 (4.3)	7 (5.2)	13 (5.8)	12 (5.8)	9 (5.6)	12 (7.5)	15 (8.1)	75 (6.1)	0.797

BANS-S: Bedford Alzheimer Nursing Severity Scale; LTCF: long term care facility; SD: standard deviation. * higher scores indicate poorer physical functioning. p values calculated using Pearson chi-square and one way ANOVAs. A p value of <0.05 indicated a statistically significant difference in values between lengths of stay. Missing data: gender $n = 8$, marital status $n = 90$, place of admission $n = 138$, BANS-S $n = 22$, dementia $n = 177$, LTCF type $n = 16$ and LTCF ownership $n = 21$.

Table 2. Indicators of end of life care of deceased LTCF residents by length of stay in a LTCF until death.

	Under 1 month	**1 to 3 months**	**3 months to 1 year**	**1 year to 2 years**	**2 year to 3 years**	**3 year to 5 years**	**5 years +**	**Total**	***p* value**
	***n* = 163**	***n* = 135**	***n* = 223**	***n* = 208**	***n* = 162**	***n* = 160**	***n* = 186**	***n* = 1237**	
Quality of care in the last month of life (QoD-LTC)									
Total score—mean (SD)	35.80 (6.96)	37.75 (6.97)	38.59 (7.56)	38.89 (7.73)	39.55 (7.32)	40.06 (8.08)	40.41 (7.65)	38.79 (7.62)	**<0.001**
Personhood subscale—mean (SD)	19.67 (3.35)	20.19 (3.52)	20.54 (3.55)	20.99 (2.94)	21.17 (3.56)	21.11 (3.61)	21.09 (3.39)	20.70 (3.44)	**<0.001**
Closure subscale—mean (SD)	8.01 (2.72)	9.03 (2.77)	9.21 (2.91)	9.29 (2.84)	9.14 (2.94)	9.47 (2.96)	9.72 (9.72)	9.15 (9.15)	**<0.001**
Preparatory tasks subscale—mean (SD)	6.92 (3.41)	7.70 (3.26)	8.02 (3.80)	8.07 (3.95)	8.32 (3.76)	8.47 (4.08)	8.58 (3.74)	8.03 (3.77)	**0.001**
Comfort in the last week of life (EOLD-CAD)									
Total score—mean (SD)	29.63 (5.50)	29.46 (5.78)	30.58 (5.33)	31.07 (5.07)	30.41 (5.42)	31.20 (5.21)	31.82 (5.06)	30.67 (5.36)	**0.001**
Physical distress subscale—mean (SD)	4.29 (1.70)	4.35 (1.80)	4.77 (1.77)	4.85 (1.66)	4.75 (1.64)	4.76 (1.81)	5.16 (1.57)	4.73 (1.72)	**<0.001**
Dying symptoms subscale—mean (SD)	6.86 (2.47)	6.97 (2.24)	7.07 (2.12)	7.15 (1.99)	7.04 (2.04)	7.05 (2.13)	7.17 (2.22)	7.05 (2.17)	0.874
Emotional distress subscale—mean (SD)	8.90 (2.69)	9.01 (2.47)	9.36 (2.27)	9.54 (2.17)	9.55 (2.08)	9.69 (2.13)	9.88 (1.85)	9.44 (2.25)	**0.001**
Wellbeing subscale—mean (SD)	5.02 (1.90)	5.23 (1.71)	5.64 (1.81)	5.83 (1.91)	5.68 (1.86)	5.82 (1.91)	6.09 (1.78)	5.65 (1.87)	**0.001**
Contact with health services in the last month of life									
Physician visits (%)									
0–5 visits	56 (51.38)	53 (54.64)	94 (58.75)	101 (70.63)	65 (61.90)	68 (55.74)	78 (60.47)	515 (59.54)	0.055
More than five visits	53 (48.62)	44 (45.36)	66 (41.25)	42 (29.37)	40 (38.10)	54 (44.26)	51 (39.53)	350 (40.46)	
Hospital admissions (%)									
None	98 (70.50)	98 (79.03)	164 (77.36)	159 (80.71)	125 (81.70)	126 (82.35)	157 (86.26)	927 (79.91)	**0.028**
One or more visits	41 (29.50)	26 (20.97)	48 (22.64)	38 (19.29)	28 (18.30)	27 (17.65)	25 (13.74)	233 (87.14)	
Emergency department visits (%)									
None	124 (88.57)	107 (86.29)	185 (86.85)	160 (82.47)	138 (90.20)	135 (87.10)	161 (89.44)	1010 (87.14)	0.396
One or more visits	16 (11.43)	17 (13.71)	28 (13.15)	34 (17.53)	15 (9.80)	20 (12.90)	19 (10.56)	149 (12.86)	
Place of death (%)									
LTCF	133 (84.7)	106 (82.8)	195 (88.6)	173 (84.8)	139 (86.9)	145 (90.6)	159 (84)	1050 (86.5)	0.460
Hospital	24 (15.3)	22 (17.2)	25 (11.4)	31 (15.2)	21 (13.1)	15 (9.4)	26 (14.1)	164 (13.5)	
Presence of advance directives									
Resident had any written advance directives in place (%)	33 (20.3)	46 (34.07)	81 (36.3)	81 (38.9)	60 (37)	74 (46.3)	88 (47.3)	463 (37.4)	**<0.001**
Resident had lasting power of attorney for personal welfare (%)	38 (28.2)	39 (36.5)	57 (32.4)	63 (37.8)	44 (35.8)	42 (32.1)	62 (43.4)	345 (35.1)	0.182
Staff spoke with the resident about end of life care (%)	20 (13.5)	28 (22.3)	50 (23.4)	51 (24.7)	39 (24.7)	39 (25.2)	60 (33.6)	287 (24.7)	**0.005**
Staff spoke with the relative about end of life care (%)	70 (44.9)	55 (43)	129 (60.6)	128 (61.9)	105 (66.9)	112 (71.4)	110 (60.8)	709 (59.2)	**<0.001**
Consensus in care and treatment									
Among staff (%)	152 (97.4)	125 (99.2)	203 (98.1)	193 (97.5)	152 (99.4)	146 (97.3)	172 (98.9)	1143 (98.2)	0.673
Among family (%) *	142 (98.6)	108 (97.3)	187 (96.9)	183 (97.7)	147 (99.3)	137 (97.2)	158 (100)	1062 (98.2)	0.299
Among all involved (%)	152 (98.7)	120 (97.6)	200 (98.1)	194 (97.5)	152 (99.4)	146 (98)	173 (98.9)	1137 (98.3)	0.836

QoD-LTC: Quality of Dying in Long-Term Care. EOLD-CAD: End of Life in Dementia Scale-Comfort Assessment while Dying. Theoretical range of QoD-LTC—total score: 11–55, personhood subscale: 5–25, closure subscale: 3–15, preparatory tasks: 3–15. Theoretical range of EOLD-CAD—total score: 14–42, physical distress subscale: 4–12, dying symptoms subscale: 4–12, dying symptoms subscale: 4–12, emotional distress: 4–12, wellbeing subscale: 3–9. Theoretical ranges based on no missing data. LTCF: long term care facility; SD: standard deviation. p values calculated using Pearson chi-square and one way ANOVAs. A p value of <0.05 indicated a statistically significant difference in values between lengths of stay. Missing data: QoD-LTC total score $n = 41$, personhood subscale $n = 13$, closure subscale $n = 18$, preparatory tasks subscale $n = 32$, EOLD-CAD total score $n = 76$, physical distress $n = 43$, dying symptoms $n = 42$, emotional distress $n = 50$, wellbeing subscale $n = 61$, physician visits $n = 372$, hospital admissions $n = 77$, emergency department visits $n = 78$, place of death $n = 23$, lasting power of attorney $n = 255$, staff member spoke with the resident about end of life care $n = 49$, staff member spoke with the relative about end of life care $n = 38$, consensus of care among staff $n = 73$, consensus of care among family $n = 89$, consensus of care among all involved $n = 80$. * family were not involved in residents care $n = 66$.

Table 3. Associations between indicators of end of life care of deceased LTCF and length of stay in a LTCF until death.

	Length of Stay—Coefficient (95% CI)						
	Under 1 month	**1 to 3 months**	**3 months to 1 year**	**1 year to 2 years**	**2 year to 3 years**	**3 year to 5 years**	**5 years +**
Quality of care in the last month of life (QoD-LTC)							
Total score	ref	1.14 (–0.77–3.05)	**2.71 (1.00–4.42)** **	**3.03 (1.23–4.84)** **	**4.03 (2.15–5.90)** **	**4.80 (2.87–6.72)** **	**4.16 (2.21–6.11)** **
Personhood subscale	ref	0.48 (–0.39–1.36)	**1.02 (0.24–1.80)** *	**1.34 (0.53–2.15)** **	**1.31 (0.47–2.15)** **	**1.53 (0.68–2.38)** **	**1.41 (0.56–2.26)** **
Closure subscale	ref	0.91 (0.18–1.64)	**1.21 (0.56–1.86)** *	**1.32 (0.65–1.99)** **	**1.26 (0.57–1.96)** **	**1.64 (0.94–2.34)** **	**1.72 (1.02–2.41)** **
Preparatory tasks subscale	ref	0.20 (–0.73–1.14)	0.72 (–0.12–1.56)	**1.00 (0.11–1.88)** *	**1.45 (0.53–2.37)** **	**1.69 (0.75–2.63)** **	0.94 (–0.01–1.90)
Comfort in the last week of life (EOLD-CAD)							
Total score	ref	–0.36 (–1.75–1.04)	0.15 (–1.11–1.40)	0.66 (–0.62–1.93)	0.31 (–1.02–1.64)	1.14 (–0.21–2.49)	**1.88 (0.58–3.18)** **
Physical distress subscale	ref	0.16 (–0.25–0.58)	0.35 (–0.03–0.73)	**0.41 (0.02–0.79)** *	0.34 (–0.06–0.75)	**0.46 (0.05–0.87)** *	**0.86 (0.46–1.25)** **
Dying symptoms subscale	ref	0.05 (–0.48–0.59)	–0.10 (–0.58–0.38)	–0.15 (–0.63–0.33)	–0.07 (–0.58–0.44)	–0.01 (–0.53–0.50)	0.06 (–0.44–0.55)
Emotional distress subscale	ref	0.10 (–0.46–0.65)	0.31 (–0.19–0.81)	0.34 (–0.16–0.85)	0.49 (–0.05–1.02)	**0.74 (0.20–1.28)** **	**0.88 (0.36–1.39)** **
Wellbeing subscale	ref	0.03 (–0.42–0.48)	0.26 (–0.14–0.66)	0.40 (–0.01–0.82)	0.29 (–0.14–0.72)	0.41 (–0.02–0.85)	**0.73 (0.31–1.15)** **
Contact with health services in the last month of life							
Physician visits (0–5 visits vs. more than five visits)	ref	0.15 (–0.49–0.80)	0.02 (–0.57–0.62)	–0.47 (–1.12–0.18)	–0.09 (–0.76–0.58)	0.13 (–0.50–0.77)	–0.29 (–0.92–0.35)
Hospital visits (none vs. one or more visits)	ref	–0.58 (–1.33–0.16)	–0.31 (–0.96–0.34)	–0.53 (–1.22–0.17)	–0.51 (–1.23–0.21)	–0.67 (–1.40–0.07)	**–1.01 (–1.76–0.26)** **
Emergency department admissions (none vs. one or more visits)	ref	0.34 (–0.50–1.17)	0.11 (–0.66–0.88)	0.30 (–0.46–1.06)	–0.04 (–0.88–0.81)	0.07 (–0.76–0.90)	–0.12 (–0.94–0.71)
Place of death (LTCF vs. hospital)	ref	0.30 (–0.57–1.17)	–0.50 (–1.33–0.33)	–0.29 (–1.13–0.55)	–0.15 (–1.03–0.73)	**–1.03 (–2.04–0.03)** *	–0.72 (–1.66–0.22)
Presence of advance directives							
Resident had any written advance directives in place	ref	0.58 (–0.17–1.33)	0.60 (–0.09–1.29)	0.67 (–0.02–1.37)	0.58 (–0.14–1.30)	**1.21 (0.46–1.96)** **	**0.91 (0.18–1.64)** *
Resident had lasting power of attorney for personal welfare	ref	0.60 (–0.01–1.21)	0.53 (–0.04–1.10)	**0.87 (0.28–1.46)** **	**0.72 (0.09–1.36)** *	**0.73 (0.10–1.36)** *	**1.10 (0.48–1.73)** **
Staff spoke with the resident about end of life care	ref	0.66 (–0.14–1.45)	0.49 (–0.25–1.23)	0.64 (–0.11–1.38)	0.54 (–0.23–1.31)	0.65 (–0.15–1.45)	**0.86 (0.08–1.64)** *
Staff spoke with the relative about end of life care	ref	–0.46 (–1.07–0.16)	0.25 (–0.30–0.81)	0.14 (–0.43–0.71)	0.51 (–0.10–1.11)	**0.72 (0.09–1.35)** *	0.19 (–0.44–0.81)
Consensus in care and treatment							
Among staff (no vs. yes)	ref	1.00 (–1.37–3.37)	0.82 (–0.83–2.47)	0.42 (–1.18–2.02)	2.16 (–0.24–4.55)	0.87 (–1.06–2.80)	1.06 (–0.90–3.01)
Among family (no vs. yes)	ref	–0.63 (–2.48–1.23)	–0.57 (–2.30–1.17)	–0.08 (–1.99–1.83)	0.75 (–1.75–3.26)	–0.52 (–2.47–1.44)	n/a
Among all involved (no vs. yes)	ref	–0.85 (–3.34–1.65)	–0.92 (–3.25–1.40)	–0.86 (–3.20–1.48)	0.30 (–2.62–3.21)	0.07 (–2.84–2.98)	–0.50 (–3.08–2.08)

QoD-LTC: Quality of Dying in Long-Term Care. EOLD-CAD: End of Life in Dementia Scale-Comfort Assessment while Dying. LTCF: long term care facility. CI: confidence interval. Generalised mixed models with each end of life care outcome as the dependant variables, length of stay as the independent variable, age, gender, marital status, place of admission, cancer, dementia, physical functioning, LTCF type, LTCF funding status and country as covariates and a variable identifying each LTCF was added as a random factor. p value < 0.05 *, p value < 0.01 **.

3.3. Contact with Health Services in the Last Month of Life and Place of Death

Residents with a length of stay of over 5 years had significantly fewer hospital admissions in the last month of life compared to under 1 month ($p = 0.008$). No significant associations were identified between physician visits and length of stay or emergency department visits and length of stay. Death in hospital was significantly less likely compared to death in a LTCF at a length of stay of 3 to 5 years ($p = 0.044$), however no trend was identified as length of stay increased.

3.4. Presence of Advance Directives

Residents were significantly more likely to have a written advance directive in place at 3 to 5 years and over 5 years, compared to under 1 month post admission ($p = 0.002$ and $p = 0.015$, respectively). Residents were also significantly more likely to have a lasting power of attorney for personal welfare in place between 1 to 2 years ($p = 0.004$), 2 to 3 years ($p = 0.025$), 3 to 5 years ($p = 0.024$) and over 5 years ($p = 0.001$), compared to under 1 month. The likelihood of a staff member having spoken with the resident about end of life preferences was significantly associated with length of stay over 5 years, compared to 1 month ($p = 0.031$). The likelihood of a staff member having spoken with a relative about end of life preferences was significantly associated with length of stay of 3 to 5 years, compared to under 1 month ($p = 0.025$).

3.5. Consensus on Care and Treatment in the Last Month of Life

No significant associations were identified between length of stay and consensus on care and treatment in the last month of life among LTCF staff, among family or among all those involved in the resident's care.

4. Discussion

4.1. Summary of Main Findings

Longer lengths of stay were associated with higher scores of quality of care in the last month of life and on the personhood, closure and preparatory tasks subscales. Longer lengths of stay were also associated with higher scores of comfort in the last week of life, on all subscales except the dying symptoms subscale. Associations between longer lengths of stay and quality of end of care occurred earlier than in comfort in the last week of life, with significantly higher scores identified from 3 months compared to 1 year.

A slight but statistically significant association was identified with fewer hospital admissions and resident deaths in hospital when length of stay was longer. In addition, longer stay residents were more likely to have written advance directives and lasting power of attorney in place, and have had a staff member discuss end of life care with either themselves or a relative. No significant associations were identified between length of stay and physician visits, emergency department visits or consensus on care and treatment. The analysis controlled for resident characteristics associated with variation in length of stay and country of residence.

4.2. Strengths and Limitations

This is the first study of which the research team is aware that focuses specifically on the relationship between length of stay in an LTCF and end of life care. A strength of the data used in this analysis is their representativeness of a large sample of LTCFs across six European countries. As the study was retrospective, the data were not limited by a follow up period, therefore data on length of stay is available for residents with especially long lengths of stay (no right censoring).

The main limitation of the study is that the data were collected by staff members up to 3 months after the resident's death. Such an approach has a number of implications for the validity of the data. Firstly, the risk of recall bias increases, however, data collected on length of stay cannot be biased as there is no loss to follow up. In addition, if such as bias exists in this dataset as opposed to non-systematic measurement error, it would be the same across all countries, although the direction of the bias is unclear [45].

Secondly, the relationship between the staff member providing the data and the resident may affect the findings. It is possible that staff members who did not feel they knew the resident well enough to answer the questionnaire, and could not access written records on the residents care, did not return the questionnaire, leading to a bias in the data towards staff members with closer relationships with the residents.

Further to this, one explanation for the findings could be that staff members may feel they know and understand residents with longer lengths of stay more than recently admitted residents, and are therefore more confident in their judgement of resident experience. As some of the indicators used in the EOLD-CAD are relatively subjective to judgement (fear, serenity, anxiety etc.) the findings may be influenced by greater confidence in the staff member to make these assessments, and therefore more likely to provide appropriate care, i.e., symptom management.

There are also specific limitations to each of the measures used to indicate quality of end of life care. For example, data were not collected on the time when written advance directives or lasting power of attorney were established, therefore it is unclear if these occurred prior to LTCF admission. Discussions with the resident and relative about end of life care may have occurred, however no data were collected on whether the decisions made in these conversations were recorded or acted upon, where possible. Data collected on advance directives are specific to the availability and legality of advance directives in each country. For example, the data from England does not necessarily indicate that a conversation has occurred between LTCF staff and the resident, it is possible that advanced care planning documentation collected as part of the Gold Standard Framework was used to obtain the answer, which were neither initiated or filled in by the residents themselves [46]. Future research could further contextualise these findings by including the approach to end of life care adopted at each facility, including staff mix and training.

Finally, the data used in this analysis is limited to consensus in care and treatment as judged only by one staff member and not family members. The analysis is limited by a lack of data collected from residents and relatives' perspectives on their perceptions of the quality of care at end of life.

4.3. Interpretation of Findings

The primary finding of this analysis is that residents who have resided in an LTCF for a longer length of time had better quality of care and comfort at end of life than recent LTCF admissions, after controlling for characteristics of short and long stay resident populations.

Differences in the findings for each of the QoD-LTC subscales require further discussion. The preparatory tasks subscale refers to activities which can be planned in advance (treatment preferences in writing, establishing a named decision-maker, funeral planning) indicating that lack of time for such activities to be enacted by LTCF staff may explain lower scores among newly admitted residents. Similarly, the personhood subscale focuses on the relationship between the resident and wider staff (a nurse or aide with whom the resident felt comfortable, affectionate touch daily, physician knew him or her as a whole person) which, again, develop over time.

However, the items on the dying symptoms subscale of the EOLD-CAD (choking, gurgling, difficulty swallowing, shortness of breath) are arguably more difficult for LTCF staff to modify without physician involvement. Additionally, data were not collected on whether the resident received treatment for such symptoms, therefore, in this study the presence of such symptoms does not necessarily indicate poorer quality of care.

In a review of preconditions for successful advance care planning in nursing homes, five domains were identified; sufficient knowledge and skills, willingness and ability to participate in advance care planning, a good relationship (between staff and family caregivers and residents), availability of an administrative system for documenting wishes and monitoring care and supportive contextual factors within the nursing home [47]. Applied to the findings of this paper, a longer length of residence before death could allow for the involvement of an appropriately skilled professional, for a record of resident wishes to be written and accessible or for sufficient time and resources to be allocated to establishing preferences at end of life care. However, as the association only becomes significant after 1 year of residence, a more plausible explanation could be that it takes this long for a relationship to be established between LTCF staff, residents and their families.

The few significant results identified for consensus in care and contact with health services shows that these experiences remain consistent regardless of subsequent length of stay. Although the analysis failed to show a difference across the groups, this could indicate that if consensus is not established in the first month after admission, it is unlikely to be subsequently achieved. Alternatively, admissions to either hospital or an emergency department for preventable reasons (pneumonia, urinary tract infections etc.) are common in this population, however, the likelihood may not differ based on length of stay.

4.4. Implications for Future Research, Policy and Practice

International epidemiological research on the health and health care needs of LTCF residents is gaining more attention [48–50], allowing for heterogeneity in the care residents' experience to be explored further. Despite the emphasis on ageing in place [51], and a common preference for older adults to remain living in the community until death [52], there is little evidence to suggest that cohorts on admission are in poorer health or have shorter lengths of stay than those in previous years [53]. Further research is needed to explore the underlying reasons for this trend, and its implications for providing good quality end of life care to all LTCF residents. The inclusion of LTCF residents in nationally representative epidemiological studies, allowing for longitudinal analysis of characteristics prior to admission [54] and better identification of LTCF residents in existing routinely collected datasets [55], would greatly support research in this area.

Although numerous interventions to improve end of life care have been developed and implemented in LTCFs, few have tailored their approach to residents depending on length of stay. In a recent scoping review of implementation strategies for such interventions, prioritising time for staff members to provide end of life care, and ensuring staff are available for residents to develop a relationship with, allowing discussions on end of life to occur, were highlighted as facilitators to successful implementation [56]. An approach which can be tailored to shorter and longer stay residents is needed, including how such an environment can be developed prior to resident admission. In particular, further research is needed to explore the experiences of residents with lengths of stay under 1 month and the underlying mechanisms that account for fewer indicators of end of life care.

5. Conclusions

Older adults residing in LTCFs often have multiple health needs, are likely to be approaching end of life and require good quality end of life care. This study explored associations between length of stay in LTCF residents with five measures of end of life care, using data on deceased residents in six European countries. In addition to the differences in population characteristics of shorter and longer stay residents, the findings of this analysis indicate that residents with longer lengths of stay experience better end of life care than those with shorter lengths of stay on some of the indicators explored. This trend is identified even after controlling for resident characteristics associated with variation in length of stay and country of residence. Further research is needed to explore why such an association is found, and how appropriate end of life care can be provided to all residents from admission to death.

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Contribution to the thesis

The fifth chapter of this thesis explores whether the experience of residents at end of life of vary with length of stay. This is the first published study that focuses primarily on the relationship between length of stay in an LTCF and palliative care. A key strength of the analysis is the inclusion of factors associated with length of stay in the generalised linear mixed model, allowing for associations between palliative care and length of stay to be fully explored. Longer lengths of stay were associated with higher scores as reported by LTCF staff for quality of care in the last month of life and comfort in the last week of life. Longer stay residents were more likely to have advance directives in place and have a lasting power of attorney for personal welfare.

Chapter five has discussed possible explanations for the trend of better outcomes at end of life among longer stay residents. These include a lack of time for LTCF staff to prepare for and provide palliative care, limited involvement of wider or external health care professionals, i.e. physicians, and the need to establish a relationship between LTCF staff, residents and their families. In chapter six, a scoping review of implementation strategies used in the introduction of palliative care interventions in long-term care facilities will be used to explore further explanations for the trends identified in chapter five. In addition, facilitators and barriers to implementing palliative care interventions in LTCFs to facilitate the uptake of palliative care interventions in LTCFs will be identified.

Chapter 6 - Paper 4: Collingridge Moore, D., Payne, S., Van Den Block, L., Ling, J. & Froggatt, K. (2020) Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review. Palliat Med, 34(5), 558-570.

Rationale

As chapter five identified variation in the experience of palliative care in LTCF residents, chapter six explores strategies to implement palliative care interventions in these settings. Interventions to improve palliative care delivery within these settings have been shown to be effective in improving care, but little is known about their implementation. Chapter six aims to provide some explanation of the findings of the previous three chapters, enriching the understanding of length of stay in LTCFs rather than providing further analyses. In doing so, chapter six provides a foundation for the implementation of palliative care in LTCFs.

Aim and objectives

The aim of chapter six is to identify facilitators and barriers to implementing palliative care interventions in LTCFs. To achieve this aim, the chapter has two objectives:

1. To describe the nature of implementation strategies used to support the delivery of palliative care interventions in LTCFs.

2. To identify facilitators and/or barriers to successful implementation of palliative care interventions in LTCFs.

Overview of methodology

The methodological approach used in chapter six was a scoping review, designed and conducted following the five-step process outlined by Arksey and O’Malley (Arksey and O'Malley, 2005). These steps are: identifying the research question, identifying relevant studies, study selection, charting the data and collating, summarizing and reporting the results (Arksey and O'Malley, 2005). Analysis was conducted using thematic synthesis (Thomas and Harden, 2008), a decision informed by the application of the RETREAT criteria (Booth et al., 2016). The review was conducted in line with the guidance from the PRISMA Extension for Scoping Reviews (PRISMA-ScR) and the ENTREQ statement (Tricco et al., 2018, Tong et al., 2012).

Overview of my contribution to the publication

In the final published paper included in this thesis, I defined the research question and protocol for the scoping review, designed and conducted the literature search, applied inclusion and exclusion criteria to the identified papers, performed data extraction and applied thematic analysis to the data. The paper was subsequently used in conjunction with wider findings from the PACE study to inform the “Palliative care implementation in long-term care facilities: European Association for Palliative Care White Paper”, published in Journal of the American Medical Directors Association (Froggatt et al., 2020).

Review Article

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Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review

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Abstract

Background: The number of older people dying in long-term care facilities is increasing; however, care at the end of life can be suboptimal. Interventions to improve palliative care delivery within these settings have been shown to be effective in improving care, but little is known about their implementation.

Aim: The aim of this study was to describe the nature of implementation strategies and to identify facilitators and/or barriers to implementing palliative care interventions in long-term care facilities.

Design: Scoping review with a thematic synthesis, following the ENTREQ guidelines.

Data sources: Published literature was identified from electronic databases, including MEDLINE, EMBASE, PsycINFO and CINAHL. Controlled, non-controlled and qualitative studies and evaluations of interventions to improve palliative care in long-term care facilities were included. Studies that met the inclusion criteria were sourced and data extracted on the study characteristics, the implementation of the intervention, and facilitators and/or barriers to implementation.

Results: The review identified 8902 abstracts, from which 61 studies were included in the review. A matrix of implementation was developed with four implementation strategies (facilitation, education/training, internal engagement and external engagement) and three implementation stages (conditions to introduce the intervention, embedding the intervention within day-to-day practice and sustaining ongoing change).

Conclusion: Incorporating an implementation strategy into the development and delivery of an intervention is integral in embedding change in practice. The review has shown that the four implementation strategies identified varied considerably across interventions; however, similar facilitators and barriers were encountered across the studies identified. Further research is needed to understand the extent to which different implementation strategies can facilitate the uptake of palliative care interventions in long-term care facilities.

Keywords

Long-term care facilities, care homes, nursing homes, palliative care, end-of-life care, palliative medicine, scoping review, literature review, implementation, intervention

What is already known about the topic?

- The provision and quality of palliative care delivered in long-term care facilities (LTCFs) varies and does not always meet the needs of the residents.
- Interventions to improve palliative care have been shown to lead to improvements in the quality of care received by long-term care facilities residents.
- The implementation of such interventions and the factors that facilitate their uptake within an long-term care facilities are not well understood.

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What this paper adds?

- This paper provides a scoping review of implementation strategies used by palliative care interventions in long-term care facilities.
- This review has identified four organizational strategies for the implementation of palliative care interventions: facilitation, education/training, internal engagement and external engagement.
- Three developmental stages comprise the implementation process: conditions to introduce the intervention, embedding the intervention within day-to-day practice and sustaining ongoing change.

Implications for practice, theory or policy

- The implementation strategies used varied across the studies identified; how implementation can support intervention uptake requires further investigation.
- The implementation strategies used to implement palliative care interventions in long-term care facilities are underreported, and separating characteristics of an intervention from the implementation process is complex. Further guidance is needed on the reporting of implementation strategies.
- The findings of this review may inform the development and implementation of future palliative care interventions in this setting and how they can be implemented more effectively.

Background

Long-term care facilities (LTCFs) are increasingly becoming the final place of care for older adults. Across the globe, long-term care facilities are a common place of death for older adults,[1] especially among those with dementia.[2] Using the definition provided by Froggatt and Reitinger,[3] a long-term care facilities is a collective institutional setting where care is provided for older people who live there for an undefined period of time, 24 h/day, 7 days/week. The care provided includes on-site provision of personal assistance with activities of daily living; nursing and medical care may be provided either on-site or from nursing and medical professionals external to the setting.[3]

Despite death being a natural progression as an individual ages, providing palliative care in long-term care facilities is complex. The majority of long-term care facilities residents live with more than one chronic condition, and dementia or high levels of cognitive impairment are common. Knowing when a resident is dying can be hard to predict, as residents with multiple chronic, life-limiting conditions may experience periods of both decline and improvement in their health before death.[4] In Europe, long-term care facilities are generally staffed by registered nurses and care assistants; staff turnover can be high and pay relatively low, with limited opportunities for further education, on the job training or professional development. Staff members often have limited knowledge of the palliative care needs of older adults, especially in terms of managing pain and other symptoms at end of life.[5]

As defined by the World Health Organization,[6] palliative care refers to

> ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’.

To deliver high-quality care at end of life, long-term care facilities require a specific approach to palliative care that is appropriate to both the needs of the residents being cared for and the staff members working within the facilities.

The European Association for Palliative Care Taskforce on Palliative Care in Long-term Care Settings for Older People mapped approaches to developing and delivering palliative care between countries using a modified typology of change at international, national, regional and organizational levels.[3,7] At an organizational level, initiatives to ensure long-term care facilities residents received palliative care could be through providing designated units (i.e. palliative care beds), care based (i.e. symptom management), care planning based (i.e. advance care planning), and organizational multicomponent interventions (i.e. Gold Standards Framework for Care Homes) or education and training.[7] Interventions at an organizational level to improve the delivery of palliative care in long-term care facilities have demonstrated improvements, including increasing the numbers of completed advance directives,[8] reducing deaths outside the long-term care facilities,[9] improving end-of-life communication between families and clinicians[10–12] and increasing staff knowledge and confidence.[13–15]

The implementation of these interventions, and the factors that facilitate their implementation, is less well understood. It is unclear how different approaches to implementation may affect the uptake of an intervention, and there is little consensus on how interventions can be embedded and sustained within an increasingly complex setting. Despite the urgent need to improve palliative care within long-term care facilities, identifying optimum ways of implementing palliative care has yet to be addressed.

Aim and objectives

This scoping review explores the implementation strategies used in organizational-level interventions that aim to improve palliative care in long-term care facilities. It aims to identify the implementation strategies used to support palliative care interventions in long-term care facilities and the facilitators and/or barriers to implementation. This study is, to our knowledge, the first to attempt to explore the implementation process supporting the introduction of palliative care interventions in long-term care facilities.

Design

This scoping review was designed and conducted using guidance from Arksey and O'Malley.[16] As the focus is the process of implementation rather than outcomes, a scoping review allows the mapping of how the intervention was implemented rather than only the effectiveness of the strategies used. The scoping review method follows a five-step process: identifying the research question, identifying relevant studies, study selection, charting the data and collating, summarizing and reporting the results.[16]

Stage 1: identifying the research question

The first stage of the scoping review was to identify the primary research question of the review by clarifying what was considered to be important. Two review questions were identified:

1. What implementation strategies were used to support the delivery of palliative care interventions in long-term care facilities?
2. What are the facilitators and/or barriers to successful implementation?

The review was restricted to studies published from 2007 onwards, which marked the publication of the first national End-of-Life Care Strategy, globally, for England and Wales.[17] It was limited to studies published in English.

Stage 2: identifying relevant studies

The systematic search strategy for the review was developed in line with guidance published by the Cochrane Handbook for Systematic Reviews of Interventions.[18] The search strategy included a combination of free text terms and subject indexing terms, such as MeSH and Emtree. The search strategy was developed through the identification of key terms in the title and abstract of relevant studies already known to the research team.

The following electronic databases were searched for articles published in peer-reviewed journals: MEDLINE, EMBASE, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Proquest, the Cochrane Library, including the Cochrane Methodology Register, Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Database of Systematic Reviews (CDSR), Database of Abstracts of Reviews of Effect (DARE), Health Technology Assessment (HTA) database and NHS Economic Evaluation Database (NHS EED), Web of Science, the Campbell Library, SCOPUS and Social Care Online. The sample strategy used for MEDLINE in this research is shown in the Supplementary Material. In addition, papers were identified through reviewing the reference lists of publications which met the inclusion criteria and study protocols identified in the search. Reverse citation searches were also undertaken on papers which were included using the ISI Web of Science Citation Databases. Grey literature was excluded as our interest was on research-based publications. Databases were searched in September 2018.

Stage 3: study selection

The process of study selection is shown in the PRISMA flowchart in Figure 1. Inclusion criteria for the initial (title and abstract) screening were developed through discussion with the research team and were piloted by two researchers on a sample of 100 randomly selected papers. Title and abstract reviewing was applied by one researcher (D.C.M.), with a final decision made by a senior researcher (K.F.) where required. The inclusion criteria were modified and refined based on the findings. The review included studies that discussed delivery strategies for, or any information on facilitators and/or barriers to, implementing palliative care interventions for older adults living in long-term care facilities. The full paper review was conducted by two researchers (D.C.M. and A.H.) independently and a decision about whether each paper met the inclusion criteria was made. References for excluded studies and the reason for their exclusion were recorded.

Stage 4: charting the data

Data from each study were extracted independently by two researchers and organized in Excel on four categories: the study design, the intervention, the implementation of the intervention and facilitators and/or barriers to implementation. Information regarding the study design and the intervention was extracted initially, allowing for further information on implementation to be contextualized. Data were extracted on the author and year, country, study design, long-term care facilities type and number of long-term care facilities in the study, duration of the intervention, description of the intervention, the main outcome measures or methods used and an overview of the

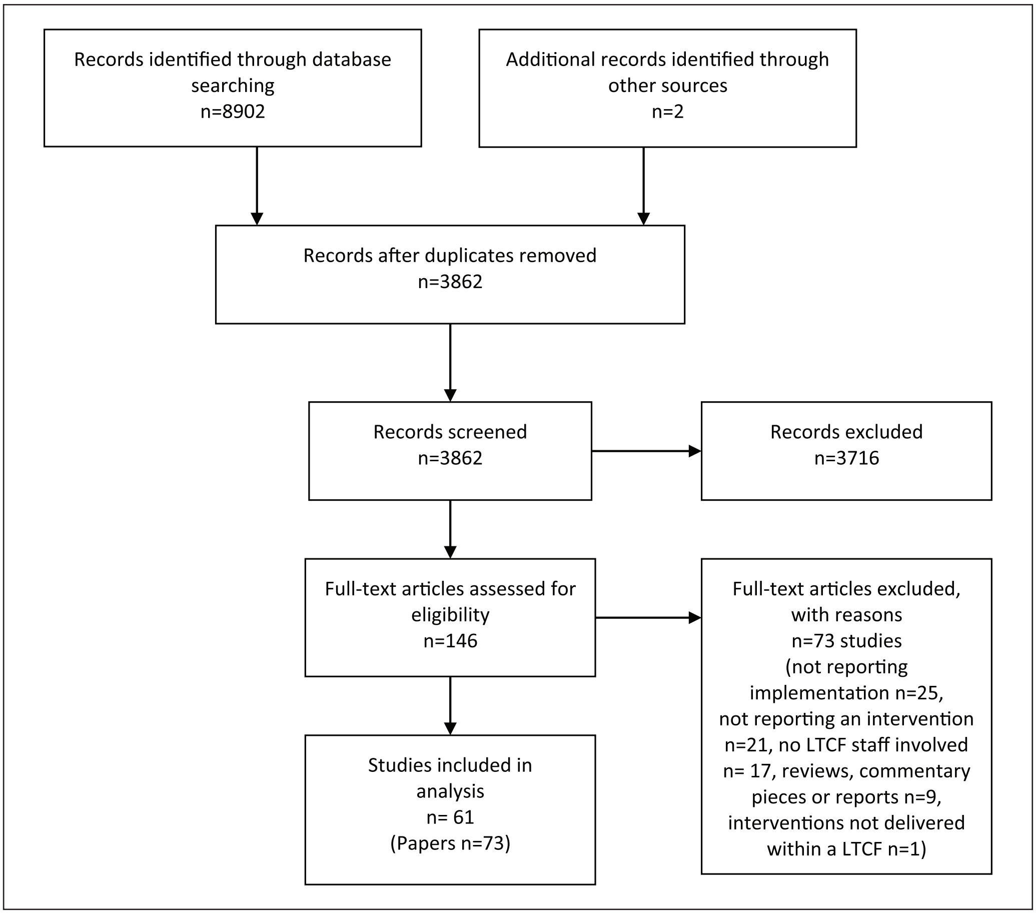

Figure 1. PRISMA flowchart.

Table 1. Data extracted on implementation and categorization criteria.

Theme	Definition
Facilitation	Facilitation referred to whether the intervention was facilitated, and if so, whether the facilitation was internal or external, the training or expertise of the facilitator and the contribution of the facilitator. Internal facilitation was defined as facilitation provided by a staff member employed within the LTCF and external facilitation was defined as a person external to the LTCF facilitating the intervention.
Training or education	Training referred to whether there was an education element to the intervention, and if so, how it was delivered and to whom.
Internal engagement	Internal engagement referred to whose behaviour the intervention was aiming to change to improve palliative care within the LTCF, that is, care home staff, managers and unregulated care providers.
External engagement	External engagement referred to whether or not any aspect of the intervention involved joint working, that is, between specialist palliative care services, primary care or hospitals. Data on joint working were only extracted where there was specific discussion of the intervention incorporating joint working, as opposed to embedding the intervention in current practice.

LTCF: long-term care facilities.

study findings. In cases where two papers reported on the same study, quantitative and qualitative outcomes were reported separately.

Data on implementation of the interventions were extracted and mapped regarding facilitation, education/training and internal and external engagement, as defined in Table 1. Finally, data about facilitators and/or barriers to implementation of the intervention were extracted. This was drawn from findings sections, including data extracts and the author's discussion of the findings of the intervention. Quotes from the papers and page numbers were extracted and tabulated.

Table 2. Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Participants	The review focused on strategies for the implementation of palliative care interventions for older adults living in LTCFs. Older adults were defined as adults aged 65 years or above; in studies where only group descriptive statistics are reported, care facilities where average age of the group was aged 65 years or above were included.	Studies which looked at other places of residence where care is provided, which do not meet the definition of an LTCF, were excluded from the study. This included hospitals, sheltered housing or residential housing with home care services. In addition, facilities, such as hospices, which specifically care for residents approaching end of life, were excluded from the study.
Outcomes	The primary outcome of interest was how the intervention was implemented. This could include delivery strategies or any information on facilitators and/or barriers to implementing interventions.	None
Study design	All studies were included if they implemented an intervention, either through quantitative or qualitative methods. Evaluation, implementation or pilot studies were included.	Protocol papers were excluded; however, the study was followed up to see if potential outcome papers had subsequently been published.
Intervention	The review included research studies which provided information or discussed the implementation of organizational level interventions that aim to improve the provision or delivery of palliative care in LTCFs. The broad areas for interventions included • providing designated units, • care based (i.e. symptom management), • care planning (i.e. advance care planning), • organizational multicomponent interventions (i.e. Gold Standards Framework for Care Homes) and • education or training.	Studies were excluded if they discussed the development of a palliative care intervention without any information about the implementation process, or only reported attitudes towards the facilitators and/or barriers to delivering palliative care in general.

LTCF: long-term care facilities.

Stage 5: collating, summarizing and reporting the results

The review methodology used was based on the guidance for selecting methods for qualitative evidence synthesis.[19] The review team applied the RETREAT criteria, which informs the choice of qualitative synthesis method used based on the aims and characteristics of the review. The review question, the epistemology underpinning the review, time frame, resources, team expertise, audience and type of data being synthesized were discussed and thematic synthesis identified as an appropriate approach.[20]

Any discussion of facilitators and/or barriers to the implementation of an intervention was extracted verbatim from the included papers as quotes. The quotes were read and coded line by line using free codes to develop a code bank. These codes were used to develop descriptive themes and reorganized into hierarchical groups for discussion within the research team. In the final stage, analytical themes were generated and fed into a cyclical process whereby themes were generated and applied to the grouped codes. The ENTREQ statement and the PRISMA Extension for Scoping Reviews (PRISMA-ScR) were used to guide the reporting of the approach used for qualitative data synthesis.[21,22]

Results

The searches of the electronic databases identified 8902 abstracts, based on the inclusion criteria detailed in Table 2. After removal of duplicates and studies not meeting the inclusion criteria, 146 abstracts were identified as potentially relevant studies. A further 73 papers were excluded on reviewing full papers. Two additional studies were identified through reverse citation and reference list searches. A total of 73 papers were included in the review, which reported on 61 studies; the characteristics of these studies are detailed in the Supplementary Material. Two studies reported three interventions; therefore, 65 interventions are reported. Of the included studies, 39% (*n* = 24) were conducted in the United Kingdom, 26% (*n* = 16) in the United States of America and Canada, 18% (*n* = 11) in the rest of Europe, 15% (*n* = 9) in Australia and New Zealand and 2% (*n* = 1) in China. Study design varied and were described by the publication as an implementation/evaluation study (52%, *n* = 32), quasi-experimental design or pre-test/post-test (28%, *n* = 17), randomized controlled trial (10%, *n* = 6), qualitative study (5%, *n* = 3) and feasibility or pilot study (5%, *n* = 3).

In terms of setting, 51% were reported as based in nursing homes (*n* = 31), 16% in care homes (*n* = 10), 13%

Table 3. Interventions used in studies included in the review.

Category	Intervention	*n* = 65
Care based	Namaste Care Programme	2
	Comfort Care Rounds Strategy	1
	Compassion Intervention	1
	Joint working, that is, case conferencing, team working, integrated working between health care professionals and care home staff	5
	Other care based	2
Care planning based	Advance care planning (ACP) based	6
	ACP – Respecting Patient Choices	3
	ACP – 'Let Me Decide'	2
	ACP – 'We Decide'	1
Organizational multicomponent interventions	Gold Standards Framework for Care Homes	8
	Steps to Success programme	3
	Liverpool Care Pathway	3
	Care pathway or toolkit	4
	Other predefined, multicomponent intervention	3
Education and training	Staff education or training on improving palliative care	19
Other	Reduction in transfers, staff grief	2

in long-term care facilities (*n* = 8) and 20% in either mixed settings or settings described as residential aged care facilities or similar (*n* = 12). Sample size ranged from 1 to 100 long-term care facilities and duration of the intervention ranged from 4 weeks to 5 years. It was unclear in the majority of studies whether the intervention time period reported referred to the length of the study or the length of intervention delivery. A number of interventions were identified as shown in Table 3, which were categorized as either care based, care planning based, organizational multicomponent interventions, education/training or other.

Data extracted on the implementation of interventions of the studies included in the review are detailed in the Supplementary Material. In terms of facilitation, 85% interventions included some kind of facilitation (*n* = 55), 82% were externally facilitated (*n* = 53), 48% were internally facilitated (*n* = 29) and 40% were both internally and externally facilitated (*n* = 26). In 15% of interventions (*n* = 10), no form of facilitation was reported. In 97% of interventions, some kind of education component was involved; 8% (*n* = 5) delivered training online and 8% (*n* = 5) specifically involved providing training to health care professionals outside the long-term care facilities, such as physicians or paramedic emergency staff.

In terms of internal engagement, 97% of interventions reported staff members engaged within the long-term care facilities. In total, 23% (*n* = 15) of studies distinguished between registered nurses and care assistants, non-clinical staff or unregulated staff members, and 23% (*n* = 15) explicitly involved long-term care facilities managers. Residents and relatives were involved in 11% (*n* = 7) of studies. In terms of external engagement, 52% interventions reported some form of engagement (*n* = 34), usually with physicians or general practitioners; however, it would be unclear whether such joint working was already in place before the intervention.

Data were extracted on facilitators and barriers to implementation, including solutions to perceived barriers, for example, strategies to mediate staff turnover. The data were coded and categorized into nine sub-themes (presented below) which were identified acting as facilitators and/or barriers to implementing palliative care interventions in long-term care facilities. These could be categorized as falling into one of the three stages of the implementation processes: (1) establishing conditions to introduce the intervention, (2) embedding the intervention within day-to-day practice and (3) sustaining ongoing change. Quotes from the papers are used to illustrate the findings as shown in Table 4.

Stage 1 – establishing conditions to introduce the intervention

*Sub-theme 1 – recognizing palliative care within the long-term care facilities (*n *= 32)*

The recognition of providing good-quality palliative care to residents as a priority by long-term care facilities managers and staff was a precursor to engagement with an intervention. In addition, an internal assessment acknowledging that palliative care within the setting could be improved was important in both supporting the initial intervention and sustaining change after implementation. An audit of the current practices at end of life within the long-term care facilities could be beneficial, as it allows staff to reflect on current practices and highlight areas

Table 4. Stages, themes and supporting quotes identified in the review.

Theme	Sub-theme	Example
Stage 1 – establishing conditions to introduce the intervention	Recognizing palliative care within the LTCF	'Only 6 of the 14 facilities had consistently working Palliative Care Teams throughout the study period. These teams, in contrast to teams in the other 8 treatment nursing homes, were characterized by clear and shared mission, a sense that the team influenced residents' care, and a perception of continued team sustainability. They also appeared to have a more tangible support from and involvement of their facility leaders including directors of nursing and administrators' (p. 3).[41]
	Support from LTCF management	'At site 1, improvements were made in pain assessment but not other measures. There were 3 different administrators during the 1 year pilot program. Despite initial interest, none of these administrators actively promoted palliative care and consequently, efforts to motivate staff to improve outcomes were hindered' (p. 38).[42]
	Raising awareness among stakeholders	'In our own project we found that involving residents and relatives in the decisions about implementation helped address staff concerns about the possible reluctance of the resident or their family member to participate in an ACP discussion. It provided an opportunity to emphasize that ACP discussions would become a routine practice with every resident so no individual resident would feel singled out' (p. 148).[43]
Stage 2 – embedding the intervention within day-to-day practice	Locating the intervention within the current context	'Overall, the time available for the NCP activities was less than anticipated. Two sessions a day was soon found to be too much for the staff to engage with, and the programme was reduced to one session held after lunch. While each session was to last for two hours, the complexity of getting all involved ready to start took longer than expected and this curtailed the duration of the activities in each session. Furthermore, although it is recommended that the NCP be held daily, in this care home it was only feasible to hold it Monday to Friday' (p. 372).[44]
	Adopting a 'whole home' approach	'Several nursing home managers have asked that we also train their non-clinical staff, who often become emotionally involved with residents, especially when these have been living in the home for a long time' (p. 233).[45]
	Flexibility in implementation	'The lack of continuity of staff was one of the most important factors affecting link nurse development. Staff shortages, high staff turnover and structuring the education around shift work were predominant features. Consequently, the delivery of education to suit different shifts had to be included. Attendance at educational sessions was therefore unpredictable' (p. 239).[46]
Stage 3 – sustaining ongoing change	Ongoing opportunities for practice and reflection	'Not all learners were equally ready to receive training at a particular level. For example, some less experienced care staff found it difficult to watch emotionally challenging content about death and dying on DVDs on their own. They preferred group work and discussions that could offer immediate debriefing. As stated by a trainer, the ability to be present during learning helped to address emotional reactions to the training' (p. 275).[47]
	Appropriate selection of facilitators	'Many facilitators reported that it was extremely important to provide a very clear outline of the commitment required from care homes in order to complete the programme. This was in terms of time allocated by managers for staff to complete the additional work needed and a requirement of attendance at the face-to-face sessions' (p. 5).[48]
	Moving from intervention to routine practice	'End of life care pathways are feasible mechanisms for delivering end of life care consistent with best practice. Strategies to facilitate acceptability by residential aged carew facility staff and GPs include incorporating end of life care pathways into existing standards and practices, and promoting awareness, education and accessibility' (p. 109).[49]

LTCF: long-term care facilities.

where there is a need for improvement. Consequently, it provides a method of measuring future progress post-intervention by defining what good palliative care is within the context of the facility. Depending on facility organization and ownership, some facilities may have little or no communication with other long-term care facilities within the geographical area. Building long-term care facilities networks can provide shared support and learning opportunities, which may be of benefit to staff and managers alike, and allow benchmarking between facilities.

*Sub-theme 2 – support from long-term care facilities management (*n *= 45)*

The review suggests that overt management support and enthusiasm to improve palliative care was extremely important, either through developing a vision for palliative care in the long-term care facilities or through supporting staff involvement by providing protected time and resource allocation for education and training. In particular, support for staff education sessions was paramount to ensuring high attendance. The establishment of a shared vision between management and facility staff regarding what the intervention is aiming to achieve facilitated implementation. Primarily, this could be achieved through either payment for attendance at sessions run outside the working day or allowing staff to attend sessions during their shift. Awarding certificates or continuing professional development credits were also used as incentives for staff to participate. Ensuring that facilities have the physical resources to complete the intervention are also important; this could range from having a space to conduct training in or access to the Internet for staff if training is being delivered online. In addition to the continuity of long-term care facilities staff, consistent long-term care facilities management able to promote the intervention was integral to success.

*Sub-theme 3 – raising awareness among stakeholders (*n *= 12)*

Raising awareness of the aims and scope of the intervention to wider stakeholders outside of those delivering the intervention was highlighted in the review as it allowed for wider investment in improving palliative care, in terms of time and resources. Establishing the importance of palliative care among higher levels of management, such as commissioners and long-term care facilities administrators, facilitated implementation. The extent to which health care professionals from external settings were involved in the intervention varied depending on the context. At a minimum, an awareness of the intervention and its goals among health care professionals providing care to residents living in the long-term care facilities ensures that the intervention being delivered is congruent with the wider care of the resident.

In addition, raising awareness of the intervention with the residents and their families meant that changes in the delivery of palliative care were expected and the reasons for changes understood. An understanding of the intervention and its aims meant that residents and families did not feel that changes within the long-term care facilities were specific to the needs of an individual resident, but reflective of a facility-wide effort to improve care. In addition, family involvement increased awareness of palliative and end-of-life care within the long-term care facilities and facilitated discussions on treatment preferences.

Stage 2 – embedding the intervention within day-to-day practice

*Sub-theme 4 – locating the intervention within the current context (*n *= 40)*

The review suggests that a central characteristic of successfully implementing an intervention was the incorporation of the changes in the delivery of palliative care into the current practices within the facility. Without such an approach, there was a risk that the intervention would be unnecessarily adding to staff workload by duplicating processes or procedures that were already in place. Incorporation into existing practices and systems could range from adjusting documentation and record-keeping to developing how staff worked within the wider health care system. In cases where the intervention required involvement from wider health care professionals outside of the facility, adaptions were needed to develop existing relationships and current practices. Locating the intervention, therefore, requires first, an understanding of the current involvement of external professionals as part of understanding the context of the facility, and second, adaptions to the intervention to incorporate existing patterns of working.

*Sub-theme 5 – adopting a 'whole home' approach (*n *= 39)*

A 'whole home' approach to change relates to developing an awareness of the intervention throughout the facility. Although the intervention may be specifically for staff undertaking certain roles, such as registered nurses or those providing clinical care, raising awareness of the intervention can improve an understanding of palliative care among all staff within the long-term care facilities. An all-encompassing approach is especially important in palliative care where residents or their family members may have conversations with staff who are not providing direct care, such as domestic or ancillary staff. In addition, clarifying how an intervention can be implemented by staff within their roles and responsibilities can build confidence, especially in non-clinical staff. Identifying staff members who have influence over others, or who are 'informal leaders' within the long-term care facilities and whose involvement in the study may inspire other staff members, can support this.

*Sub-theme 6 – flexibility in implementation (*n *= 37)*

The review suggests that implementation of palliative care interventions can be hindered by a high turnover of staff in the facility. More than one staff member is needed for an intervention to be adopted into common practice; if there is a lack of continuity in staffing, this can be difficult to achieve. A 'critical mass' of staff who have completed the appropriate training and are motivated and supported in implementing changes is needed. Uneven participation, staff absences and high staff turnover are major barriers to achieving this, so maximizing opportunities to cascade knowledge and changes to practice between all staff is needed. Ensuring the intervention can be delivered flexibly, depending on the individual needs of the long-term care facilities, can improve implementation. This could be through the timing and frequency of education or training sessions, the mode of delivery (face-to-face or online) and the location of training, that is, internal or external. Aids to training, such as workbooks or decision aids, may also improve the integration of the intervention into every day practice, such as a resource folder or reference material that can be referred to as required and may serve as a training aid for new staff.

Stage 3 – sustaining ongoing change

*Sub-theme 7 – ongoing opportunities for practice and reflection (*n *= 30)*

The review highlighted the importance of developing opportunities for reflective debriefing time, staff discussion and confidence building through face-to-face workshops, role-play and on-the-job training. Although this strategy may support implementation of generic improvement initiatives, providing time and space for staff to talk openly about their feelings specifically towards delivering palliative and end-of-life care was highlighted as important. In some long-term care facilities, staff may not receive the emotional support they need, which can further hinder the improvement of palliative care. Reflection on practice could be achieved using examples that staff members can relate to, either through talking about experiences or through discussing the palliative care needs of a current resident. Workshops that are delivered face-to-face, role-play and on-the-job training can facilitate the transition from training to practice. In addition to reflecting on current palliative care practices, an assessment of the current levels of team working within the facility is required. In cases where team working within the facility is poor, interventions may be required, including training and guidance on wider elements of team working, development of communication skills and other 'soft skills' which may not be in place.

*Sub-theme 8 – appropriate selection of facilitators (*n *= 29)*

The review highlighted the need for interventions to be either internally and/or externally facilitated. The review further suggested that facilitators (or trainers) should be identified appropriate to the number of residents in the facility, based on role and on their palliative care expertise. Whether or not facilitation is externally or internally provided, how facilitators will work with the facility to support the intervention and be trained and supported should be established early as part of the intervention. Internal facilitation requires appropriate selection of an existing staff member who can champion the intervention within the long-term care facilities. While an internal facilitator may have an understanding of the long-term care facilities, in terms of barriers to implementation and how they can be overcome, it may be difficult to manage the dual role and responsibility of being a staff member and internal facilitator. An external facilitator may have more clarity regarding their role and may have the ability to coordinate links with wider palliative care services; implementation may become reliant on the external facilitators visiting the long-term care facilities and may not be sustained once this is withdrawn. In larger long-term care facilities, a greater number of facilitators, either internal or external, will be needed to ensure that staff have access to the support they require to develop palliative care. In addition, facilitators should be identified as champions of palliative care possessing the ability to signpost less experienced staff members and aiding further education and development.

*Sub-theme 9 – moving from intervention to routine practice (*n *= 12)*

The review clearly identified that successfully implementing an intervention requires its incorporation into existing practices in the long-term care facilities. Without such an approach, there was a risk that the intervention would be unnecessarily adding to staff workload by duplicating processes or procedures that were already in place. As part of the training or education element, communicating to staff members on how the new knowledge is going to be applied to routine care is important in changing practice. In some cases, this may require changing organizational structures or adapting the intervention to sit within current structures, for example, changing documentation to reflect new approaches. Consolidating and sustaining the changes made in the intervention post-delivery are seldom acknowledged in implementation studies. Data are limited regarding strategies to ensure sustainability; this is due to limited follow-up of long-term care facilities post-intervention, opportunities to retrain staff on an ongoing basis or as part of an induction and availability of funding to continue development roles or ongoing partnerships. These are beneficial when initiated as part of the original intervention.

Discussion

Main findings

This review aimed to identify the implementation strategies used in organizational level interventions to improve palliative care in long-term care facilities. It explored four implementation strategies: facilitation, education/training, and internal and external engagement. Based on the data reported in the papers that were included, nine themes were identified as potential facilitators and/or barriers to successful implementation of these interventions, which were then grouped into three development stages: establishing conditions to introduce the intervention, embedding the intervention within day-to-day practice and sustaining ongoing change.

The findings of the review have highlighted that the feasibility of implementing palliative care interventions is largely dependent on the context, and the extent to which delivery can be tailored to the individual needs of the facility, its staff and its residents. In addition, successfully implemented interventions were able to either improve or adapt to relatively poor existing conditions. These included poor communication between health professionals, long-term care facilities staff and families, high staff turnover and unsupportive management or a lack of leadership.

Palliative care interventions are increasingly complex, and exploring the implementation strategies that lead to changes in palliative care practice is a priority to inform future intervention development. This review categorized four implementation strategies: facilitation, education/training and internal and external engagement; however, the extent to which each strategy supports successful implementation is unclear. In previous systematic reviews on interventions that attempted to change staff practice to improve long-term care facilities resident outcomes and on implementing advance care planning in nursing homes, similar barriers and facilitators to implementing interventions were identified as those found in this review.[23,24]

The Promoting Action on Research Implementation (PARIHS) framework has been used to guide implementation of interventions in long-term care facilities and focuses on the interplay between the evidence being introduced, contextual characteristics of the setting and facilitation.[25] In the Facilitating Implementation of Research Evidence (FIRE) study, a cross-country comparison of two facilitation approaches in 24 long-term nursing care units, an improvement based and practitioner inquiry approach, against standard dissemination of clinical guideline recommendations found no significant differences between the two approaches.[26] Similar barriers were identified as those discussed in this paper, such as issues with recruitment and retention of internal facilitators, issues in preparing facilitators for the role and application of facilitation knowledge, skills and tools.[27] The evaluation of a standardized education intervention of Mekki et al.[28] to reduce restraint and agitation in residents living with dementia in nursing home residents, using the PARIHS framework, identified that while success required interplay between the three elements of the framework, a specific focus on leadership was needed for successful intervention.

In addition to the extent to which different implementation strategies contribute to success, how these strategies can be utilized requires further examination. In a systematic literature review on the role, use and preparation of champions within nursing homes to inform quality improvement approaches, Woo et al.[29] found that although all the included studies suggested that implementing nurse or aid champions in their quality improvement initiatives were important facilitators of success, how the champions were selected and trained in their role was underreported. Kinley et al.[30] found that nursing homes that received high facilitation and action learning to implement the Gold Standards Framework for Care Homes were more likely to be accredited than those with high facilitation only. How we measure implementation, in terms of fidelity and sustainability, in addition to the intended outcomes of the intervention, also requires further thought.

Research on palliative care interventions in long-term care facilities has a dual purpose; first it determines whether an intervention is effective in improving care, and second, it explores whether an intervention can be used in a real-world setting. An integrative review of effective implementation strategies previously used to improve the organization of palliative care in adults across care settings identified a number of approaches: feedback, educational strategies, process mapping, feedback, multidisciplinary meetings and multifaceted interventions.[31] While there is potential for learning from other settings within the health system, exploring what works specifically in palliative care in long-term care facilities is crucial to move from evidence to changing practice.

Strengths and limitations

This scoping review has followed the methodological steps described in the Arksey and O'Malley[16] framework and incorporated enhancements of the method discussed by Levac et al.,[32] including ensuring adequate clarity on the scope of the review, using the research question to guide decision-making and adopting an iterative approach to study selection and data charting.[33]

A strength of this review is the inclusion of all study designs, which has allowed data to be extracted on intervention studies using both quantitative and qualitative approaches. The inclusion of studies using qualitative methods greatly added to the understanding of facilitators and barriers to implementation, as themes emerging through data collection were reported as results in addition to insights from the study authors.

The review was restricted to studies published in English between 2007 and 2018, meaning studies outside these limits were missed. However, for the purpose of the review, the aim was to produce an overview of the research area focusing on breadth rather than depth of understanding, which has been achieved. In addition, guidance from methodological papers on scoping review reporting standards[16,19,22] has provided a framework to add methodological integrity to the review, despite not being a systematic review. Implementation may be reported in grey literature; however, this is harder to access, often published as reports within national bodies.

A limitation of this review is that data on reporting of fidelity of implementation within studies, if reported, were not extracted, and characteristics of implementation were not linked to reported outcomes. In addition, the implementation strategies identified in this scoping review have predominantly been used in the context of funded research. However, outcome measures of staff perception, competence and confidence may not lead to actual changes in practice. Data on the long-term sustainability of an intervention can be difficult to capture within limited funding time periods for research studies. This can make it difficult to explore how implementation strategies can support intervention longevity. In addition, it is unclear how variation between wider health care systems within which these interventions were implemented may affect successful implementation.

The final stage of the Arksey and O'Malley[16] framework, consultation with stakeholders to provide insights into the findings, was also not completed. The inclusion of this stage could have allowed an opportunity to provide further understanding of the findings from long-term care facilities staff and managers.

Implications for further research

Long-term care facilities are complex and challenging environments in which to enact change, and developing an understanding of approaches which facilitate implementation requires attention. As discussed, further research is needed to identify the contribution of individual implementation strategies as well as the interplay between them. In the development of palliative care interventions, adopting a theory of change tailored to the aims of the intervention that can guide implementation may be beneficial in delivering the intervention within a real-world scenario. In future, better reporting of implementation strategies and their successes is needed to further inform the development of palliative care interventions. Checklists, such as the template for intervention description and replication (TIDIER) checklist, could be adopted as reporting guidelines for intervention studies.[34] In addition to reporting implementation, implementation fidelity in palliative care is also underreported; strategies to improve implementation fidelity have been proposed.[35]

This review specifically focused on long-term care facilities taking part in research studies or evaluations, all of which had an initial willingness from within the facility to actively receive a palliative care intervention and had some form of involvement from a research team to collect data, at a minimum. It is unclear how implementation may differ without the involvement of a research team or without an evaluation or audit process. Separating barriers and facilitators to implementation with that of the research process, such as recruitment, retention and attrition, is an additional complexity, as is how to engage long-term care facilities who are unwilling to take part in such studies.[36]

Information on implementation is seldom reported in detail, creating difficulties in establishing the elements of an intervention that is being newly delivered or being incorporated in current practice. For example, while some studies have reported multidisciplinary team meetings as part of their intervention, it is unclear whether such meetings were in place before the intervention and to what extent. Further research could also explore the cost-effectiveness of interventions and their sustainability after external facilitation has ended.

Implications for practice

The potential for interventions to improve palliative care in long-term care facilities is well-documented in previous research; however, implementation of such interventions is under reported. This review has highlighted the difficulty of separating characteristics of palliative care interventions with their implementation. In some studies, the challenges encountered in implementation may be inherent to the nature of the intervention, for example, staff members fearing engaging in advance care planning discussions with residents.[37] A key finding of the review is the need for palliative care interventions to support wider skills, such as supporting team work, in addition to improving palliative care knowledge. Facilitators include strong leaderships within the facility; availability of external facilitation and a culture of learning indicate that future research should explore support for managers to develop a culture of palliative care learning and reflection among staff members. These facilitators move interventions from understanding to sustained changes in practice and improvement in palliative care. Drawing on wider implementation literature, specifically theories of implementation from other areas of health care, could inform implementation within this area.[38–40]

Implications for policy

The review has identified a number of factors associated with implementing palliative care initiatives in long-term care facilities at an organizational level; the majority of which are understandably located at an organizational level. It is unclear from these findings how the promotion of palliative care at regional, national and international level can support change at an organizational level. Fully integrated palliative care within long-term care facilities will require the establishment of minimum palliative care competencies for long-term care facilities staff and appropriate regularity frameworks and guidance, which will require a multilevel approach.

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Author contributions

D.C.M. conducted the scoping review with guidance from K.F. and S.P. J.L. and L.V.d.B. provided feedback on each stage of the review and contributed to the development of the paper. All authors read and approved the final manuscript.

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Contribution to the thesis

The sixth chapter of this thesis explores the implementation process supporting the introduction of palliative care interventions in LTCF. The review has identified four organisational strategies for the implementation of palliative care interventions: facilitation, education/training, internal engagement and external engagement. Three developmental stages comprise the implementation process: conditions to introduce the intervention, embedding the intervention within day-to-day practice and sustaining ongoing change.

A key finding of the review was that variation in the implementation strategies used across the studies identified were often underreported. As chapter five identified variation in palliative care between shorter and longer stay populations, the implementation of palliative care also varies. The final paper of this thesis can be used to inform the development and implementation of future palliative care interventions in this setting, and how they can be implemented more effectively.

Chapter 7: Discussion

Overview

This chapter reflects on the principal research question underpinning this thesis; "How are resident length of stay and palliative care in LTCFs associated?" and discusses the knowledge that has been uncovered through the process of answering this question. Firstly, it discusses how each of the research aims have been met, summarising the main findings from each chapter and exploring the contributions made within this thesis to the research area within the context of the wider literature. Secondly, it critically reflects on the contribution of the research to the fields of ageing, long-term care and palliative care. Finally, it discusses the strengths and limitations of the four methodological approaches used, and of the thesis as a whole.

Aim 1: To systematically identify, synthesise and quality assess data on factors associated with resident length of stay in LTCFs.

In chapter three, a systematic review identified, assessed the quality of and synthesized factors identified in international literature as associated with length of stay of residents in LTCFs. The review's primary finding was that the resident and facility characteristics of the shorter and longer stay LTCF resident populations varied. The findings will be discussed in the context of a resident's intrinsic capacity, their available environmental resources prior to admission and the resulting functional ability.

Resident characteristics related to reductions in intrinsic capacity, including poorer physical functioning, poorer general health, limited mobility and the presence of pressure ulcers, were identified as associated with shorter subsequent lengths of stay. In terms of specific diagnoses, cancer and respiratory disorders were associated with shorter lengths of stay, a possible reflection of the trajectory of rapid and intermittent physical decline associated with such conditions (Murray et al., 2017). The review identified stronger evidence supporting measures of intrinsic capacity, as opposed to specific diagnoses, indicating that measures of functioning may be more accurate predictors of length of stay than individual diagnoses.

Characteristics and associated treatments common in older adults approaching end of life, such as shortness of breath, low body mass index (BMI) or malnutrition, and receipt of oxygen therapy were also associated with shorter lengths of stay. This finding could reflect higher care needs experienced at end of life, however it may also indicate that the need for end of life care is prompting LTCF admission shortly before death, where care in the community may not be available, not accessible or not sufficient to meet the care needs of older adults. As discussed previously, older people are less likely to be referred or access palliative care, receive specialist palliative care services at home and are less likely to be referred to or admitted to hospices than younger people (Burt and Raine, 2006; Dixon et al., 2015; Parajuli et al., 2020), which could explain why characteristics related to end of life are associated with shorter stay after admission, as residents are admitted later in their illness trajectory. The trend of residents admitted to an LTCF with lower levels of intrinsic capacity, and subsequently functional ability, for a relatively short time before death, support the theory of a 'compression of morbidity' in the older adult population (Chatterji et al., 2015b; Fries, 2003). In comparison, the systematic review identified only weak evidence for an association between dementia or cognitive impairment and shorter lengths of stay; indicating that older adults with dementia were likely to have longer lengths of stay than those without a dementia diagnosis. Similar findings were identified for associated behaviour problems, such as hallucinations, wandering, delirium and delusions. Length of stay, therefore, cannot fully be explained by levels of intrinsic capacity alone.

As dementia and cognitive impairment are characterized by reductions in both mental and physical ability, and older adults with such conditions have an increased risk of LTCF admission, it could be expected that older adults with these conditions would subsequently also have shorter stays before death. However, while dementia and cognitive impairment were identified as the strongest predictors of LTCF admission, the findings of this review indicate that neither are associated with shorter lengths of stay (Luppa et al., 2010). The care needs of older adults with dementia may explain earlier admission and subsequently longer lengths of stay; this group often have higher, more demanding care needs than those with limitations in physical functioning only, and may be less able to access appropriate care to remain in the community, leading to reductions in functional ability (Bertrand et al., 2006) In addition, levels of carer burden can be high, especially among spouses who may be older adults with care needs themselves (Afram et al., 2014). The findings support the 'expansion of morbidity' theory, where gains in life expectancy are characterized, or offset, by progressive disability, resulting in a long period of decline post LTCF admission (Rechel et al., 2009; Salomon et al., 2012).

The availability of environmental resources prior to admission, in addition to deterioration in intrinsic ability, may explain variation in length of stay. The likelihood of shorter lengths of stay was found to be higher among men and married older adults. Although women have longer life expectancies than men do, evidence from previous systematic reviews suggests that men are more likely than women to enter an LTCF; however, the results were inconsistent, as shown in the introduction in table 1.3. It is clear from this research, however, that men are more likely to stay for a shorter time before death, with women more likely to stay for longer before death, resulting in a higher proportion of women in the LTCF population. The underlying reasons for this are unclear; however, it is common for a spouse to act as an informal caregiver in the community, potentially delaying the need for LTCF admission in married couples (Garlo et al., 2010; Sutcliffe et al., 2017). Differences in life expectancies, with women tending to live longer than men, could explain why partnerless women, either unmarried or widowed, are overly represented in the LTCF population, and have longer lengths of stay.

Building on the findings of chapter three, a theory of LTCF length of stay, the ‘theoretical framework of deferred admission’ emerges, combining the components of the WHO framework for healthy ageing; intrinsic capacity, environment and their combined influence on functional ability with simplified trajectories of illness (Murray et al, 2017, Luppa et al., 2010; World Health Organization, 2015). The theoretical framework of deferred admission asserts that:

> *two forces can explain length of stay post LTCF admission, the trajectory of decline in an older adult's intrinsic capacity, and the availability of resources in the environment prior to admission that either hasten, delay or negate altogether LTCF admission by compensating for losses in intrinsic capacity and maintaining the level functional ability required to age in place.*

Figures 7.1 and 7.2 show two examples of the theoretical framework of deferred admission, each with the same trajectory of decline in intrinsic capacity, but with varying resources within the environment prior to admission that either hasten or delay the point at which functional ability no longer supports ageing in place.

In figure 7.1, the trajectory shows an older adult with reducing intrinsic capacity, but is lacking in resources in the environment, resulting in hastened LTCF admission and subsequently longer lengths of stay. Residents are characterised by a dementia diagnosis, deteriorations in cognitive as well as physical functioning, and are more likely to be younger, a woman and reside in facilities providing relatively lower level of care. Admission from the community is more likely than in shorter stay residents.

In figure 7.2, the trajectory again shows an older adult with reducing intrinsic capacity compensated for with an abundance of resources in the environment, resulting in delayed LTCF admission and subsequently shorter lengths of stay. Residents are characterised by deteriorations in physical functioning, symptoms common at end of life and are more likely to be older, be a man, and to require the level of care provided by facilities providing onsite-nursing care. Admission from hospital is more likely than in longer stay residents.

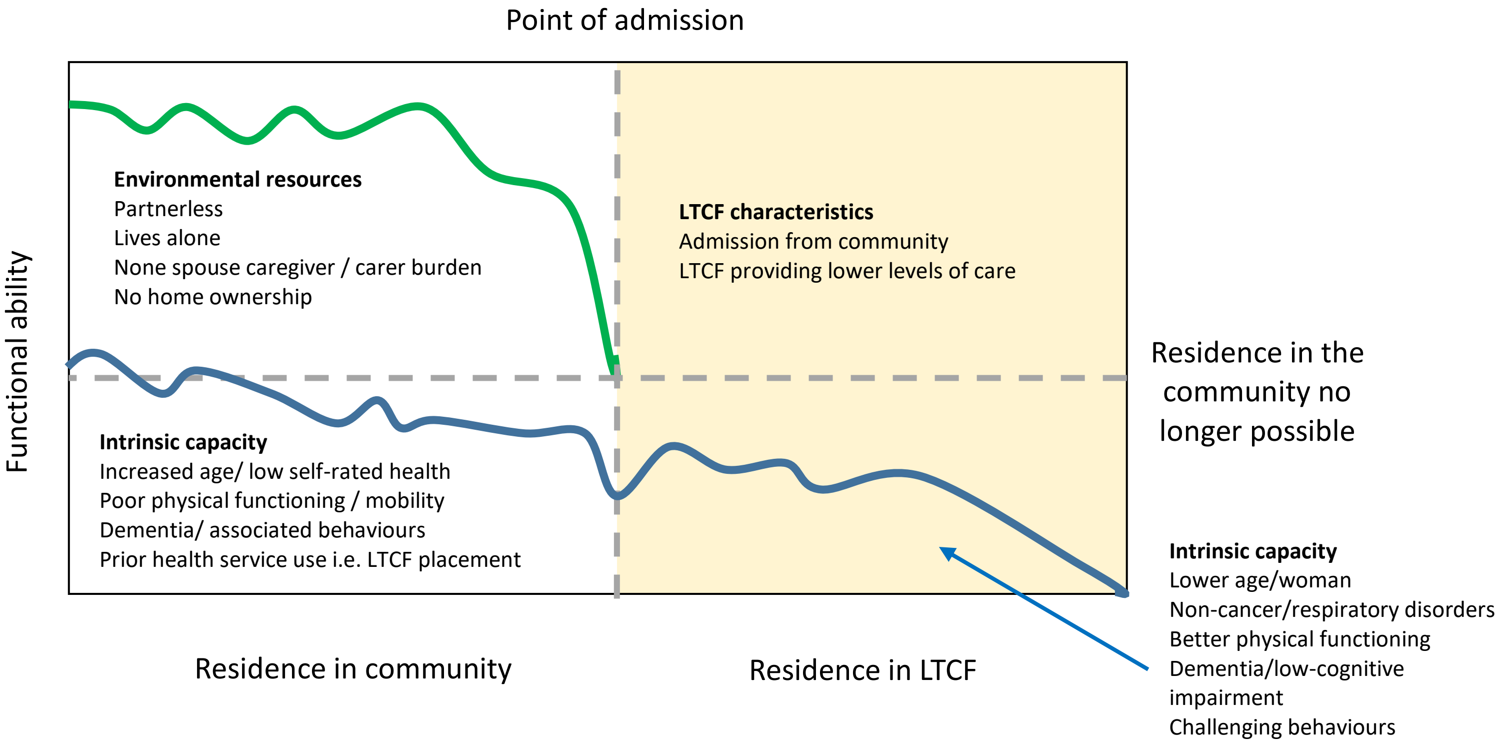

Figure 7.1: Theoretical framework of deferred admission – reducing functional ability with few resources in the environment, characterised by longer length of stay, post LTCF admission.

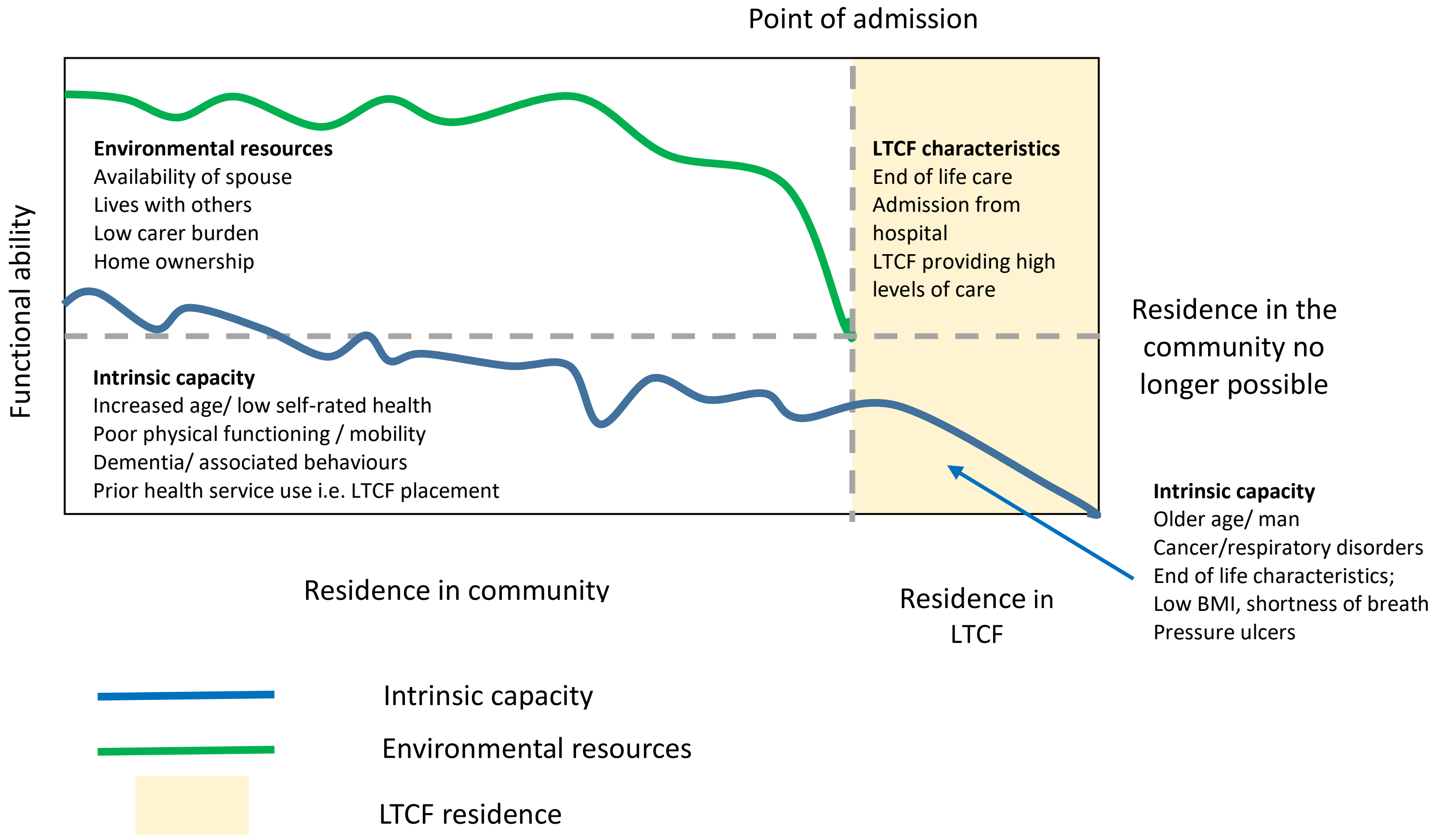

Figure 7.2. Theoretical framework of deferred admission – reducing functional ability with availability of resources in the environment, characterised by shorter length of stay, post LTCF admission.

The figures shown are simplified models for comparative purposes and, for illustration, only show intrinsic capacity based on the physical trajectory of gradual decline. In reality, admission to an LTCF could be due to declines in social, emotional and spiritual wellbeing rather than physical, and the interactions between intrinsic capacity and environmental resources are increasingly complex (Hanratty et al., 2018),

The availability of other long-term care services and settings, and the impact this has on how older adults utilise LTCFs, is difficult to judge given the limited context of the data synthesized in the review, including the funding of long-term care, health system organisation and national policies on ageing in place. Shorter lengths of stay were associated with residence in LTCFs, which provide higher levels of care; residents in nursing homes had shorter lengths of stay than those in residential homes that provide lower levels of care than nursing homes. Without the reporting of wider contextual knowledge in the studies included in the review, it is difficult to determine the reasons behind this finding. It could be that older adults are delaying admission until their care needs are relatively high, entering settings providing higher levels of care for shorter periods to avoid losing independence. In addition, the findings could also reflect restrictions placed on admission to LTCFs, such as an assessment of need required as a prerequisite for admission or the implications of the cost of higher levels of care.

Interpretations of findings on place of admission encounter similar methodological issues. Admission from hospital indicates that an older adult may be unable to return to residence in the community, reflecting the catastrophic event trajectory; a sudden reduction in functional ability such as an acute event such as a hip fracture or stroke, followed by a gradual decline that can no longer be compensated for by resources available in the environment (Ballentine, 2013; Ballentine, 2018). Further interpretations based on place of admission are dependent on an understanding of the wider health system, access to other long-term care services and settings, and the availability of formal and informal support.

Two caveats to the theoretical framework of deferred admission warrant further discussion. Firstly, the framework aims to explain length of stay, however it could be argued that many of the factors identified as having explanatory value on length of stay are also related to theories of LTCF admission. There is understandable overlap between these two areas, however further research is needed to explore the nuances between the two.

Secondly, the framework emerging from this thesis is a start point to guide future research in this area and requires further testing and investigation. Ideally, this would capture the experiences of older adults who remained in the community until death alongside those who were admitted to a LTCF to allow comparison. The theoretical framework of deferred admission needs refining, and testing on larger, more diverse samples of LTCF residents is needed.

Aim 2: To explore the association of resident, facility and country level factors with length of stay in LTCFs, using internationally comparable data.

The resident and facility variables identified in chapter three that were supported by strong or moderate evidence, and the methodological approaches of the studies included in the review, were used to inform the development of the analysis in chapter four.

This chapter's principal contribution to the research area is the finding that when using a representative (where possible), comparable sample across countries, residents' length of stay varied significantly between LTCFs in the six countries included in the analysis, and between different resident groups within countries. The analysis identified two subpopulations, residents who died relatively soon after admission, and residents who resided in the facility for months or years post-admission, like previous literature on this area (Froggatt and Payne, 2006). In both analyses conducted in this chapter, four factors were consistently identified as associated with shorter lengths of stay; increased age at admission, being a man, being married or in a civil partnership and admission from either a hospital or another LTCF.

The consistency of findings on length of stay across all six countries supports the role of environmental resources in the theoretical framework of deferred admission to European LTCFs, irrespective of the national context of long-term care. The findings are indicate that partnerless women are entering LTCFs due to a lack in resources in the environment prior to admission, rather than reductions in intrinsic capacity, leading to longer lengths of stay and subsequent over representation in this sample, and the wider LTCF population.

The within country analysis reported conflicting results regarding the association between functional ability and length of stay. Firstly, none of the diagnoses in the model, including severe pulmonary disease, diabetes and stroke, were associated with length of stay, with the exception of cancer, which was significant only in Italy. This supports the findings of chapter three, that indicators of physical functioning may be better predictors of length of stay than specific diagnoses or measures of general health (Luppa et al., 2010). However, only one measure of physical functioning, moderate or severe problems in mobility, in one country, England, was associated with shorter lengths of stay. In comparison, moderate or severe problems in mobility were associated with longer lengths of stay in Belgium and Poland and moderate or severe problems in dressing and assistance with eating and drinking in Italy and Finland. Whereas the majority of studies included in the systematic review collected data at admission; data in this study referred to the residents' condition in the month prior to death, therefore the relationship between poor physical functioning and longer lengths of stay could reflect a deterioration over time from admission to death, resulting in poor mobility before death in longer stay residents.

A strength of this analysis is that the methodological approach allowed for the influence of dementia and cognitive impairment to be controlled for, allowing associations between physical functioning, cognitive functioning and length of stay to be explored separately. As discussed by Luppa et al, in analyses on factors associated with LTCF admission that control for dementia or cognitive impairment, the influence of physical impairment increases the risk of LTCF admission (Luppa et al., 2010). In this analysis, dementia and cognitive impairment were associated with longer lengths of stay in England and Italy. As dementia and cognitive impairment affect both cognitive and physical functioning, and physical functioning arguably has a less detrimental influence on cognitive functioning, the findings support that the influence of dementia may hide the influence of physical impairments alone (Luppa et al., 2008). These findings also support those identified in chapter three, that although poor physical functioning was associated with shorter lengths of stay, dementia and cognitive impairment were not.

Neither measures of physical functioning nor cognitive functioning were associated with shorter lengths of stay in the between country analysis, indicating that the availability of environmental resources within each country may have more influence on length of stay than individual functional ability. Similarly, a cancer diagnosis at the time of death was significantly associated with shorter lengths of stay in the between country analysis, but in only one country, Italy, in the within country analysis. A possible explanation for this inconsistency is the availability of care for cancer patients within each country. If cancer care is available in the community, or referral to a hospice is available, it may be that older adults with cancer are dying in other settings as opposed to entering LTCFs (Allsop et al., 2018) It is also unclear from the data as to whether cancer is the primary cause of death or a comorbidity; in the UK population approximately 62%, of those who die have dementia, however it was recorded as the underlying cause of death in only 31% of deaths (National End of Life Care Intelligence Network, 2017).

In the within and between country analysis, shorter lengths of stay were identified among residents in LTCFs with higher levels of care provision, however the findings were inconsistent. In Poland and England, shorter lengths of stay were significantly associated with residence in type 2 and type 1 LTCFs respectively; settings providing the highest level of care available within each country. However, this was not seen in Italy and Netherlands, which, like Poland, have type 1 and type 2 facilities available. In the between country analysis, type 2 facilities in Finland, Italy, Poland and England had significantly shorter lengths of stay compared to Belgium.

A possible explanation for this finding is that England has only type 2 and type 3 facilities; applying the theoretical framework of deferred admission, the subset of residents in type 2 facilities included in this analysis would have higher health needs and would therefore be more likely to have shorter lengths of stay. However, Italy and Poland have type 1 and type 2 facilities, in applying this theory it would be expected that residents in type 2 facilities in these countries would have longer lengths of stay, compared to Belgium and Finland, which only have type 2 facilities, as older adults with high health needs would reside in type 1 facilities, however this trend was not found in the data.

Aim 3: To explore the relationship between length of stay and care at end of life in LTCFs, using internationally comparable data.

The third research aim was addressed in chapter five, using generalised linear mixed models to explore the relationship between length of stay and care at end of life in LTCFs, using internationally comparable data collected in the PACE mortality follow-back study. The analysis included the factors identified as associated with length of stay as covariates to control for the influence of confounding characteristics, such as age, gender and diagnoses, which were identified in chapters four and five.

The analysis focused on five indicators of palliative care, rated by LTCF staff; quality of care in the last month of life, comfort in the last week of life, contact with health services in the last month of life, presence of advance directives and consensus in care among facility staff and relatives (Kiely et al., 2006; Munn et al., 2007).

The sample used in this analysis included LTCFs, which provided varying levels of palliative care, across three types of facility within six countries. Although the sample was too small to conduct within-country analysis, the inclusion of a random-effects term in the model controlled for characteristics specific to the individual facility. Therefore, the results reflect a trend across LTCFs, regardless of whether the facility offered a palliative care approach, general palliative care, or specialist palliative care (Radbruch and Payne, 2009).

The primary contribution of this analysis is the finding that indicators of the quality of palliative care varied between residents with shorter and longer lengths of stay. Longer lengths of stay were associated with higher scores of overall quality of care in the last month of life, specifically on the personhood, closure and preparatory tasks subscales. In terms of scores of comfort in the last week of life, longer lengths of stay were associated with higher overall scores, and all subscales except the dying symptoms subscale. Associations between longer lengths of stay and quality of end of care occurred earlier than in comfort in the last week of life, with significantly higher scores identified from three months compared to one year. Finally, longer stay residents were more likely to have written advance directives and lasting power of attorney in place and have had a staff member discuss palliative care with either themselves or a relative.

The findings were consistent after controlling for the characteristics associated with length of stay in the PACE dataset (identified in chapter four). Two patterns emerged; firstly, the trend was characterized by better indicators of palliative care the longer an older adult resided in a facility, a trend emerging around two years post-admission. Secondly, the trend was not consistent across all five measures, with no significant associations between length of stay and physician visits, emergency department visits or consensus on care and treatment.

The data may be reflecting the effect of transition between care settings. Transitions into a LTCF can be challenging, as identity, independence and autonomy are renegotiated within a restrictive, regulated setting, in addition to the physical process of moving setting, especially if the transition is via an acute care setting or for those with cognitive impairment (Fitzpatrick and Tzouvara, 2019; O'Neill et al., 2020; Sury et al., 2013). A partial explanation for the findings may be that recent admissions to an LTCF are negatively impacted by the transition itself, however this effect is not captured in the data on physical functioning alone, as the measure was collected in the month before death. Comparable data collected at admission may also not differentiate between pre-existing levels of intrinsic capacity and the effect of transition between care settings; however, it may explain why shorter stay residents have fewer indicators of palliative care, especially on the personhood and closure subscales of the quality of care in the last month of life questionnaire.

In addition, LTCFs are busy, complex settings, and previous research has identified time pressures, limited resources and lack of continuity in staff as critical barriers to providing palliative care in LTCFs (Midtbust et al., 2018). A further explanation for the findings is that LTCFs are not sufficiently resourced, in terms of time or staffing, to provide palliative care to residents with lengths of stay under one month, the reference group in this analysis. In a secondary analysis of data collected in the PACE study, focusing specifically on receipt of palliative care, the median time of initiating palliative care did not exceed two weeks before death, slightly shorter than the on average twenty-nine days before death identified in the USA (Ten Koppel et al., 2019). In addition, the knowledge of nurses and care assistants concerning basic palliative care issues and the extent of agreement with the fundamental principles of palliative care varies considerably between countries (Honinx et al., 2019a; Smets et al., 2018b).

It is possible that staff are either unable to identify residents at end of life, or unable to initiate palliative care within a relatively short period prior to death. However, this does not explain why the better indicators of palliative care are identified at two years post-admission, or explain the trend found in the presence advance directives, which may be in place prior to admission.

Differences in the significance of subscales and their relationship to length of stay warrant further discussion. The specific questions that make up the personhood subscale are dependent on the relationship between the resident and wider staff (a nurse or aide with whom the resident felt comfortable, affectionate touch daily, a physician who knew him or her as a whole person). Likewise, the preparatory tasks subscale refers to discussions with residents and activities which can be planned in advance (treatment preferences in writing, establishing a named decision-maker, funeral planning). The components of both measures would require facility staff to have time available to develop a relationship with the resident or to discuss advance care planning, despite the high turnover of staff in such settings reducing consistency and stability.

Applying the theoretical framework of deferred admission, residents with shorter lengths of stay are more likely to have wider support in the environment to facilitate their remaining in the community for longer. Post-admission, family caregiver involvement can involve monitoring the care provided, ensuring continuity in care due to their personal knowledge of the resident and their needs and facilitating communication between the resident and staff (Davies and Nolan, 2006). It is possible that residents with shorter lengths of stay score less on the personhood and preparatory tasks scales as these roles are taken on by family carers rather than staff, and are not being captured when measures are reported by staff. Figures 7.3 and 7.4 show two examples of the theoretical framework of deferred admission, combined with trends in indicators of palliative care.

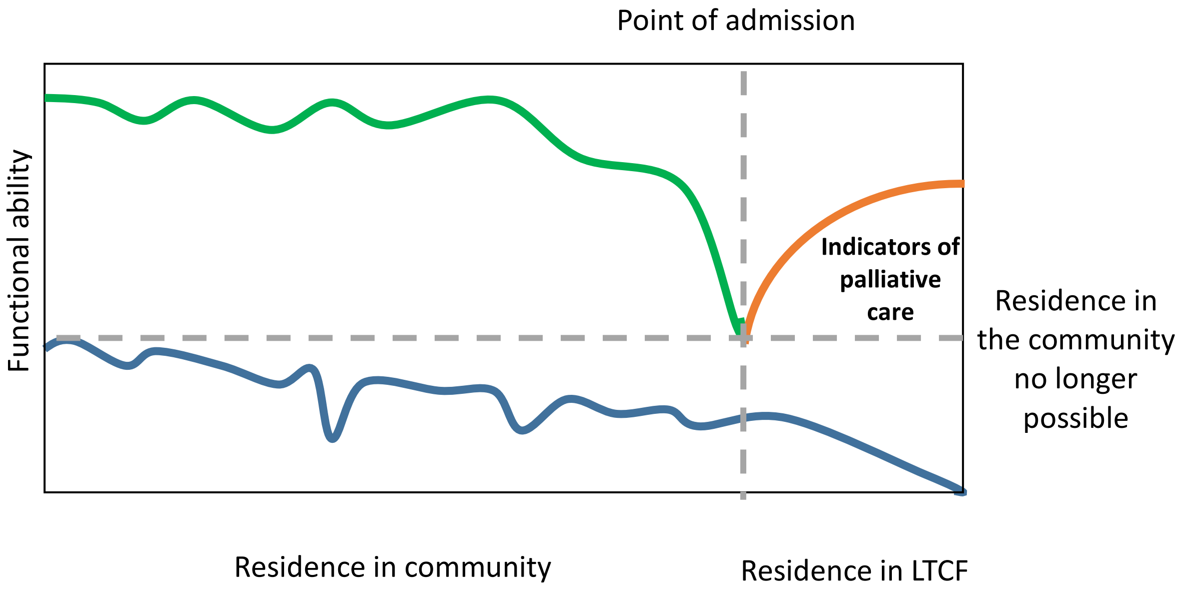

Figure 7.3. Theoretical framework of deferred admission combined with trends in indicators of end of life care - reducing functional ability with few resources in the environment, characterised by longer length of stay.

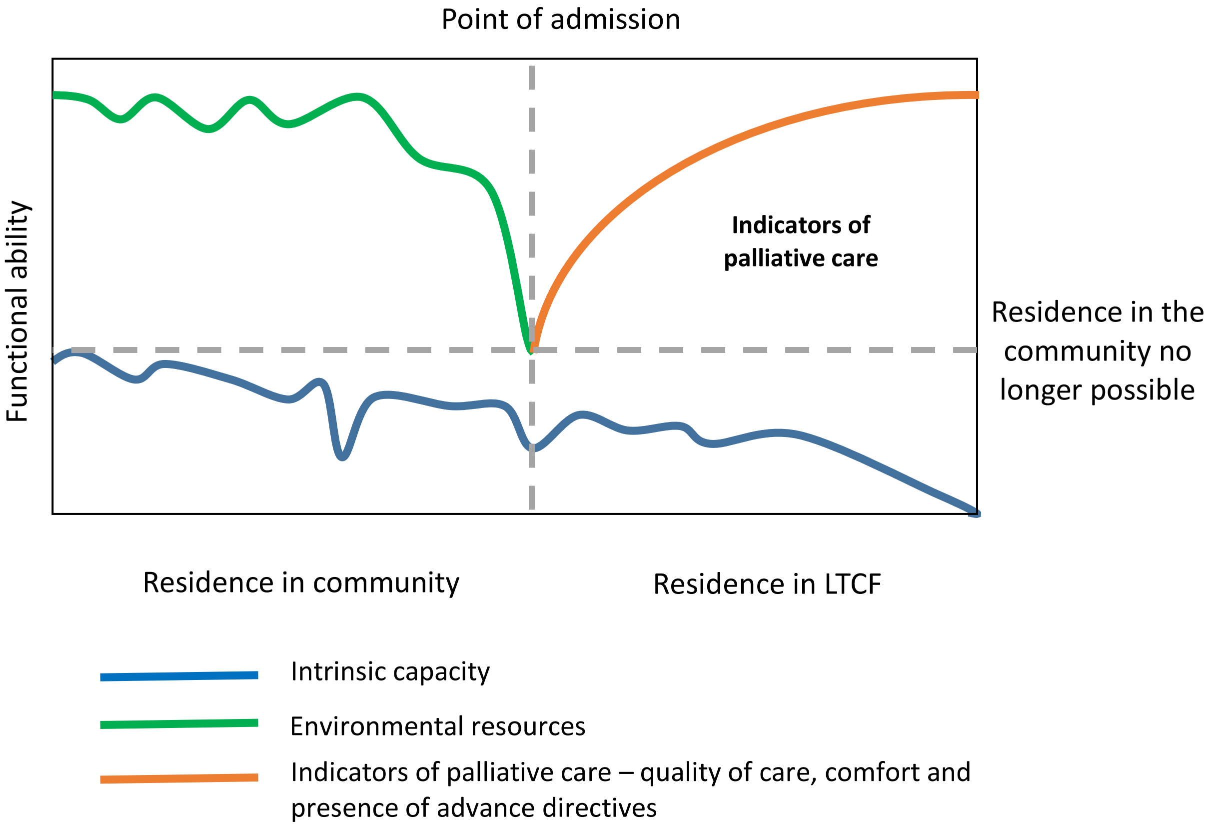

Figure 7.4. Theoretical framework of deferred admission combined with trends in indicators of end of life care - reducing functional ability with availability of resources in the environment, characterised by shorter length of stay post LTCF admission.

A further explanation could be that longer lengths of stay allow time for staff to develop relationships with residents and their relatives, where present or involved in the residents care, facilitating conversations regarding advance directives and preferences. In Brandburg's model of transition into a facility, the final 'acceptance' phase occurred between six and twelve months after admission, and was characterised by the formation of new relationships, including with facility staff (Brandburg, 2007). If longer stay residents are less likely to have resources in the community to remain living at home, it is possible that longer stay residents are also less likely to have a relative involved in their care post-admission. A limitation of this research, and the PACE study overall, is its lack of data collected on the involvement of family carers, prior to and post-admission.

Finally, the findings could be explained by the nature of the data reporting rather than the existence of an actual trend. The data in this analysis are proxy measures, reported by LTCF staff members only, although it is unclear whether this has led to a bias in the data. Previous studies, which used staff members as proxies to report care at end of life, identified that agreement was poorest for subjective aspects of the patient's experience, such as pain, anxiety and depression and subscales compared to index scores (Devine et al., 2014; McPherson and Addington-Hall, 2003). In addition, further analysis of the PACE dataset combining staff and relative scores indicated that staff judged physical distress and dying symptoms in residents to be better than when judged by relatives (Tanghe et al., 2020).

Staff members may feel more confident in their judgement of palliative care needs of longer stay residents, due to having known the resident longer. Greater confidence in assessing resident needs may lead to better palliative care, such as of symptom management. Alternatively, the findings may not be an accurate reflection of the care received at end of life, but rather differences in how care needs are judged. As longer stay residents are more likely to have dementia, such residents may be unable to communicate their needs, leading to an overestimation by staff that needs are being met, however the effect of dementia should have been controlled for in the analysis.

It should also be noted that the trend identified does not assess whether the palliative care found is either good or poor, only that care is relatively constant across length of stay. In consensus in care and contact with health services, the data showed no significant differences between various lengths of stay on either measure. It could be that either consensus in care is established within the first month of admission, or not all or that frequency of contact with health services is established relatively soon post-admission.

Aim 4: To identify facilitators and barriers to implementing palliative care interventions in LTCFs.

The fourth and final aim of the thesis was to identify facilitators and barriers to implementing palliative care interventions in LTCFs and is the focus of chapter six. The findings of this chapter were used to inform and, where possible, provide an explanation for the variation in indicators of palliative care between shorter and longer lengths of stay identified in chapter six. The aim was achieved by conducting a scoping review, using thematic analysis. The primary contribution of chapter six was that there are numerous implementation strategies reported as being applied to interventions to improve palliative care in LTCFs, however their efficacy is unclear.

The review focused specifically on four strategies: facilitation, training or education, internal engagement and external engagement. Within these strategies, there was also wide variation in their definition, application and reporting, in terms of staff roles involved in the intervention, the delivery of education and training, and joint working with other healthcare professionals.

The studies included in the scoping review reported numerous facilitators and barriers to the implementation of palliative care interventions, which were coded and categorised into nine sub-themes. The themes were placed into one of the three stages of the implementation processes, establishing conditions to introduce the intervention, embedding the intervention within day-to-day practice and sustaining ongoing change, as shown in figure 7.5. Overall, the feasibility of implementation appears to be based on conditions within the LTCF, and the extent to which the intervention can be tailored to the individual facility and residents.

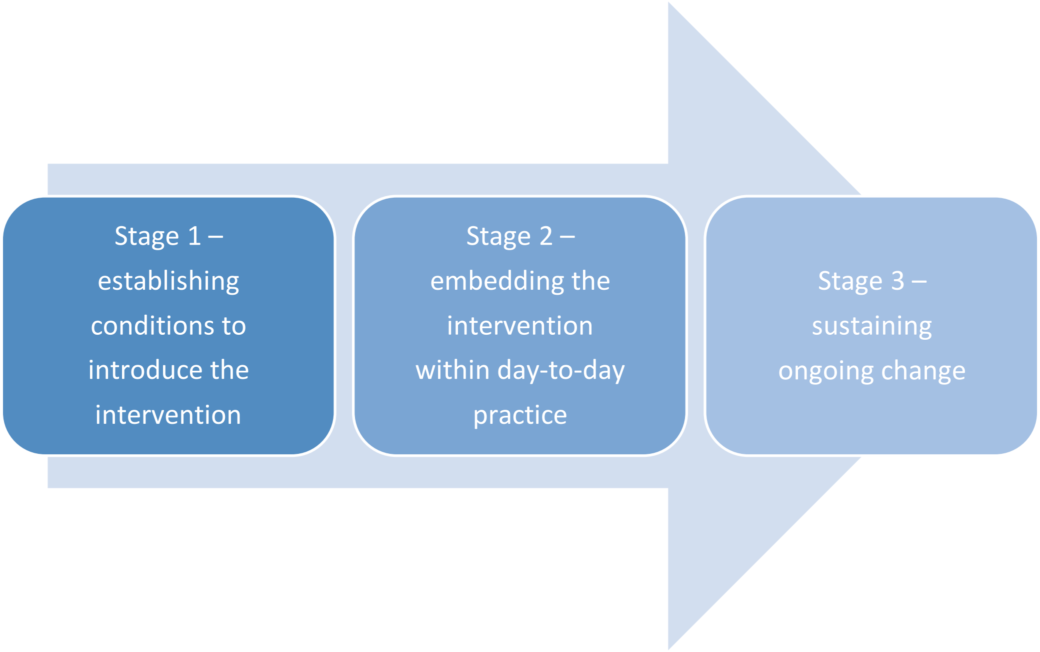

Figure 7.5. Three stage framework for the implementation of palliative care interventions in LTCFs.

The findings of the review are aligned with wider literature on implementation science and the importance of understanding LTCFs contextual factors, such as the individual, the organisation and wider environmental factors (Benzer et al, 2017, Greenhalgh et al, 2004, Shortell, 2004), Despite LTFCs being complex, fast paced environment with the potential for high staff turnover, there is relatively little research on how implementation is affected by existing context (Cammer et al, 2014).

Bunn et al conducted a systematic review of the extent to which researchers have considered LTCFs organisation and context prior to implementing interventions in care homes (Bunn et al, 2020). The systematic review applied the Alberta Context Tool to assess whether studies conducted in LTCFs reported any consideration of context and its implications for the care homes to engage with the introduction of change (Estabrooks et al, 2009, Estabrooks et al 2011). Context was defined using ten dimensions; leadership, culture, evaluation, social capital, structural and electronic resources, formal interactions, informal interactions and organisational slack; split into staffing, space, and time. The review found that none of the 48 studies included a structured assessment of context, however the most commonly considered areas were leadership, culture, formal interactions, and staff availability (Bunn et al, 2020).

On application to the findings of chapter five, the framework goes some way to explaining why better indicators of palliative care are associated with longer resident lengths of stay. The characteristics of successful implementation identified, such as ensuring that enough LTCF staff are trained to deliver an intervention, maintaining training alongside staff turnover and developing ongoing opportunities for practice and reflection, all require time.

In particular, high staff turnover can lead to the lack of a ‘critical mass’ of staff able to provide palliative care, potentially reducing continuity in practice. In the UK, it is common for staff to move employment between LTCFs, bringing acquired expertise and knowledge gained through either formal training or informal learning at previous facilities (Cavendish, 2013). In longer stay residents, it is possible that longer residence allows for contact with a greater number of facility staff, allowing residents to benefit from a wider range of knowledge and skills, including palliative care.

Adoption of a whole LTCF approach, whereby awareness of palliative care and the expectations of every staff member is promoted throughout the facility, regardless of their role within the facility, may also have explanatory value. If only a subset of staff within the facility are trained in palliative care, it may be less likely that shorter stay residents have access to appropriate staff members, and their needs are either not recognised or not met. Alternatively, in facilities where non-clinical staff do not receive training on palliative care, additional time available for the development of relationships in longer stay residents allows for communication of needs between staff members, and subsequently more staff members, both clinical and non-clinical, are involved in the residents care. This, combined with high levels of staff turnover, argues that palliative care is facilitated by the development of relationships between residents and LTCF staff, and ensuring that all staff members understand how to act upon or report observations or conversations with residents regarding end of life.

Palliative care is one part of a spectrum of care and treatment provided to LTCF residents, which may include dementia care, diagnosis-specific care and primary care for acute conditions, such as pneumonia and urinary tract infections. Due to time constraints, palliative care may be less prioritised among shorter stay residents, who may have higher care needs, may be experiencing the negative impact of the recent transition to the facility and may be under the care of more than one physician during handover (Iliffe et al., 2016). In addition, appropriate palliative care depends on staff recognising end of life and associated care needs; raising awareness among higher levels of management and commissioners, and the consequent allocation of time, resources and funding to be allocated to providing palliative care, through either staff training or delivery, could also explain the trend observed.

The importance of raising awareness of the intervention among residents and relatives may also explain why shorter stay residents receive arguably poorer palliative care than longer stay residents do. On LTCF admission, relatives may not have a clear understanding of what to expect as the resident approaches end of life, and what care is available. Longer lengths of stay allow time for residents and relatives to gain a better understanding of palliative care, either through their own experiences or through being present for end of life care in other residents in the facility

Finally, the recognition of end of life in a resident and opportunities for ongoing reflection on practice may be more common in longer stay residents. This could take the form of opportunities to discuss the resident's care with other staff members, or through opportunities to monitor and identify changes and decline in the residents' condition, such as the mapping the trajectory of the resident's condition step of the PACE Steps to Success intervention (Payne et al., 2018).

The explanatory value of some of the other facilitators of implementation identified, including management support, appropriate facilitation, and raising awareness among stakeholders, on variation in palliative care by length of stay, is less direct. Recognition of the need for palliative care within a LTCF may create an ethos of identifying end of life and providing appropriate care routinely, however it is unlikely to account for variation between shorter or longer stay residents. The findings support previous research on the importance of recognising and acknowledging LTCFs as a place of death and dying to implement change in the delivery of end of life care (Amador et al., 2016). In addition, support from LTCF management may promote palliative care and encourage staff members to engage with palliative care interventions. Previous research has recognised the role and importance of LTCF managers becoming leaders in implementing change, in particular in being supported and knowledgeable about palliative care for it to be delivered within a facility, but again, would not explain the variation identified in chapter five (Håkanson et al., 2015; Penney and Ryan, 2018).

It should also be clarified that longer lengths of stay, and the conditions which they create, cannot improve indicators of palliative care in the absence of the provision of palliative care within the wider LTCF. Longer stay residents are unlikely to benefit from the early identification of decline in condition if staff lack appropriate training on recognising end of life, for example. In addition, if staff feel unable to engage in conversations with residents and relatives regarding end of life, or in facilities where the importance of palliative care is not integrated into daily practice, a longer time frame in which such conversations could occur will be largely redundant.

In addition to the three stages of the implementation process presented, the review highlighted the need for better reporting of implementation to identify which strategies should be prioritised. Interventions may be effective in a research setting, however the extent to which they can be successfully implemented in LTCFs without research staff support and additional resources, and the strategies that support this, are yet to be established. The development of interventions may benefit from incorporation of a theory of change approach, or a process evaluation element, in addition to measuring the effectiveness of an intervention, both of which have been successfully applied to palliative care in LTCFs (Gilissen et al., 2018; Oosterveld-Vlug et al., 2019).

Critical review of the contribution of the thesis

This thesis offers three main contributions to knowledge in the field. Firstly, the identification of variation within the characteristics of the LTCF population by length of stay underpins the development of the theoretical framework of deferred admission. Secondly, the thesis uncovered variation in the palliative care experienced by shorter and longer stay residents, using international data and controlling for the factors that characterise these subpopulations. Finally, the thesis offers a framework for the implementation of palliative care interventions in LTCFs.

The thesis has shown that the LTCF population is heterogeneous. In the same way that there is wide variation in older adults' functional ability, there is also wide variation in the LTCF population, in the trajectories that precede admission, and the trajectories to death post-admission. The emergence of two distinct LTCF populations, characterised by shorter and longer lengths of stay, has already been identified in the literature (Froggatt and Payne, 2006). This thesis has built on existing literature to create a profile of each of these subpopulations in terms of their likely characteristics, and the palliative care they are likely to receive.

The theoretical framework of deferred admission proposed in figures 7.1 and figures 7.2 are characterised by two factors, the availability of resources within the environment that hasten, delay or negate LTCF admission, and factors that influence an individual's intrinsic capacity. Although an understanding of predictors of LTCF admission is already well established both in dementia and non-dementia populations (Cepoiu-Martin et al., 2016; Luppa et al., 2010; Toot et al., 2017), this thesis provides the first synthesis of factors associated with length of stay and their exploration in an international dataset. This thesis has connected factors associated with the likelihood of admission to factors associated with length of stay, to create a fuller understanding of LTCF use.

The findings have also shown that, from a staff perspective, palliative care is not delivered equally to all residents, irrespective of the level of palliative care delivered within the facility. Efforts to improve palliative care within these settings require an understanding of the resident population, and how implementation can be adapted to ensure that shorter and longer stay residents receive quality palliative care. Raising awareness of end of life in older adults and ensuring that staff receive appropriate training and education to deliver such care, is imperative.

A lack of understanding regarding variation within the LTCF population can potentially mask differences in care. Prior to the analyses undertaken for this thesis, it would have been easy to mistake the association between length of stay and palliative care for an association with the attributes of longer or shorter stay residents, for example, as longer stay residents are more likely to be women, it could have been assumed that women have better indicators of palliative care than men. This thesis has shown that to make an accurate assessment of palliative care in LTCFs requires an in-depth understanding of the LTCF population, within a national context. Although the focus of this thesis is on palliative care, it provides an exemplar of how care differs between the two subpopulations identified and raises the question of what other variations in care are present within the LTCF population.

Finally, the identification of facilitators and barriers to implementing palliative care interventions in LTCFs provides a framework on which future interventions can be developed. Previous literature has identified the main components of palliative care interventions, including those delivered in LTCFs (Kochovska et al., 2020; Luckett et al., 2014), however implementation strategies have been relatively overlooked. The contribution of this thesis is an understanding of how such interventions can be implemented successfully, based on the experience of previous studies.

Strengths and limitations of the thesis

Critical reflections on systematic reviews

The systematic review methodology's strength is its adherence to a pre-existing, well-established approach, based on a transparent, protocol, allowing for replicability. Incorporating the quality assessment in the data synthesis allowed for a judgement on the strength of evidence for each variable, which was comparable to previous research in this area (Luppa et al., 2010). However, the inherent limitations of conducting literature reviews, and their application to the field of long-term care, require further discussion.

Firstly, ensuring the identification of all studies relevant to the review is challenging, given the variation in terms used to refer to LTCFs across countries, inconsistent coverage in MeSH and relatively poor indexing. Underreporting of LTCF types or the services offered makes applying a typology, such as that suggested by Froggatt et al and used in this thesis, and subsequent comparisons, difficult (Froggatt and Reitinger, 2013).

Secondly, the review inclusion criteria potentially limited the generalisability of the findings to the actual LTCF population. The inclusion criteria specifically excluded studies in adults under 65 years of age, older adults with learning disabilities and those with a length of stay resulting in discharge rather than death, despite both being present in the LTCF population. In doing so, the findings may not be representative of the wider LTCF population. The review was also not limited to a specific time range, however, given advances in both life expectancy and health care, the applicability of findings from the oldest study included (published in 1985) to the current older adult population, is debatable (Lichtenstein et al., 1985).

Thirdly, the findings of the review are limited by the methodological weaknesses of individual studies. It is unclear how representative of LTCFs the findings reported in each study are. In the majority of included studies, sampling applied some delimitation to the data collected, with the possible exception of USA based studies utilising MDS data (Flacker and Kiely, 2003; Lapane et al., 2001; Mitchell et al., 2004). Studies excluding residents identified as at end of life, for example, will likely underestimate associations between length of stay and characteristics related to end of life. The majority of studies collected data at one time point, overlooking factors that may change over time, such as cognitive impairment, and followed up resident deaths until a pre-specified time point, the longest follow up being 11 years, potentially underrepresenting the characteristics of residents with longer lengths of stay. Diagnoses, physical functioning and mobility were consistently reported across the included studies, however their measurement varied, ranging from validated tools to proxy reporting.

Fourthly, the approach to data synthesis estimates the strength of evidence for an association of each factor with length of stay, but does not estimate the extent of the association. The effect size of covariates included in any statistical model is relative to other variables present; if a variable with a high explanatory value is omitted from a model, the findings may not be meaningful. As the majority of studies collected data on the resident at admission, characteristics prior to admission that may have explanatory value could have been missed, such as those related to the availability of environmental resources. In addition, the synthesis of the data loses the wider context within which the data was collected. For example, of the fifteen cohorts that found an association between ethnicity and length of stay, all but one was conducted in the USA, where the implications of ethnicity may vary compared to Europe (Connolly et al.,2014).

Finally, no published quality assessment tool could be identified that was appropriate for application in this review. This is partly due to a wider lack of quality assessment tools for observational studies, however research conducted in LTCFs has its own inherent challenges (Sanderson et al., 2007). A strength of this review was the clear comparison that could be made with the review conducted by Luppa et al, allowing a comparable synthesis of factors associated with LTCF admission and length of stay, which could be combined to create a greater understanding of LTCF use (Luppa et al., 2010). However, further research is needed to ensure that validated, replicable quality assessment tools are available for observational studies in LTCFs.

Critical reflections on time to event analysis

The use of data collected in the PACE study to meet the second and third aims of this thesis had numerous advantages. The study used high quality data from a representative sample of LTCFs (where possible) from six European countries, recorded data on resident and facility characteristics and was not restricted to a pre-specified follow-up period, allowing representation of longer stay residents.

The PACE study encountered its own methodological challenges in the recruitment and retention of LTCFs, and response rates for questionnaires, which have implications for the generalisability, reliability and validity of the results of the analysis and are discussed in full in Appendix E (Collingridge Moore et al., 2019). Briefly, the success of recruitment of LTCFs for each country varied, and the extent to which the samples were representative of LTCFs is debatable, as arguably LTCFs that choose to take part in research may also provide a higher standard of care.

The thesis used time to event analysis to build a statistical model to explain length of stay in residents included in the PACE study. As with studies included in the systematic review, the explanatory value of the model is limited by the variables included. It is possible that a key explanatory variable was either not collected or not included in the model; however, using the findings of the systematic review to inform the choice of variables goes some way to mediate this. The data used in this analysis was provided retrospectively by proxy, specifically a staff member identified as having known the resident well. It is unclear whether resident records were consulted, or if the data was recorded, increasing the risk of recall bias.

The major limitation of this analysis, and previous analyses included in the systematic review, is the limited data on resident characteristics prior to admission and a lack of longitudinal data measured at multiple time points. This analysis has shown that data from mortality follow-back studies can be successfully modelled to explore length of stay, and has shown the explanatory value of data collected at different time points, including admission and end of life. However, the influence of changes in access to resources in the environment prior to admission, such as the death of a spouse, and changes in intrinsic capacity post-admission, such as deteriorations in physical functioning or new diagnoses, have not been explored in this context.

Finally, the analysis potentially underestimates the influence of facility characteristics and wider national approaches to ageing and long-term care. The analysis included three facility characteristics; LTCF type, size and funding provision, and controlled for clustering of resident data by including a facility specific random-effects term. However, data on wider long-term care provision, including home care in the community, assisted living facilities or hospices, on the funding of long-term care for older adults and wider societal influences on ageing, such as familial structures, employment and poverty in older adults, are missing. The results show a clear difference in how LTCFs are being used by older adults in each country, but cannot provide an explanation as to why such variation exists.

Critical reflections on generalised linear mixed models

Generalised linear mixed models were used to explore the association between length of stay and indicators of palliative care in chapter four. A key strength of this analysis is that the model included covariates, which were known to be associated with length of stay within the dataset, identified in chapter three and four. Generalised linear mixed modelling controlled for the effect of multiple covariates in the analysis, allowing the individual effect of each factor to be explored independently. In addition, the ability to control for the influence of characteristics intrinsic to each facility is important in exploring indicators of palliative care, as facility characteristics, such as staff mix, management and access to specialist palliative care providers, are likely to influence the findings (Carlson et al., 2011).

The main limitation of the data included in this analysis is it’s reporting by staff members only, restricting the measures to one perspective. Data from a physician and relatives’ perspective was collected in the PACE dataset, but was not utilised in the analysis as the response rate for physicians was lower than for facility staff. Similar to chapter three, it is unclear whether resident records were available and, if so, consulted, or the effect of recall bias on the data. It is also possible that staff members who did not feel they knew the resident well enough to complete some or all of the questions asked did not return the questionnaire, influencing the subsequent findings.

In terms of the data included in the analysis, the choice of variables was limited to those collected in the PACE study. The aim of the mortality follow back study element of the PACE programme of research was to compare effectiveness of health care systems with and without formal palliative care structures in LTCFs in six EU countries. The analysis performed in this thesis capitalised on the data available, however the data collected was not guided by the aim of the analysis.

Since the inception of the PACE study, further research has explored the need for palliative care for frail older adults. Stow et al found that older adults with frailty have specific care needs at end of life, and the measurement of frailty could be used to guide clinical decision making (Stow et al., 2018; Stow et al., 2019). Compared to frailty, there has been less research focusing on measuring intrinsic capacity, the inclusion of a measure of frailty within the PACE study could have been well utilised within this analysis. The decision to omit a measure of frailty from the questionnaires developed for data collection in the PACE study predates my own involvement in the research and this thesis, however the exclusion of a frailty variable is a limitation of this thesis.

The choice of indicators of palliative care used in this analysis also warrants further discussion. The measures were chosen to explore a range of indicators of palliative care in older adults, and the use of two validated tools allowed for comparability to previously conducted studies (Agar et al., 2017; Boyd et al., 2019). However, to ensure comparability across the six countries included in the analysis the measures were simplified, for example, advance directives on euthanasia were excluded as data was only available from Belgium and the Netherlands, and data was not contextualised by availability or legality within each country. Other aspects of palliative care, such as care after death, spiritual care and involvement of specialist palliative care providers, may provide different findings (van Soest-Poortvliet et al., 2011).

Finally, the analysis allows the identification of trends, however, does not offer further explanation as to why these trends exist or the underlying mechanism that support them. A statistical model can explain the correlation but cannot confirm the direction of the association. Indicators of poorer palliative care may result in shorter lengths of stay; however, this is a wider question, requiring careful consideration, which is outside the scope of this thesis.

Critical reflections on scoping reviews

The primary strength of the scoping review methodology used in chapter six was its inclusion of a wide range of publications, as reflected in the multiple types of studies, quantitative and qualitative, included and the range of palliative care interventions identified. Similar to a systematic review, guidance on ensuring methodological rigour in scoping reviews has been established and provided a framework to conduct this review (Tricco et al., 2018). A lack of quality assessment allowed the inclusion of varied intervention contexts, including funded research studies and organisation evaluations, increasing the findings' breadth. In particular, by including studies that would have been assessed as of poorer quality, it is likely that valuable insights on implementation were captured.

The main limitation of the review is the lack of linkage between the implementation strategies used and the outcomes of the studies. It is unclear from the findings whether specific implementation strategies lead to better outcomes. It is also unclear whether specific implementation strategies are required for different types of interventions. Interventions based on advance care planning, for example, require the development of very different skills to interventions based on joint working, and may benefit from specific approaches to implementation.

The methods used to extract data identified within the review restrict data collection to what the publication authors choose to report. The extent to which facilitators and barriers are reported, and the reason for their reporting, could easily lead to bias, providing an incomplete understanding of implementation. The majority of papers discussed barriers and facilitators in the results and discussion sections of the paper, with few having a clear section reporting the approach to implementation in the methodology. In addition, it was more common for publications to report barriers than facilitators, usually in the context of why the outcomes the intervention aimed to produce were not achieved. It is possible that other facilitators and barriers exist and had an impact on the success of the intervention but were either not identified by the study authors or not reported. With the exception of a minority of qualitative studies, which specifically discussed implementation approaches with facility staff members, the study authors, who were predominantly not LTCF staff members, identified barriers and facilitators. The perspectives of staff members on barriers and facilitators may be more insightful than observations from external stakeholders.

A difficulty with the data is establishing the difference between barriers and facilitators to implementation of the intervention, to delivering the intervention and to conducting research to evaluate the intervention. It is common for staff initiating and engaging in advance care planning to find the discussions difficult, and to be unsure of how and when to approach a resident to discuss end of life preferences and wishes (Lund et al., 2015). An unwillingness to begin such discussions is a challenge of the intervention, rather than implementation, however strategies to improve implementation may also improve the delivery of the intervention. In addition, challenges to conducting research or evaluating an intervention can be similar, for example, a poor response rates may reflect that an intervention is not being implemented, or it could reflect the approach used to collect data on implementation.

Finally, a limitation of a scoping review is in its reliance on the extraction of relatively limited data to create themes. The themes were created using thematic analysis, and it is likely that my perspective as a non-clinical researcher has influenced the formation of these themes, informed by my own observations and experiences in the PACE study, and from working in this research area. The Arksey and O’Malley framework’s final stage, consultation with stakeholders to provide insights into the scoping review findings, would provide an opportunity for further understanding of the barriers and facilitators (Arksey and O'Malley, 2005).

Strengths and limitations of the thesis

A primary strength of this thesis is in its direct use of knowledge identified in previous chapters to build subsequent chapters on. The application of factors associated with resident length of stay to internationally comparable data, and subsequent application to the exploration of relationship between resident length of stay and provision of palliative care, uses the factors previously identified as associated with length of stay in the PACE study. By each paper directly informing the next, the findings are located within novel research specific to the research area.

An additional strength is in its efforts towards comparable findings, from which generalisations can be made. The methodological approach chosen in the systematic review allowed for direct comparison to the synthesised findings of Luppa's et als previous review on predictors of LTCF admission, resulting in the development of the theoretical framework of deferred admission (Luppa et al., 2010). The data analysed in the fourth and fifth chapters were comparable in all six countries, in terms of resident and facility characteristics and indicators of palliative care. Finally, the use of thematic analysis in the scoping review to code the facilitators and barriers to implementation within specific studies into themes allows for application to any palliative intervention. Each of the main contributions to new knowledge, outlined in table 7.1, can be applied to LTCFs across Europe.

Finally, this thesis is located within the PACE programme of research (PACE Consortium, 2018). Throughout the construction of this thesis, the findings were discussed at international consortium meetings, formally and informally. This opportunity allowed the thesis to benefit from the perspectives of experts from each country involved in the programme of research. My interpretation of the findings was shaped by this discourse, building on and challenging my own perspective as a researcher in English LTCFs to create a thesis appropriate for an international audience.

The central limitation of this thesis is its reliance on data mainly from Europe and North America. The PACE data used is from six European countries, 77% of included studies in the systematic review and 84% of included studies in the scoping review were conducted in Europe and North America. Although neither review specifically excluded literature from resource poor countries, it is possible that by excluding non-English publications and conducting limited follow up of grey literature; these regions are underrepresented in the thesis. Alternatively, it is possible that there is little published literature on LTCFs in these countries, or if literature does exist, and it is not being captured by the search strategies developed in this thesis. It may also be the case that LTCFs are not as prevalent in resource poor countries, or at least not in the form explored in this thesis. Neither the African, South American nor Eastern Mediterranean region Atlas of Palliative Care include data on LTCFs; it is unclear if similar trajectories to LTCF admission exist in these areas (Osman et al., 2017; Pastrana et al., 2013; Rhee et al., 2017). This raises the question of how generalizable the findings of this thesis are to non-European countries, and whether the socio-cultural construction of long-term care in such countries follows similar trends as those identified here.

A second limitation relates to the datasets used in the first three studies. The majority of studies included in the systematic review either used data from routine resident records collected within the LTCF, or datasets which were specific to one LTCF provider or region. Similar to the PACE dataset, any interpretation of the findings is limited to how representative the data is of LTCFs within the particular country.

A third limitation is the reliance on previously conducted systematic reviews of predictors of admission to LTCFs to combine with the findings of this thesis and develop the theoretical framework of deferred admission. It is unclear whether variation in the samples of studies included in previous reviews has comprised comparability with the findings from the analysis of length of stay in chapter four. Ideally, the analysis could be conducted on data collected across an older adult's life course, capturing changes in functional ability prior to and post admission. However, in the absence of such data, the theoretical framework of deferred admission provides a basis for future research in this area, specifically in terms of identifying variables to collect data on.

As stated in the methodology chapter, a hypothesis was developed, tested and disproved, generating theory, and that knowledge is gained through experimentation

(Bryman.A, 2008). Such an approach was suitable for answering the research aims of this thesis and has allowed for the hypotheses stated at the beginning of the thesis to be disproved. However, the approach does not provide any further understanding of the underlying mechanisms, which resulted in these findings, or how trends identified at population levels are applied to an individual resident. Possible explanations can be provided by previous research, but how these trends are lived and experienced at an individual level cannot be explored using the data or analytical methods used in this thesis.

A final limitation is the extent to which the findings of this thesis can be used in practice. An understanding of the LTCF population is useful from a wider perspective, in terms of planning services and anticipating likely resident use, however the extent to which the data could be used to predict length of stay on admission is unclear. The accuracy of prognostic tools to identify residents at high risk of dying is debatable, and an area of ongoing research that the findings of this thesis could add to (van der Steen et al., 2011).

Research question	**How are resident length of stay and palliative care in long-term care facilities associated?**			
Chapter	Chapter 3	Chapter 4	Chapter 5	Chapter 6
Paper	Collingridge Moore, D., Keegan, T. J., Dunleavy, L. & Froggatt, K. (2019) **Factors associated with length of stay in care homes: a systematic review of international literature.** Syst Rev, 8(1), 56.	Collingridge Moore, D., Payne, S., Keegan, T., Van Den Block, L., Deliens, L., Gambassi, G., Heikkila, R., Kijowska, V., Pasman, H. R., Pivodic, L. & Froggatt, K. (2020) **Length of stay in long-term care facilities: a comparison of residents in six European countries. Results of the PACE cross-sectional study.** BMJ Open, 10(3), e033881.	Collingridge Moore, D., Keegan T, Payne S, Deliens L, Smets, T., Gambassi G, Kylänen, M., Kijowska V, Onwuteaka-Philipsen, B. & Van Den Block L (2020) **Associations between length of stay in long-term care facilities and palliative care. Analysis of the PACE cross-sectional study**. International Journal of Environmental Research and Public Health, 17(8), E2742.	Collingridge Moore, D., Payne, S., Van Den Block, L., Ling, J. & Froggatt, K. (2020) **Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review.** Palliat Med, 34(5), 558-570.
Research aim	To systematically identify, synthesise and quality-assess data on factors associated with resident length of stay in LTCFs.	To explore the association of resident, facility and country-level factors with length of stay in LTCFs, using internationally comparable data.	To explore the relationship between length of stay and care at end of life in LTCFs, using internationally comparable data.	To identify facilitators and barriers to implementing palliative care interventions in LTCFs.
Hypothesis	N/A	There is no variation in length of stay between LTCF residents.	There is no association between length of stay and care at end of life in LTCFs	N/A
Design	Systematic literature review	Mixed time to event analysis of data from mortality follow-back study	Generalised linear mixed model of data from mortality follow-back study	Scoping literature review with thematic analysis
Focus of analysis	Identification and assessment of factors associated with resident length of stay	Application of factors associated with resident length of stay to internationally comparable data	Exploration of relationship between resident length of stay and indicators of palliative care, using internationally comparable data	Identification of facilitators and barriers to the implementation of palliative care interventions
Contribution to research field	Development of the theoretical framework of deferred admission		Identification of variation in the palliative care experienced by shorter and longer stay residents	Creation of a framework for the implementation of palliative care interventions in LTCFs.

Table 7.1. Framework of the structure of the thesis to answer the research question, including contribution to the research field.

Chapter 8: Conclusion

This chapter discusses the implications for further research, to improve research practice and methods, and for clinical practice, and recommendations for policy emerging from the thesis. It provides a final statement concluding the thesis based on what is already known, what this thesis adds and the wider implications of this research.

Recommendations for further research

This thesis has identified multiple research gaps in the field of long-term care and palliative care for older adults, in terms of our understanding of LTCF residents and how palliative care can be delivered in such settings. Most importantly, it has shown that delivering appropriate, adequate palliative care in such settings cannot be achieved without a full understanding of the LTCFs resident population. High quality research is required to allow the needs of LTCF residents to be identified, recognised, and subsequently advocated for.

The development of the theoretical framework of deferred admission produced within this thesis has shown that the WHO Public Health Framework for Healthy Ageing can be applied to the trajectories of decline discussed by Murray et al to explain length of stay (Murray et al., 2017; World Health Organization, 2015). To further test this theory, further research is needed to map the trajectories of LTCF residents from admission to death, within the context of intrinsic capacity and their environmental resources, such as formal and informal carer involvement. Longitudinal research, both quantitative and qualitative, which follows older adults from living in the community through to LTCF admission and death could further develop and strengthen this theory. There is also potential for comparative research between those who remain in the community and those who are admitted to an LTCF to further understand barriers and facilitators to dying at home, if appropriate.

In addition, further research is needed to identify key environmental resources prior to admission that can be modified to delay or negate LTCF admission and allow ageing in place, where this is appropriate to the needs of the older adult. Particular attention is needed to develop and test the efficacy of interventions focused on supporting carers, especially of those with dementia, to determine the elements of environmental resources that could be adapted to allow ageing in place (Etters et al., 2008). Further research is required on the experiences of carers, both informal and formal, who are acting as environmental resources in allowing an older adult to remain living in their home.

The findings of this thesis support the need for joined up care prior to and post LTCF admission, especially for shorter stay residents. This could be through involvement and communication between carers, both formal and informal, and LTCF staff to ensure continuity of care and facilitate the development of relationships. For example, domiciliary care workers may view their role as delaying or negating the need for LTCF admission by facilitating independence, however there is relatively little research on this workforce or how their knowledge of and relationship with a resident could be utilised (Moore et al., 2014). The area would benefit from research on how a joined-up approach to palliative care can be provided to older adults as they move between long term care settings.

Recommendations to improve research practice and methods

A key hurdle to overcome is the lack of a standardised, working definition of an LTCF that can be applied internationally, across research and policy contexts. At present, neither the WHO or the United Nations have adopted an LTCF definition, which makes identifying comparable settings and services providing similar levels of care to older adults problematic, especially in resource poor countries. Any of the definitions discussed in this thesis would allow for research that is inclusive of all LTCFs within a country without reducing the variation in the organisation, services provided and funding of LTCFs. Consistency in the terminology used to define LTCFs would also allow easier identification of relevant publications; a dedicated, standardised MeSH term for LTCFs would go some way to achieving this.

In addition, further reporting of the context within which LTCFs operate would support greater generalisability of studies conducted in this area. Application of a typology of LTCFs could be standardised and applied if studies reported a full description of the characteristics of and services provided by a LTCF, such as that offered by Froggatt et al would improve the generalisability of the findings to other contexts, especially between countries (Froggatt et al., 2016). A strength of the data collected in the PACE study was the inclusion of facility characteristics, the resident populations of which varied considerably, as shown in the comparisons of LTCFs with and without nursing care provision. Discussion of the wider long-term care system within which LTCFs operate would facilitate an understanding of wider influences on how older adults are using such facilities, including perquisites to admission, funding care and the availability of services within the community.

In order for epidemiological longitudinal research on older LTCF residents to be improved, there is an urgent need for routinely collected, accessible data on all LTCFs and their residents at a national level, to allow a representative sample from which resident length of stay can be explored. At present, most longitudinal data that is collected on older adults either censors' potential residents on admission or exclude those who reside in an LTCF at baseline (Collingridge Moore and Hanratty, 2013). An inclusive approach will provide longitudinal data following community dwelling older adults through LTCF admission to death, allowing a full understanding of the trajectories of older adults admitted to and residing in LTCFs to be developed. In particular, data on environmental resources prior to admission, such as carer involvement, would be captured. In addition, the limitations of this thesis have reinforced the need for further development of instruments to measure both resident experiences of palliative care in LTCFs and how LTCF staff measure their knowledge of palliative care (Albers et al., 2012; Iida et al., 2020; Parker and Hodgkinson, 2011).

In addition to recommendations for empirical data in the area, further work is needed to improve the reporting of existing research on LTCFs and their residents. Systematic reviews of observational studies in LTCFs would benefit from the development and application of a validated, replicable quality assessment tool that appropriate for studies conducted in settings where deaths are common. The assessment tool specifically developed for the systematic review conducted in chapter three used a modified version of a tool developed by Luppa et al to allow for comparability between the reviews, however currently no available quality assessment tool would otherwise have been appropriate (Luppa et al., 2010). Ideally, an assessment tool developed for studies conducted in LTCFs would include items on whether the study sample is nationally or regionally representative of the LTCF population of the country, a description of facility and resident characteristics and reporting of loss to follow up that accurately accounts for the relatively high proportion of deaths compared to other settings.

As well as epidemiological research within the LTCF population, the field would also benefit from the application of a qualitative approach to data collection and analysis to enhance our understanding of why the factors identified as associated with variation in length of stay exist.

In particular, a constructivist approach could explore the perspectives of residents, families and LTCF staff to uncover why longer stay residents appear to experience better indicators of palliative care than longer stay residents. Such research could contribute significantly to the understanding the findings of chapter five, specifically how palliative care in LTCFs can be tailored to residents with shorter and longer lengths of stay, and the reasons underlying variation between the two subgroups. Exploring this trend from the perspectives of LTCF staff could also inform the development of palliative care interventions and ensure that intended outcomes are achieved in all residents, regardless of length of stay.

Further research is required to understand how palliative care interventions can be successfully implemented in LTCFs. This thesis has identified facilitators and barriers to implementing such interventions; however, the specific elements that make these interventions successful are neither clear nor defined. Studies that focus specifically on the extent to which different implementation strategy contribute to an interventions success are urgently needed.

Within the field of implementation, there are also key areas that require further investigation. Firstly, the role of implementation needs refocusing from being supplementary to the intervention to being viewed in conjunction to the intervention, an equally important component to achieving the intended aims. From the offset, implementation should be incorporated and monitored throughout the intervention. The majority of data reported on barriers and facilitators to implementation were reported within the discussion of studies, and it likely that further barriers were not reported. A systematic, transparent approach to reporting implementation, such as that encouraged by the TIDIER checklist, could provide a wealth of data in this area and inform the development of future studies (Hoffmann et al., 2014).

In addition, the majority of palliative care interventions included in the scoping review were supported in their organisation and delivery by research teams external to the facility, it is unclear how LTCFs can implement interventions successfully without this support. Given this context, the extent to which the barriers identified are reflective of challenges to research rather than implementation are unclear, however the research area runs the risk of underrepresenting LTCFs who are unwilling to take part in research studies. Further research is needed to understand why some facilities are more responsive than others are, and how both recruitment and implementation strategies can be developed to ensure all LTCFs benefit from palliative care interventions. This also applies to LTCFs who continue to adopt behaviour changes once the intervention is no longer directly being delivered, and the strategies that facilitate long term embedding of the behaviours the interventions aimed to change. Again, qualitative methodologies could also be applied to explore the perspectives of LTCF staff on the facilitators and barriers to implementation, and how these may vary between different staff roles and LTCF contexts.

Recommendations for clinical practice

The focus of this thesis was on exploring the association between length of stay and palliative care within the LTCF population, by exploring variation in the characteristics of residents. In doing so, it has developed a theory that can be applied to older adults to identify the potential length of stay post admission. Further to this, the two subgroups of shorter and longer stay residents identified in this thesis require two very different approaches to palliative care.

The key recommendation for clinical practice from this thesis is that providing good palliative care to LTCFs residents cannot take a uniform approach. Using the theoretical framework of deferred admission, older men with partners could be prioritised for an ACP discussion relatively soon after admission, on the basis that they are more likely to have shorter lengths of stay. Alternatively, older, partnerless women may benefit from trajectory mapping, to allow staff to identify the onset of end of life and subsequently plan and prepare for death. It is likely that both groups would benefit from ACP discussions and trajectory mapping, however the extent to which they should be prioritised may differ.

The thesis has discussed the transition effect, the negative impact of transitioning from one care setting to an LTCF, as a possible explanation for poorer indicators of palliative care in shorter stay residents. It raises the question of whether providing palliative care for short stay residents in LTCFs cannot be achieved in such a short time frame without discussion and preparation prior to admission. In doing so, responsibility for initiating palliative care is removed from LTCF staff, who may not have the time or capacity to establish a relationship with the resident or may lack the knowledge or experience to engaging in such a conversation. Adopting a multidisciplinary approach to resident's care, such as achieved through multi-disciplinary team meetings, would potentially allow healthcare professionals involved in the resident's care in the community to be seamlessly integrated with care in the facility. In addition, the resident's relationships with carers, both formal and informal, who provided care in the community prior to admission, could be utilised.

The strategies identified in the framework of implementation of palliative care interventions could also be applied to improving clinical practice. In particular, efforts to reduce staff turnover, consistency in contact between staff and residents and the involvement of relatives, where possible, could improve palliative care, especially among shorter stay residents. This thesis has also highlighted the role of LTCF managers in developing a culture of palliative care within the facility, and the need for further support to achieve this.

The experience of shorter stay residents raises the question of whether LTCFs are appropriate settings of death for older adults who have not received ongoing care in the facility. This thesis found that longer lengths of stay are associated with better indicators of palliative care, however it is unclear whether the relatively poorer palliative care experienced by shorter stay residents is still of a higher quality than that available in the community. It is possible that improvements in the availability of appropriate palliative care in the home could avoid admissions that result in shorter stays (Bone et al., 2016; Shepperd et al, 2016). Further work is required to determine the necessity of admissions for shorter stay residents and how these could potentially be avoided

Finally, further work is needed to continue to develop a set of indicators of palliative care in LTCFs, as has been seen in older adults with dementia (Amador et al., 2019; Van der Steen et al., 2014; van Riet Paap et al., 2014). As stated, LTCFs have only recently been included in the Atlas of Palliative Care in Europe, using seven indicators of palliative care in LTCFs developed specifically for the Atlas. Such indicators should go beyond adapting measures used for older adults in the community, and be applicable to LTCF residents, relatives and staff.

Recommendations for policy

The introduction to this thesis highlighted that while the WHO has recognised that there is a range of functional abilities in the older adult population, and has prepared policies to accommodate this, the role of LTCFs is largely absent from this narrative. This is despite a recognition that within the paradigm of healthy ageing and its focus on ageing in place, settings are needed to provide long-term care for care-dependant older adults unable to remain in the community. This thesis argues that the current model of healthy ageing may be too simplistic and does not adequately account for the trajectories of older adults admitted to LTCFs or their needs.

A first step to ensuring that older adults in LTCF are recognised as a heterogeneous population, with health and care needs as varied and complex as those in residing in the community is the inclusion of residents within national and international policies on ageing. In any approach to population ageing, a spectrum of long-term care settings are needed, including care in the community, sheltered housing and residential care facilities as required, to provide care for older adults at any stage in their trajectory.

The extent to which policy initiatives aimed at delaying or avoiding LTCF admission are achievable is an ongoing debate; however, as shown in the theoretical framework of deferred admission, LTCF use is largely dependent on a combination of an older adult's intrinsic capacity and environmental resources. Therefore, interventions aimed at maintaining such resources, either through minimising carer burden, adaptions within the home or maintaining social networks, may be more effective at reducing admissions than those targeting deteriorations in intrinsic capacity.

The delaying of LTCF admission until living in the community is exhausted is likely to be perpetuated by a negative portrayal of LTCFs in the media and the widespread belief that LTCFs residents experience a poor quality of life. Although it has been established that the majority of older adults would prefer to die at home, the extent to which this preference is influenced by the perception of LTCFs is unclear. Further work is needed to reduce the negative connotations associated with residing in a LTCF admission, a mentality that can lead to older adult's sacrificing quality of life to remain in their own homes even when their care needs are no longer being met.

Wider recognition is needed for the role of LTCF and their staff in providing care for older adults. This thesis has shown that LTCFs are negotiating two roles;

simultaneously providing end of life care relatively soon after admission for shorter stay residents in addition to providing a residential home for long stay residents, who often have cognitive impairments and may survive for many years post-admission. With this in mind, any policy decisions regarding the future of LTCFs, in terms of their remit, funding and organisation of care should be appropriate to all residents, taking into account the variation between them.

In terms of improving the implementation of palliative care provided to LTCF residents, a number of the barriers identified in chapter six require change much higher than at an organisational level. High staff turnover, low staff pay and a lack of education or training on palliative care would be difficult to change at an organisational level or on a national basis, but remain key barriers to providing appropriate care to residents. Identification of the barriers to the recruitment and retention of LTCF staff is ongoing, however further work is needed to develop and tests strategies address these challenges (Devi et al., 2020).

Finally, the promotion of palliative care at a national, an international level, would go some way to combatting this, as discussed in the European Association for Palliative Care White Paper on Palliative Care Implementation in Long-Term Care Facilities (Froggatt et al., 2020). Ideally, this would include the establishment of a set of minimum competencies for palliative care in LTCF staff and appropriate regulatory framework and guidance on how palliative care can be provided in such settings.

Concluding remarks

LTCFs are becoming a common place of end of life and death for a growing number of care-dependant older adults. Prior to this thesis, the factors associated with the likelihood of LTCF admission had been explored, but less was known about the factors associated with subsequent length of stay in a facility and how these varied between longer and shorter stay residents. In addition, the association between length of stay and indicators of palliative care was unclear, as was how organisational interventions could be successfully implemented in such settings was unknown.

This thesis has shown that the LTCF population is varied, characterised by shorter and longer stay residents, each with their own characteristics and experiences of palliative care. It has developed the theoretical framework of deferred admission, based within the WHO Public Health Framework for Healthy Ageing, to explain how intrinsic capacity and environmental resources interact to delay, negate or hasten LTCF admission and subsequent length of stay. In addition, it found that longer stay residents were more likely to experience better indicators of palliative care, and identified how the implementation of palliative care interventions in LTCFs could be improved through establishing conditions to introduce the intervention, embedding the intervention within day-to-day practice and sustaining ongoing change.

Population ageing is a global achievement; however, it will bring substantial challenges in how older adults can be cared for. The current strategy to managing this challenge is based on the promotion of healthy ageing in place; however, any approach to managing this challenge must include all older adults, including those unable to reside in the community. LTCFs occupy a unique role in the long-term care spectrum; however, these settings and their residents are relatively excluded from the current discourse on ageing. As the likely impact of population ageing can be anticipated, characterised by a predominantly older, partnerless women LTCF population, with a high prevalence of dementia, this knowledge can be used to develop appropriate services and settings to provide care for future ageing populations.

Glossary

Ageing in place – an approach to ageing based on an older adult remaining in his or her own home or community until death.

Ageing population – a population characterised by a larger proportion of older adults compared to younger adults, as a result of the combined effect of declining fertility rates and longer life expectancy.

Care-dependant – referring to an older adult with significant ongoing losses in intrinsic capacity, requiring a significant level of care.

Compression of morbidity - a trajectory of old age characterised by long periods of relatively good health and a postponed onset of poorer health, experienced for a relatively short time before death (Chatterji et al., 2015b; Fries, 2003).

End of life care - care provided one to two years prior to death where the life-limiting nature of the patient’s illness or condition becomes apparent to the patient, their family and health professionals involved in providing care (Radbruch and Payne, 2009). Internationally, the term end of life is used to describe a much shorter period before death, usually the last weeks, days or hours of life. In this thesis, the term end of life care is used interchangeably with palliative care.

Expansion of morbidity - a trajectory of old age characterised by disability and the effects of multiple chronic conditions (Rechel B et al., 2009; Salomon et al., 2012).

Functional ability - the combined influence of an individual’s intrinsic capacity and their interactions with their environment; resulting in the ability to live a good quality of life, as judged by the individual.

Healthy ageing - the "process of developing and maintaining the functional ability that enables wellbeing in older age". (World Health Organisation, 2019a).

Intrinsic capacity - the sum of an individual's mental and physical ability.

Long-term care facility - a collective institutional setting where care is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period. The care provided includes on site provision of personal assistance with activities of daily living; nursing and medical care may be provided on-site or by nursing and medical professionals working from an organisation external to the setting (Froggatt and Reitinger, 2013).

Multi-morbidity - the experience of two or more chronic conditions concurrently.

Older adult - an adult aged 65 years and older.

Oldest old - older adults aged over 85 years.

Palliative care - the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual, that improves the quality of life of patients and their families facing the problem associated with life-threatening illness (World Health Organization, 2018). In this thesis, the term palliative care is used interchangeably with end of life care.

Theoretical framework of deferred admission – the theory that two forces can explain length of stay post LTCF admission, the trajectory of decline in an older adult's intrinsic capacity, and the availability of resources in the environment prior to admission that either hasten, delay or negate altogether LTCF admission by compensating for losses in intrinsic capacity and maintaining the level functional ability required to age in place.

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Appendices

Appendix A: Statements of Authorship

Statement of Authorship

Title	Factors associated with length of stay in care homes: a systematic review of international literature
Publication status	Published
Journal	BMC Systematic Reviews
Publication details	Collingridge Moore, D., Keegan, T. J., Dunleavy, L. & Froggatt, K. (2019) Factors associated with length of stay in care homes: a systematic review of international literature. Syst Rev, 8(1), 56.

By signing the Statement of Authorship, each co- author certifies that

a) Danni Collingridge Moore is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that

b) Permission is granted for the publication to be included in the candidate's thesis.

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Title	Length of stay in long-term care facilities: a comparison of residents in six European countries. Results of the PACE cross-sectional study.
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Appendix B: Supplementary Material for Paper 1

Additional file 1: Criteria for assessing methodological quality of studies.

Item	Question	Notes
1	Study sample is nationally or regionally representative of the care home population of the country.	**AWARD 1 IF:** ▪ More than one LTCF which is representative of the area. **AWARD 0 IF:** ▪ There is one site/LTCF OR ▪ There are a number of sites with the same characteristics i.e. ran by social services, Medicaid
2	Sample inclusion and/or exclusion criteria are formulated for care homes: Facility types (i.e. nursing home and/or other facilities) is reported.	**AWARD 1 IF:** ▪ There is discussion of the type of care home(s) and the services offered. **AWARD 0 IF:** ▪ There is no discussion of the care home facility.
3	Sample inclusion and/or exclusion criteria are formulated for care home residents.	**AWARD 1 IF:** ▪ There is discussion of the resident age, or admission status or diagnoses. **AWARD 0 IF:** ▪ There is little or no discussion of resident inclusion criteria
4	Information on participant's lost-to-follow-up is reported.	**AWARD 1 IF:** ▪ The number included in the baseline and final sample is the same OR ▪ The dropouts are discussed. **AWARD 0 IF:** ▪ The numbers differ without explanation.
5	The process of data collection is described (e.g. interview or self-report).	**AWARD 1 IF:** ▪ The characteristics of the dataset or the process of data collection is discussed **AWARD 0 IF:** ▪ There is no discussion of how the data was collected

6	Training and quality control methods for interviewers' technique are applied.	**AWARD 1 IF:** ▪ The validity of the dataset is discussed, or the training/ experience of the data collectors is discussed. **AWARD 0 IF:** ▪ There is no discussion of training/ data quality <u>OR</u> ▪ The role of the data collector is discussed i.e. geriatrician, but no training <u>OR</u> ▪ The data collector is described as trained or experienced, with no further information.
7	Definition of the outcome criteria of death is provided.	**AWARD 1 IF:** ▪ The follow up period is discussed <u>AND</u> there is information on how death is notified, i.e. through death certificates or on a dataset. **AWARD 0 IF:** ▪ Only one or neither of these are discussed.
8	Descriptive data are provided on survival (e.g. number of individuals died/survived time to death).	**AWARD 1 IF:** ▪ The study reports the number of residents who died during follow up. **AWARD 0 IF:** ▪ There is no discussion of the overall number who survived.
9	Characteristics of study participants (socio-demographic, clinical, social) are given.	**AWARD 1 IF:** ▪ The characteristics of the dataset at baseline are provided, and discuss at least two of the three: socio-demographic, clinical, social characteristics. **AWARD 0 IF:** ▪ None are discussed, or the discussion is brief.
10	For each variable of interest, sources of data and details of methods of assessment are given.	**AWARD 1 IF:** ▪ The measurement and collection of all the variables included in the study is discussed. **AWARD 0 IF:** ▪ There is no or little discussion of the variables and how they are measured/ collected.

11	Reliability and/or validity of study instruments is reported.	**AWARD 1 IF:** ▪ The reliability and/or validity of at least one measure used is reported. **AWARD 0 IF:** ▪ None are reported.
12	Detailed description of statistical analyses is given.	**AWARD 1 IF:** ▪ There is a discussion of the statistical measures used. **AWARD 0 IF:** ▪ The discussion is absent or brief.
13	Information on non-significant predictor variables is reported.	**AWARD 1 IF:** ▪ There non-significant results are reported either at univariate or multivariate analysis. **AWARD 0 IF:** ▪ No significance is reported in the paper
14	Precision of estimates is given (e.g. 95% confidence interval).	**AWARD 1 IF:** ▪ A 95% confidence interval or equivalent is provided in the data extracted. **AWARD 0 IF:** ▪ No 95% confidence interval or equivalent is provided.

Current version modified from original developed by Luppa M, Luck T, Weyerer S, König H-H, Brähler E, Riedel-Heller S. Prediction of institutionalization in the elderly. A systematic review. Age and Ageing. 2010;39(1):31-8

Additional file 2: Factors associated with length of stay before death in care home residents in all studies and split between high, moderate and low quality studies.

Predictor	All							High					Medium					Low				
	Total	+		NS		-		Total		+	NS	-	Total		+	NS	-	Total		+	NS	-
	N	N	%	N	%	N	%	N	%	N	N	N	N	%	N	N	N	N	%	N	N	N
Admission source - care home /assisted living	10	1	10	7	70	2	20	2	20	0	2	0	8	80	1	5	2	0	0	0	0	0
Admission source - home	5	0	0	3	60	2	40	2	40	0	2	0	3	60	0	1	2	0	0	0	0	0
Admission source - hospital	14	6	43	6	43	2	14	3	21	2	1	0	11	79	4	5	2	0	0	0	0	0
Age	53	35	66	18	34	0	0	14	26	8	6	0	37	70	25	12	0	2	4	2	0	0
Alcohol	4	0	0	3	75	1	25	3	75	0	2	1	1	25	0	1	0	0	0	0	0	0
Anaemia	8	1	13	7	88	0	0	4	50	1	3	0	4	50	0	4	0	0	0	0	0	0
Anxiety	3	0	0	3	100	0	0	0	0	0	0	0	3	100	0	3	0	0	0	0	0	0
Arthritis	8	0	0	8	100	0	0	5	63	0	5	0	3	38	0	3	0	0	0	0	0	0
Behaviour problems	36	3	8	33	92	0	0	8	22	1	7	0	28	78	2	26	0	0	0	0	0	0
Biochemical indicators*	97	8	8	84	87	5	5	4	4	1	3	0	93	96	7	81	5	0	0	0	0	0
Blood pressure and hypertension	19	1	5	18	95	0	0	7	37	0	7	0	12	63	1	11	0	0	0	0	0	0
Cancer	27	16	59	11	41	0	0	10	37	5	5	0	17	63	11	6	0	0	0	0	0	0
Cardiovascular disorders*	78	21	27	54	69	3	4	29	37	6	22	1	49	63	15	32	2	0	0	0	0	0
Care home characteristics - nursing	10	8	80	2	20	0	0	4	40	2	2	0	6	60	6	0	0	0	0	0	0	0
Care home characteristics - ownership	7	2	29	2	29	3	43	0	0	0	0	0	7	100	2	2	3	0	0	0	0	0
Care home characteristics - size	3	0	0	3	100	0	0	0	0	0	0	0	3	100	0	3	0	0	0	0	0	0
Clinical intervention - aspiration	5	0	0	5	100	0	0	2	40	0	2	0	3	60	0	3	0	0	0	0	0	0
Clinical intervention - oxygen therapy	4	4	100	0	0	0	0	3	75	3	0	0	1	25	1	0	0	0	0	0	0	0
Cognitive function*	59	14	24	41	69	4	7	10	17	2	8	0	49	83	12	33	4	0	0	0	0	0
Communication problems	11	2	18	9	82	0	0	3	27	0	3	0	8	73	2	6	0	0	0	0	0	0
Contact with primary care - number of contacts	3	2	67	1	33	0	0	2	67	2	0	0	1	33	0	1	0	0	0	0	0	0
Dehydration	8	1	13	7	88	0	0	4	50	1	3	0	4	50	0	4	0	0	0	0	0	0
Dementia or Alzheimer’s Disease	32	3	9	27	84	2	6	10	31	1	8	1	21	66	2	18	1	1	3	0	1	0
Depression	19	5	26	14	74	0	0	4	21	1	3	0	15	79	4	11	0	0	0	0	0	0
Diabetes	26	10	38	16	62	0	0	10	38	2	8	0	16	62	8	8	0	0	0	0	0	0
Education - low	9	1	11	7	78	1	11	3	33	1	1	1	6	67	0	6	0	0	0	0	0	0
Ethnicity - white	15	0	0	11	73	4	27	11	73	0	9	2	4	27	0	2	2	0	0	0	0	0
Falls and fractures	30	2	7	23	77	5	17	13	43	0	11	2	17	57	2	12	3	0	0	0	0	0
Feeding - appetite	11	5	45	6	55	0	0	2	18	2	0	0	9	82	3	6	0	0	0	0	0	0
Feeding - feeding tube, help with feeding or diet	21	6	29	13	62	2	10	7	33	2	5	0	14	67	4	8	2	0	0	0	0	0
Feeding - swallowing problems	8	2	25	6	75	0	0	1	13	0	1	0	7	88	2	5	0	0	0	0	0	0
Fever	4	0	0	4	100	0	0	1	25	0	1	0	3	75	0	3	0	0	0	0	0	0
Gastrointestinal disorder	4	0	0	3	75	1	25	0	0	0	0	0	4	100	0	3	1	0	0	0	0	0
Gender - being female	46	0	0	21	46	25	54	14	30	0	9	5	30	65	0	11	19	2	4	0	1	1

General health	21	12	57	9	43	0	0	7	33	5	2	0	14	67	7	7	0	0	0	0	0	0
Genitourinary problems (including UTIs)	11	2	18	9	82	0	0	6	55	1	5	0	5	45	1	4	0	0	0	0	0	0
Hallucinations, delusions, wandering or delirium	17	5	29	12	71	0	0	3	18	1	2	0	14	82	4	10	0	0	0	0	0	0
Hearing impairment	17	2	12	14	82	1	6	3	18	1	1	1	14	82	1	13	0	0	0	0	0	0
Hospitalisation	16	3	19	12	75	1	6	11	69	2	9	0	5	31	1	3	1	0	0	0	0	0
Incontinence or catheter use	34	13	38	21	62	0	0	8	24	3	5	0	26	76	10	16	0	0	0	0	0	0
Infections	18	4	22	14	78	0	0	0	0	0	0	0	12	67	2	10	0	6	33	2	4	0
Involvement - activity	11	0	0	10	91	1	9	0	0	0	0	0	11	100	0	10	1	0	0	0	0	0
Involvement - children and visits	8	2	25	6	75	0	0	2	25	0	2	0	6	75	2	4	0	0	0	0	0	0
Involvement - social engagement	6	0	0	4	67	2	33	1	17	0	0	1	5	83	0	4	1	0	0	0	0	0
Kidney or liver disorder	13	3	23	10	77	0	0	7	54	2	5	0	6	46	1	5	0	0	0	0	0	0
Length of stay in care home**	7	1	14	6	86	0	0	2	29	1	1	0	5	71	0	5	0	0	0	0	0	0
Level of care	6	2	33	3	50	1	17	3	50	1	2	0	3	50	1	1	1	0	0	0	0	0
Marital status - being married	15	2	13	12	80	1	7	8	53	2	5	1	7	47	0	7	0	0	0	0	0	0
Marital status - not married (other)	7	0	0	4	57	3	43	4	57	0	3	1	3	43	0	1	2	0	0	0	0	0
Medicine use	45	3	7	40	89	2	4	15	33	2	13	0	30	67	1	27	2	0	0	0	0	0
Mobility	10	5	50	5	50	0	0	4	40	2	2	0	6	60	3	3	0	0	0	0	0	0
Multimorbidity or comorbidity	12	3	25	9	75	0	0	4	33	0	4	0	8	67	3	5	0	0	0	0	0	0
Musculoskeletal problem	3	0	0	3	100	0	0	0	0	0	0	0	3	100	0	3	0	0	0	0	0	0
Neurological disorders	14	1	7	13	93	0	0	6	43	0	6	0	8	57	1	7	0	0	0	0	0	0
Nutrition - low BMI or malnutrition	31	16	52	14	45	1	3	5	16	5	0	0	26	84	11	14	1	0	0	0	0	0
Pain	13	1	8	12	92	0	0	5	38	0	5	0	8	62	1	7	0	0	0	0	0	0
Parkinson’s disease	12	3	25	8	67	1	8	6	50	2	4	0	6	50	1	4	1	0	0	0	0	0
Physical functioning - poor*	95	56	59	39	41	0	0	28	29	13	15	0	66	69	42	24	0	1	1	1	0	0
Pressure ulcers	15	9	60	6	40	0	0	5	33	4	1	0	10	67	5	5	0	0	0	0	0	0
Previous care home use	6	2	33	3	50	1	17	6	100	2	3	1	0	0	0	0	0	0	0	0	0	0
Respiratory disorders/COPD	31	15	48	16	52	0	0	9	29	4	5	0	22	71	11	11	0	0	0	0	0	0
Restraint use	6	1	17	5	83	0	0	2	33	1	1	0	4	67	0	4	0	0	0	0	0	0
SES Facility - area deprivation	10	7	70	3	30	0	0	1	10	0	1	0	9	90	7	2	0	0	0	0	0	0
SES Resident - home ownership	5	0	0	3	60	2	40	0	0	0	0	0	5	100	0	3	2	0	0	0	0	0
SES Resident - payment support	8	3	38	5	63	0	0	3	38	0	3	0	5	63	3	2	0	0	0	0	0	0
Shortness of breath	8	7	88	1	13	0	0	3	38	3	0	0	5	63	4	1	0	0	0	0	0	0
Sleep - excess	13	2	15	11	85	0	0	2	15	0	2	0	11	85	2	9	0	0	0	0	0	0
Smoking	6	1	17	5	83	0	0	1	17	0	1	0	5	83	1	4	0	0	0	0	0	0
Stroke	20	3	15	16	80	1	5	6	30	1	5	0	13	65	2	11	0	1	5	0	0	1
Use of additional services	16	0	0	16	100	0	0	13	81	0	13	0	3	19	0	3	0	0	0	0	0	0
Vaccinations	6	0	0	3	50	3	50	2	33	0	1	1	4	67	0	2	2	0	0	0	0	0
Vision impairment	15	3	20	12	80	0	0	3	20	1	2	0	12	80	2	10	0	0	0	0	0	0

Notes: (n) Number of studies which included the factors; (+) positive, statistically significant associations i.e. related to shorter stay; (-) negative statistically significant association i.e. related to longer stay; (ns) non-significant associations

*In cases where the number of results for a group of factors exceeds the number of cohorts (57), some studies collected data from multiple measures.
** Length of stay in care home before study baseline

BMI Body mass index
COPD Chronic obstructive pulmonary disease
SES Socioeconomic status

Additional file 3: Factors associated with length of stay before death in care home residents in all studies and split between high, moderate and low quality studies-limited to one year follow up.

Predictor	All							High					Medium					Low				
	Total	+		NS		-		Total		+	NS	-	Total		+	NS	-	Total		+	NS	-
	N	N	%	N	%	N	%	N	%	N	N	N	N	%	N	N	N	N	%	N	N	N
Admission source - care home /assisted living	4	0	0	4	100	0	0	0	0	0	0	0	4	100	0	4	0	0	0	0	0	0
Admission source - home	3	0	0	2	67	1	33	2	67	0	2	0	1	33	0	0	1	0	0	0	0	0
Admission source - hospital	7	2	29	4	57	1	14	2	29	1	1	0	5	71	1	3	1	0	0	0	0	0
Age	25	14	56	11	44	0	0	11	44	6	5	0	14	56	8	6	0	0	0	0	0	0
Alcohol	3	0	0	2	67	1	33	3	100	0	2	1	0	0	0	0	0	0	0	0	0	0
Anaemia	6	1	17	5	83	0	0	4	67	1	3	0	2	33	0	2	0	0	0	0	0	0
Arthritis	6	0	0	6	100	0	0	4	67	0	4	0	2	33	0	2	0	0	0	0	0	0
Behaviour problems	21	0	0	21	100	0	0	5	24	0	5	0	16	76	0	16	0	0	0	0	0	0
Biochemical indicators*	42	6	14	36	86	0	0	4	10	1	3	0	38	90	5	33	0	0	0	0	0	0
Blood pressure and hypertension	10	0	0	10	100	0	0	6	60	0	6	0	4	40	0	4	0	0	0	0	0	0
Cancer	18	10	56	8	44	0	0	9	50	5	4	0	9	50	5	4	0	0	0	0	0	0
Cardiovascular disorders*	49	12	24	35	71	2	4	27	55	5	22	0	22	45	7	13	2	0	0	0	0	0
Care home characteristics - nursing	4	2	50	2	50	0	0	4	100	2	2	0	0	0	0	0	0	0	0	0	0	0
Care home characteristics - ownership	4	1	25	1	25	2	50	0	0	0	0	0	4	100	1	1	2	0	0	0	0	0
Clinical intervention - aspiration	3	0	0	3	100	0	0	1	33	0	1	0	2	67	0	2	0	0	0	0	0	0
Clinical intervention - oxygen therapy	4	4	100	0	0	0	0	3	75	3	0	0	1	25	1	0	0	0	0	0	0	0
Cognitive function*	37	10	27	26	70	1	3	6	16	1	5	0	31	84	9	21	1	0	0	0	0	0
Communication problems	10	1	10	9	90	0	0	3	30	0	3	0	7	70	1	6	0	0	0	0	0	0
Dehydration	8	1	13	7	88	0	0	4	50	1	3	0	4	50	0	4	0	0	0	0	0	0
Dementia or Alzheimer’s Disease	14	1	7	11	79	2	14	9	64	1	7	1	5	36	0	4	1	0	0	0	0	0
Depression	4	2	50	2	50	0	0	1	25	0	1	0	3	75	2	1	0	0	0	0	0	0
Diabetes	14	2	14	12	86	0	0	7	50	0	7	0	7	50	2	5	0	0	0	0	0	0
Education - low	4	1	25	2	50	1	25	2	50	1	0	1	2	50	0	2	0	0	0	0	0	0
Ethnicity - white	9	0	0	9	100	0	0	7	78	0	7	0	2	22	0	2	0	0	0	0	0	0
Falls and fractures	20	1	5	15	75	4	20	10	50	0	9	1	10	50	1	6	3	0	0	0	0	0
Feeding - appetite	9	5	56	4	44	0	0	2	22	2	0	0	7	78	3	4	0	0	0	0	0	0
Feeding - feeding tube, help with feeding or diet	18	6	33	11	61	1	6	6	33	2	4	0	12	67	4	7	1	0	0	0	0	0

Feeding - swallowing problems	8	2	25	6	75	0	0	1	13	0	1	0	7	88	2	5	0	0	0	0	0	0
Fever	4	0	0	4	100	0	0	1	25	0	1	0	3	75	0	3	0	0	0	0	0	0
Gender - being female	22	0	0	11	50	11	50	11	50	0	8	3	11	50	0	3	8	0	0	0	0	0
General health	16	9	56	7	44	0	0	5	31	3	2	0	11	69	6	5	0	0	0	0	0	0
Genitourinary problems (including UTIs)	8	1	13	7	88	0	0	6	75	1	5	0	2	25	0	2	0	0	0	0	0	0
Hallucinations, delusions, wandering or delirium	11	4	36	7	64	0	0	1	9	0	1	0	10	91	4	6	0	0	0	0	0	0
Hearing impairment	7	0	0	7	100	0	0	0	0	0	0	0	7	100	0	7	0	0	0	0	0	0
Hospitalisation	11	2	18	9	82	0	0	11	100	2	9	0	0	0	0	0	0	0	0	0	0	0
Incontinence or catheter use	18	8	44	10	56	0	0	5	28	2	3	0	13	72	6	7	0	0	0	0	0	0
Infections	15	2	13	13	87	0	0	12	80	2	10	0	3	20	0	3	0	0	0	0	0	0
Involvement - activity	7	0	0	6	86	1	14	0	0	0	0	0	7	100	0	6	1	0	0	0	0	0
Involvement - children and visits	3	0	0	3	100	0	0	2	67	0	2	0	1	33	0	1	0	0	0	0	0	0
Kidney or liver disorder	9	3	33	6	67	0	0	7	78	2	5	0	2	22	1	1	0	0	0	0	0	0
Length of stay in care home**	4	1	25	3	75	0	0	2	50	1	1	0	2	50	0	2	0	0	0	0	0	0
Level of care	5	2	40	3	60	0	0	3	60	1	2	0	2	40	1	1	0	0	0	0	0	0
Marital status - being married	8	2	25	6	75	0	0	6	75	2	4	0	2	25	0	2	0	0	0	0	0	0
Medicine use *	32	3	9	27	84	2	6	15	47	2	13	0	17	53	1	14	2	0	0	0	0	0
Mobility	5	2	40	3	60	0	0	2	40	1	1	0	3	60	1	2	0	0	0	0	0	0
Multimorbidity or comorbidity	3	0	0	3	100	0	0	3	100	0	3	0	0	0	0	0	0	0	0	0	0	0
Neurological disorders	11	0	0	11	100	0	0	6	55	0	6	0	5	45	0	5	0	0	0	0	0	0
Nutrition - low BMI or malnutrition	16	10	63	5	31	1	6	3	19	3	0	0	13	81	7	5	1	0	0	0	0	0
Pain	7	1	14	6	86	0	0	2	29	0	2	0	5	71	1	4	0	0	0	0	0	0
Parkinson’s disease	7	1	14	5	71	1	14	4	57	1	3	0	3	43	0	2	1	0	0	0	0	0
Physical functioning - poor*	54	35	65	19	35	0	0	23	43	9	14	0	31	57	26	5	0	0	0	0	0	0
Pressure ulcers	9	4	44	5	56	0	0	2	22	2	0	0	7	78	2	5	0	0	0	0	0	0
Previous care home use	6	2	33	3	50	1	17	6	100	2	3	1	0	0	0	0	0	0	0	0	0	0
Respiratory disorders/COPD	17	7	41	10	59	0	0	7	41	4	3	0	10	59	3	7	0	0	0	0	0	0
Restraint use	4	0	0	4	100	0	0	0	0	0	0	0	4	100	0	4	0	0	0	0	0	0
SES Facility - area deprivation	5	3	60	2	40	0	0	1	20	0	1	0	4	80	3	1	0	0	0	0	0	0
SES Resident - payment support	4	1	25	3	75	0	0	3	75	0	3	0	1	25	1	0	0	0	0	0	0	0
Shortness of breath	6	6	100	0	0	0	0	2	33	2	0	0	4	67	4	0	0	0	0	0	0	0
Sleep - excess	7	2	29	5	71	0	0	2	29	0	2	0	5	71	2	3	0	0	0	0	0	0

Stroke	6	0	0	6	100	0	0	3	50	0	3	0	3	50	0	3	0	0	0	0	0	0
Use of additional services	16	0	0	16	100	0	0	13	81	0	13	0	3	19	0	3	0	0	0	0	0	0
Vaccinations	4	0	0	2	50	2	50	2	50	0	1	1	2	50	0	1	1	0	0	0	0	0
Vision impairment	7	0	0	7	100	0	0	0	0	0	0	0	7	100	0	7	0	0	0	0	0	0

Notes: (n) Number of studies which included the factors; (+) positive, statistically significant associations i.e. related to shorter stay; (-) negative statistically significant association i.e. related to longer stay; (ns) non-significant associations

*In cases where the number of results for a group of factors exceeds the number of cohorts (26), some studies collected data from multiple measures.
** Length of stay in care home before study baseline

BMI Body mass index
COPD Chronic obstructive pulmonary disease
SES Socioeconomic status

Additional file 4: Factors associated with length of stay before death in care home residents.

Author/year Country Study Design QAS*	Sample-baseline/ analysis	Inclusion criteria	Mean age (SD) Gender	Care home type / number	Methodological notes	Average length of stay	Predictors and severity direction	Risk	Risk measure	Sig
Bebbington et al, 2000(1-4) England Prospective follow up study QAS: 10	n=2,629/ n=2,191	Local authority supported residents aged 65 years and older	85 (SD NR) 78% female	Nursing and residential homes, n=NR	Baseline data collection over a three month period in 1995, follow up for six month, eighteen months, thirty months and forty two months – survey data provided by social services staff and care home managers, death registrations through the Office for National Statistics (ONS) Analysis: Cox Proportional Hazard Models	20.4.00% residents died within six months 38.8% residents died within eighteen months 60% residents died within thirty months 72.4% residents died within forty two months	**Death within six months:**			
							Age at admission 65-69 (ref) vs 70-74	0.8862	OR	NS
							Age at admission 65-69 (ref) vs 75-79	1.1668	OR	NS
							Age at admission 65-69 (ref) vs 80-84	1.1906	OR	NS
							Age at admission 65-69 (ref) vs 85+	1.4635	OR	NS
							Barthel Score: 13+ (ref) vs 0-4	4.4328	OR	<.0.01
							Barthel Score: 13+ (ref) vs 5-8	2.0756	OR	<.0.01
							Barthel Score: 13+ (ref) vs 9-12	1.7976	OR	<.0.01
							Gender (male ref)	0.7187	OR	<.0.05
							Household composition: lived alone (ref) vs lived with others	1.0839	OR	NS
							Household tenure: Owner occupied/mortgaged (ref) vs other	0.8913	OR	NS
							Household tenure: Owner occupied/mortgaged (ref) vs privately rented	1.3058	OR	NS
							Household tenure: Owner occupied/mortgaged (ref) vs rented from LA/NT/HA	1.3114	OR	<.0.10
							MDS Cognitive Scale: Intact (ref) vs mild impairment	0.9042	OR	NS
							MDS Cognitive Scale: Intact (ref) vs severe impairment	0.971	OR	NS
							Source of admission: domestic/sheltered household (ref) vs hospital	1.261	OR	<.0.10
							Source of admission: domestic/sheltered household (ref) vs nursing home	0.665	OR	NS
							Source of admission: domestic/sheltered household (ref) vs other	2.7942	OR	<.0.05
							Source of admission: domestic/sheltered household (ref) vs residential care	0.7083	OR	NS
							Death within eighteen months:			
							Age at admission 65-74 (ref) vs 75-84	1.49	RR	<.0.01
							Age at admission 65-74 (ref) vs 85+	1.89	RR	<.0.01
							Area of origin: Shire county (ref) vs London	1.11	RR	NS
							Area of origin: Shire county (ref) vs Metropolitan District	0.96	RR	NS
							Barthel Score: 13+ (ref) vs 0-4	2.23	RR	<.0.01
							Barthel Score: 13+ (ref) vs 5-8	1.44	RR	<.0.01
							Barthel Score: 13+ (ref) vs 9-12	1.47	RR	<.0.01
							Cardiovascular	1.03	RR	NS
							Dementia	0.95	RR	NS
							Depression	1.25	RR	<.0.01
							Gender (male ref)	0.73	RR	<.0.01
							Incontinent (urine or faeces)	0.95	RR	NS
							Initial placement: Local authority home (ref) vs nursing bed	1.32	RR	<.0.01
							Initial placement: Local authority home (ref) vs residential bed in private home	0.92	RR	<.0.01
							Malignancy	2.34	RR	<.0.01
							Respiratory	1.32	RR	<.0.01

							Source of admission: private household (ref) vs care home	0.79	RR	<.0.01
							Source of admission: private household (ref) vs hospital	1.21	RR	<.0.01
							Source of admission: private household (ref) vs other	1.33	RR	<.0.01
							Stroke	0.95	RR	NS
							Death within thirty months:			
							Age at admission 65-74 (ref) vs 75-84	1.33	RR	<.0.01
							Age at admission 65-74 (ref) vs 85+	1.79	RR	<.0.01
							Area of origin: Shire county (ref) vs London	0.94	RR	NS
							Area of origin: Shire county (ref) vs Metropolitan District	0.93	RR	NS
							Barthel Score: 13+ (ref) vs 0-4	2.5	RR	<.0.01
							Barthel Score: 13+ (ref) vs 5-8	1.51	RR	<.0.01
							Barthel Score: 13+ (ref) vs 9-12	1.41	RR	<.0.01
							Cardiovascular	1.09	RR	NS
							Dementia	0.97	RR	NS
							Depression	1.04	RR	NS
							Gender (male ref)	0.74	RR	<.0.01
							Incontinent (urine or faeces)	0.93	RR	NS
							Initial placement: Local authority home (ref) vs nursing bed	1.54	RR	<.0.01
							Initial placement: Local authority home (ref) vs residential bed in private home	1.09	RR	<.0.01
							Malignancy	2.44	RR	<.0.01
							MDS Cognitive Scale: Intact (ref) vs mild impairment	1.14	RR	NS
							MDS Cognitive Scale: Intact (ref) vs severe impairment	1.23	RR	NS
							Respiratory	1.35	RR	<.0.01
							Source of admission: private household (ref) vs care home	0.88	RR	<.0.01
							Source of admission: private household (ref) vs hospital	1.21	RR	<.0.01
							Source of admission: private household (ref) vs other	1.45	RR	<.0.01
							Stroke	0.98	RR	NS
							Death within forty two months:			
							Age at admission 65-74 (ref) vs 75-84	1.42	RR	0.00
							Age at admission 65-74 (ref) vs 85+	1.99	RR	0.00
							Area of origin: Shire county (ref) vs London	0.89	RR	0.08
							Area of origin: Shire county (ref) vs Metropolitan District	0.89	RR	0.08
							Barthel Score: 13+ (ref) vs 0-4	1.89	RR	0.00
							Barthel Score: 13+ (ref) vs 5-8	1.3	RR	0.00
							Barthel Score: 13+ (ref) vs 9-12	1.27	RR	0.00
							Cardiovascular	1.1	RR	0.15
							Dementia	0.96	RR	0.49
							Depression	1.04	RR	0.61
							Gender (male ref)	0.75	RR	0.00
							Incontinent (urine or faeces)	0.93	RR	0.28
							Initial placement: Local authority home (ref) vs nursing bed	1.51	RR	0.00
							Initial placement: Local authority home (ref) vs residential bed in private home	1.16	RR	0.00
							Malignancy	2.34	RR	0.00
							MDS Cognitive Scale: Intact (ref) vs mild impairment	1.15	RR	0.04
							MDS Cognitive Scale: Intact (ref) vs severe impairment	1.25	RR	0.04
							Respiratory	1.4	RR	0

							Source of admission: private household (ref) vs care home	1.01	RR	0.12
							Source of admission: private household (ref) vs hospital	1.13	RR	0.12
							Source of admission: private household (ref) vs other	1.29	RR	0.12
							Stroke	1.02	RR	0.77
Breuer et al, 1998 (5) USA Retrospective cohort study QAS: 8	n=1,157/ n=1,145	Residents who had resided in the nursing home for at least six months.	86.8 (median) 59.7-102.6 (range) 80.3% female	Nursing home, n=1	Baseline data collection 1986 to 1996, follow up for nine years and six months - medical charts reviewed by the research team. Analysis: Cox Proportional Hazard Models	92.3% residents died within nine years and six months	Age	0.031 (0.004)	Coef (SE)	0.0001
							Cardiac impairment	-0.16 (0.027)	Coef (SE)	0.0001
							Endocrine/metabolic impairment	-0.09 (0.027)	Coef (SE)	0.006
							Eye, ear, nose or throat impairment	NR	Coef (SE)	NS
							Kidney impairment	NR	Coef (SE)	NS
							Length of stay	NR	Coef (SE)	NS
							Liver impairment	NR	Coef (SE)	NS
							Lower gastrointestinal impairment	NR	Coef (SE)	NS
							Marital status	NR	Coef (SE)	NS
							Musculoskeletal-integumentary impairment	NR	Coef (SE)	NS
							Neurological impairment	-0.06 (0.026)	Coef (SE)	0.024
							Other genitourinary impairment	NR	Coef (SE)	NS
							Psychiatric impairment - including dementia and depression	NR	Coef (SE)	NS
							Respiratory impairment in females	-0.1 (0.037)	Coef (SE)	0.0056
							Respiratory impairment in males	-0.3 (0.06)	Coef (SE)	0.0001
							Sex (female ref)	-0.34 (0.067)	Coef (SE)	0.0001
							Summary ADL Index	-0.12 (0.012)	Coef (SE)	0.0001
							Upper gastrointestinal impairment	NR	Coef (SE)	NS
							Vascular impairment	NR	Coef (SE)	NS
Carlson et al, 2001 (6) USA Prospective observational study QAS: 9	n=132	Newly admitted residents aged 55 and older with dementia or AD	79.4 (7.8) 72.1% female	LTCF, n=1	Baseline data collection 1994 to 1996, follow up for five years, data collection through patient medical records and knowledgeable informants. Analysis: Cox Proportional Hazard Models	45.4% residents died within five years	Activity disturbance (BEHAVE-AD)	NR	HR (CI)	NS
							ADLs	NR	HR (CI)	NS
							Affective disturbance (BEHAVE-AD)	NR	HR (CI)	NS
							Age	NR	HR (CI)	NS
							Aggressiveness (BEHAVE-AD)	NR	HR (CI)	NS
							Alzheimer's disease	NR	HR (CI)	NS
							Anxiety and phobias (BEHAVE-AD)	NR	HR (CI)	NS
							Behaviour (PGDRS)	NR	HR (CI)	NS
							Delusions (BEHAVE-AD) (lower scores = better functioning)	0.766 (0.613-0.958)	HR (CI)	0.195
							Depression (CSD)	NR	HR (CI)	NS
							Diurnal disturbance (BEHAVE-AD)	NR	HR (CI)	NS
							Education	NR	HR (CI)	NS
							Extrapyramidal Rating Scale	NR	HR (CI)	NS
							General Medical Health Rating	0.609 (0.416-0.891)	HR (CI)	0.107
							Hallucinations (BEHAVE-AD)	NR	HR (CI)	NS
							MMSE	NR	HR (CI)	NS
							Orientation (PGDRS)	NR	HR (CI)	NS
							Sex (female ref)	NR	HR (CI)	NS
							Weight loss - more than 5% in past 6 weeks	NR	HR (CI)	NS
							Years Ill	NR	HR (CI)	NS
Cereda et al, 2013 (7) Italy Prospective	n=395/ n=378	Newly admitted residents aged over 65 with AD	80.8 (6.3) AD, 86.7 (7.6) other diagnosis, 87.6 (7.2) Dementia	LTCF, n=1	Baseline data collection 2002 to 2009, follow up for nine years and seven months, data collection through	69.3% residents died within nine years and seven months	Admission diagnosis	NR	HR (CI)	NS
							Age	1.05 (1.03–1.07)	HR (CI)	NR
							Albumin	0.65 (0.47–0.89)	HR (CI)	NR
							BMI	0.97 (0.94–0.99)	HR (CI)	NR
							Diabetes	1.48 (1.05–2.07)	HR (CI)	NR
							Functional status (Barthel Index) (lower score=greater	NR	HR (CI)	NS

cohort study QAS: 10		NR			patient medical records. Analysis: Cox Proportional Hazard Models		dependence)			
							Multiple comorbidities (additional comorbidity)	1.13 (1.01–1.28)	HR (CI)	NR
							Nutritional support during follow-up	0.53 (0.31–0.90)	HR (CI)	NR
							Sex (female ref)	2.06 (1.54–2.76)	HR (CI)	NR
Chan et al, 2012 (8) Hong Kong Prospective cohort study QAS: 9	n=585	Residents who had resided it the nursing home for at least 6 months	85.6 (7.7) 65.3% female	Nursing home, n=12	Baseline data collection April to June 2009, follow up for two years, data collection through patient medical records. Analysis: Multivariate Cox Regression Model	32.1% residents died within two years	Age =>91 years	1.681 (1.101–2.565)	OR (CI)	<0.016
							Age 86–90 years	1.589 (1.036–2.438)	OR (CI)	<0.034
							Barthel Index 0 - (total dependence)	4.172 (2.612–6.664)	OR (CI)	<0.001
							Barthel Index 5 to 60 - (lower score=greater dependence)	2.054 (1.375–3.069)	OR (CI)	<0.001
							Cerebrovascular disease	NR	OR (CI)	NS
							Chronic liver disease	NR	OR (CI)	NS
							Chronic pulmonary disease	NR	OR (CI)	NS
							Chronic renal impairment	NR	OR (CI)	NS
							Comorbidity (CCI) Score of >=4	2.374 (1.652–3.412)	OR (CI)	<0.001
							Congestive heart failure	NR	OR (CI)	NS
							Dementia	NR	OR (CI)	NS
							Diabetes	NR	OR (CI)	NS
							Drinking	NR	OR (CI)	NS
							Education	NR	OR (CI)	NS
							Feeding status (non-oral feeding i.e. PEG)	NR	OR (CI)	NS
							Ischemic heart disease	NR	OR (CI)	NS
							Marital status	NR	OR (CI)	NS
							Number of hospital admissions in preceding year: 1	1.816 (1.145–2.882)	OR (CI)	<0.003
							Number of hospital admissions in preceding year: 2	1.924 (1.090–3.396)	OR (CI)	<0.024
							Number of hospital admissions in preceding year:>= 3	1.981 (1.271–3.087)	OR (CI)	<0.011
							Number of medications	NR	OR (CI)	NS
							Peripheral vascular disease	NR	OR (CI)	NS
							Smoking	NR	OR (CI)	NS
							Use of social security allowance	NR	OR (CI)	NS
Cohen-Mansfield et al, 1999 (9) USA Prospective cohort study QAS: 9	n=399	Residents aged between 70 and 100 years	85.7 (6.56) 77.7% female	Nursing home, n=1	Baseline data collection 1985 to 1986, follow up for nine years, data collection through nursing home records and questionnaires to nursing staff. Analysis: Multivariate Cox Regression Model	Median survival 33 months (2.75 years)	**Cohort 1 – cognitively intact (based on BCRS)**			
							ADL - bathing (RDRS-2)	NR	RR	NS
							ADL - dressing (RDRS-2)	NR	RR	NS
							ADL - eating (RDRS-2)	NR	RR	NS
							ADL - grooming (RDRS-2)	NR	RR	NS
							ADL - toileting (RDRS-2)	NR	RR	NS
							ADL - walking (RDRS-2)	NR	RR	NS
							ADLs (RDRS-2)	NR	RR	NS
							Age	NR	RR	NS
							Agitation (CMAI)	NR	RR	NS
							Appetite	NR	RR	NS
							Cognitive function (BCRS)	NR	RR	NS
							Dementia	NR	RR	NS
							Depression (DRS)	NR	RR	NS
							Frequency of wake at night (SPQ)	NR	RR	NS
							Hearing problem	NR	RR	NS
							High levels of screaming (CMAI item)	NR	RR	NS
							Hours of sleep (SPQ)	NR	RR	NS
							Incontinence	NR	RR	NS

							Number of diagnoses	1.76	RR	<.05
							Number of falls	NR	RR	NS
							Number of medications	NR	RR	NS
							Pain	NR	RR	NS
							Physically nonaggressive behaviours	3	RR	<.05
							Quality and size of social network (HHSNRS)	NR	RR	NS
							Sex (female ref)	1.65	RR	<.05
							Surgery in the last 2 years	NR	RR	NS
							Years in nursing home	NR	RR	NS
							Cohort 2 – cognitively impaired (based on BCRS)			
							ADL - bathing (RDRS-2)	NR	RR	NS
							ADL - dressing (RDRS-2)	NR	RR	NS
							ADL - eating (RDRS-2)	NR	RR	NS
							ADL - grooming (RDRS-2)	NR	RR	NS
							ADL - toileting (RDRS-2)	NR	RR	NS
							ADL - walking (RDRS-2)	NR	RR	NS
							ADLs (RDRS-2)	1.6	RR	<.01
							Age	1.04	RR	<.01
							Agitation (CMAI)	NR	RR	NS
							Appetite	NR	RR	NS
							Cognitive function (BCRS)	NR	RR	NS
							Dementia	NR	RR	NS
							Depression (Depression Rating Scale)	NR	RR	NS
							Frequency of wake at night (SPQ)	NR	RR	NS
							Hearing problem	NR	RR	NS
							High levels of screaming (CMAI)	1.39	RR	<.05
							Hours of sleep (SPQ)	NR	RR	NS
							Incontinence	NR	RR	NS
							Number of diagnoses	NR	RR	NS
							Number of falls	NR	RR	NS
							Number of medications	1.21	RR	NS
							Pain	NR	RR	NS
							Physically nonaggressive behaviours	NR	RR	NS
							Quality and size of social network (HHSNRS)	NR	RR	NS
							Sex (female ref)	NR	RR	NS
							Surgery in the last 2 years	NR	RR	NS
							Years in nursing home	NR	RR	NS
Connolly, Broad and Boyd, 2014 (10) New Zealand Prospective follow up study QAS: 11	n=6,271/ n=380	Residents admitted within 30 days prior to the baseline	86 (median) 69.7% female	Residential aged care, n=152	Baseline data collection 2008, follow up for 6 months, data collected from facility staff. Variables associated with time to death in residents with length of stay under 1 month. Analysis: Cox	20% residents died within 6 months	Acute hospital into long-term hospital care vs other pathway (ref)	2.02 (1.2- 3.3)	HR (CI)	< 0.05
							Age	NR	HR (CI)	NS
							Ethnicity	NR	HR (CI)	NS
							Level of care	NR	HR (CI)	NS
							Marital status	NR	HR (CI)	NS
							Number of admissions in 2 years prior, none (ref) vs 3+	5.40 (1.6-17.6)	HR (CI)	< 0.05
							Number of admissions in 2 years prior, none (ref) vs 1	4.60 (1.4-15.7)	HR (CI)	< 0.05
							Number of admissions in 2 years prior, none (ref) vs 2	4.50 (1.3-15.5)	HR (CI)	< 0.05
							Previous residence	NR	HR (CI)	NS
							Recent medical history	NR	HR (CI)	NS

					Proportional Hazard Models		Sex	NR	HR (CI)	NS
							Special nursing care (inc. tube care or diabetes management)	NR	HR (CI)	NS
							Unable to manage personal care at all vs some or no assistance required (ref)	1.90 (1.7- 3.07)	HR (CI)	< 0.05
							Unscheduled GP visit during prior 2 weeks- none (ref) vs 1+	1.90 (1.2- 3.2)	HR (CI)	< 0.05
							Urgent visit to hospital in previous 2 weeks	NR	HR (CI)	NS
Dale et al, 2001 (11) England Retrospective case note audit - matched case control QAS: 10	n=507/ n=90	Deceased residents and living residents matched on age, sex and time in care home	75.1 (male) / 81.1 (females) (SD NR) 64.3% female	Nursing homes, n=59	Baseline data collection 1994 to 1995, follow up for one year, data collected from the Manchester Social Services Department Community Assessment Analysis: Cox Proportional Hazard Models	32.6% residents died within one year	ADLs - (greater scores=greater impairment)	1.02 (1.00-1.03)	HR (CI)	0.25
							Age	1.02 (1.00-1.05)	HR (CI)	0.027
							Appetite - feeding tube/fluids only	4.05 (1.40-1.73)	HR (CI)	0.009
							Appetite - nil by mouth/anorexic	2.06 (0.87-4.88)	HR (CI)	0.098
							Appetite - poor	2.16 (1.59-2.93)	HR (CI)	0.001
							Being cooperative	NR	HR (CI)	NS
							Build - above / below average	NR	HR (CI)	NS
							Cardiovascular disease	NR	HR (CI)	NS
							Dementia (CDR) (greater scores=greater impairment)	10.5 (1.02-1.08)	HR (CI)	0.003
							Excess sleeping	NR	HR (CI)	NS
							Malignancy	3.04 (1.00-4.67)	HR (CI)	0.001
							Marital status	NR	HR (CI)	NS
							Number of drugs	1.07 (1.01-1.34)	HR (CI)	0.144
							Obstructive airway disease	1.67 (1.11-2.52)	HR (CI)	0.013
							Placement prior to admission - geriatric long stay bed	0.81 (0.43-1.52)	HR (CI)	0.508
							Placement prior to admission - geriatric medical bed	1.16 (0.76-1.77)	HR (CI)	0.492
							Placement prior to admission - hospice	9.80 (3.30-29.13)	HR (CI)	0.001
							Placement prior to admission - medical bed	0.95 (0.43-2.12)	HR (CI)	0.909
							Placement prior to admission - nursing home	0.87 (0.48-1.56)	HR (CI)	0.636
							Placement prior to admission - orthopaedic bed	1.53 (0.76-3.11)	HR (CI)	0.243
							Placement prior to admission - psychiatric bed	1.63 (0.71-3.71)	HR (CI)	0.248
							Placement prior to admission - psychiatric long stay bed	0.47 (0.10-2.15)	HR (CI)	0.33
							Pressure ulcers - Waterlow score (greater scores=greater risk)	1.03 (1.00-1.06)	HR (CI)	0.028
							Reason for admission	NR	HR (CI)	NS
							Sex (male ref)	0.49 (0.36-0.66)	HR (CI)	0.001
Dontas et al, 1991 (12) Greece Prospective study QAS: 8	n=408	Newly admitted residents aged 68 years and over	79.1 (7.1) (male) / 79.4 (6.2) (females) 65.4% female	Residential home, n=1	Baseline data collection 1978 to 1983, follow up for eleven years, data collected by study authors and care home staff. Analysis: Cox Proportional Hazard Models	78.6% male and 78.% female residents died within eleven years	Age	1.10 (0.99-1.22)	MRR (CI)	0.08
							Bacteriuria	1.13 (0.85-1.47)	MRR (CI)	0.34
							Blood pressure	0.96 (0.92-1.01)	MRR (CI)	0.15
							ECG abnormalities	1.26 (0.97-1.01)	MRR (CI)	0.08
							Haematocrit	0.86 (1.51-2.54)	MRR (CI)	0.02
							Mobility impairment	1.96 (1.52-4.45)	MRR (CI)	0.001
							Serum cholesterol	0.93 (0.85-1.01)	MRR (CI)	0.9
							Sex (female ref)	1.25 (0.89-1.74)	MRR (CI)	0.2
							Smoking - non-smoker (ref) vs smoker	1.63 (1.14-2.32)	MRR (CI)	0.01
							Socioeconomic status- not paying fees (ref) vs paying fees	1.00 (0.77-1.31)	MRR (CI)	0.98
							Weight - 5kn increments	1.01 (0.95-1.07)	MRR (CI)	0.83
Engle and Graney, 1993 USA Prospective	n=647	Newly admitted residents aged 60 and over who were	78.4 (10.6) 74.6% female	Nursing homes, n=8	Baseline data collection over one year, year not stated, follow up for three months and six months, data	NR	**Cohort 1: Three months**			
							ADL - feeding (Eight Scaled Outcome Criteria)	NR	OR (CI)	NS
							ADL - defecation (Eight Scaled Outcome Criteria)	NR	OR (CI)	NS
							ADL - dressing (Eight Scaled Outcome Criteria)	NR	OR (CI)	NS
							ADL - grooming (Eight Scaled Outcome Criteria)	NR	OR (CI)	NS
							ADL - hygiene (Eight Scaled Outcome Criteria) (lower score=	NR	OR (CI)	NS

longitudinal study QAS: 11		medically stable			collected from resident interview, caretaker interview and chart review. Analysis: Multiple logistic regression		more dependence)			
							ADL - transferring	NR	OR (CI)	NS
							Admission from the community	NR	OR (CI)	NS
							Age	NR	OR (CI)	NS
							Cancer	8.07 (3.91-16.65)	OR (CI)	NR
							Dementia	NR	OR (CI)	NS
							Education low (ref) vs high	1.51 (1.18-1.93)	OR (CI)	NR
							Ethnicity	NR	OR (CI)	NS
							Hip fracture	NR	OR (CI)	NS
							Level of care - Intermediate (ref) vs skilled	NR	OR (CI)	NS
							Mental status (SPMSQ) (memory, orientation etc.)	NR	OR (CI)	NS
							Number of children living within one mile of the care home	NR	OR (CI)	NS
							Number of diagnoses	NR	OR (CI)	NS
							Number of medications	NR	OR (CI)	NS
							Poor ambulation	2.14 (1.25-3.66)	OR (CI)	NR
							Poor urination	2.32 (1.3-4.14)	OR (CI)	NR
							Readmission to the nursing home	NR	OR (CI)	NS
							Sex	NR	OR (CI)	NS
							Type of nursing home	NR	OR (CI)	NS
							Type of payment for care	NR	OR (CI)	NS
							Cohort 2: Six months			
							ADL - feeding (Eight Scaled Outcome Criteria)	NR	OR (CI)	NS
							ADL - defecation (Eight Scaled Outcome Criteria)	NR	OR (CI)	NS
							ADL - dressing (Eight Scaled Outcome Criteria)	NR	OR (CI)	NS
							ADL - grooming (Eight Scaled Outcome Criteria)	NR	OR (CI)	NS
							ADL - hygiene (Eight Scaled Outcome Criteria) (lower score= more dependence)	NR	OR (CI)	NS
							ADL - transferring	4.33 (2.31-8.11)	OR (CI)	NR
							Admission from the community	NR	OR (CI)	NS
							Age	1.06 (1.01 -1.12)	OR (CI)	NR
							Cancer -	10.77 (5.17 -22.44)	OR (CI)	NR
							Dementia	NR	OR (CI)	NS
							Education (Low)	1.31 (1.05 -1.63)	OR (CI)	NR
							Ethnicity	NR	OR (CI)	NS
							Hip fracture	NR	OR (CI)	NS
							Level of care - Intermediate (ref) vs skilled	2.83 (1.8 - 4.47)	OR (CI)	NR
							Marital status - Other (ref) vs Married	2.68 (1.66-4.34)	OR (CI)	NR
							Mental status (SPMSQ) (memory, orientation etc.)	NR	OR (CI)	NS
							Number of children living within one mile of the care home	NR	OR (CI)	NS
							Number of diagnoses	NR	OR (CI)	NS
							Number of medications	1.44 (1.12-1.84)	OR (CI)	NR
							Poor ambulation	NR	OR (CI)	NS
							Poor urination	NR	OR (CI)	NS
							Readmission to the nursing home	NR	OR (CI)	NS
							Sex	NR	OR (CI)	NS
							Type of nursing home	NR	OR (CI)	NS
							Type of payment for care	NR	OR (CI)	NS
Fernandez and	n=15,237	Residents	NR	Nursing	Baseline data	50%	ADL Score - mild (ref) vs moderate	1.29 (1.12-1.49)	RR (CI)	NR

Lapane, 2002 (13) USA Follow up study QAS: 10		with PD	59.6% female	homes, n=1,492	collection 1992-1996, follow up for three years, data collected using the MDS. Analysis: Cox Proportional Hazard Models	residents died within three years	ADL Score - mild (ref) vs severe	1.81 (1.53-2.13)	RR (CI)	NR
							Age - 65-74 (ref) vs 75-84	1.37 (1.24-1.51)	RR (CI)	NR
							Age - 65-74 (ref) vs 85+	2.22 (1.99-2.47)	RR (CI)	NR
							Alzheimer’s disease	0.89 (0.79-1.00)	RR (CI)	NR
							Anxiety	0.86 (0.73-1.01)	RR (CI)	NR
							Arteriosclerotic heart disease	1.06 (0.97-1.15)	RR (CI)	NR
							Arthritis	1.05 (0.96-1.14)	RR (CI)	NR
							Aspiration	1.58 (0.97-2.56)	RR (CI)	NR
							Balance problems	1.10 (1.01-1.21)	RR (CI)	NR
							Bladder incontinence	1.16 (1.04-1.29)	RR (CI)	NR
							Bowel incontinence	1.06 (0.59-1.18)	RR (CI)	NR
							Chronic obstructive pulmonary disease	1.35 (1.19-1.54)	RR (CI)	NR
							Cognitive Impairment - mild (ref) vs moderate	1.28 (1.17-1.40)	RR (CI)	NR
							Cognitive Impairment - mild (ref) vs severe	1.54 (1.38-1.72)	RR (CI)	NR
							Congestive heart failure	1.49 (1.35-1.65)	RR (CI)	NR
							Constipation	0.90 (0.81-1.0)	RR (CI)	NR
							Depression	0.91 (0.82-1.01)	RR (CI)	NR
							Diabetes	1.22 (1.11-1.35)	RR (CI)	NR
							Ethnicity - White, non-Hispanic (ref) - African American	0.74 (0.62-0.87)	RR (CI)	NR
							Ethnicity - White, non-Hispanic (ref) - Other minority	0.73 (0.61-0.87)	RR (CI)	NR
							Fractures	0.81 (0.64-1.07)	RR (CI)	NR
							Hallucinations	0.74 (0.77-1.15)	RR (CI)	NR
							Hearing impairment	1.15 (0.99-1.33)	RR (CI)	NR
							Hypertension	0.96 (0.89-1.04)	RR (CI)	NR
							Peripheral vascular disease	1.11 (0.96-1.28)	RR (CI)	NR
							Physically abusive	1.02 (0.87-1.20)	RR (CI)	NR
							Pneumonia	1.39 (1.09-1.77)	RR (CI)	NR
							Pressure ulcers	1.25 (1.14-1.37)	RR (CI)	NR
							Sex (male ref)	0.58 (0.54-0.62)	RR (CI)	NR
							Speech impairment	1.18 (1.06-1.31)	RR (CI)	NR
							Urinary tract infection	0.99 (0.88-1.10)	RR (CI)	NR
							Verbally abusive	0.90 (0.78-1.05)	RR (CI)	NR
							Vision problems	1.38 (1.20-1.57)	RR (CI)	NR
							Wandering	0.97 (0.88-1.12)	RR (CI)	NR
Flacker and Kiely, 1998 (14) USA Retrospective cohort study QAS: 8	n=780	Residents residing in the LTCF for at least one year	88.3 (6.4) 75.9% female	LTCFs, n=1	Baseline data collection 1994 to 1997, follow up for one year, data collected using MDS. Analysis: Proportional Hazards Regression Model	20.4% residents died within one year	Activities - shopping trips	NR	RR (CI)	NS
							Activities - spiritual involvement	NR	RR (CI)	NS
							Activities - outdoor walking/wheeling	NR	RR (CI)	NS
							Age >88 years	1.48 (1.07-2.05)	RR (CI)	0.019
							Anaemia	NR	RR (CI)	NS
							Arthritis	NR	RR (CI)	NS
							Behavioural problems increase past 90 days	NR	RR (CI)	NS
							Body mass index <=22	1.75 (1.26-2.43)	RR (CI)	<0.001
							Bowel incontinence	NR	RR (CI)	NS
							Care needs increase past 90 days	NR	RR (CI)	NS
							Chewing problems	NR	RR (CI)	NS
							Chronic obstructive pulmonary disease	NR	RR (CI)	NS
							Cognitive decline past 90 days	NR	RR (CI)	NS
							Cognitive functioning (CPS)	NR	RR (CI)	NS

							Congestive heart failure	1.57 (1.01-2.25)	RR (CI)	0.014
							Dementia	NR	RR (CI)	NS
							Diabetes	NR	RR (CI)	NS
							Diuretic medication use	NR	RR (CI)	NS
							Fall in past 180 days	NR	RR (CI)	NS
							Functional ability (higher numbers = higher impairment)	2.50 (1.73-3.60)	RR (CI)	<0.001
							Hearing problem	NR	RR (CI)	NS
							Impaired decision making	NR	RR (CI)	NS
							Mechanical diet	NR	RR (CI)	NS
							Pain	NR	RR (CI)	NS
							Pain medication use	NR	RR (CI)	NS
							Persistent abnormal mood	NR	RR (CI)	NS
							Pressure ulcer	NR	RR (CI)	NS
							Problem making self-understood	NR	RR (CI)	NS
							Problem understanding others	NR	RR (CI)	NS
							Reduced activity time	NR	RR (CI)	NS
							Resists care	NR	RR (CI)	NS
							Restraint use - bed rail	NR	RR (CI)	NS
							Restraint use - trunk	NR	RR (CI)	NS
							Sex (female ref)	1.76 (1.24-2.50)	RR (CI)	0.001
							Short term memory impairment	NR	RR (CI)	NS
							Shortness of breath	2.08 (1.26-3.43	RR (CI)	0.004
							Socially inappropriate behaviour	NR	RR (CI)	NS
							Stroke	NR	RR (CI)	NS
							Swallowing problems	1.81 (1.1 8-2.78)	RR (CI)	0.006
							Unstable conditions (conditions which make cognition, ADLs or behaviour unstable)	NR	RR (CI)	NS
							Urine infection	NR	RR (CI)	NS
							Vision impairment	NR	RR (CI)	NS
							Wandering	NR	RR (CI)	NS
							Weight loss past 180 days	2.26 (1 563.28)	RR (CI)	<0.001
Flacker and Kiely, 2003 (15) USA Retrospective cohort study QAS: 9	n=60,341	Residents aged 65 and over	NR 69.0% female	Nursing homes, n= NR	Baseline data collection 1994 to 1997, follow up for one year, data collected using MDS. Proportional Hazards Regression Analysis	32.1% residents died within one year	**Cohort 1 Long stay residents (in nursing home over 1 year)**			
							Activities - Whether a resident prefers spiritual/religious activity	NR	HR (CI)	NS
							Activities - Whether they are usually sleeping	NR	HR (CI)	NS
							Age >=84	1.24 (1.16–1.32)	HR (CI)	NR
							Antianxiety medications	NR	HR (CI)	NS
							Antidepressant medications	NR	HR (CI)	NS
							Antipsychotic medications	NR	HR (CI)	NS
							Balance problems	NR	HR (CI)	NS
							Bed rail	NR	HR (CI)	NS
							Bedfast	NR	HR (CI)	NS
							Body mass index <23 kg/m2	1.47 (1.38–1.57)	HR (CI)	NR
							Bowel incontinence	NR	HR (CI)	NS
							Cancer	NR	HR (CI)	NS
							Chewing problem	NR	HR (CI)	NS
							Cognitive functioning (CPS)	NR	HR (CI)	NS
							Congestive heart failure	1.58 (1.48–1.69)	HR (CI)	NR

							Dehydration	NR	HR (CI)	NS
							Delirium	NR	HR (CI)	NS
							Diabetes	1.32 (1.22–1.42)	HR (CI)	NR
							Exacerbation of chronic condition	NR	HR (CI)	NS
							Fall in past 30 days	NR	HR (CI)	NS
							Fall in past 31 to 180 days	NR	HR (CI)	NS
							Feeding tube	2.09 (1.73–2.51)	HR (CI)	NR
							Fever	NR	HR (CI)	NS
							Functional ability - low score	1.99 (1.74–2.27)	HR (CI)	NR
							Hearing problem	NR	HR (CI)	NS
							Intravenous fluids	NR	HR (CI)	NS
							Intravenous medications	NR	HR (CI)	NS
							Less than 25% of food uneaten	1.86 (1.64–2.11)	HR (CI)	NR
							Long term memory problems	NR	HR (CI)	NS
							Mechanically altered diet	NR	HR (CI)	NS
							More than >5% of food uneaten	NR	HR (CI)	NS
							New medication in past 90 days	NR	HR (CI)	NS
							Orientation problem	NR	HR (CI)	NS
							Pain - frequent	NR	HR (CI)	NS
							Physically abusive behaviour	NR	HR (CI)	NS
							Pressure ulcers	NR	HR (CI)	NS
							Problem making oneself understood	NR	HR (CI)	NS
							Problem with decision-making	NR	HR (CI)	NS
							Recent changes behaviour	NR	HR (CI)	NS
							Recent changes cognition	NR	HR (CI)	NS
							Recent changes communication	NR	HR (CI)	NS
							Recent changes urinary continence	NR	HR (CI)	NS
							Recent decline in function	NR	HR (CI)	NS
							Refuses fluids	NR	HR (CI)	NS
							Sex (female ref)	1.59 (1.49–1.70)	HR (CI)	NR
							Short term memory problems	NR	HR (CI)	NS
							Shortness of breath	2.69 (2.20–3.29)	HR (CI)	NR
							Social engagement (SCS)	NR	HR (CI)	NS
							Socially inappropriate behaviour	NR	HR (CI)	NS
							Swallowing problem	NR	HR (CI)	NS
							Therapeutic diet	NR	HR (CI)	NS
							Unstable conditions (conditions which make cognition, ADLs or behaviour unstable)	2.16 (1.86–2.50)	HR (CI)	NR
							Urinary catheter	NR	HR (CI)	NS
							Verbally abusive behaviour	NR	HR (CI)	NS
							Vision problem	NR	HR (CI)	NS
							Wandering	NR	HR (CI)	NS
							Weight loss	2.04 (1.72–2.34)	HR (CI)	NR
							Cohort 2 Newly admitted residents			
							Activities - Whether a resident prefers spiritual/religious activity	NR	HR (CI)	NS
							Activities - Whether they are usually sleeping	NR	HR (CI)	NS
							Age >=84	NR	HR (CI)	NS

							Antianxiety medications	NR	HR (CI)	NS
							Antidepressant medications	NR	HR (CI)	NS
							Antipsychotic medications	NR	HR (CI)	NS
							Balance problems	NR	HR (CI)	NS
							Bed rail	NR	HR (CI)	NS
							Bedfast	1.92 (1.75–2.10)	HR (CI)	NR
							Body mass index less than 23 kg/m sq	1.29 (1.25–1.34)	HR (CI)	NR
							Bowel incontinence	1.39 (1.32–1.48)	HR (CI)	NR
							Cancer	2.48 (2.34–2.63)	HR (CI)	NR
							Chewing problem	NR	HR (CI)	NS
							Cognitive functioning (CPS)	NR	HR (CI)	NS
							Congestive heart failure	1.65 (1.60–1.71)	HR (CI)	NR
							Dehydration	NR	HR (CI)	NS
							Delirium	NR	HR (CI)	NS
							Diabetes	NR	HR (CI)	NS
							Exacerbation of chronic condition	NR	HR (CI)	NS
							Fall in past 30 days	NR	HR (CI)	NS
							Fall in past 31 to 180 days	NR	HR (CI)	NS
							Feeding tube	NR	HR (CI)	NS
							Fever	NR	HR (CI)	NS
							Functional ability = Low)	1.76 (1.66–1.87)	HR (CI)	NR
							Hearing problem	NR	HR (CI)	NS
							Intravenous fluids	NR	HR (CI)	NS
							Intravenous medications	NR	HR (CI)	NS
							Less than 25% of food uneaten	1.80 (1.71–1.89)	HR (CI)	NR
							Long term memory problems	NR	HR (CI)	NS
							Mechanically altered diet	NR	HR (CI)	NS
							More than >5% of food uneaten	NR	HR (CI)	NS
							New medication in past 90 days	NR	HR (CI)	NS
							Orientation problem	NR	HR (CI)	NS
							Pain - frequent	NR	HR (CI)	NS
							Physically abusive behaviour	NR	HR (CI)	NS
							Pressure ulcers	NR	HR (CI)	NS
							Problem making oneself understood	NR	HR (CI)	NS
							Problem with decision-making	NR	HR (CI)	NS
							Recent changes behaviour	NR	HR (CI)	NS
							Recent changes cognition	NR	HR (CI)	NS
							Recent changes communication	NR	HR (CI)	NS
							Recent changes urinary continence	NR	HR (CI)	NS
							Recent decline in function	NR	HR (CI)	NS
							Refuses fluids	NR	HR (CI)	NS
							Sex (female ref)	1.52 (1.47–1.57)	HR (CI)	NR
							Short term memory problems	NR	HR (CI)	NS
							Shortness of breath	2.24 (2.09–2.40)	HR (CI)	NR
							Social engagement (SCS)	NR	HR (CI)	NS
							Socially inappropriate behaviour	NR	HR (CI)	NS
							Swallowing problem	1.53 (1.43–1.64)	HR (CI)	NR
							Therapeutic diet	NR	HR (CI)	NS

							Unstable conditions (conditions which make cognition, ADLs or behaviour unstable)	1.87 (1.76–1.98)	HR (CI)	NR
							Urinary catheter	NR	HR (CI)	NS
							Verbally abusive behaviour	NR	HR (CI)	NS
							Vision problem	NR	HR (CI)	NS
							Wandering	NR	HR (CI)	NS
							Weight loss	NR	HR (CI)	NS
Foebel et al, 2013 (16) Canada Prospective cohort study QAS: 11	n=546	Newly admitted residents aged 65 and over	84.2 (6.6) 67% female	LTCFs, n=42	Baseline data collection 2004 to 2006, follow up for one year, data collected from care home staff and medical records. Analysis: Cox Proportional Hazards Regression model	24% residents died within one year	Admission source	NR	HR (CI)	NS
							Age	1.02 (0.98-1.07)	HR (CI)	0.31
							Agitation (CMAI)	NR	HR (CI)	NS
							Arthritis	NR	HR (CI)	NS
							Atrial fibrillation	NR	HR (CI)	NS
							Baseline function and cognition	NR	HR (CI)	NS
							Cancer	NR	HR (CI)	NS
							Cerebrovascular disease	NR	HR (CI)	NS
							Cognitive functioning (MDS Cog)	NR	HR (CI)	NS
							Coronary artery disease	NR	HR (CI)	NS
							Dementia	NR	HR (CI)	NS
							Diabetes	NR	HR (CI)	NS
							Functioning - Barthel Index (lower score=greater dependence)	0.91 (0.86-0.96)	HR (CI)	0.0007
							Heart failure	3.13 (1.71-5.71)	HR (CI)	0.0002
							Hospitalisations or ED visits in the year before admission	NR	HR (CI)	NS
							Hyperlipidaemia	NR	HR (CI)	NS
							Hypertension	NR	HR (CI)	NS
							Left ventricular ejection fraction	NR	HR (CI)	NS
							Mood disorders	NR	HR (CI)	NS
							Neuropsychiatric Inventory	NR	HR (CI)	NS
							Osteoporosis and/or fragility fractures,	NR	HR (CI)	NS
							Peripheral vascular disease	NR	HR (CI)	NS
							Prescribed medications - and minor tranquilizers (benzodiazepines and other sedative hypnotic medications)	NR	HR (CI)	NS
							Prescribed medications - angiotensin receptor blockers	NR	HR (CI)	NS
							Prescribed medications - angiotensin-converting enzyme inhibitors	1.08 (0.60-1.94)	HR (CI)	0.8
							Prescribed medications - antidepressants	NR	HR (CI)	NS
							Prescribed medications - antiplatelet agents	NR	HR (CI)	NS
							Prescribed medications - beta-adrenergic receptor blockers	0.99 (0.52-1.87)	HR (CI)	0.98
							Prescribed medications - calcium channel blockers	NR	HR (CI)	NS
							Prescribed medications - digoxin	NR	HR (CI)	NS
							Prescribed medications - loop diuretics	NR	HR (CI)	NS
							Prescribed medications - major tranquilizers (inc antipsychotics)	1.99 (1.07-3.71)	HR (CI)	0.3
							Prescribed medications - spironolactone	NR	HR (CI)	NS
							Pulmonary disease	2.41 (1.34-4.34)	HR (CI)	0.003
							Pulmonary disease	NR	HR (CI)	NS
							Renal failure	NR	HR (CI)	NS
							Sex (female ref)	1.15 (0.63-2.08)	HR (CI)	0.65

							Smoking - prior exposure	NR	HR (CI)	NS
							Valvular heart disease	NR	HR (CI)	NS
Forder and Fernandez, 2011 (17) UK Retrospective observational study QAS: 8	n= 11,565	All residents residing in care homes	85.0 (SD NR) 68.0% female	Care homes, n=305	Baseline data collection varied, residents who died in 2008-2010, care home records reviewed by the research team. Analysis: Cox Proportional Hazard Models	90% residents died within less than six years, median length of stay was 462 days	Age on admission (+1 over mean age)	103.70%	RHR	< 0.001
							Attendance Allowance uptake rate (+10%)	100.50%	RHR	0.049
							Dementia patient (frail older people reference)	114.80%	RHR	< 0.001
							Gender (male reference)	151.80%	RHR	< 0.001
							Locality employment ranking (+10%)	100.70%	RHR	0.126
							Locality income ranking (+10%)	99.10%	RHR	0.032
							Nursing bed (residential bed reference)	109.20%	RHR	0.001
Formiga, Ferrer and Lopez Soto, 2009 (18) Spain Population based study QAS: 9	n=49	Nona-genarian residents in one town	92.9 (3.0) 89.7% female	Nursing homes, n=NR	Baseline data collection not reported, follow up for three years. Data collection not reported. Analysis: Cox Multivariate Analysis	57.1 % residents died within three years	Age	1.22 (1.09-1.36)	OR (CI)	<0.0001
							Chronic obstructive pulmonary disease	NR	OR (CI)	NS
							Cognitive function (Mini Mental State Examination)	0.95 (0.91-0.98)	OR (CI)	<0.007
							Comorbidity (CCI)	NR	OR (CI)	NS
							Diabetes	NR	OR (CI)	NS
							Dyslipidaemia	NR	OR (CI)	NS
							Education	NR	OR (CI)	NS
							Functional status (Barthel Index/Lawton- Brody Index)	NR	OR (CI)	NS
							Heart failure	4.17 (1.83-9.49)	OR (CI)	<0.001
							Hypertension	NR	OR (CI)	NS
							Ischemic cardiomyopathy	NR	OR (CI)	NS
							Marital status	NR	OR (CI)	NS
							Number of drugs	NR	OR (CI)	NS
							Previous stroke	NR	OR (CI)	NS
							Sex	NR	OR (CI)	NS
Gambassi et al, 1999 (19) USA Longitudinal follow up study QAS: 12	n=9,264	Newly admitted residents with AD aged 65 years and over	82.1 (6.8) 69.2% female	Nursing homes, n=NR	Baseline data collection 1992-1995, follow up until 1997 (5 years), data collected using the SAGE database and the MDS. Analysis: Cox Proportional Hazards Model	50% residents died within five years	Age (65-74 ref) 75-84	1.34 (1.22-1.48)	RR (CI)	NR
							Age (65-74 ref) 85+	1.83 (1.65-2.03)	RR (CI)	NR
							Aphasia	1.12 (0.89-1.40)	RR (CI)	NR
							Behaviour problems	0.93 (0.88-1.00)	RR (CI)	NR
							Cardiovascular disease	1.22 (1.14-1.30)	RR (CI)	NR
							Chronic obstructive pulmonary disease	1.26 (1.14-1.39)	RR (CI)	NR
							Cognitive Function (CPS) normal (ref) vs moderate impairment	1.04 (0.91-1.17)	RR (CI)	NR
							Cognitive Function (CPS) normal (ref) vs severe impairment	1.13 (0.99-1.29)	RR (CI)	NR
							Delirium	1.17 (1.09-1.27)	RR (CI)	NR
							Depression	1.11 (1.04-1.18)	RR (CI)	NR
							Diabetes	1.32 (1.21-1.43)	RR (CI)	NR
							Ethnicity - White (ref) vs African American	0.82 (0.72-0.94)	RR (CI)	NR
							Ethnicity - White (ref) vs Other minorities	0.69 (0.57-0.85)	RR (CI)	NR
							Hearing problems	1.10 (1.00-1.21)	RR (CI)	NR
							History of falls	1.01 (0.96-1.07)	RR (CI)	NR
							Malnutrition	1.31 (1.23-1.39)	RR (CI)	NR
							Marital status - Widowed (ref) vs married	1.04 (0.97-1.12)	RR (CI)	NR
							Marital status - Widowed (ref) vs other	0.86 (0.75-0.97)	RR (CI)	NR
							Parkinson’s disease	0.98 (0.86-1.10)	RR (CI)	NR

							Physical function (ADL score) normal (ref) vs need supervision	1.25 (1.11-1.41)	RR (CI)	NR
							Physical function (ADL score) normal (ref) vs requires assistance	1.45 (1.27-1.66)	RR (CI)	NR
							Pressure ulcers	1.24 (1.13-1.36)	RR (CI)	NR
							Restraint use	1.03 (0.95-1.11)	RR (CI)	NR
							Sex (female ref)	1.81 (1.70-1.94)	RR (CI)	NR
							Stroke	1.05 (0.96-1.16)	RR (CI)	NR
							Urinary incontinence	1.15 (1.06-1.24)	RR (CI)	NR
							Vision problems	1.13 (1.03-1.23)	RR (CI)	NR
Hedinger, Hamming and Bopp, 2015 (20) Switzerland Linked observational study QAS: 10	n=35739 (11,486 men, 35,739 women)	Residents aged 65 years and over at admission and who had died in 2007 and 2008	83.6 (male) / 85.2 (female) (SD NR) 69.2% female	Nursing homes, n=NR	Baseline data collection varied, residents who died in 2007-2008, data collected using three datasets - Swiss National Cohort, Statistics of socio-medical institutions (SOMED) and Medstat- Medical statistics of Swiss hospitals. Analysis: Negative binomial regression models	Mean LOS: 790 days (male) / 1250 days (female)	**Men only:**			
							Age	0.96 (0.96–0.97)	IRR (CI)	<0.001
							Care level - low (ref) vs high	0.55 (0.52–0.58)	IRR (CI)	<0.001
							Care level - low (ref) vs medium	0.71 (0.67–0.75)	IRR (CI)	<0.001
							Care level - unknown/not specified	0.30 (0.27–0.33)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs COPD	1.63 (1.46–1.82)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs coronary heart disease	1.75 (1.62–1.88)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs Dementia	1.93 (1.79–2.09)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs other	1.91 (1.80-2.04)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs stroke	2.02 (1.85–2.21)	IRR (CI)	<0.001
							Children - yes (ref) vs no	1.16 (1.08–1.24)	IRR (CI)	<0.001
							Children - yes (ref) vs unknown	1.16 (1.06–1.27)	IRR (CI)	<0.001
							Education - medium vs high	0.98 (0.91–1.05)	IRR (CI)	<0.001
							Education - medium vs low	1.17 (1.10–1.23)	IRR (CI)	<0.001
							Education - medium vs unsure	1.10 (1.03–1.17)	IRR (CI)	<0.001
							Home ownership - tenant (ref) vs owner-occupier	0.67 (0.64–0.71)	IRR (CI)	<0.001
							Hospitalisation in the 365 days preceding death	0.36 (0.35-0.38)	IRR (CI)	<0.001
							Marital status - married (ref) vs divorced	1.14 (1.03–1.25)	IRR (CI)	<0.001
							Marital status - married (ref) vs never married	1.36 (1.24–1.48)	IRR (CI)	<0.001
							Marital status - married (ref) vs widowed	1.23 (1.17–1.29)	IRR (CI)	<0.001
							Multi-morbidity - no (ref) vs unsure	0.96 (0.89–1.03)	IRR (CI)	<0.001
							Multi-morbidity - no (ref) vs yes	1.07 (1.02–1.13)	IRR (CI)	<0.001
							Nationality - Swiss (ref) vs foreigner	0.77 (0.69–0.85)	IRR (CI)	<0.001
							Women only:			
							Age	0.96 (0.95–0.96)	IRR (CI)	<0.001
							Care level - low (ref) vs high	0.81 (0.78–0.84)	IRR (CI)	<0.001
							Care level - low (ref) vs medium	0.86 (0.83–0.89)	IRR (CI)	<0.001
							Care level - unknown/not specified	0.44 (0.41–0.48)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs COPD	1.58 (1.44–1.75)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs coronary heart disease	1.89 (1.79–1.99)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs Dementia	1.96 (1.86–2.06)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs other	1.91 (1.83–2.00)	IRR (CI)	<0.001
							Cause of death - cancer (ref) vs stroke	1.79 (1.68–1.90)	IRR (CI)	<0.001
							Children - yes (ref) vs no	1.10 (1.05–1.14)	IRR (CI)	<0.001
							Children - yes (ref) vs unknown	1.22 (1.16–1.28)	IRR (CI)	<0.001
							Education - medium vs high	0.96 (0.88–1.05)	IRR (CI)	<0.001
							Education - medium vs low	1.09 (1.06–1.13)	IRR (CI)	<0.001
							Education - medium vs unsure	0.98 (0.94–1.02)	IRR (CI)	<0.001
							Home ownership - tenant (ref) vs owner-occupier	0.65 (0.63–0.67)	IRR (CI)	<0.001

							Hospitalisation in the 365 days preceding death	0.42 (0.41–0.43)	IRR (CI)	<0.001
							Marital status - married (ref) vs divorced	0.95 (0.89–1.01)	IRR (CI)	<0.001
							Marital status - married (ref) vs never married	1.17 (1.10–1.24)	IRR (CI)	<0.001
							Marital status - married (ref) vs widowed	1.17 (1.13–1.22)	IRR (CI)	<0.001
							Multi-morbidity - no (ref) vs unsure	1.03 (0.99–1.07)	IRR (CI)	<0.05
							Multi-morbidity - no (ref) vs yes	0.98 (0.95–1.01)	IRR (CI)	<0.05
							Nationality - Swiss (ref) vs foreigner	0.83 (0.76–0.89)	IRR (CI)	<0.001
Heppenstall et al, 2015 (21) New Zealand Cohort study QAS: 7	n=500 (sample randomly selected from 6,289)	Residents across all certified LTCFs	83 (SD NR) Gender NR	LTCFs, n=NR	Baseline data collection 2008, follow up for one year, data collected using the Older Persons Ability Level Study. Analysis: Multivariate logistic regression analysis	13% residents in rest home care, 26% residents in dementia care, 28% residents in psychogeriatric care and 34% residents in private hospital care died within one year	Age	4% (0.8-7.4%)	%	0.014
							Needing attention twice or more per night	2.51 (1.50–4.20)	RR	0.001
							Needing help with feeding	3.07, (1.69–5.59)	RR	0.002
							Sex (female ref)	2.10 (1.22-3.60)	RR	0.007
Hjaltadootir et al, 1991 (22) Iceland Cohort study QAS: 12	n=2,206	Residents who were assessed once at baseline with a MDS within 90 days of admission	82.5 (7.60) 70% female	Nursing homes, n=NR	Baseline data collection 1996 to 2006, follow up for three years, data collected using the MDS. Analysis: Weibull Model	53.1% residents died within three years	Physical functioning (ADL Long Scale) (greater scores = greater dependency)	NR	HR (CI)	<0.001
							ADL Long Scale 0-3 (ref) vs 10-17	1.33 (1.08-1.63)	HR (CI)	0.007
							ADL Long Scale 0-3 (ref) vs 18-28	1.80 (1.45-2.23)	HR (CI)	<0.001
							ADL Long Scale 0-3 (ref) vs 4-9	1.17 (0.95-1.43)	HR (CI)	0.134
							Admission source	NR	HR (CI)	0.011
							Admitted from private home, with and without home help (ref) vs acute care hospital/ rehabilitation hospital	1.27 (1.10-1.47)	HR (CI)	0.001
							Admitted from private home, with and without home help (ref) vs board and care/assisted living/group home	1.11 (0.86-1.45)	HR (CI)	0.417
							Admitted from private home, with and without home help (ref) vs nursing home/nursing ward	1.09 (0.88-1.37)	HR (CI)	0.408
							CHESS Score (low score = stable condition)	NR	HR (CI)	0.079
							CHESS Score: 0 (ref) vs 1	1.18 (0.98-1.42)	HR (CI)	0.079
							CHESS Score: 0 (ref) vs 2	1.61 (1.35-1.93)	HR (CI)	<0.001
							CHESS Score: 0 (ref) vs 3	2.16 (1.70-2.75)	HR (CI)	<0.001
							CHESS Score: 0 (ref) vs 4	3.95 (3.08-5.07)	HR (CI)	<0.001
							CHESS Score: 0 (ref) vs 5	16.18 (11.41-22.95)	HR (CI)	<0.001
							Cognitive functioning (CPS)	NR	HR (CI)	NS
							Depression (DRS)	NR	HR (CI)	NS
							ISE Score: (higher score = more social engagement)	NR	HR (CI)	0.007
							ISE Score: 6 (ref) vs 0	1.63 (1.22-2.19)	HR (CI)	0.001

							ISE Score: 6 (ref) vs 3	1.32(0.96-1.81)	HR (CI)	0.092
							ISE Score: 6 (ref) vs 4	1.19 (0.86-1.65)	HR (CI)	0.303
							ISE Score: 6 (ref) vs 5	1.36 (0.94-1.97)	HR (CI)	0.102
							ISE Score: 6 (ref)vs 1	1.62 (1.19-2.22)	HR (CI)	0.002
							ISE Score: 6 (ref)vs 2	1.49 (1.09-2.04)	HR (CI)	0.013
							Pain (Pain Scale)	NR	HR (CI)	NS
Hui,Wong and Woo, 2004 (23) Hong Kong Prospective cohort study QAS: 10	n=590/ n=536	Residents aged 65 years and over	80.0 (7.9) 59.8% female	Nursing homes, n=4	Baseline data collection not reported, follow up for two years, data collected by research team. Analysis: Multivariate Cox regression model	13.8% residents died within eighteen months	Age	-0.0306 (0.0121)	Coef (SE)	0.021
							Cancer	-0.9512 (0.3046)	Coef (SE)	0.002
							Clinic visits in the last three months	NR	Coef (SE)	NS
							Education	NR	Coef (SE)	NS
							Functional performance (greater scores=greater dependency)	-0.131 (0.0239)	Coef (SE)	<0.0000
							Hearing impairment	NR	Coef (SE)	NS
							History of falling in the last three months	NR	Coef (SE)	NS
							Hospitalisations in the last three months	NR	Coef (SE)	NS
							Marital status	NR	Coef (SE)	NS
							Medication use in the last three months	NR	Coef (SE)	NS
							Nutritional status - CAMA <= 1 SD	-0.8417 (0.1957)	Coef (SE)	0.00002
							Sex (female ref)	-1.1802 (0.4548)	Coef (SE)	0.009
							Vision impairment	NR	Coef (SE)	NS
Lapane et al, 2001 (24) USA Population cohort QAS: 12	n=9,223	Newly admitted residents with AD aged 65 years and over	81.5 (7.0) (male)/ 83.3 (7.1) (female) 69.2% female	Nursing homes, n=<1500	Baseline data collection 1992 to 1995 for four years and ten months, data collected using the Systematic Assessment of Geriatric Drug Use via Epidemiology and MDS Analysis: Cox Proportional Hazard Models	Death - links with Medicare.	**Men only**			
							ADLs - mild limitations (ref) vs dependant	1.14 (0.91–1.43)	RR (CI)	NR
							ADLs - mild limitations (ref) vs needs supervision	1.05 (0.86–1.28)	RR (CI)	NR
							Aphasia	1.00 (0.68–1.49)	RR (CI)	NR
							Behaviour problems	1.02 (0.92–1.13)	RR (CI)	NR
							Cardiovascular disease	0.85 (0.77–0.94)	RR (CI)	NR
							Chronic obstructive pulmonary disease	1.12 (0.98–1.29)	RR (CI)	NR
							Cognitive function (CPS) - minimal (ref) vs moderate impairment	1.18 (0.95–1.48)	RR (CI)	NR
							Cognitive function (CPS) - minimal (ref) vs severe impairment	1.53 (1.21–1.94)	RR (CI)	NR
							Delirium	1.21 (1.07–1.36)	RR (CI)	NR
							Depression	1.00 (0.90–1.11)	RR (CI)	NR
							Diabetes	1.39 (1.22–1.58)	RR (CI)	NR
							Ethnicity - White (ref) vs African American	0.80 (0.65–0.99)	RR (CI)	NR
							Ethnicity - White (ref) vs Other minorities	1.00 (0.70–1.44)	RR (CI)	NR
							Falls	1.01 (0.91–1.11)	RR (CI)	NR
							Gait problems	0.83 (0.73–0.93)	RR (CI)	NR
							Hearing problems	0.69 (0.60–0.79)	RR (CI)	NR
							Malnutrition (BMI< 21kg/m2)	1.04 (0.94–1.15)	RR (CI)	NR
							Marital status - married (ref) vs divorced/separated	1.44 (1.13–1.84)	RR (CI)	NR
							Marital status - married (ref) vs never married	1.04 (0.83–1.31)	RR (CI)	NR
							Parkinson's disease	1.24 (1.05–1.46)	RR (CI)	NR
							Pressure ulcers	1.01 (0.88–1.17)	RR (CI)	NR
							Restrain use	1.16 (1.03–1.30)	RR (CI)	NR
							Stroke	1.08 (0.93–1.25)	RR (CI)	NR
							Urinary incontinence	1.01 (0.88–1.17)	RR (CI)	NR
							Vision problems	0.98 (0.86–1.13)	RR (CI)	NR
							Women only			

							ADLs - mild limitations (ref) vs dependant	1.33 (1.12–1.58)	RR (CI)	NR
							ADLs - mild limitations (ref) vs needs supervision	1.22 (1.05–1.41)	RR (CI)	NR
							Aphasia	1.34 (1.01–1.77)	RR (CI)	NR
							Behaviour problems	1.08 (0.99–1.17)	RR (CI)	NR
							Cardiovascular disease	0.92 (0.84–0.99)	RR (CI)	NR
							Chronic obstructive pulmonary disease	1.45 (1.25–1.67)	RR (CI)	NR
							Cognitive function (CPS) - minimal (ref) vs moderate impairment	0.98 (0.84–1.14)	RR (CI)	NR
							Cognitive function (CPS) - minimal (ref) vs severe impairment	1.21 (1.02–143)	RR (CI)	NR
							Delirium	1.09 (0.98–1.20)	RR (CI)	NR
							Depression	1.09 (1.00–1.18)	RR (CI)	NR
							Diabetes	1.39 (1.24–1.55)	RR (CI)	NR
							Ethnicity - White (ref) vs African American	0.89 (0.76–1.06)	RR (CI)	NR
							Ethnicity - White (ref) vs Other minorities	0.82 (0.65–1.05)	RR (CI)	NR
							Falls	0.91 (0.84–0.99)	RR (CI)	NR
							Gait problems	0.93 (0.84–1.02)	RR (CI)	NR
							Hearing problems	0.71 (0.63–0.80)	RR (CI)	NR
							Malnutrition (BMI< 21kg/m2)	1.14 (1.06–1.23)	RR (CI)	NR
							Marital status - married (ref) vs divorced/separated	1.31 (1.09–1.59)	RR (CI)	NR
							Marital status - married (ref) vs never married	0.90 (0.78–1.05)	RR (CI)	NR
							Parkinson's disease	1.50 (1.24–1.82)	RR (CI)	NR
							Pressure ulcers	1.15 (1.02–1.30)	RR (CI)	NR
							Restrain use	1.18 (1.07–1.31)	RR (CI)	NR
							Stroke	1.17 (1.03–1.33)	RR (CI)	NR
							Urinary incontinence	1.10 (0.99–1.21)	RR (CI)	NR
							Vision problems	0.94 (0.84–1.05)	RR (CI)	NR
Lichtenstein, Federspiel and Shaffner, 1985 (25) USA Case- control study QAS: 8	n=2,049 / matched pairs n=49	Residents aged 65 years and older newly admitted to the nursing home	Dead: 81.5 (7.5) Survived: 79.6 (7.3) Matched dead: 81.6 (6.5) Matched survivors: 81.7 (6.8) Dead: 63% Survived: 79% Matched dead: 83% Matched survivors:	Nursing homes, n=13	Baseline data collection 1976 to 1977, follow up for one year, data collected using Tennessee Medicaid Programme medical records. Analysis: Odds ratios were calculate using techniques for matched data	1124 dead and 925 survivors within one year	Age	NR	OR (CI)	NS
							Arrhythmias	NR	OR (CI)	NS
							Atherosclerosis	NR	OR (CI)	NS
							Bathes independently or with assistance (ref) vs is bathed by attendants	8.0 (2.2-47.8)	OR (CI)	NR
							Bladder - continent (ref) vs incontinent	2.0 (1.1-4.9)	OR (CI)	NR
							Bowels - continent (ref) vs incontinent	2.6 (1.0 -7.6)	OR (CI)	NR
							Cardiac disease	NR	OR (CI)	NS
							Cerebrovascular disorders	NR	OR (CI)	NS
							Communication of needs - Verbal (ref) vs language barrier or non-communicative	3.7 (1.5-14.1)	OR (CI)	NR
							Decubitus ulcers	NR	OR (CI)	NS
							Dental impairment	NR	OR (CI)	NS
							Diabetes	NR	OR (CI)	NS
							Dresses independently or with assistance (ref) vs is dressed by attendants or is not dressed	6.3 (2.2-24.2)	OR (CI)	NR
							Education	NR	OR (CI)	NS
							Ethnicity	NR	OR (CI)	NS
							Feeding - feeds self (ref) vs is fed	2.4 (1.1-7.0)	OR (CI)	NR
							Fractures - number occurring within the nursing home	NR	OR (CI)	NS
							Genitourinary disorders	NR	OR (CI)	NS
							Hearing impairment	NR	OR (CI)	NS

			83%				Hypertension	NR	OR (CI)	NS
							Marital status	NR	OR (CI)	NS
							Missing limbs	NR	OR (CI)	NS
							Mobile with aid of wheelchair (ref) vs immobile despite wheelchair being available	4.6 (2.3-12.7)	OR (CI)	NR
							Muscoskeletal disorders	NR	OR (CI)	NS
							Neoplasms	NR	OR (CI)	NS
							Number of children	NR	OR (CI)	NS
							Orientation - orientated (ref) vs disorientated	2.0 (0.8-7.2)	OR (CI)	NR
							Other diagnoses	NR	OR (CI)	NS
							Previous living arrangements	NR	OR (CI)	NS
							Respiratory disorders	NR	OR (CI)	NS
							Sex	NR	OR (CI)	NS
							Toileting - Uses toilet or commode (ref) vs does not use either	2.6 (1.0 -7.6)	OR (CI)	NR
							Transferring - transfers self (ref) vs lifted or bedfast	3.0 (1.3-10.1)	OR (CI)	NR
							Unspecified adjustment reaction	NR	OR (CI)	NS
							Vision impairment	NR	OR (CI)	NS
							Walks independently or with assistance (ref) vs is bedridden or chair fast	5.0 (1.5-19.7)	OR (CI)	NR
Lucchetti et al, 2015 (26) Brazil Prospective study QAS: 8	n=150	NR	76.03 (10.08) 73.3% female	Nursing home, n=1	Baseline data collection not reported, follow up for five years. Data collection not reported. Analysis: Logistic Regression	50% residents died within five years	Age	1.089 (1.046–1.135)	OR (CI)	< 0.001
							Anaemia	NR	OR (CI)	NS
							Cancer	NR	OR (CI)	NS
							Cardiovascular diseases	NR	OR (CI)	NS
							Dementia	NR	OR (CI)	NS
							Depression	NR	OR (CI)	NS
							Diabetes	3.789 (1.266–1.336)	OR (CI)	0.017
							Functional dependency	1.290 (1.100–1.513)	OR (CI)	0.002
							Glycated haemoglobin	NR	OR (CI)	NS
							Hyperlipidaemia	3.207 (1.023–0.060)	OR (CI)	0.046
							Hypertension	NR	OR (CI)	NS
							Number of medications	NR	OR (CI)	NS
							Other neurological disorders	NR	OR (CI)	NS
							Sex	NR	OR (CI)	NS
							Stroke	NR	OR (CI)	NS
							Total cholesterol	NR	OR (CI)	NS
							Use of antidiabetic drugs	NR	OR (CI)	NS
							Use of statins	NR	OR (CI)	NS
Luk et al, 1993 (27) Hong Kong Cohort longitudinal study QAS: 11	n=312	Residents aged 65 years and older with advanced cognitive impairment	88 (8) 77% female	Residential care homes, n=66	Baseline data collection October to December 2010, follow up for one year, data collected using community care nurses. Analysis: Logistic Regression	37% residents died within one year	Active influenza vaccination	NR	OR (CI)	NS
							Acute and emergency department attendance	NR	OR (CI)	NS
							Acute hospital - admission	NR	OR (CI)	NS
							Acute hospital - length of stay	NR	OR (CI)	NS
							Advance Directive in place	NR	OR (CI)	NS
							Age	NR	OR (CI)	NS
							Bowel incontinence	NR	OR (CI)	NS
							Chronic obstructive pulmonary disease	3.4 (1.3-8.8)	OR (CI)	0.011
							Chronic renal failure	NR	OR (CI)	NS
							Community Care Nursing Services - Enteral feeding tube care	NR	OR (CI)	NS
							Community Care Nursing Services - Injection of medicine	NR	OR (CI)	NS

							service			
							Community Care Nursing Services - Urinary catheter care	NR	OR (CI)	NS
							Community Care Nursing Services - Wound care	NR	OR (CI)	NS
							Contact with Community Geriatric Assessment Team fast-track clinic	NR	OR (CI)	NS
							Contact with Community Visiting Medical Officer consultation	NR	OR (CI)	NS
							Contact with on-site Community Geriatric Assessment Team consultation	NR	OR (CI)	NS
							Convalescence hospital - admission	NR	OR (CI)	NS
							Convalescence hospital - length of stay	NR	OR (CI)	NS
							Depression	NR	OR (CI)	NS
							Diabetes mellitus	NR	OR (CI)	NS
							Dietitian intervention	NR	OR (CI)	NS
							Enteral feeding	2.0 (1.2-3.4)	OR (CI)	0.008
							Functioning - Barthel Index (lower score=greater dependence)	NR	OR (CI)	NS
							Gender	NR	OR (CI)	NS
							Heart failure	NR	OR (CI)	NS
							Hip fracture	NR	OR (CI)	NS
							History of pneumococcal vaccine	0.47 (0.28-0.78)	OR (CI)	0.004
							Hypertension	NR	OR (CI)	NS
							Indwelling urinary catheter use	3.2 (1.46-7.2)	OR (CI)	0.004
							Ischaemic heart disease	NR	OR (CI)	NS
							Marital status	NR	OR (CI)	NS
							Number of diagnosis	NR	OR (CI)	NS
							Number of medications	NR	OR (CI)	NS
							Occupational therapist intervention	NR	OR (CI)	NS
							On Guardianship Order	NR	OR (CI)	NS
							Parkinson's Disease	NR	OR (CI)	NS
							Physiotherapist intervention	NR	OR (CI)	NS
							Pressure sores (Norton score)	2.7 (1.37-5.1)	OR (CI)	0.004
							Psychogeriatric team consultation	NR	OR (CI)	NS
							Speech therapist assessment	NR	OR (CI)	NS
							Stroke	NR	OR (CI)	NS
							Tracheostomy	NR	OR (CI)	NS
							Urinary incontinence	NR	OR (CI)	NS
							Use of Comprehensive Social Security Assistance	NR	OR (CI)	NS
							Visiting Medical Officer consultation	NR	OR (CI)	NS
McCann et al 2009 (28) Northern Ireland Prospective longitudinal	n=2,112	Residents aged 65 and over admitted in the past year at the time of the 2001	83 (7.3) 74% female	Residential, nursing and dual registered care homes, n=257	Baseline data collection 2001, follow up for five years, data collected using Northern Ireland Mortality Study.	65% residents died within five years	Age > 65–74 (ref) vs 75–84	1.50 (1.23 - 1.83)	HR (CI)	< 0.001
							Age > 65–74 (ref) vs 85–94	2.09 (1.72 - 2.54)	HR (CI)	< 0.001
							Age > 65–74 (ref) vs 95+	3.25 (2.39 - 4.41)	HR (CI)	< 0.001
							Care home type - not in care home (ref) vs dual registered home*	2.09 (1.81 - 2.40)	HR (CI)	NR
							Care home type - not in care home (ref) vs nursing home*	2.17 (1.96 - 2.41)	HR (CI)	NR
							Care home type - not in care home (ref) vs residential home*	1.63 (1.44 - 1.85)	HR (CI)	NR
							General health - good (ref) vs fairly good	0.96 (0.78 - 1.19)	HR (CI)	< 0.001

study QAS: 12		census			Analysis: Cox Proportional Hazards		General health - good (ref) vs not good	1.29 (1.05 - 1.58)	HR (CI)	< 0.001
							Marital Status - married (ref) vs single/ widowed / divorced	0.99 (0.84 - 1.18)	HR (CI)	< 0.001
							Presence of limiting long term illness	NR	HR (CI)	NR
							Sex (female ref)	1.34 (1.18 - .53)	HR (CI)	< 0.001
Mehr, Williams and Fries, 1997 (29) USA NR QAS: 11	n=6,467 / n=5,895	Newly admitted residents aged 65 and over	NR 66.8% female	Department of Veteran Affairs nursing homes, n=NR	Baseline data collection 1986 to 1987, follow up for six months and one year, data collected using patient records from Veteran Affairs. Analysis: Cox Proportional Hazards Model	NR	**Cohort 1 - All admissions:**			
							ADL Dependency - Least dependant (ref) vs most dependant (RUG II ADL Index)	6.93 (4.98-9.65)	OR (CI)	NR
							Age Group and Malignancy - Assumes 75-84 age group	NR	OR (CI)	NR
							Alcoholism	NR	OR (CI)	NR
							Anaemia	1.62 (1.17-2.25)	OR (CI)	NR
							Arthritis	NR	OR (CI)	NR
							Atherosclerotic heart disease	NR	OR (CI)	NR
							Behaviour problems	NR	OR (CI)	NR
							Cerebrovascular disease	NR	OR (CI)	NR
							Congestive heart failure	2.73 (1.97-3.78)	OR (CI)	NR
							COPD	NR	OR (CI)	NR
							Dementia	NR	OR (CI)	NR
							Diabetes	NR	OR (CI)	NR
							Ethnicity	NR	OR (CI)	NR
							Fluid or electrolyte disorder	NR	OR (CI)	NR
							Gender	NR	OR (CI)	NR
							Hip Fracture	0.40 (0.21-0.74)	OR (CI)	NR
							Hospitalisation since nursing home	NR	OR (CI)	NR
							Hypertension	NR	OR (CI)	NR
							Infection (except Pneumonia)	NR	OR (CI)	NR
							Kidney disease	NR	OR (CI)	NR
							Major Psychiatric Disorders	NR	OR (CI)	NR
							Malignancy	2.56 (1.90-3.45)	OR (CI)	NR
							Married	NR	OR (CI)	NR
							Nasogastric feeding	NR	OR (CI)	NR
							Older age - 64-74 group (ref) vs 85+ group	1.54 (1.15-2.07)	OR (CI)	NR
							Oxygen Use	2.35 (1.47-3.76)	OR (CI)	NR
							Pneumonia	NR	OR (CI)	NR
							Prior nursing home stay	0.49 (0.32-0.76	OR (CI)	NR
							Recent dehydration	NR	OR (CI)	NR
							Recent UTI	NR	OR (CI)	NR
							Rehabilition program	NR	OR (CI)	NR
							Terminally ill	6.04 (4.19-8.71)	OR (CI)	NR
							Cohort 2 - Six months survival cohort:		OR (CI)	
							ADL Dependency - Least dependant (ref) vs most dependant (RUG II ADL Index)	2.43 (1.73-1.73	OR (CI)	NR
							Age Group and Malignancy - Assumes 75-84 age group	NR	OR (CI)	NR
							Alcoholism	0.22 (0.10-0.50)	OR (CI)	NR
							Anaemia	NR	OR (CI)	NR
							Arthritis	0.71 (0.49-1.03)	OR (CI)	NR
							Atherosclerotic heart disease	NR	OR (CI)	NR
							Behaviour problems	NR	OR (CI)	NR

							Cerebrovascular disease	NR	OR (CI)	NR
							Congestive heart failure	1.34 (0.97-1.86)	OR (CI)	NR
							COPD	1.36 (1.01-1.84)	OR (CI)	NR
							Dementia	NR	OR (CI)	NR
							Diabetes	NR	OR (CI)	NR
							Ethnicity	NR	OR (CI)	NR
							Fluid or electrolyte disorder	1.55 (1.12-2.13)	OR (CI)	NR
							Gender	NR	OR (CI)	NR
							Hip Fracture	NR	OR (CI)	NR
							Hospitalisation since nursing home	1.60 (1.24-2.07)	OR (CI)	NR
							Hypertension	NR	OR (CI)	NR
							Infection (except Pneumonia)	NR	OR (CI)	NR
							Kidney disease	2.59 (1.62-4.15)	OR (CI)	NR
							Major Psychiatric Disorders	NR	OR (CI)	NR
							Malignancy	2.20 (1.50-3.21	OR (CI)	NR
							Married	NR	OR (CI)	NR
							Nasogastric feeding	NR	OR (CI)	NR
							Older age - 64-74 group (ref) vs 85+ group	2.11 (1.52-2.92)	OR (CI)	NR
							Oxygen Use	1.83 (1.07-3.15)	OR (CI)	NR
							Pneumonia	1.50 (1.12-2.03)	OR (CI)	NR
							Prior nursing home stay	NR	OR (CI)	NR
							Recent dehydration	NR	OR (CI)	NR
							Recent UTI	NR	OR (CI)	NR
							Rehabilition program	NR	OR (CI)	NR
							Terminally ill	4.82 (2.92-7.96)	OR (CI)	NR
							Cohort 3 – Twelve months survival cohort:			
							ADL Dependency - Least dependant (ref) vs most dependant (RUG II ADL Index)	2.64 (1.70 - 4.10)	OR (CI)	NR
							Age Group and Malignancy - Assumes 75-84 age group	NR	OR (CI)	NR
							Alcoholism	NR	OR (CI)	NR
							Anaemia	NR	OR (CI)	NR
							Arthritis	NR	OR (CI)	NR
							Atherosclerotic heart disease	NR	OR (CI)	NR
							Behaviour problems	NR	OR (CI)	NR
							Cerebrovascular disease	NR	OR (CI)	NR
							Congestive heart failure	2.21 (1.53-3.20)	OR (CI)	NR
							COPD	1.36 (1.01-1.84)	OR (CI)	NR
							Dementia	NR	OR (CI)	NR
							Diabetes	NR	OR (CI)	NR
							Ethnicity	NR	OR (CI)	NR
							Fluid or electrolyte disorder	NR	OR (CI)	NR
							Gender	NR	OR (CI)	NR
							Hip Fracture	NR	OR (CI)	NR
							Hospitalisation since nursing home	1.61 (1.14-2.29)	OR (CI)	NR
							Hypertension	NR	OR (CI)	NR
							Infection (except Pneumonia)	NR	OR (CI)	NR
							Kidney disease	NR	OR (CI)	NR
							Major Psychiatric Disorders	NR	OR (CI)	NR

							Malignancy	2.49 (1.66-3.74)	OR (CI)	NR
							Married	1.51 (1.09 -2.08)	OR (CI)	NR
							Nasogastric feeding	NR	OR (CI)	NR
							Older age - 64-74 group (ref) vs 85+ group	2.06 (1.41 - 3.01)	OR (CI)	NR
							Oxygen Use	2.61 (1.30 -5.21)	OR (CI)	NR
							Pneumonia	1.74 (1.23-2.46)	OR (CI)	NR
							Prior nursing home stay	1.92 (1.18-3.13)	OR (CI)	NR
							Recent dehydration	NR	OR (CI)	NR
							Recent UTI	NR	OR (CI)	NR
							Rehabilitation program	NR	OR (CI)	NR
							Terminally ill	4.31 (2.10 -8.84)	OR (CI)	NR
Mitchell et al, 2004 (30) USA Retrospective cohort study QAS: 10	N=7,014/ n=6,799	Newly admitted residents aged 68 years and over with advanced dementia	83 (median) 77% female	Nursing homes, n=643	Baseline data collection 1994 to 1998, follow up for six months, data collected using MDS. Analysis: Cox Proportional Hazards model	28% residents died within six months	ADLs (higher scores = greater dependency)	1.9 (1.7-2.1)	HR (CI)	NR
							Age	1.4 (1.3 -1.6)	HR (CI)	NR
							Any fracture in the previous 180 days	NR	HR (CI)	NS
							Aspiration	NR	HR (CI)	NS
							Asthma or emphysema/COPD	NR	HR (CI)	NS
							Bedfast	1.5 (1.3 -1.7)	HR (CI)	NR
							Body mass index	NR	HR (CI)	NS
							Bowel incontinence	1.5 (1.3 -1.7)	HR (CI)	NR
							Cancer	1.7 (1.5-1.9)	HR (CI)	NR
							Cardiac dysrhythmia	NR	HR (CI)	NS
							Chewing or swallowing problem	NR	HR (CI)	NS
							Congestive heart failure	1.6 (1.4-1.7)	HR (CI)	NR
							Dehydration	NR	HR (CI)	NS
							Diabetes	NR	HR (CI)	NS
							Edema	NR	HR (CI)	NS
							Ethnicity	NR	HR (CI)	NS
							Fever	NR	HR (CI)	NS
							Hallucinations or delusions	NR	HR (CI)	NS
							Insufficient fluid intake	NR	HR (CI)	NS
							Less than 25% of food eaten at most meals	1.5 (1.3-1.7)	HR (CI)	NR
							Not awake most of day	1.4 (1.2-1.6)	HR (CI)	NR
							Oxygen therapy in prior 14 days	1.6 (1.4-1.8)	HR (CI)	NR
							Pneumonia or respiratory tract infection	NR	HR (CI)	NS
							Pressure ulcers	NR	HR (CI)	NS
							Recent weight loss	NR	HR (CI)	NS
							Septicaemia	NR	HR (CI)	NS
							Sex (female ref)	1.9 (1.7-2.1)	HR (CI)	NR
							Shortness of breath	1.5 (1.3-1.9)	HR (CI)	NR
							Unstable conditions (conditions which make cognition, ADLs or behaviour unstable)	1.5 (1.3 -1.6)	HR (CI)	NR
							Urinary tract infection	NR	HR (CI)	NS
Mitchell et al, 2010 (31) USA Retrospective	n= 245,132/ n= 218,088	Residents aged 65 years and over with advanced dementia	85.4 (7.5) Gender NR	Nursing homes, n=NR	Baseline data collection 2002, follow up for one year, data collected using MDS.	40.6% of residents died within one year	ADL score	1.42 (1.40-1.44)	OR (CI)	NR
							Age	1.18 (1.17-1.18)	OR (CI)	NR
							Alzheimer's disease	NR	OR (CI)	NS
							Anaemia	NR	OR (CI)	NS
							Arteriosclerotic heart disease	NR	OR (CI)	NS
							At least one pressure ulcers >=Stage 2	1.44 (1.41-1.46)	OR (CI)	NR

cohort study QAS: 11					Analysis: Multivariate logistic regression		Bedfast most of day	1.41 (1.38-1.44)	OR (CI)	NR
							BMI <18.5 kg/m	1.35 (1.32-1.37)	OR (CI)	NR
							Bowel incontinence	1.37 (1.34-1.40)	OR (CI)	NR
							Cancer	NR	OR (CI)	NS
							Cardiac dysrhythmias	NR	OR (CI)	NS
							Chewing or swallowing problem	NR	OR (CI)	NS
							Chronic obstructive pulmonary disease	NR	OR (CI)	NS
							Cognitive deterioration in past 90 days	NR	OR (CI)	NS
							Cognitive functioning (CPS)	NR	OR (CI)	NS
							Congestive heart failure	1.28 (1.26 -1.30)	OR (CI)	NR
							Diabetes	NR	OR (CI)	NS
							Fever in prior seven days	NR	OR (CI)	NS
							Functional deterioration in past 90 days	NR	OR (CI)	NS
							Hallucinations or delusions	NR	OR (CI)	NS
							Hip fracture prior 180 days	NR	OR (CI)	NS
							Hypertension	NR	OR (CI)	NS
							Insufficient oral intake	1.39 (1.37-1.41)	OR (CI)	NR
							Lethargic or not awake most of the day	NR	OR (CI)	NS
							Other (non-hip) fracture prior 180 days	NR	OR (CI)	NS
							Other infections	NR	OR (CI)	NS
							Parkinson's disease	NR	OR (CI)	NS
							Peripheral edema	NR	OR (CI)	NS
							Peripheral vascular disease	NR	OR (CI)	NS
							Pneumonia or respiratory tract infection	NR	OR (CI)	NS
							Race	NR	OR (CI)	NS
							Rarely makes oneself understood	NR	OR (CI)	NS
							Recent nursing home admission	1.72 (1.69-1.75)	OR (CI)	NR
							Recurrent lung aspirations in prior 90 days	NR	OR (CI)	NS
							Renal failure	NR	OR (CI)	NS
							Seizure disorder	NR	OR (CI)	NS
							Sex (female ref)	1.71 (1.68-1.74)	OR (CI)	NR
							Shortness of breath	1.57 (1.53-1.61)	OR (CI)	NR
							Stroke	NR	OR (CI)	NS
							Urinary tract infection in prior 30 days	NR	OR (CI)	NS
							Weight loss	1.30 (1.27-1.33)	OR (CI)	NR
Navarro-Gil et al 2014 (32) Spain Retrospective longitudinal study QAS: 9	n=525 Gender NR	Residents aged 60 and over with Dementia	85.6 (6.8) Gender NR	Nursing homes, n=NR	Baseline data collection not reported, follow up for 19 months, data collected using questionnaire completed by resident caregiver within the facility. Analysis: Multivariate logistic regression	NR	Activities of daily living (EQ-5D)	NR	OR (CI)	NS
							Age - 60–85 years (ref) vs over 85 years	1.986 (1.229-3.209)	OR (CI)	0.005
							Allergy/generalized pruritus	NR	OR (CI)	NS
							Alzheimer's	NR	OR (CI)	NS
							Anxiety or Depression (EQ-5D)	NR	OR (CI)	NS
							Bone problems	NR	OR (CI)	NS
							Breathing problems	NR	OR (CI)	NS
							Cancer	NR	OR (CI)	NS
							Change in health at 12 months-better/the same (ref) vs worse	1.653 1.018-2.685	OR (CI)	0.042
							Degree of dementia (CDRS)	NR	OR (CI)	NS
							Depression, sadness, distress	NR	OR (CI)	NS
							Diabetes	2.322 (1.350-3.996)	OR (CI)	0.002
							Digestive problems	NR	OR (CI)	NS

							Frequency of visits	NR	OR (CI)	NS
							Genitourinary problems (including recurrent UTIs)	2.455 (1.419-4.248)	OR (CI)	0.001
							Haematological problems	NR	OR (CI)	NS
							Hearing problems	NR	OR (CI)	NS
							Heart problems	NR	OR (CI)	NS
							Hypercholesterolemia	NR	OR (CI)	NS
							Hypertension	1.695 (1.044-2.753)	OR (CI)	0.033
							Insomnia	NR	OR (CI)	NS
							Living children	NR	OR (CI)	NS
							Marital status	NR	OR (CI)	NS
							Memory problems	NR	OR (CI)	NS
							Mobility (EQ-5D)	NR	OR (CI)	NS
							Mouth and dental problems	NR	OR (CI)	NS
							Nervous system diseases	NR	OR (CI)	NS
							Other endocrine and metabolic problems	NR	OR (CI)	NS
							Pain, discomfort (EQ-5D)	NR	OR (CI)	NS
							Parkinson’s	NR	OR (CI)	NS
							Participates in active leisure	NR	OR (CI)	NS
							Participates in cultural leisure	NR	OR (CI)	NS
							Participates in passive leisure	1.616 (0.968-2.700)	OR (CI)	0.067
							Participates in social leisure	2.242 (1.170-4.299)	OR (CI)	0.015
							Personal care (EQ-5D)	NR	OR (CI)	NS
							Receives visits	NR	OR (CI)	NS
							Sex	NR	OR (CI)	NS
							Skin problems	NR	OR (CI)	NS
							Vision problems	NR	OR (CI)	NS
Netten et al, 1995 (33) UK Longitudinal study QAS: 3	n=73	NR	87 (SD NR) 75% female	Nursing home, n=1	Baseline data collection 1990 to 1994, follow up for four years, data collected using assessment within the nursing home. Analysis: Cox Proportional Hazard Model	58% residents died within four years	Age - years above 65	1.05	HR	NR
							Barthel Score - 1 to 18 (lower score=greater dependence)	0.88	HR	NR
							Sex (male ref)	0.5	HR	NR
Nygaard and Laake, 1990 (34) Norway Retrospective cohort study QAS: 5	N=318	NR	81 (SD NR) 70.1% female	Nursing home, n=1	Baseline data collection 1980 to 1984, follow up for one to two years. Data collection not reported. Analysis: Cox Proportional Hazard Model	43.7% residents died within two years	Age	1.48 (1.02-2.14)	OR (CI)	NR
							Dementia	0.48 (0.52-1.05)	OR (CI)	NR
							Sex (male ref)	0.74 (0.47-1.30)	OR (CI)	NR
							Stroke	0.79 (0.33-0.70)	OR (CI)	NR

Porock et al, 2005 (35) USA Retrospective cohort study QAS: 11	n=43,510	Residents aged 65 and over	NR 73.56% female	LTCF, n=NR	Baseline data collection 1999 to 2000, follow up for six months. Data collection using MDS. Analysis: Logistic Regression	23% residents died within six months	Activities of daily livings (lower scores = less dependence)	1.280 (1.254-1.306)	OR (CI)	NR
							Affect change	NR	OR (CI)	NS
							Age	NR	OR (CI)	NS
							Alzheimer's disease or Dementia	0.787 (0.737-0.840)	OR (CI)	NR
							Cancer	NR	OR (CI)	NS
							Chronic heart failure	1.458 (1.367-1.555)	OR (CI)	NR
							Cognitive function (CPS) (lower scores = less impairment)	1.095 (1.073-1.117)	OR (CI)	NR
							Communication problems	NR	OR (CI)	NS
							COPD	NR	OR (CI)	NS
							Dehydration	1.585 (1.416-1.774)	OR (CI)	NR
							Deteriorating condition	NR	OR (CI)	NS
							Edema	NR	OR (CI)	NS
							Falls	NR	OR (CI)	NS
							Infection, antibiotic-resistant infection	NR	OR (CI)	NS
							Infection, Clostridium difficile	NR	OR (CI)	NS
							Infection, pneumonia	NR	OR (CI)	NS
							Infection, tuberculosis	NR	OR (CI)	NS
							Loss of appetite	1.589 (1.496-1.668)	OR (CI)	NR
							Loss of spouse	NR	OR (CI)	NS
							No. of times hospitalized in the past 90 days	NR	OR (CI)	NS
							Pain	NR	OR (CI)	NS
							Pain, moderate to severe nearly every day	NR	OR (CI)	NS
							Parkinson's disease	NR	OR (CI)	NS
							Recent admission to nursing home	NR	OR (CI)	NS
							Renal disease/failure	1.856 (1.632-2.110)	OR (CI)	NR
							Sex (female ref)	1.801 (1.689-1.921)	OR (CI)	NR
							Shortness of birth	2.192 (2.019-2.381)	OR (CI)	NR
							Sleep - no further information	NR	OR (CI)	NS
							Weight loss	1.547 (1.428-1.676)	OR (CI)	NR
Rothera et al, 2002 (36) England Retrospective cohort study QAS: 10	n=641/n= 514	Newly admitted residents aged 65 years and over and funded by Social Services	NR 69.9% female	Residential, nursing and dual registered care home, n=NR	Baseline data collection 1997 to 1999, follow up for twenty months. Data collection using Social Services Assessments. Analysis: Cox Regression Analysis	31% residents in nursing homes and 17% in residential homes died within twenty months	Age - 85+ (ref) vs 65-74	0.70 (0.53 – 0.93)	OR (CI)	<0.01
							Age - 85+ (ref) vs 75-84	0.77 (0.64 – 0.91)	OR (CI)	<0.01
							Care home type - Residential (ref) vs Dual	1.80 (1.46 – 2.21)	OR (CI)	<0.001
							Care home type - Residential (ref) vs Nursing	1.85 (1.50 – 2.23)	OR (CI)	<0.001
							Continence - low (ref) vs high	1.1 (0.68 – 1.77)	OR (CI)	0.91
							Continence - low (ref) vs medium	1.0 (0.58 – 1.71)	OR (CI)	0.91
							Mobility – low (ref) vs high	2.40 (1.27-4.55)	OR (CI)	0.02
							Mobility - low (ref) vs medium	1.70 (0.88 – 3.27)	OR (CI)	0.02
							Number of cognitive problems - Score of 1-3 (ref) vs 0	1.55 (0.96 – 2.49)	OR (CI)	0.07
							Sex (female ref)	1.71 (1.44 – 2.03)	OR (CI)	<0.001
							Source - community (ref) vs hospital	1.32 (1.11 – 1.56)	OR (CI)	<0.01
Shah et al 2013 (37) England and Wales Prospective cohort study	n=9,772/ 9,172	Residents aged between 65–104 years	NR Gender NR	Residential and nursing homes, n=NR	Baseline data collection 2009, follow up for one year. Data collection using the Health Improvement Network dataset.	26.2% residents died within one year	Age - 65–74 (ref) vs 75–84	1.49	HR (CI)	NR
							Age - 65–74 (ref) vs 85–94	2.19	HR (CI)	NR
							Age - 65–74 (ref) vs 95–104	3.05	HR (CI)	NR
							Asthma/COPD	1.17 (1.04–1.33)	HR (CI)	NR
							Cancer	1.36 (1.21–1.53)	HR (CI)	NR
							Care home type: Residential (ref) vs Nursing	1.48 (1.36–1.61)	HR (CI)	NR
							Care home type: Residential (ref) vs Unclassified	1.14 (1.01–1.30)	HR (CI)	NR
							Clinical contacts - 0 (ref) vs 6+	1.65 (1.43–1.92)	HR (CI)	NR

QAS: 14					Analysis: Cox Proportional Hazard Model		Clinical contacts - 0 (ref) vs 1–2	1.04 (0.92–1.18)	HR (CI)	NR
							Clinical contacts - 0 (ref) vs 3–5	1.27 (1.12–1.45)	HR (CI)	NR
							Coronary heart disease	0.99 (0.89–1.09)	HR (CI)	NR
							Dementia	1.26 (1.16–1.37)	HR (CI)	NR
							Deprivation (IMD quintiles): 1 (ref) vs 5 (lower scores = less deprivation)	1.02 (0.87–1.19)	HR (CI)	NR
							Deprivation IMD quintiles: One (ref) vs Four	1.04 (0.92–1.18)	HR (CI)	NR
							Deprivation IMD quintiles: One (ref) vs Three	0.99 (0.88–1.12)	HR (CI)	NR
							Deprivation IMD quintiles: One (ref) vs Two	1.07 (0.96–1.21)	HR (CI)	NR
							Diabetes	0.99 (0.88–1.12)	HR (CI)	NR
							Heart failure	1.13 (0.99–1.29)	HR (CI)	NR
							Number of drugs - 0-2 (ref) vs 11+	1.59 (1.26–2.00)	HR (CI)	NR
							Number of drugs - 0-2 (ref) vs 3–5	1.16 (0.92–1.47)	HR (CI)	NR
							Number of drugs - 0-2 (ref) vs 6–10	1.34 (1.07–1.67)	HR (CI)	NR
							Parkinson's disease	1.23 (1.04–1.45)	HR (CI)	NR
							Practice region - South (ref) vs North	1.04 (0.96–1.12)	HR (CI)	NR
							Registration with GP - 5 years (ref) vs <90 days:	1.45 (1.24–1.71)	HR (CI)	NR
							Registration with GP - 5 years (ref) vs 1–5 years	1.14 (1.05–1.25)	HR (CI)	NR
							Registration with GP - 5 years (ref) vs 90–365 days:	1.09 (0.97–1.23)	HR (CI)	NR
							Sex (female ref)	1.49 (1.36–1.63)	HR (CI)	NR
							Stroke	1.11 (1.00–1.23)	HR (CI)	NR
Sharifi et al, 2012 (38) Iran Prospective cohort study QAS: 9	n=247/ n=145	Residents aged 65 years and older from the KES prospective study	76.7 (18.4) 59.7% female	Nursing home, n=1	Baseline data collection 2006 to 2009, follow up for thirty-nine months. Data collection using the KCF computerised bank, medical records and care home staff. Analysis: Cox Proportional Hazards Model	30% residents died within thirty nine months	Age	1.04 (1.01-1.07)	HR (CI)	NR
							Albumin	0.19 (0.10–0.36)	HR (CI)	<0.05
							Apolipoprotein A	NR	HR (CI)	NS
							Apolipoprotein B	NR	HR (CI)	NS
							Barthel Index (lower score=greater dependence)	0.62 (0.49–0.78)	HR (CI)	<0.05
							Barthel Index - Components: Bladder incontinence	1.56 (1.02–2.48)	HR (CI)	<0.05
							Barthel Index - Components: Bowel incontinence	2.14 (1.32–3.47)	HR (CI)	<0.05
							Barthel Index - Components: Dressing inability	2.12 (1.33–3.39)	HR (CI)	<0.05
							Barthel Index - Components: Immobility	1.79 (1.32–3.47)	HR (CI)	<0.05
							Barthel Index - Components: Stairs climbing inability	3.05 (1.38–6.76)	HR (CI)	<0.05
							Barthel Index - Components: Transferring inability	2.51 (1.34–4.64)	HR (CI)	<0.05
							Barthel Index - First quartile (ref) vs Fourth quartile	0.23 (0.10–0.50)	HR (CI)	<0.05
							Barthel Index - First quartile (ref) vs Second quartile	0.47 (0.26–0.83)	HR (CI)	<0.05
							Barthel Index - First quartile (ref) vs Third quartile	0.44 (0.24–0.84)	HR (CI)	<0.05
							BMI	0.81 (0.57-1.16)	HR (CI)	NS
							Bodyweight - Ideal bodyweight (ref) vs Overweight	0.82 (0.50-1.34)	HR (CI)	NS
							Bodyweight - Ideal bodyweight (ref) vs Underweight	1.07 (0.45-2.56)	HR (CI)	NS
							BUN-to-creatinine ratio > 20	2.60 (1.59–4.25)	HR (CI)	<0.05
							Calf circumference	0.92 (0.87-0.98)	HR (CI)	NS
							Cholesterol	NR	HR (CI)	NS
							Cognition (MMSE)	1.14 (0.70-1.89)	HR (CI)	NS
							Cognition (MMSE) - Normal Cognition (ref) vs Mild cognition impairment	1.01 (0.56-1.84)	HR (CI)	NS
							Cognition (MMSE) - Normal Cognition (ref) vs Moderate cognition impairment	1.08 (0.61-1.92)	HR (CI)	NS
							Cognition (MMSE) Components - Place orientation	0.84 (0.71–0.99)	HR (CI)	<0.05
							Cognition (MMSE) Components - Time orientation	0.87 (0.75–1.02)	HR (CI)	NS

							Depression (GDS) (lower score = lower depression)	1.26 (1.00–1.58)	HR (CI)	<0.05
							Depression (GDS) Normal (ref) vs Mild depression	1.00 (0.54-1.87)	HR (CI)	NS
							Depression (GDS) Normal (ref) vs Moderate depression	1.51 (0.80-2.85)	HR (CI)	NS
							Depression (GDS) Normal (ref) vs Severe depression	1.07 (0.44-2.62)	HR (CI)	NS
							Diabetes mellitus	1.13 (0.65–1.95)	HR (CI)	NS
							Diuretics use	1.38 (0.60–2.37)	HR (CI)	NS
							Erythrocyte sedimentation rate	NR	HR (CI)	NS
							Hearing loss	1.90 (1.18–3.06)	HR (CI)	<0.05
							Hemoglobin	0.79 (0.71–0.87)	HR (CI)	<0.05
							High sensitive C-reactive protein	NR	HR (CI)	NS
							High-density lipoprotein	NR	HR (CI)	NS
							History of Coronary Artery Disease	1.79 (1.13–2.84)	HR (CI)	<0.05
							History of stroke	1.12 (0.56–2.76)	HR (CI)	NS
							Hypertension	1.01 (0.28–3.71)	HR (CI)	NS
							Lipoprotein	NR	HR (CI)	NS
							Low-density lipoprotein	NR	HR (CI)	NS
							Mid-arm circumference	0.93 (0.87-0.99)	HR (CI)	NS
							Nutrition - (MNA)	1.72 (1.15–2.57)	HR (CI)	<0.05
							Nutrition - (MNA) Well-nourished (ref) vs At risk	1.92 (1.15–3.18)	HR (CI)	<0.05
							Nutrition - (MNA) Well-nourished (ref) vs Malnourished	2.44 (0.84–7.08)	HR (CI)	NS
							Polypharmacy	1.38 (0.60–2.30)	HR (CI)	NS
							Pressure Ulcers - Norton Index (higher scores = better prognosis)	1.86 (1.09–3.18)	HR (CI)	<0.05
							Red blood cell	NR	HR (CI)	NS
							Serum albumin	NR	HR (CI)	NS
							Serum insulin	NR	HR (CI)	NS
							Sleep duration per day	NR	HR (CI)	NS
							Smoking	2.22 (0.80–6.14)	HR (CI)	NS
							Smoking - non smoker (ref) vs ex smoker	2.28 (0.82–6.32)	HR (CI)	NS
							Smoking - non smoker (ref) vs smoker	1.17 (0.28–4.76)	HR (CI)	NS
							Total protein	NR	HR (CI)	NS
							Total protein	0.46 (0.27–0.77)	HR (CI)	<0.05
							Triglyceride	NR	HR (CI)	NS
							Visual loss	1.23 (0.71–1.79)	HR (CI)	NS
							Waist-to-hip ratio	NR	HR (CI)	NS
							White blood cell	NR	HR (CI)	NS
Sokejima et al, 1996 (39) Japan NR QAS: 11	n=451/ n=407	Newly admitted residents aged 65 years and over	78.3 (6.7) 66.6% female	Nursing homes, n=3	Baseline data collection 1976 to 1990, follow up for five years. Data collection not reported. Analysis: Cox Proportional Hazards Model	44.2% residents died within five years	Age - 65-75 (ref) vs 76+	1.27 (0.92-1.74)	RH (CI)	NS
							Mobile without stroke (ref) vs 1 year after admission of 'immobile with stroke'	1.38 (1.17-1.62)	RH (CI)	<0.001
							Mobile without stroke (ref) vs Immobile without stroke	3.62 (2.58-5.09)	RH (CI)	<0.0001
							Mobile without stroke (ref) vs Mobile with stroke	2.20 (1.07-4.51)	RH (CI)	<0.05
							Sex (female ref)	1.16 (0.85-1.59)	RH (CI)	NS
Spector and Takada, 1991 (40)	n=2,603/ n=	All residents residing in	NR NR	Nursing homes, n=80	Baseline data collection from Rhode Island Nursing Home	9.9% residents died within	Affective disorders	NR	OR	NS
							Age	NR	OR	NS
							Cancer	NR	OR	NS

USA Prospective cohort study QAS: 9		nursing homes			Study between 1984 to 1986, follow up for five to seven months - medical charts reviewed by the nurses. Facility data from other sources. Analysis: Logistic Regression	seven months	Cognitive impairment	NR	OR	NS
							COPD	NR	OR	NS
							Disruptive behaviour	NR	OR	NS
							Facility mean ADL score	NR	OR	NS
							Facility received federal citations	0.67	OR	NS
							For profit status (not for profit status reference)	0.42	OR	0.01
							Functioning (Katz Index of Activities of Daily Living)	NR	OR	NS
							Length of stay > 3months	NR	OR	NS
							Mean organised activity days/resident/month (<3 reference vs >6)	0.45	OR	0.05
							Mean organised activity days/resident/month (<3 reference vs 3-6)	0.63	OR	0.05
							Number of beds	NR	OR	NS
							Operating cost	NR	OR	NS
							Percentage of residents with more than 7 medications	NR	OR	NS
							Percentage of residents with skilled care	NR	OR	NS
							Receipt of therapies	NR	OR	NS
							Receipt of therapies	NR	OR	NS
							Receipt of skilled services	NR	OR	NS
							Resident days private pay (<10% reference vs > 40%)	0.86	OR	NS
							Resident days private pay (<10% reference vs 10 - 40%)	1.03	OR	NS
							Residents with 1+ psychoactive drug (<10% reference vs > 20%)	1.1	OR	NS
							Residents with 1+ psychoactive drug (<10% reference vs >10 - 20%)	0.99	OR	NS
							Residents with catheters (0% reference vs >10%)	1.66	OR	NS
							Residents with catheters (0% reference vs 1%-10%)	1.91	OR	NS
							Residents with skin care (<20% reference vs > 40%)	0.90	OR	NS
							Residents with skin care (<20% reference vs >20 - 40%)	0.92	OR	NS
							Schizophrenia or mental retardation	NR	OR	NS
							Staff ratio (high staff/ high ADLs reference vs low staff)	1.23	OR	NS
							Staff ratio (high staff/ high ADLs reference vs moderate staff)	1.5	OR	NS
							Staff turnover	NR	OR	NS
Suh et al, 2005 (41) Korea Prospective follow-up QAS: 13	n=145	Residents aged over 50 with AD	80.8 (7.9) 84.4% female	Nursing home, n=1	Baseline data collection 2002 to 2003, follow up for six months and one year. Data collection using face to face interviews. Analysis: Cox proportional hazards model	17.2% residents died within one year	Age	1.03 (1.00–1.07)	RR (CI)	<0.05
							Auditory hallucinations (BEHAVE-AD)	1.25 (1.01–1.54)	RR (CI)	<0.05
							Basic ADL (DAD-K)	0.97(0.96–0.99)	RR (CI)	<0.05
							Behavioural and psychological symptoms of dementia (BEHAVE-AD) (higher score - more severe)	1.03 (1.01–1.05)	RR (CI)	<0.05
							Cognitive status - (MMSE score) (lower score - poorer status)	0.88 (0.81–0.96)	RR (CI)	<0.05
							Cognitive status - Alzheimer's Disease Assessment Scale (ADAS-K-cog) (higher score - poorer status)	1.04 (1.01–1.07)	RR (CI)	<0.05
							Delusions (BEHAVE-AD)	1.11 (1.01–1.22)	RR (CI)	<0.05
							Dementia Severity - Global Deterioration Scale (GDS)	2.76 (1.59–4.80)	RR (CI)	<0.05
							Depression (BEHAVE-AD)	1.08(1.03–1.14)	RR (CI)	<0.05
							Duration of AD at study entry	1.09 (1.04–1.12)	RR (CI)	<0.05
							Education (years)	0.98 (0.90–1.06)	RR (CI)	NS
							Functional ability - (DAD-K) (lower score - poorer status)	0.96(0.93–0.98)	RR (CI)	<0.05
							Gait disturbance	NR	RR (CI)	NS

							Gender	NR	RR (CI)	NS
							Initiation (DAD-K)	0.97(0.95–0.98)	RR (CI)	<0.05
							Instrumental ADL (DAD-K)	0.97(0.94–0.99)	RR (CI)	<0.05
							Performance (DAD-K)	0.96(0.93–0.98)	RR (CI)	<0.05
							Planning and organization (DAD-K)	0.96(0.94–0.99)	RR (CI)	<0.05
							Sensory impairment (hearing and vision)	NR	RR (CI)	NS
							Tactile hallucinations (BEHAVE-AD)	2.97(1.50–5.88)	RR (CI)	<0.05
							Vascular risk factor (hypertension, heart disease, diabetes mellitus, hyperlipidemia)	4.07(1.77–9.37)	RR (CI)	<0.05
							Wandering (BEHAVE-AD)	2.18(1.20–3.96)	RR (CI)	<0.05
Sund Levander et al, 2016 (42) Sweden Retrospective study QAS: 9	Cohort 1: n=262/ n=149 Cohort 2: n=210/ n=200	Residents aged 65 years and older	Cohort 1: 84.4 (6.9) Cohort 2: 85.6 (6.9) Cohort 1: 73% female Cohort 2: 70% female	Nursing home, n=NR	Baseline data collection 2000 to 2004 (cohort 1), follow up for five years and 2007 (cohort 2), follow up for one year. Data collection using medical records, interviews with nursing staff or resident. Analysis: Cox Proportional Hazard Model	Cohort 1: 28% residents died within five years Cohort 2: 23% residents died within one year	**Cohort 1 – five year follow up:**			
							Activities of daily living	0.844 (0.766–0.930)	HR (CI)	< 0.01
							Age	NR	HR (CI)	NS
							Anti-depressants	NR	HR (CI)	NS
							Autoimmune disease	0.079 (0.009–0.685)	HR (CI)	< 0.05
							Body mass index	NR	HR (CI)	NS
							Cardiovascular disease	NR	HR (CI)	NS
							Chronic obstructive pulmonary disease	NR	HR (CI)	NS
							Cortisone	NR	HR (CI)	NS
							Dementia	NR	HR (CI)	NS
							Diabetes	3.587 (1.633–7.878)	HR (CI)	< 0.01
							Influenza vaccination	0.455 (0.237–0.872)	HR (CI)	< 0.05
							Malnutrition	NR	HR (CI)	NS
							Paracetamol (>= 3 g daily)	NR	HR (CI)	NS
							Pneumocockiae vaccination	NR	HR (CI)	NS
							Sedatives/tranquillisers	NR	HR (CI)	NS
							Sex	NR	HR (CI)	NS
							Stroke Factor	2.308 (1.162–4.584)	HR (CI)	< 0.05
							Thyroid disease	NR	HR (CI)	NS
							Cohort 2 – one year follow up:			
							Activities of daily living	0.718 (0.644-0.801)	HR (CI)	< 0.001
							Age	NR	HR (CI)	NS
							Anti-depressants	NR	HR (CI)	NS
							Autoimmune disease	NR	HR (CI)	NS
							Body mass index	1.058 (1.000–1.119)	HR (CI)	< 0.05
							Cardiovascular disease	NR	HR (CI)	NS
							Chronic obstructive pulmonary disease	NR	HR (CI)	NS
							Cortisone	NR	HR (CI)	NS
							Dementia	NR	HR (CI)	NS
							Diabetes	NR	HR (CI)	NS
							Influenza vaccination	0.439 (0.208-0.924)	HR (CI)	< 0.05
							Malnutrition	0.844 (0.766-0.930)	HR (CI)	< 0.001
							Paracetamol (>= 3 g daily)	0.409 (0.207–0.808)	HR (CI)	< 0.05
							Pneumocockiae vaccination	NR	HR (CI)	NS
							Sedatives/tranquillisers	0.473 (0.256-0.873)	HR (CI)	< 0.05
							Sex	NR	HR (CI)	NS
							Stroke Factor	NR	HR (CI)	NS
							Thyroid disease	NR	HR (CI)	NS

Sung, 2014 (43) South Korea Retrospective study QAS: 13	n=195	Newly admitted residents aged over 65 years.	81.59 (7.66) 76.4% female	Nursing home, n=6	Baseline data collection 2008 to 2012, follow up until death. Data collection using evaluation table data. Analysis: Logistic Regression	47.7% residents died within follow up period	ADL 0-8 score (ref) vs. 9-16 score (higher score = higher dependence)	3.61	OR	0.014
							ADL 9-16 score (ref) vs. 17-24 score	3.22	OR	0.004
							Arthritis	NR	OR	NS
							Aspiration care	1.69	OR	0.465
							Cancer	NR	OR	NS
							Care for cancer pain	2.14	OR	0.165
							Care for pressure sores	NR	OR	NS
							Cognitive function	NR	OR	NS
							Dementia	NR	OR	NS
							Diabetes mellitus	NR	OR	NS
							Dialysis care	NR	OR	NS
							Dyspnea	4.88	OR	0.001
							Hearing loss	NR	OR	NS
							Hypertension	NR	OR	NS
							Insertion of urinary catheters	NR	OR	NS
							Lower back pain and sciatic pain	NR	OR	NS
							Ostomy care	NR	OR	NS
							Oxidization therapy	1.86	OR	0.336
							Problematic behaviours 5-9 score (ref) vs. 10-14	1.29	OR	0.648
							Problematic behaviours 0-4 score (ref) vs. 5-9 (higher score = higher dependence)	3.95	OR	0.015
							Range of motion (0-4 vs.5-8) (higher score = higher dependence)	1.99	OR	0.086
							Sequelae of accidents such as fractures and dislocations	NR	OR	NS
							Stroke	NR	OR	NS
							Tracheostomy care	NR	OR	NS
							Tube feeding	NR	OR	NS
							Visual disturbance such as cataracts and glaucoma	NR	OR	NS
Troyer, 2004 (44) USA NR QAS: 9	n= 394,196	NR	76.62 (13.7) Gender NR	Nursing facilities, n=677	Baseline data collection 1986 to 1997, follow up for one to two years. Data collection using Florida Agency for Health Care Administration. Analysis: Probit Model	NR	**Cohort 1: Death within one year**			
							Age	-0.003	Probit Est	<0.01
							Arteriosclerotic heart disease	-0.012	Probit Est	<0.05
							Brain/neurological disorder, including organic brain syndrome, Alzheimer's and Parkinson's Disease	-0.013	Probit Est	<0.01
							Cancer	0.0328	Probit Est	<0.01
							Cerebrovascular accident	-0.011	Probit Est	<0.05
							Chronic heart failure or hypertension	0.025	Probit Est	<0.01
							Facility characteristics: Chain owned	-0.005	Probit Est	NS
							Facility characteristics: Facility size (no of beds)	0	Probit Est	NS
							Facility characteristics: Government owned	0.11	Probit Est	<0.05
							Facility characteristics: Market share	0.013	Probit Est	<0.05
							Facility characteristics: Non-profit	0.003	Probit Est	NS
							Facility characteristics: Occupancy rate	0.023	Probit Est	<0.01
							Facility characteristics: Percent Medicaid	0.151	Probit Est	<0.01
							Facility characteristics: Percent private pay	0.154	Probit Est	<0.01
							Fractures/ musculoskeletal	-0.012	Probit Est	<0.01
							Location characteristics: Beds per elderly capita	0.117	Probit Est	<0.05
							Location characteristics: Per Income Capital	0.036	Probit Est	<0.05

							Location characteristics: Population of individuals aged 65+	-0.033	Probit Est	<0.01
							Mental disorder	-0.073	Probit Est	NS
							Origin of Resident - assisted living facility	0.014	Probit Est	NS
							Origin of Resident - home	-0.021	Probit Est	<0.05
							Origin of Resident - hospital	-0.02	Probit Est	<0.05
							Receiving Medicaid	0.023	Probit Est	<0.01
							Respiratory disorder/ disease	0.048	Probit Est	<0.01
							Cohort 2: Death within two years:			
							Age	0.004	Probit Est	<0.01
							Arteriosclerotic heart disease	-0.003	Probit Est	NS
							Brain/ neurological disorder, including organic brain syndrome, Alzheimer’s and Parkinson’s	0.004	Probit Est	NS
							Cancer	0.0328	Probit Est	<0.01
							Cerebrovascular accident	-0.008	Probit Est	NS
							Chronic heart failure or hypertension	0.027	Probit Est	<0.01
							Facility characteristics: Chain owned	-0.009	Probit Est	<0.05
							Facility characteristics: Facility size (no of beds)	0	Probit Est	NS
							Facility characteristics: Government owned	0.129	Probit Est	<0.05
							Facility characteristics: Market share	-0.019	Probit Est	<0.05
							Facility characteristics: Non-profit	0.009	Probit Est	NS
							Facility characteristics: Occupancy rate	0.038	Probit Est	<0.01
							Facility characteristics: Percent Medicaid	0.178	Probit Est	<0.01
							Facility characteristics: Percent private pay	0.188	Probit Est	<0.01
							Fractures/ musculoskeletal	0.131	Probit Est	<0.01
							Location characteristics: Beds per elderly capita	-0.148	Probit Est	<0.05
							Location characteristics: Per Income Capital	0.076	Probit Est	<0.01
							Location characteristics: Population of individuals aged 65+	-0.043	Probit Est	<0.01
							Mental disorder	-0.068	Probit Est	<0.01
							Origin of Resident - assisted living facility	0.035	Probit Est	<0.01
							Origin of Resident - home	-0.023	Probit Est	<0.05
							Origin of Resident - hospital	-0.038	Probit Est	<0.01
							Receiving Medicaid	0.054	Probit Est	<0.01
							Respiratory disorder/ disease	0.048	Probit Est	<0.01
van Dijk et al, 2005 (45) USA Retrospective cohort study QAS: 7	n= 44,062/ n=43,510	Residents aged 65 and over with a full MDS assessment	84.4 (7.8) 74% female	Nursing homes, n=522	Baseline data collection 1999, follow up for one year. Data collection using MDS. Analysis: Logistic Regression	35% residents died within one year	Age	1.034 (1.030–1.038)	OR (CI)	NR
							Allergies	NR	OR (CI)	NS
							Anaemia	NS	OR (CI)	NR
							Arteriosclerotic heart disease	NR	OR (CI)	NS
							Arthritis	NR	OR (CI)	NS
							Asthma	NR	OR (CI)	NS
							Bipolar disease	NR	OR (CI)	NS
							Cancer	374 (174–804)	OR (CI)	NR
							Cancer by age	0.059 (0.93–0.95)	OR (CI)	NR
							Cerebral palsy	NR	OR (CI)	NS
							Dementia (CPS)	NS	OR (CI)	NR
							Depression	NR	OR (CI)	NS
							Diabetes mellitus	1.20 (1.14–1.27)	OR (CI)	NR
							Dysrhythmias	NR	OR (CI)	NS
							Emphysema/ COPD	1.59 (1.51–1.68)	OR (CI)	NR

							Eye disease	NR	OR (CI)	NS
							Functioning (ADLs) (higher score = higher dependence)	1.12 (1.12–1.13)	OR (CI)	NR
							Heart failure	1.59 (1.52–1.67)	OR (CI)	NR
							Hypertension	NR	OR (CI)	NS
							Hyperthyroidism	NR	OR (CI)	NS
							Hypotension	NR	OR (CI)	NS
							Hypothyroidism	NR	OR (CI)	NS
							Multiple sclerosis	NR	OR (CI)	NS
							Osteoporosis	NR	OR (CI)	NS
							Other cardiovascular disease	NR	OR (CI)	NS
							Parkinson’s disease	NR	OR (CI)	NS
							Peripheral vascular disease	NR	OR (CI)	NS
							Renal failure	2.14 (1.90–2.41)	OR (CI)	NR
							Schizophrenia	NR	OR (CI)	NS
							Seizures	NR	OR (CI)	NS
							Sex (female ref)	1.71 (1.63–1.80)	OR (CI)	NR
							Stroke	NR	OR (CI)	NS
							Transient ischemic attack	NR	OR (CI)	NS
							Traumatic brain injury	NR	OR (CI)	NS
van Dijk et al, 1996 (46) Netherlands Follow up study QAS: 10	n=606	Newly admitted residents with dementia	80.8 (6.8) 72.1% female	Nursing homes, n=1	Baseline data collection 1982 to 1988, follow up for eight years. Data collection using retrospective chart review. Analysis: Multivariate proportional hazards regression analysis	65% residents died within eight years	Age	1.04 (1.03-1.06)	RR (CI)	NR
							Anaemia	NR	RR (CI)	NR
							Atrial fibrillation	2.0 (1.4-2.7)	RR (CI)	NR
							Chronic lung disease	NR	RR (CI)	NR
							Coming from home	0.95 (0.8-1.2)	RR (CI)	NS
							Coming from hospital	1.2 (0.9-1.5)	RR (CI)	NS
							Dementia	NR	RR (CI)	NR
							Diabetes mellitus	1.6 (1.2-2.1)	RR (CI)	NR
							Faecal incontinence	NR	RR (CI)	NR
							Hearing impairment	NR	RR (CI)	NR
							Heart failure	1.7 (1.2-2.4)	RR (CI)	NR
							Hip fracture	NR	RR (CI)	NR
							Hypertension	NR	RR (CI)	NR
							Malignancy	2.2 (1.4-3.3)	RR (CI)	NR
							Parkinsonism	1.9 (1.4-2.5)	RR (CI)	NR
							Pressure sores	1.8 (1.2-2.6)	RR (CI)	NR
							Previous hip operation	NR	RR (CI)	NR
							Previous myocardial infarction	NR	RR (CI)	NR
							Previous stroke	NR	RR (CI)	NR
							Previous TIA	NR	RR (CI)	NR
							Pulmonary infection and stroke	16.4 (7.4-43.8)	RR (CI)	NR
							Pulmonary infection, no stroke	1.8(1.3-2.4)	RR (CI)	NR
							Severity of dementia (BOP)	NR	RR (CI)	NR
							Sex (female ref)	1.7 (1.4-2.1)	RR (CI)	NR
							Urinary incontinence	1.3 (1.1-1.6)	RR (CI)	NR
							Urinary tract infection	NR	RR (CI)	NR
							Visual problems	1.3 (1.0-1.6	RR (CI)	NR
Wallace and Prevost, 2006	n=21,852	NR	NR	Nursing facilities,	Baseline data collection January to	17.5% residents	Bowel incontinence	1.1	OR	≤ 0.0001
							Cognitive measures: disorganized speech, recent onset	NR	OR	NS

(47) USA Secondary analysis QAS: 8			70% female	n=111	June 2003, follow up for six months. Data collection using the MDS. Analysis: Logistic Regression	died within six months	Current condition unstable	1.1	OR	≤ 0.0001
							Days receives diuretics	1	OR	≤ 0.0001
							Dehydration	NR	OR	NS
							Easily distracted	0.8	OR	≤ 0.0001
							Fed through tube	0.7	OR	≤ 0.0001
							Fell in past 31 to 180 days	1.2	OR	≤ 0.0001
							Hip fracture in last 180 days	0.7	OR	≤ 0.0001
							Inability to feed self	1.1	OR	≤ 0.0001
							Inability to get out of bed	1.3	OR	≤ 0.0001
							Inability to make own decisions	1.1	OR	≤ 0.0001
							Inability to perform personal hygiene	1.1	OR	≤ 0.0001
							Inability to walk in corridor	1.1	OR	≤ 0.0001
							Inability to walk on unit	1.1	OR	≤ 0.0001
							Insufficient fluid intake	NR	OR	NS
							Limitation in range of motion of leg	0.8	OR	≤ 0.0001
							Limited time involved in activities	1.4	OR	≤ 0.0001
							Loss of voluntary movement of hand	0.9	OR	≤ 0.0001
							Oral debris	NR	OR	NS
							Other fracture in last 180 days −0.514 0.6	0.6	OR	≤ 0.0001
							Overall decline in condition	1.1	OR	≤ 0.0001
							Periods of lethargy	1.3	OR	≤ 0.0001
							Presence of indwelling catheter	1.3	OR	≤ 0.0001
							Receives suctioning	NR	OR	NS
							Recent weight loss	1.6	OR	≤ 0.0001
							Recurrent lung aspirations	NR	OR	NS
							Resists care, not easily altered	1.3	OR	≤ 0.0001
							Sad or pained facial expressions	1.1	OR	≤ 0.0001
							Short-term memory loss	1.2	OR	≤ 0.0001
							Skin ulcers: Higher stage pressure ulcers	1.1	OR	≤ 0.0001
							Skin ulcers: Higher stage stasis ulcers	1.2	OR	≤ 0.0001
							Skin ulcers: Number of stage 1 ulcers	1.1	OR	≤ 0.0001
							Terminal diagnosis	3.1	OR	≤ 0.0001
Woo et al, 1989 (48) Hong Kong NR QAS: 7	n=208	Either all residents in the LTCF or residents referred by relatives, social workers, or doctors	75.6 (9.6) (male) / 79.5 (8.4) (females) 72.1% female	Chronic care institutions, n=4	Baseline data collection 1987 to 1998, follow up for three months. Data collection by study author and nurse. Analysis: Stepwise Regression Analysis	13.5 % residents died within three months	% neutrophils	NR	PCC	NS
							Age	NR	PCC	NS
							Albumin	NR	PCC	NS
							Albumin adjusted calcium	NR	PCC	NS
							Ascorbic acid	NR	PCC	NS
							Aspartate aminotransferase activities	NR	PCC	NS
							Beta carotene	NR	PCC	NS
							Blindness	NR	PCC	NS
							Calcium	NR	PCC	NS
							Cerebrovascular accident	NR	PCC	NS
							Cholesterol (umol/l)	NR	PCC	NS
							Chronic heart disease	NR	PCC	NS
							Chronic lung diseases	NR	PCC	NS
							Complete blood count	NR	PCC	NS
							Copper	NR	PCC	NS

							Corrected arm muscle area (cm2)	NR	PCC	NS
							Creatinine	NR	PCC	NS
							Cyanocobalamin	NR	PCC	NS
							Dementia	NR	PCC	NS
							Duration of stay in months	NR	PCC	NS
							Ferritin	NR	PCC	NS
							Folic acid	NR	PCC	NS
							Fructosamine	0.25	PCC	0.001
							Functional ability	NR	PCC	NS
							Glucose	NR	PCC	NS
							Glutathionine reductase	NR	PCC	NS
							Glycosylated haemoglobin	0.04	PCC	0.04
							Haemoglobin	0.04	PCC	0.04
							Hydroxyroline	NR	PCC	NS
							Hypertension	NR	PCC	NS
							Infection	NR	PCC	NS
							Mid arm circumference (cm)	NR	PCC	NS
							Musculoskeletal problem	NR	PCC	NS
							Musculoskeletal problems	NR	PCC	NS
							Neoplasm	NR	PCC	NS
							Number of drugs taken	NR	PCC	NS
							Parkinson's disease	NR	PCC	NS
							Phosphate	NR	PCC	NS
							Prealbumin	0.03	PCC	0.05
							Red blood cell thiamine transketolase	NR	PCC	NS
							Renal and liver function tests	NR	PCC	NS
							Retinol	NR	PCC	NS
							Retinol binding protein	NR	PCC	NS
							Self-feeding	NR	PCC	NS
							Systolic blood pressure (mm Hg)	NR	PCC	NS
							Total protein	NR	PCC	NS
							Total thyoxine (pmolfl)	NR	PCC	NS
							Total white cell count	NR	PCC	NS
							Transferrin	0.07	PCC	0.01
							Triceps skin fold (mm)	NR	PCC	NS
							Urate	NR	PCC	NS
							Urinary electrolytes	NR	PCC	NS
							Urinary hydroxyproline	NR	PCC	NS
							Vitamin B12	NR	PCC	NS
							Vitamin D	NR	PCC	NS
							Vitamin E	NR	PCC	NS
							Vitamins or mineral supplements	NR	PCC	NS
							Zinc	NR	PCC	NS
Zuiliani et al, 2001(49) Italy	n=344	Residents aged 66 years and over who have been	81.1 (7.2) survived 83.8 (7.0) deceased	Nursing home, n=1	Baseline data collection 1990, follow up for two years. Data collection by geriatricians within	NR	% fat free	NR	OR (CI)	NS
							% fat free mass	NR	OR (CI)	NS
							ADLS: 0-1 lost ADLs (ref) vs 2-5 lost ADLs	1.85 (0.90-3.95)	OR (CI)	0.9
							ADLS: 0-1 lost ADLs (ref) vs 6 lost ADLs	3.37 (1.56-7.30)	OR (CI)	0.02
							Age	NR	OR (CI)	NS

Longitudinal study QAS: 8		residents for at least two months	79% female		the nursing home. Analysis: Stepwise logistic regression		Albumin	NR	OR (CI)	NS
							Apolipoprotein B (apo B)	NR	OR (CI)	NS
							Apolipoprotein A-I (apo A-I)	NR	OR (CI)	NS
							Blood glucose	NR	OR (CI)	NS
							Blood nitrogen	NR	OR (CI)	NS
							Blood Pressure ≥4.35 g/dL (ref) vs <3.95	3.0 (1.65-5.43)	OR (CI)	0.34
							Blood Pressure ≥4.35 g/dL (ref) vs 3.95-4.34	1.05 (0.53-2.07)	OR (CI)	0.08
							Blood urea	NR	OR (CI)	NS
							Body mass index	NR	OR (CI)	NS
							Body reactance	NR	OR (CI)	NS
							Body resistance	NR	OR (CI)	NS
							Body water content	NR	OR (CI)	NS
							Chloride (Cl)	NR	OR (CI)	NS
							Comorbidity	NR	OR (CI)	NS
							Current drug use	NR	OR (CI)	NS
							Folic acid	NR	OR (CI)	NS
							Gender	NR	OR (CI)	NS
							Glycated haemoglobin (HbA1c)	NR	OR (CI)	NS
							HDL-cholesterol	NR	OR (CI)	NS
							Hematocrit	NR	OR (CI)	NS
							Hemoglobin	NR	OR (CI)	NS
							Low-density lipoprotein cholesterol (LDL)	NR	OR (CI)	NS
							Potassium (K)	NR	OR (CI)	NS
							Red blood cells	NR	OR (CI)	NS
							Serum iron	NR	OR (CI)	NS
							Sodium	NR	OR (CI)	NS
							Subscapular skinfold thickness	NR	OR (CI)	NS
							T3	NR	OR (CI)	NS
							T4	NR	OR (CI)	NS
							Thyroid-stimulating hormone (TSH)	NR	OR (CI)	NS
							Total cholesterol	NR	OR (CI)	NS
							Total protein	NR	OR (CI)	NS
							Transferrin	NR	OR (CI)	NS
							Tricipital skinfold thickness	NR	OR (CI)	NS
							Triglycerides	NR	OR (CI)	NS
							Vitamin B-12	NR	OR (CI)	NS
							Waist/hip ratio	NR	OR (CI)	NS
							White blood cell count	NR	OR (CI)	NS

Notes: Unless otherwise stated higher scores = poorer prognosis.
*QAS = Quality Assessment Score
** presented for reference only, not included in analysis.

Abbreviations:

AD - Alzheimer's disease, ADL -Activities of daily living, BCRS - Brief Cognitive Rating Scale , BEHAVE-AD - Behavioural Pathology in Alzheimer’s Disease Rating Scale, BMI - Body Mass Index, BOP - Behaviour Rating Scale for Elderly Patients, CAMA - corrected arm muscle area , CCI - Charlson Comorbidity Index, CDR/CDRS - Clinical Dementia

Rating Scale, CI - Confidence Interval, CMAI - Cohen-Mansfield Agitation Inventory, COPD - chronic obstructive pulmonary disease, CSD - Cornell Scale for Depression , DAD-K - Disability Assessment for Dementia Scale - Korean , DRS - Depression Rating Scale, ECG - electrocardiogram, EQ-5D - EuroQol- 5 Dimension , GDS - Global Deterioration Scale , GMHR - General Medical Health Rating, HHSNRS - Hebrew Home Social Network Rating Scale, HR - Hazard Ratio, IMD - Index of multiple deprivation, IRR – Incidence Rate Ratio, ISE - Index for Social Engagement , MDS- Minimum Data Set, MDS Cog - Minimum Data Set Cognition Scale, MMSE - Mini Mental State Exam, MNA - Mini Nutritional Assessment, MRR – Mortality rate ratio, OR - Odds ratio, PAI - Patient assessment instrument, PCC – Partial Correlation Coefficient, PD - Parkinson's Disease, PGDRS - Psychogeriatric Dependency Rating Scale, RDRS-2 - Rapid Disability Rating Scale-2, RHR – Relative hazard rate, RR- Risk ratio, SCS- Self-Compassion Scale, SE - Standard Error, SPMSQ - Short portable mental status questionnaire, SPQ - Sleep Patterns Questionnaire, TIA - transient ischaemic attack, UTI - urinary tract infection.

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Appendix C: Supplementary Material for Paper 2

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page number
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	page 1 line 1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	page 1 line 23
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	page 2 line 74
Objectives	3	State specific objectives, including any prespecified hypotheses	page 2 line 95
Methods			
Study design	4	Present key elements of study design early in the paper	page 3 line 117
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	page 3 line 117
Participants	6	(*a*) *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	page 3 line 117 Figure 1
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	N/A – cross sectional study
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Table 1
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	page 3 line 147
Bias	9	Describe any efforts to address potential sources of bias	N/A
Study size	10	Explain how the study size was arrived at	page 5 line 188
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Table 1
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	page 5 line 183
		(*b*) Describe any methods used to examine subgroups and interactions	page 5 line 183
		(*c*) Explain how missing data were addressed	N/A
		(*d*) *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	N/A
		(*e*) Describe any sensitivity analyses	N/A
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Figure 1

		(b) Give reasons for non-participation at each stage	Figure 1
		(c) Consider use of a flow diagram	Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 2
		(b) Indicate number of participants with missing data for each variable of interest	N/A
Outcome data	15*	*Cross-sectional study*—Report numbers of outcome events or summary measures	Table 2
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Table 3
		(*b*) Report category boundaries when continuous variables were categorized	Table 1
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A
Discussion			
Key results	18	Summarise key results with reference to study objectives	page 14 line 291
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	page 14 line 297
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	page 14 line 319
Generalisability	21	Discuss the generalisability (external validity) of the study results	page 14 line 329
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	page 16 line 443

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix D: Supplementary Material for Paper 4

Supplementary material 1: Example search strategy – Ovid Medline

1. exp Nursing Homes/
2. exp Homes for the Aged/
3. "care home*".ti,ab.
4. "nursing home*".ti,ab.
5. "nursing care home*".ti,ab.
6. "nursing facilit*".ti,ab.
7. "residential home*".ti,ab.
8. "residential care".ti,ab.
9. "residential long term care".ti,ab.
10. "institutional* care*".ti,ab.
11. ("long term" adj1 "care facilit*").ti,ab.
12. ("long term" adj1 "care residen*").ti,ab.
13. ("long term" adj1 "care institution*").ti,ab.
14. ("long term" adj1 "institution* care*").ti,ab.
15. ("institution*" adj1 "long term care*").ti,ab.
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. exp Palliative Care/
18. exp Palliative Medicine/
19. "palliative care".ti,ab.
20. "palliative support".ti,ab.
21. "palliative medicine".ti,ab.
22. "end of life".ti,ab.
23. "supportive care".ti,ab.
24. exp Terminal Care/
25. "terminal".ti,ab.
26. exp Hospice Care/
27. "hospice care".ti,ab.
28. exp Resuscitation Orders/
29. exp Advance Care Planning/
30. "advance care planning".ti,ab.
31. "ACP".ti,ab.
32. exp Advance Directives/
33. "advance directive*".ti,ab.
34. “Gold standards framework".ti,ab.
35. "GSF".ti,ab.
36. "Steps to success".ti,ab.
37. "Route* to success".ti,ab.
38. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
39. "Implement*".ti,ab.
40. "Effect*".ti,ab.
41. "Coordinat*".ti,ab.
42. "Facilit*".ti,ab.
43. "Strateg*".ti,ab.
44. "Improv*".ti,ab.
45. "Review*".ti,ab.
46. "Manag*".ti,ab.
47. "Involv*".ti,ab.
48. "Integrat*".ti,ab.
49. "Multi?disciplinary ".ti,ab.
50. "Multi?professional".ti,ab.
51. "Debreif*".ti,ab.
52. "Train*".ti,ab.
53. "Educati*".ti,ab.
54. "Support*".ti,ab.
55. "Deliver*".ti,ab.
56. 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55
57. 16 and 38 and 56
58. limit 57 to yr="2007 -Current"
59. Aged/
60. 58 and 59

Supplementary material 2: Overview of interventions identified

Author / year Country Study design	Aim of study	Setting Sample size Participants	Study / intervention duration	Description of intervention	Outcome measures and findings
Aasmul et al, 2018 (1) Norway Cluster randomized controlled trial	To describe the content of advance care planning (ACP) in the COSMOS study and the evaluation of the implementation process of the intervention in Norwegian nursing homes.	Nursing homes n=37 765 patients	4 months/ NR	Education programme to learn early and repeated communication with patients and families and to implement ACP.	**Outcome measures:** Feedback during midway seminars and individual patient logs. **Findings:** The patient logs showed that ACP was successfully implemented in 62% (n=183) of patients. The staff emphasized the clear communication of the relevance of ACP addressed to leaders and staff as important facilitators, along with the clearly defined routines, roles and responsibilities. Identified barriers included lack of competence, perceived lack of time, and conflicting culture and staff opinions.
Agar et al 2017, Luckett et al, 2017 (2, 3) * Australia Cluster randomized controlled trial	To explore the benefits of facilitated case conferencing and the Palliative Care Planning Coordinator (PCPC) role, as well as factors influencing implementation, as perceived by PCPCs themselves and the health professionals who participated.	Nursing homes n=20/n=10 131 residents/40 staff members	18 months/ 18 months	Facilitated case conferencing organised by PCPCs.	**Outcome measures:** Family rated quality of end of life care (End of life Dementia [EOLD] Scales), nurse-rated EOLD scales, resident quality of life (Quality of Life in Latest age Dementia) and quality of care over the last month of life (pharmacological/ non-pharmacological palliative strategies, hospitalization or inappropriate interventions). Semi structured interviews focused on perceptions regarding the impacts of facilitated case conferencing and barriers and facilitators to this as a means of improving resident care. **Findings:** Facilitated case conferencing facilitates a palliative approach to care. Perceived benefits of facilitated case conferencing included better communication between staff and families, greater multi-disciplinary involvement in case conferences and care planning, and improved staff attitudes and capabilities for dementia palliative care. Key factors influencing implementation included staffing levels and time; support from management, staff and physicians; and positive family feedback.
Amador et al, 2016 (4) United Kingdom Mixed methods study	To report on the qualitative component of a mixed method study aimed at evaluating an organisational intervention shaped by Appreciative Inquiry to promote integrated working between visiting health care practitioners and care home staff.	Care homes n=3 4 staff members in each care home (care home manager, deputy manager, GP, district nurse)	6 months/ 18 months	Appreciative Inquiry (Social Identity Approach).	**Outcome measures:** Semi structured interviews. **Findings:** The intervention supported integrated working through the development of a common group identity built on shared views and goals, but also recognition of knowledge and expertise specific to each service group, which served common goals in the delivery of end of life care. It supported the development of context specific practice innovations and the introduction of existing end of life care tools and frameworks.
Ampe et al, 2017 (5) * Belgium Quasi-experimental pre-test/post-test study with an intervention and control group	To evaluate the influence of the intervention 'we DECide – Discussing End of life Choices' on the policy and actual practice of ACP in nursing home dementia care units and to investigate barriers and facilitators for the implementation of we DECide.	Nursing homes n=18 90 nursing home staff members	8 months/ 4 weeks	''We DECide', an educational intervention for nursing home staff on shared decision-making in the context of ACP for residents with dementia.	**Outcome measures:** Compliance with best practice of ACP policy, ACP practice and degree of involvement of residents and families in conversations, perceived barriers and facilitators for the implementation of shared decision making in ACP practice. **Findings:** ACP was significantly more compliant with best practice after the intervention, however was not discussed more frequently, nor were residents and families involved to a higher degree in conversations after the intervention was implemented. Barriers to realizing ACP included staff's limited responsibilities.
Andrews et al, 2009 (6) Australia Action research	To explore how staff members from residential dementia special care units could develop strategies to support a palliative approach to care following the Guidelines for Palliative approach in residential aged care.	Residential dementia special care unit n=1 5 staff members/ 10 family members	18 months/ 18 months	Action research involved semi-structured interviews to staff, residents and family members, resulting in an information package.	**Outcome measures:** Evaluation questionnaires. **Findings:** Staff accessed evidence-based resources and developed strategies to address the information needs of family members. Evaluation by family members showed a positive response to the information provided.

				provided to family caregivers.	
Arcand et al, 2009 (7) Canada Pre-test/post-test study	To assess the impact, in terms of family satisfaction with end of life care, of a nursing home pilot educational program for nursing staff and physicians on comfort care and advanced dementia.	Nursing home n=1 NR staff members 21 relatives of residents who died of dementia (post intervention)	NR/ 4 months	Educational program and a booklet for staff, and optionally to families.	**Outcome measures:** After death bereaved family interview/nursing home version. Educational program providing an information booklet. **Findings:** Scores on satisfaction with pain control, emotional support, treating patient with respect, and information on what to expect while patient was dying improved post intervention. There were no statistical differences between the two groups, although the post-intervention group expressed greater satisfaction in communication with the health care team and greater global satisfaction with care.
Badger et al, 2007, Badger et al, 2009, Badger et al, 2012 (8-10) United Kingdom Pre-test/post-test study and qualitative case study	To evaluate the impact of a training programme to improve end of life care in nursing homes, on collaboration between nursing home staff and other health practitioners.	Nursing homes n=95 n=44 included in the final analysis NR managers, staff, residents and family	8 months/ 8 months	Gold Standards Framework in Care Homes.	**Outcome measures:** After death analysis and case study methodology. **Findings:** Post intervention, more homes had a register of residents' end of life care needs and were using guidelines to help identify residents. Hospital deaths reduced from 18% to 11% and in crisis hospital admissions from 38% to 26%. Improved collaborations were anticipated by 31% of managers. Staff reported increased knowledge of end of life care, and enhanced confidence, which in turn resulted in improved communication and collaboration. Key improvements included better care planning, communication, staff confidence, collaboration with others and significantly reduced crisis hospital admissions and a reduction in hospital deaths.
Beck et al, 2012, Beck et al, 2015 (11, 12) Sweden Quasi-experimental pre-test/post-test study and semi structured interviews	To compared the efficacy of facilitated case conferencing versus usual care in improving end of life care for persons with advanced dementia living in nursing homes. To describe the nurse assistants' experience of how an intervention with a palliative care approach had influenced them in their work in residential care for older people.	Residential care facilities n=9/n=3 82 nurse assistants, 9 managers/ registered nurses	12 months/ 7 months	Circle sessions interspersed with workshops, semi-structured individual interviews.	**Outcome measures:** Job satisfaction questionnaire, Psychosocial Aspects of Job Satisfaction scale, Strain in Dementia Care Scale, Stress of Conscience Questionnaire, Leadership Behaviour Questionnaire. **Findings:** After the intervention, nurse assistants increased awareness of, and respect for, the needs of the residents and their relatives, increased understanding of their own importance in the encounter with residents and relatives. Increased openness and understanding among colleagues. Nurse assistants described lack of resources and supportive leadership. Job satisfaction of nurse assistants decreased and they perceived the leadership more negatively than before the intervention.
Blackford et al, 2007 (13) Australia Evaluation	To report on the lessons learnt from the implementation of the Respecting Patient Choices intervention and identify strategies which foster sustainability of ACP.	Residential aged care facilities n=17 1000 frail elderly 14 staff	18 months/ NR	Respecting Patient Choices.	**Outcome measures:** Audit of the ACP documentation and medical records of those residents who had died, semi structured interviews to staff in facilities. **Findings:** Post intervention, 51% residents had been introduced to Respecting Patient Choices, with an uptake of 52%. Governance structure, educational processes, resident documentation, and quality audit processes as well as communication across organisations ensured sustainability,. as did an audit of current practices, ACP process, maintaining ongoing ACP education and support for staff, documentation and medical records, promoting continuity in ACP-information transfer and quality processes.
Booth et al, 2014 (14) United Kingdom	To explore advantages and disadvantages of three initiatives to delivering end of life education to care homes in southeast England.	Care homes n=11 14 managers or deputy managers	24 months/ 24 months	Action learning project.	**Outcome measures:** Hennessey and Hicks Training Needs Tool, confidence and competence questionnaires and focus groups. **Findings:** Participants were empowered as managers and role models in end of life care.

Evaluation of educational interventions		Care homes n=18 38 staff members	8 months/ 8 months	Six Steps to Success programme.	**Outcome measures:** Audits of knowledge, skill and confidence, post-death information, and care home quality markers, accreditation. **Findings:** Results were positive and encouraging.
		Care homes n=23 70 students	12 months/ 12 months	Gold Standards Framework for Care Home.	**Outcome measures:** Accreditation. **Findings:** All homes completed the first programme, but only one undertook accreditation. Others decided to ensure the programme was fully embedded prior to accreditation in 2014.
Brajtman et al, 2012 (15) Canada Pilot study/evaluation	To test an educational intervention about end of life delirium for inter-professional teams.	LTCF n=11 22 nursing, rehab, social workers	NR	Educational intervention.	**Outcome measures:** Inter-professional collaborative competencies attainment survey, and the We Learn seven-point Likert scale to measure overall satisfaction in an inter-professional education activity. **Findings:** Participants at hospice and long-term facilities gave high satisfaction ratings to the overall content, structure, service and outcomes of the intervention. At long-term facilities, significant increases were found for all competencies; however, there was no significant change after intervention.
Brännström et al, 2005 (16) Sweden Evaluation	To compare the effects of the Liverpool Care Pathway (LCP) for the Dying Patient and usual care on patients' symptom distress and well-being during the last days of life, in residential care homes.	Residential care homes n=19 135 family members of deceased participants	15 months/ 15 months	Liverpool Care Pathway.	**Outcome measures:** Edmonton Symptom Assessment (ESAS), Views of Informal Carers – Evaluation of Service (VOICES) questionnaire. **Findings:** Shortness of breath and nausea were significantly reduced. A statistically significant improvement in shortness of breath was also found on the VOICES questionnaire.
Campion et al, 2016 (17) United Kingdom Implementation study	To describe an innovative model of education and training for nursing home staff ... to improve end of life care for residents.	Nursing homes n=33 NR Nursing home staff NR nursing home residents	NR/NR	Education and training including clinical rounds, advice and guidance, communication, and care co-ordination.	**Outcome measures:** Place of death, contact with the ambulance service, transfers to hospital. **Findings:** Post implementation, 85% died in their preferred place, 18% died in an acute hospital setting. Introduction of 'Coordinate my Care' records coincided with a reduction in the number of contacts with the ambulance service and of transfers to hospital - there were 8.3% fewer calls from nursing homes to the ambulance service. There was also a reduction in the number of ambulance transfers of nursing home residents to hospital.
Chapman et al, 2018 (18) Australia Quasi-experimental design	To introduce a model which provides proactive specialist palliative care to supplement the palliative approach to residents' care.	Residential facilities n=4 104 residents	9 months/ 6 months	Palliative Care Needs Round, including monthly onsite clinical meeting.	**Outcome measures:** Number and length of hospitalisations, preferred place of death and location of death. **Findings:** The intervention was associated with a reduction in the length of hospital stays and a lower incidence of death in the acute care setting. Rates of hospitalisation were unchanged on average, length of admission was reduced by an average of 3.22 days ($p<0.01$ and 95% CI −5.05 to −1.41), a 67% decrease in admitted days.
Chisholm et al, 2017, Hanson et al, 2016, Hanson et al, 2017 (19-21) USA	To understand nursing home staff perceptions of adoption and sustainability of the Goals of Care video decision aid for families of residents with advanced dementia. To describe the Goals of Care cluster randomized trial and the methods used to	Nursing homes n=22/n=11 151 family decision-makers and residents dyads	18 months/ NR	Two-component intervention: a video decision aid about goals of care choices and a structured decision-making discussion with the nursing home care plan team.	**Outcome measures:** Quality of communication and decision making using the Quality and Communications questionnaire, toolkit ACP Problem score, treatment plan, family satisfaction with care, patient comfort, patient quality of life, hospice referral, and hospitalizations, family report of concordance with clinicians on the primary goal of care, family ratings of symptom management and care, palliative care domains in care plans, Medical Orders for Scope of Treatment (MOST) completion and hospital transfers.

Cluster randomized controlled trial Evaluation	monitor and promote fidelity to a goals of care decision aid intervention delivered in nursing homes. To test a Goals of Care decision aid intervention to improve quality of communication and palliative care for nursing home residents with advanced dementia.	94 nursing home staff (nurses, social works, therapists, nutritionists)			**Findings:** Key supports for implementation included design features that aligned with nursing home practice, efficient staff training, and a structured guide for goals of care discussions between family decision-makers and staff. Family decision makers reported better quality of communication and better end of life communication with clinicians. Clinicians were more likely to address palliative care in treatment plans, use Medical Orders for Scope of Treatment, and less likely to send patients to the hospital. Family ratings of treatment consistent with preferences, symptom management, and quality of care did not differ. Residents in the intervention group had more palliative care content in treatment plans, MOST order sets, and half as many hospital transfers. Nursing home staff reported high ratings for adoption and sustainability of the Goals of Care intervention. On a scale from 1 to 6, staff perceived the Goals of Care intervention as relatively advantageous (mean 5.09), compatible with practice (mean 5.01) and easy to use (mean 5.16), indicating strong potential for adoption.
Cornally et al, 2015 (22) Ireland Focus groups	To evaluate the systematic implementation of the 'Let Me Decide' advance care directive and palliative care education programme.	Nursing homes n=3 15 clinical nurse managers / 2 directors of nursing	2 years/ NR	'Let Me Decide' - advance care-planning programme.	**Outcome measures:** Impact on quality of care, nurses' knowledge, ACP uptake rates, compliance with resident's wishes at end of life and barriers to implementing the programme. **Findings:** The main benefits included enhanced communication and staff morale, changing the care culture, promoting preference-based care and avoiding crisis decision making. The main challenges reported by staff included establishing capacity among residents and indecision.
Cox et al, 2017 (23) United Kingdom Exploratory mixed methods design with pre and post intervention evaluation	To increase the confidence and competence of care home staff in end of life care; and enable more residents the opportunity to experience end of life care in their care home rather than an acute setting.	Residential care homes, nursing homes n=12 (4 RCH, 2 NH) NR	6 months/ 3 months	End of Life Care toolkit.	**Outcome measures:** Staff confidence and competence, number of residents experiencing end of life care in an acute setting. **Findings:** Following the intervention, there was a trend for staff to report feeling more supported both in terms of emotional and clinical support within the care home and feeling able to source external support. Staff confidence in managing pain management, addressing anxiety, nausea and vomiting and mouth care increased post intervention, however this trend did not reach statistical significance. A comparison of a 5-month period before and after the intervention indicated a 59% reduction in the number of residents who died in the local hospital from the six participating care homes in comparison to a 21% reduction from six comparison care homes who had not received the intervention.
Cronfalk et al, 2015 (24) Sweden Focus groups	To describe nursing home staff's attitudes to three competence-building programs in palliative care.	Nursing homes n=20 118 staff members (registered nurses, enrolled nurses, care assistants)	1 year / NR	Education of one to two persons per ward.	**Outcome measures:** Focus groups, experiences of competence based programmes and palliative care, tension between different professions, encounter older people's dying and death. **Findings:** Attitudes toward the intervention were positive independent of their design or content. Enrolled nurses and care assistants felt that they carried out advanced care without the necessary theoretical and practical knowledge. Further, the results also suggest that lack of support from ward managers and insufficient collaboration and of a common language between different professions caused tension in situations involved in caring for dying people.
		Nursing homes n=11 363 staff members (registered nurses, enrolled nurses, care assistants)	1 year / NR	Separate seminars for different with a focus on the principles of palliative care.	

		Nursing homes n=6 371 staff members	1 year / NR	Seminars introducing the LCP.	
Farrington, 2014 (25) United Kingdom Pre-test/post-test study and semi structured interviews	To evaluate whether a blended e-learning training programme generate a positive change in participants' understandings of, and confidence in delivering end of life care in care homes and identify the main barriers to translating new understandings into practice.	Nursing homes / residential care homes n=1 14 health care assistants/ 6 administrative staff	8 months/ NR	The 'ABC' course, a blended e-learning programme (face-to-face facilitated workshops alongside online content).	**Outcome measures:** Staying Healthy Assessment questionnaire, a free text questionnaire, audit of clinical notes for deceased residents, semi-structured interviews. **Findings:** Improvements in participants' confidence in delivering end of life care. The questionnaire showed an increase in confidence in assessment and care planning, symptom management and well-being, communication, and ACP/ end of life tools. The overall average improvement in mean confidence levels was 0.8, representing a 28.7% advance in confidence across all competency areas. Several barriers were encountered, including uneven participation, the absence of mechanisms for disseminating new insights and knowledge within the home, and a widespread perception that nurses' professional dominance in the home made sustainable change difficult to enact.
Fernandes, 2008 (26) Australia Pre-test/post-test study	To examine the process of how residents' end of life care wishes are recorded and to ensure the implementation of an advance care plan is performed according to the best available evidence.	Long term care facility (LTCF) / residential aged care places (RACP) n=100 LTCF / n=1 (RACP)	5 months/ NR	The Getting Research into Practice process of the Practical Application of Clinical Evidence System program.	**Outcome measures:** Audit of current practice. **Findings:** Compliance with five evidence-based audit criteria on advance care planning, pre- and post-implementation of best practice increased from 77% to 100%. The barriers identified for ACP included deficits related to the knowledge and education of residents, families and staff members, and issues related to administration and documentation, and concerns that any implementation process would not be sustainable.
Finucane et al, 2013 (27) United Kingdom Evaluation	To sustain the results achieved following the initial Gold Standards Framework in Care Homes project using a lower level of care home support.	Nursing homes n=7 132 residents 16 key champions (care assistants and trained staff nurses-original project) 3 key champions (following project)	20 months/ NR	Gold Standards Framework in Care Homes.	**Outcome measures:** Do Not Attempt Cardiopulmonary Resuscitation documentation in place, proportion of deceased residents where Do Not Attempt Cardiopulmonary Resuscitation documentation completed, proportion of residents with any form of anticipatory care plan in place, proportion of residents known to have died on the adapted LCP, inappropriate hospital deaths and hospital deaths. **Findings:** Increases in the proportion of deceased residents with an anticipatory care plan in place, the proportion of those with Do Not Attempt Cardiopulmonary Resuscitation documentation in place and the proportion of those who were on the LCP when they died. Furthermore, there was a reduction in inappropriate hospital deaths of frail and elderly residents with dementia.
Frey et al, 2017 (28) New Zealand Pre-test/post-test study and interviews	To explore the impact of Supportive Hospice Aged Residential Exchange for staff.	Residential care facilities n=2 58 registered nurses and health care assistants (questionnaire) 11 registered nurses and healthcare assistants, managers, hospice nurses (interviews)	6 months/ NR	Supportive Hospice Aged Residential Exchange.	**Outcome measures:** Staff survey, including the Brief Screen depression measure and the Empowerment Scale, manager and staff interviews. **Findings**: Results indicate that the intervention overall is seen as a success, especially in relation to advanced care planning documentation. Relationships between hospice and facility staff, and consequently facility staff and residents are seen as the key to the success of the project. Staff survey results indicated increased confidence in palliative care delivery and decreased depression. Key lessons learnt from for the development of any palliative care intervention within aged residential care include the importance of reciprocal learning, as well as the necessity of a strong partnership with key stakeholders.

Garden et al, 2016 (29) United Kingdom Evaluation	To provide guidance for others wishing to set up a similar service. The two objectives were to examine steps required to put this programme into practice, and to demonstrate the effects of doing so.	Care homes n=7 107 residents with dementia	24 months/ 24 months	Bromhead Care Home Service - Education programme based on the Stop Delirium! Material.	**Outcome measures:** Staff confidence, carer satisfaction, place of death, hospital admission. **Findings**: Marked improvements in staff confidence were seen in recognition (64%), prevention (67%) and management (60%) of delirium which were all highly significant ($p<0.01$). There were also marked improvements in confidence levels in recognition (55%, $p=0.0005$) and management (48.4%, $p=0.0039$) of dysphagia with more modest improvement in knowledge of signs of dysphagia in dementia. High levels of carer satisfaction; 92% carers rated the service >9/10. Admissions fell by 37% from baseline in the first year and 55% in the second and third years. All but one resident died in the preferred place of care.
Giuffrida, 2015 (30) USA Evaluation	To describe the development of two innovative programs whose goals were to increase the number of residents receiving palliative care, increase the number of completed advance directives, reduce re-hospitalizations, and increase hospital referrals to the nursing home for palliative care.	Nursing and rehabilitation facility n=1 NR	NR/NR	Comprehensive palliative care program.	**Outcome measures:** Residents on palliative care, number of rehospitalisation's, residents with health care proxies, residents with Do Not Resuscitate orders, residents with feeding tubes. **Findings**: Post intervention, the number of residents on palliative care increased from 5% to 25%, re-hospitalization rates decreased from 17.4% to 15.2%, residents with health care proxies increased from 65% to 69%, residents with DNR orders increased from 64% to 73%, residents with feeding tubes declined from 24% to 14%.
Hall et al, 2011 (31) United Kingdom Evaluation - qualitative methods	To explore the views of care home staff, residents and their families on the benefits of and barriers to implementation of the Gold Standards Framework for Care Homes, to inform the development of palliative care interventions in care homes for older people.	Care homes n=9 26 staff members (9 care home managers 8 nurses 9 care assistants) 11 residents 7 family members	From 3 to 26 months/from 3 to 26 months	Gold Standards Framework for Care Homes.	**Outcome measures:** Semi-structured interviews. **Findings:** Perceived benefits 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. Perceived barriers included increased paperwork; lack of knowledge and understanding of end of life care; costs; and gaining the cooperation of GPs. Although staff described the benefits of supportive care registers, coding predicted stage of illness and ACP, which included improved communication, some felt the need for more experience of using these, and there were concerns about discussing death.
Hasson et al, 2008 (32) United Kingdom Evaluation - qualitative study	To explore link nurses' views and experiences regarding the development, barriers and facilitators to the implementation of the role of palliative care in the nursing home.	Nursing homes n=10 14 link nurses	3 years/NR	Palliative care educational programme and link nurse role.	**Outcome measures:** Focus groups. **Findings:** The link nurse system shows potential to enhance palliative care within nursing homes. However, link nurses experienced a number of difficulties in implementing education programmes. Facilitators of the role included external support, monthly meetings, access to a resource file and peer support among link nurses themselves. Lack of management support, a transient workforce and lack of adequate preparation for link nurses were barriers to fulfilling this role.
Hewison et al, 2008 (33) United Kingdom Case study approach / evaluation - qualitative study	To report on how teamwork is perceived and managed in homes after the introduction of the Gold Standards Framework for end of life care in care homes, with particular emphasis on the relationship between teamwork and organisational and practice change. It explores two key areas: perceptions of staffing levels and team working in nursing homes.	Nursing homes n=95 n=9 (interviews) 14 managers (telephone interviews) 61 staff (group interviews)	NR/NR	Gold Standards Framework for Care Homes.	**Outcome measures:** Team working questionnaire, interviews face-to-face, group and telephone, audit data and direct observation of the Gold Standards Framework in action. **Findings:** Teamwork is central to the successful introduction of the Gold Standards Framework in Care Homes. Good staffing levels and management support were key factors in homes where the Framework became established. Organisations wishing to implement such programmes should assess the quality of teamwork and may need to address this first.

		7 residents, 3 relatives (face-to-face interviews)			
Hickman et al, 2016 (34) USA Implementation study	To describe processes and preliminary outcomes from the implementation of a systematic ACP intervention in the nursing home setting.	Nursing homes n=19 2,709 residents 25 nurses (registered nurses, nurse practitioners)	17 months/ NR	Advanced Care Planning, using a structured interview guide.	**Outcome measures:** Advanced care planning conversations **Findings:** The intervention resulted 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 barrier to ACP was lack of time.
Ho et al, 2016a, Ho et al, 2016b (35, 36) China Evaluation	To describe systematically the development and implementation mechanisms of a novel Dignity-Conserving End of life Care model. To critically examine the underpinnings of palliative long-term care provision.	Nursing homes n=3 9 residents 9 medical professionals 9 management administrators 6 nursing home staff members 6 family members	NR/NR	End of life integrated care pathway / Dignity-Conserving End of life Care Model.	**Outcome measures:** McGill Quality of Life Questionnaire, Nursing Facilities Quality of Life Questionnaire, focus groups. **Findings:** Although significant deterioration was recorded for physical quality of life, significant improvement was observed for social quality of life. Moreover, a clear trend toward significant improvements was identified for the quality of life domains of individuality and relationships. Three factors were required for the successful implementation of the intervention - regulatory empowerment, family centred care, and collective compassion.
Hockley and Kinley, 2016 (37) United Kingdom Intervention audit	To implement the Gold Standards Framework in Care Homes Programme and audit outcomes within nursing care homes across five clinical commissioning groups over a 7-year period using a research-based model of facilitation and to reflect on the practice development model.	Nursing homes n=76 NR	2 years/NR	Gold Standards Framework in Care Homes	**Outcome measures:** Audit. **Findings:** The percentage of residents dying in increased from 57% (19 NCHs) in 2007/8; to 79% (76 NCHs) in 2014/15 Further data revealed an increase in ACP (from 51% to 82%), the last days of life (from 21% to 60%) and cardio-pulmonary resuscitation decisions (from 52% to 87%). The percentage of residents dying in nursing care homes increased from 57% to 79%, with improvement in other outcomes.
Hockley et al, 2010, Watson et al, 2010 (38, 39) United Kingdom Evaluation - qualitative pre/post implementation	To report the impact of implementing both end of life care tools (Gold Standards Framework in Care Homes and an adapted LCP) together using the same facilitator while proactively visiting the nursing homes two to three times a month using a model of empowerment. To reports on the qualitative interviews with bereaved relatives/friends and care home managers.	Nursing homes n=7 228 residents who had died 68 staff members 22 relatives pre implementation, 14 relatives/friends and 6 managers post implementation	18 months / NR	Gold Standards Framework in Care Homes and an adapted LCP.	**Outcome measures:** Review of clinical notes of deceased, staff audit, qualitative interviews. **Findings:** Do Not Attempt Resuscitation (DNAR) instructions rose by 72%. Written evidence of ACP conversations also increased from 4% to 53%. The use of the adapted LCP rose from 3% to 30% with three homes regularly using the documentation before the end of the project, 8% of staff returning the audit stated that the project had helped them realize the importance of 'quality of life' for residents rather than 'striving to keep alive'. A third of people admitted they had only received end of life care training since taking part in the project. Over half said that the study had helped them prepare new staff for caring for dying residents and families, with staff from one of the nursing homes saying that this had never been done before. An apparent reduction in unnecessary hospital admissions and a reduction in hospital deaths from 15% deaths pre-study to 8% deaths post-study were also found. Post implementation, the results indicate more informed end of life decision-making involving families/friends, staff and GPs.
Horey et al, 2012 (40) Australia Action research/ evaluation	To investigate the acceptability and feasibility of using end of life care pathways in residential aged care facilities.	Residential aged care facilities n=14 63 residents NR staff members	14 months/NR	Introduction of end of life care pathways.	**Outcome measures:** Rate of pathway usage, interviews from staff members, hospital transfers, length of time on pathways, whether care was consistent with best practice. **Findings:** Use of end of life care pathways across the facilities were in either low, moderate and high uptake groups - acceptability was critical to success implementation. There were fewer unnecessary admissions to hospital before death.

					The pathways encouraged documentation, and the audits demonstrated that care for residents on pathways was consistent with best practice of end of life.
in der Schmitten et al, 2014 (41) * Germany Controlled trial - evaluation	To evaluate the feasibility of implementing an Advanced Care Planning program specifically developed for use in German nursing homes and associated health care structures of a given town, and whether it leads to an increase in the number of clearly formulated, valid advance care plans.	Nursing homes n=13 (3 intervention and 10 in control) 575 residents	16.5 months/ NR	Advanced Care Planning program; "beizeiten begleiten, based on the US "Respecting Choices" programme.	**Outcome measures:** Case notes, interviews with residents and the responsible nurse. **Findings:** 49 (36.0%) participating residents completed a new advance directives over the period of the study, compared to 18 (4.1%) in the control region; these advance directives included 30 by proxy in the intervention region versus 10 in the control region. Proxies were designated in 94.7% versus 50.0% of cases, the advance directives was signed by a physician in 93.9% versus 16.7%, and an emergency order was included in 98.0% versus 44.4%. Resuscitation status was addressed in 95.9% versus 38.9% of cases. The implementation of an ACP program in German nursing homes led, much more frequently than previously reported, to the creation of advance directives with potential relevance to medical decision-making.
Kataoka-Yahiro et al 2017 (42) USA Evaluation	To evaluate a palliative and hospice care training of staff in two nursing homes in Hawaii - (a) to evaluate knowledge and confidence over three time periods, and (b) to compare staff and family caregiver satisfaction at end of program.	Long term care facilities n=2 52 staff members	NR/NR	Palliative and hospice care training palliative and hospice care training.	**Outcome measures:** Staff evaluation included knowledge and confidence surveys, pre- and post-test knowledge tests, and FAMCARE-2 satisfaction instrument. **Findings:** The staff rated overall satisfaction of palliative care services lower than the family caregivers did. Statistically significant results were obtained for both self-rated perception of knowledge and confidence improvement in palliative and hospice care training (p<.05) The staff at 2 long-term care facilities who participated in the evaluation of palliative and hospice care training did very well in acquiring knowledge and confidence (p<.05), however, they expressed dissatisfaction of their performance in delivering palliative care services to their patients and families.
Kinley et al, 2014 Kinley et al, 2018 (43, 44) United Kingdom Cluster randomized controlled trial	To examine the impact of providing high facilitation and action learning when implementing the Gold Standards Framework for Care Homes programme.	Nursing homes n=38 1508 residents	3 years/NR	Gold Standards Framework for Care Homes.	**Outcome measures:** Place of death, use of Integrated Care Pathway (ICP), undertaking ACP, having a cardiopulmonary resuscitation decision. **Findings:** There were no significant effects in place of death. There was a significant effect in the high facilitation and action learning arm in the use of ICP. Undertaking ACP, having a cardiopulmonary resuscitation decision, revealed no significant effect. There was a significant association between the type of facilitation and the nursing homes completing the programme through to accreditation. Within the high facilitation and action learning arm, 83% (n=10/12) achieved accreditation compared to 27% (n= 3/11) in the high facilitation only arm (p=0.012). Within the observational group, 7% (n= 1/11) were externally accredited to have successfully implemented and embedded the programme into practice compared to 57% (n= 13/23) in the combined trial arms (p=0.005). A greater proportion of residents died in those nursing homes receiving high facilitation and action learning but not significantly so. There was a significant association between the level of facilitation and nursing homes completing the programme through to accreditation. Year-on-year change occurred across all outcome measures. The nurse manager of a care home must be actively engaged when implementing the programme.
Kinley et al, 2017 (45) United Kingdom	To describe the implementation of an end of life care programme to empower staff to meet their resident's end of life care needs.	Residential care homes n=71 118 staff members	1 year/4 years	Steps to Success programme.	**Outcome measures:** Audit. **Findings:** The audit found an increase of home deaths from 44% (n=8/18) within four residential care homes to 64% (n=74/115) in 23 residential care homes. There has been a corresponding increase in ACP discussions from 11% (n=2/18) to 58%

Programme implementation and audit, evaluation-audit					(n=67/115) and completion of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms from 6% (n=1/18) to 63% (n=73/115).
Knight et al, 2008 (46) United Kingdom Evaluation	To give an overview of the education needs analysis carried out at the beginning of the project, whilst also exploring some of the methods through which the educational needs identified were addressed.	Nursing homes n=15 320 staff members	3 years/NR	All Wales Integrated Care Pathway for the last days of life.	**Outcome measures:** Audit, questionnaire of knowledge to assess education needs. **Findings:** The audit demonstrated an improvement in the recording of end of life care. The All-Wales Integrated Care Pathway use had increased from 3% to 31% in one year.
Kortes-Miller et al, 2007 (47) Canada Implementation and evaluation	To describe an approach to developing and delivering a research-based palliative care education curriculum in long-term care homes in rural north western Ontario that can serve as a model for other rural areas. The ultimate aim of providing palliative care education is to improve access to quality end of life care for seniors living in rural long-term care homes.	Long term care facilities n=3 128 registered nurses, registered practical nurses, health care aides and recreational therapists	6 months / NR	The Palliative Care in Long Term Care curriculum.	**Outcome measures:** Participant evaluation (educational needs assessment survey). **Findings:** Evaluations from every long-term care facility were very positive. Staff confidence and participation in delivering palliative care increased.
Kortes-Miller et al, 2015 (48) Canada Evaluation	To describe the development, implementation, and evaluation of a pilot educational intervention utilizing high fidelity simulation to improve unregulated care providers' (frontline workers) confidence and skills communicating about death and dying in long term care homes.	Long term care facilities n=2 18 staff members	NR/NR	A high-fidelity simulation educational experience.	**Outcome measures:** Self- Efficacy in End of life Care survey, focus groups with unregulated providers, simulation lab education sessions, telephone interviews. **Findings:** Quantitative data showed statistically significant improvements in participants' self-efficacy scores related to communicating about death and dying and end of life care. Qualitative data indicated that the experience was a valuable learning opportunity and helped participants develop insights into their own values, beliefs, and fears providing end of life care. Pre–post results indicated statistically significant change in communication and patient management. Participants indicated they benefited by participating in the simulation through increased awareness, confidence, or comfort.
Kuhn and Forrest, 2012 (49) USA Pilot study/ evaluation	To evaluate a pilot program of palliative care education, training, consultations, and administrative coaching (pre training, 6-month post training and 12-month post training).	Nursing homes n=2 80 staff members 31 residents 33 family members	1 year NR	Palliative care intervention; including training, consultations and administrative coaching.	**Outcome measures:** Resident data from chart reviews, questionnaire of Palliative Care for Advanced Dementia. **Findings:** Improvements were demonstrated on all measures (e.g. using 2 or more antipsychotics, laboratory draws, pain assessment, pain score, pain meds, antibiotic use, tube feeding, diet without restrictions, dietary supplements, body weight, hospital admissions, hospital referrals) for residents, staff members, and family members at site 2 but improvements were not demonstrated at site 1 except for pain assessment.
Lansdell and Mahoney, 2011 (50) United Kingdom Implementation study / evaluation	To drive up standards of end of life care in care homes to a best level of practice by providing a clearer, structured model for ongoing education and support. To develop a competency package that could be disseminated to other care homes.	Care homes n=4 NR	3 years/NR	End of life care training programme (competency development package), including Principles of End of Life Care course.	**Outcome measures:** Self-reported feedback. **Findings:** All of the feedback reported an increase in confidence with providing end of life care and in accepting appropriate specialist support.

Livingston et al, 2013 (51) United Kingdom Pre-test/post-test study / mixed methods study	To improve end of life care for people with dementia in a care home by increasing the number and implementation of advanced care wishes.	Nursing home n=1 98 residents 20 family members 58 staff members	NR/NR	End of life care intervention, including interactive training program.	**Outcome measures:** Family members interviewed after their relative died and completed quality of life, Quality of Life in Alzheimer's Disease and General Health Questionnaire. **Findings:** Post-intervention there were significant increases in documented advance care wishes arising from residents and relatives' discussions with staff about end of life. These included do not resuscitate orders (16/22, 73% vs. 4/28, 14%; p<0.001); and dying in the care homes as opposed to hospital (22/29, 76% vs. 14/30, 47%; p<0.02). Bereaved relatives overall satisfaction increased from 7.5 (SD = 1.3) pre-intervention to 9.1 (SD = 2.4) post-intervention; p = 0.06. Relatives reported increased consultation and satisfaction about decisions. Staff members were more confident about end of life planning and implementing advanced wishes.
Lyon, 2007 (52) Australia Pre-post implementation study	To document implementation of best practice in ACP in a residential aged care facility using a cycle of audit, feedback and re-audit cycle audit with a clinical audit software program, the Practical Application of Clinical Evidence System.	Residential aged care facility n=1 46 resident files 14 staff members	NR/NR	Respecting Patient Choices.	**Outcome measures:** Documented evidence that the resident has been involved in ACP, that the residents family or significant others have had the opportunity to be involved in ACP, that staff who complete ACP have received training, have received regular education regarding end of life care issues, and there is evidence of ongoing assessment to ensure the ACP addresses all relevant issues as the resident's state of health alters. **Findings**: The post-implementation audit showed a clear improvement as compliance ranged from 15-100% for the five audit criteria.
Magee et al, 2017 (53) United Kingdom Pre-test/post-test study / mixed methods study	To outline the process of introducing this programme into a care home and its impact upon those who were involved.	Care home n=1 5 staff members (registered nurses, care assistants and activity coordinator) 9 residents 3 residents' families	4 weeks/NR	Namaste Care Programme.	**Outcome measures:** Cohen-Mansfield Agitation Inventory, the Cornell Scale for Depression in Dementia and the Challenging Behaviour Scale, focus groups with staff and family members. **Findings:** The majority of participants had an improvement in all three of the scales Advantages from the programme included that staff found out details about the residents of which they had been previously unaware, having families involved in the delivery of the programme was helpful in terms of building relationships and it was easier to talk to them.
Mayrhofer et al, 2016 (54) United Kingdom Mixed method study / evaluation	The goal of the Train-the-Trainer pilot project was to consolidate the success of the ABC end of life care programme, increase the capacity of the care home workforce to provide end of life care, and develop a model that could sustain training in and provision of end of life care in care homes' and to identify what supported or hindered the uptake of the programme.	Care homes n=17 274 residents 34 staff members/trainers	9 months/NR	Train-the-Trainer End of Life Care Education Programme.	**Outcome measures:** Service use logs, data collected using modified InterRAI forms, and care notes of residents who had died post intervention. Face to face interviews and focus groups. **Findings:** 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 end of life care and resident characteristics were not associated with programme completion. Working with facilitators was important to trainers, but insufficient to compensate for 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.
McGlade et al, 2016 (55) Ireland Feasibility study	To identify challenges in implementing the 'Let Me Decide' ACP programme in long term care.	Nursing homes n=2 83 staff (senior nurses) 70 residents NR family members	NR/NR	The 'Let Me Decide' - ACP programme.	**Outcome measures:** Residents who completed some form of end of life care plan, Standardised Mini Mental State Examination and Instrument to Assess Competency to Complete an Advance Directive. **Findings:** Following implementation of the programme, more than 50% of residents in each of the three study sites had some form of end of life care plan in place. Of the 70 residents who died in the post-implementation period, 14% had no care plan, 10%

					(with 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.
Moore et al, 2017, Saini et al, 2016 (56) (57) * United Kingdom Feasibility study	To (1) understand how the intervention operated in nursing homes in different health economies; (2) collect preliminary outcome data and costs of an interdisciplinary care leader to facilitate the Intervention; (3) check the Intervention caused no harm. To examine practices relating to end of life discussions with family members of people with advanced dementia residing in nursing homes and to explore strategies for improving practice.	Nursing homes n=2 9 residents 4 residents' family members 28 staff members/ 19 staff interviews	6 months/3 years	Compassion Intervention.	**Outcome measures:** Symptoms were recorded monthly for recruited residents. Semi structured interviews were conducted with nursing home staff, external healthcare professionals and family carers. Data collected on documented resuscitation status; a pain management plan; preferred place of death recorded; hospital admissions, emergency phone calls and location of deaths. Resident outcomes included Waterlow Scale (pressure ulcer risk), Neuropsychiatric Inventory, Cohen-Mansfield Agitation Inventory, Pain Assessment in Advanced Dementia Scale, Symptom Management at end of life in Dementia and Quality of Life in Late-Stage Dementia Scale. Carer outcomes included the Zarit Burden Interview, the Hospital Anxiety and Depression Scale, Satisfaction with Care at end of life in Dementia Scale and the Resource Utilization in Dementia Questionnaire. Ethnography, fieldwork notes, observations recorded in a reflective diary and post-intervention in-depth interviews. **Findings:** The intervention prompted improvements in ACP, pain management and person-centred care. Implementation was feasible to differing degrees across sites, dependent on context. The intervention provided insights into existing routines critical for driving practice improvements, often highlighting existing deficits in the care being provided. Four major themes described strategies for improving practice: educating families and staff about dementia progression and end of life care; appreciating the greater value of in-depth end of life discussions compared with simple documentation of care preferences; providing time and space for sensitive discussions; and having an independent healthcare professional or team with responsibility for end of life discussions.
Morris and Galicia-Castillo, 2017 (58) USA Evaluation	To describe the Caring About Residents' Experience and Symptoms (CARES) program, a model of palliative care for nursing home residents.	Nursing home n=1 170 residents	NR/NR	CARES Program.	**Outcome measures:** Symptom burden, treatment plans, goals of care hospitalizations. **Findings:** Following consultation, 67% of residents had a change in code status. Of residents desiring a palliative course, 90% were never hospitalized. Overall, 53% of residents died; and those in long term care dying more often with hospice.
Nilsen et al, 2018 (59) Sweden Evaluation	To explore the organizational readiness to implement palliative care in nursing homes in Sweden based on the evidence-based guidelines to support staff.	Nursing home n=20 200 staff members / 20 nursing home managers	6 months/NR	Educational intervention intended to facilitate the development of an evidence based palliative care.	**Outcome measures:** Interviews. **Findings:** Analysis of the data yielded ten factors (i.e., sub-categories) acting as facilitators and/or barriers. Four factors constituted barriers: the staff's beliefs in their capabilities to face dying residents, their attitudes to changes at work as well as the resources and time required. Five factors functioned as either facilitators or barriers because there was considerable variation with regard to the staff's competence and confidence, motivation, and attitudes to work in general, as well as the managers' plans and decisional latitude concerning efforts to develop evidence-based palliative care. Leadership was a facilitator to implementing evidence-based palliative care.

O’Brien et al, 2016 (60) United Kingdom Evaluation	An evaluation of the implementation of Six Steps with the first cohort of care homes to complete the programme; to explore the experiences of the facilitators of the programme, specifically with regard to the implementation approach they had adopted and to obtain a detailed account of the impact of Six Steps on individual care homes.	Care homes n=NR 18 CH staff-facilitators	6 months/NR	Six Steps to Success programme.	**Outcome measures:** Questionnaire, case studies, interviews. **Findings**: Post intervention improvement in ACP, 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.
Oliver et al, 2009 (61) USA Implementation study / evaluation	To describe the experience of a yearlong quality improvement initiative using the Missouri Mortality Risk Index to facilitate discussions of goals of care for nursing home residents.	Nursing home n=1 NR	12 months/NR	Missouri Mortality Risk Index to facilitate goals of care discussions. Predictive model based on the minimum dataset.	**Outcome measures:** Use of minimum dataset scores to identify residents for end of life care review, Cognitive Performance Scale and the Minimum Dataset-ADL Hierarchical Scale, Flacker score, Minimum Dataset Mortality Risk Index – Risk (MMRI-R) score. **Findings:** The goals of the study were not met, however numerous challenges were identified (related to data generation/administration and logistics to implement the intervention).
Raunker and Timm, 2010 (62) Denmark Evaluation	To evaluate an attempt to develop- through three pedagogical methods-the palliative care competencies of the personnel and make organizational improvements at three Danish nursing homes.	Nursing homes n=3 22 staff members (assistant nurse, nursing aide, home helper, social worker)	2 months/NR	Care initiative.	**Outcome measures:** Focus groups with nursing home staff members and teachers to review and evaluate the project and its benefits including reflection of their practice. **Findings:** Staff felt that their competencies in palliative care had significantly improved and that the organizational initiatives taken had improved the palliative care efforts in the nursing home, although to a lesser degree. It highlights the need for recognition by colleagues, active involvement of nursing home managers, and a certain understanding of the methods, including the importance of prioritizing practice-based competence training.
Stacpoole et al, 2015, Stacpoole et al, 2017 (63, 64) United Kingdom Evaluation Qualitative focus groups	To evaluate the effects of the Namaste Care programme on the behavioural symptoms of residents with advanced dementia in care homes and their pain management. To establish whether the Namaste Care program can be implemented in UK care homes; and what effect Namaste Care has on the quality of life of residents with advanced dementia, their families and staff.	Care homes n=2 / n=6 (4 completed) 30 residents	4 to 6 months/NR	Namaste Care Programme.	**Outcome measures:** Neuropsychiatric Inventory—Nursing Homes and Doloplus-2 behavioural pain assessment scale, Charlson index of co-morbidities, Bedford Alzheimer’s Nursing Severity Scale. Staff focus groups were held in each care home before and after the implementation of Namaste**.** **Findings:** The severity of behavioural symptoms, pain and occupational disruptiveness decreased in four care homes. Increased severity of behavioural symptoms in one care home was probably related to poor pain management, reflected in increased pain scores, and disrupted leadership. Comparison of Neuropsychiatric Inventory—Nursing Homes scores showed that severity of behavioural symptoms and occupational disruptiveness were significantly lower after initiation of Namaste Care (n=34, p<0.001) and after the second interval (n=32, p<0.001 and p=0.003). However, comparison of these measures in the second and third intervals revealed that both were slightly increased in the third interval (n=24, p<0.001 and p= 0.001). The characteristics of care uncovered before Namaste was implemented were chaos and confusion, rushing around, lack of trust, and rewarding care. After the programme was implemented these perceptions were transformed, and themes of calmness, reaching out to each other, seeing the person, and, enhanced well-being, emerged.
Taylor and Randall, 2007 (65) New Zealand Evaluation	This article will consider and demonstrate the use of process mapping as a quality improvement tool to enhance the effective implementation and sustained use of the LCP for the dying patient within aged residential care.	Residential aged care facilities n=3 NR	6 months/NR	LCP Pilot Project – including process mapping.	**Outcome measures:** Bottlenecks and solutions identified by members of the multidisciplinary team, pre-emptive prescribing. **Findings:** The following bottlenecks were identified: GP not always available to prescribe for residents' symptoms as they occur, varying levels of GP knowledge and experience, GP may not have prescription pad or controlled drug prescribing pad

					when visiting the facility, unavailability of medications, access to syringe driver difficult in rural setting, access to equipment to assemble syringe driver, staff not deemed competent in use of syringe drivers, limited after-hours pharmacy services. Solutions to each bottleneck were also identified (e.g. pre-emptive prescribing increased post implementation for pain, agitation, respiratory tract and secretions, nausea and vomiting and dyspnoea).
Temkin-Greener et al, 2017a, Temkin-Greener et al, 2017b (66, 67) USA Randomized controlled trial	To examine the efficacy of nursing home-based integrated palliative care teams in improving the quality of care processes and outcomes for residents at the end of life.	Nursing homes n=31 1018 staff members NR residents	2 years/NR	Improving Palliative Care through Teamwork (IMPACTT).	**Outcome measures:** Place of death, number of hospitalizations, self-reported pain and depression in the last 90-days of life, staff satisfaction surveys and impact on care processes and conducted rapid ethnographic assessments in all treatment homes using in-depth interviews. **Findings:** Overall, no statistically significant effect of the intervention was found. However, independent analysis of the interview data found that only 6 of the 14 treatment facilities had continuously working palliative care teams throughout the study period. Decedents in 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), control (OR, 0.482; p<0.05), and nonrandomized control nursing homes (0.581; p<0.01). Decedents in these nursing homes had reduced rates of depressive symptoms (OR, 0.191; p<0.01), but not pain or hospitalizations.
Unroe et al, 2015 (68) USA Evaluation	To reduce avoidable hospitalizations of long-stay residents using the Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC) project.	Nursing homes n=19 910 residents	12 months/NR	OPTIMISTIC Approach.	**Outcome measures:** Root-cause analyses for all acute transfers, structured interviews and physical examination with a focus on geriatric syndromes. **Findings:** Of the transfers, 29% as avoidable (57% were not avoidable and 15% were missing), and opportunities for quality improvement were identified in 54% of transfers. Lessons learned in early implementation included defining new clinical roles, integrating into nursing facility culture, managing competing facility priorities, communicating with multiple stakeholders, and developing a system for collecting and managing data.
Verreault et al, 2018 (69) Canada Quasi-experimental study	To evaluate the impact of a multidimensional intervention to improve quality of care and quality of dying in advanced dementia in long-term care facilities.	Long term care facilities n=4 193 residents with advanced dementia and their close family members	22 months/12 months	Multicomponent intervention, including training program clinical monitoring of pain, communication with families, and involvement of a nurse facilitator.	**Outcome measures:** Quality of care was assessed with the Family Perception of Care Scale. The Symptom Management for End of life Care in Dementia and the Comfort Assessment in Dying scales were used to assess the quality of dying. **Findings:** The Family Perception of Care score was significantly higher in the intervention group than in the usual care group (157.3 vs 149.1; p = 0.04). The Comfort Assessment and Symptom Management scores were also significantly higher in the intervention group. The proportion of highly satisfied families was higher in the intervention group than in the control group (71.7% vs 55.3%), although the difference was not statistically significant. CAD-EOLD scores were significantly higher in the intervention group (35.8 vs 33.1, p= 0.03), and the difference remained statistically significant within all but one subscale.
Vis et al, 2016 (70) Canada Evaluation	To develop, implement, and assess the benefits of a peer-led debriefing intervention to help staff manage their grief and provide long term care homes an organizational approach to support them.	Long term care facilities n=4 23 staff members	5 years/NR	The INNPUT intervention; a peer-led debriefing intervention to help staff manage their grief.	**Outcome measures:** Qualitative and quantitative questionnaires, field notes and interviews. **Findings:** The intervention offered staff an opportunity to express grief in a safe context with others, an opportunity for closure and acknowledgment.
Waldron et al, 2008 (71) United Kingdom	To describe an evaluation of a comprehensive palliative care education programme.	Nursing homes n=48	NR/NR	Palliative care education programme with link nurses (link nurse model)	**Outcome measures:** Survey of link nurses who attended the training course, including both qualitative and quantitative data.

Evaluation		30 staff members (nurse manager, sister, staff nurse)			**Findings:** 30/39 link nurses participated. The course and content was viewed positively, the link nurses felt they had benefited from the training course facilitator that the course material was good, and their knowledge and understanding increased. Many respondents (83%) had not commenced cascading training within their nursing home due to lack of time and competing mandatory demands.
Wickson-Griffiths et al, 2015 (72) Canada Semi structured individual /focus group interviews	To pilot evaluation of Comfort Care Rounds - a strategy for addressing long-term care home staff's palliative and end of life care educational and support needs.	Long term care facilities n=2 40 participants	18 months/10 months	Comfort Care Rounds Strategy.	**Outcome measures:** Semi structured individual and focus group interviews. **Findings:** Study participants identified that effective advertising, interest, and assigning staff to attend Comfort Care Rounds facilitated their participation. The key barriers to their attendance included difficulty in balancing heavy workloads and scheduling logistics. Inter-professional team member representation was sought but was not consistent.
Wils et al, 2017 (73) Belgium Evaluation	To assess the effect of an education program for nurses on the registration of care goals in a nursing home with a population of elderly residents suffering from dementia, to explore the views of nursing home staff on ACP in patients with dementia.	Nursing home n=1 124 residents 13 nursing staff	12 months/NR	Conceptual Framework for Implementation of ACP (model of care goals).	**Outcome measures:** Questionnaire on facilitating and obstructing factors concerning the implementation of ACP, pre-and post-measurement of all ACP-related registrations, based on a novel care goal model, semi-structured interviews. **Findings:** Apart from the number of advanced directives (p=1.00) and appointed representatives (p=0.08), all items increased significantly in all residents still alive after the registration period p<0.05), intervention included all 124 residents diagnosed with dementia, including ACP conversation with appointed representative, ACP conversation with resident. Significant changes in caregiver's views on ACP at the end of the intervention period. At 12 months, there were significant increase in the number of interviews regarding ACP held with the residents, and a significant increase in the number of care goals documented.

*Additional information sourced from published protocol.

Supplementary material 3: Overview of implementation strategies identified

Author / year Country Study design	Description of intervention	Facilitation	Details of training /education	Internal engagement	External engagement
Aasmul et al, 2018 (1) Norway Cluster randomized controlled trial	Education programme to learn early and repeated communication with patients and families and to implement ACP.	**External facilitation:** Researchers were in contact with the nursing home units during the intervention period by means of regular telephone contact every second week to support the implementation. **Internal facilitation:** Nurses attending the education seminar were named COSMOS ambassadors. After the two-day seminar, the COSMOS ambassadors were responsible for teaching their colleagues in the unit about the ACP process. The ambassadors were encouraged to find an optimal setting, according to their local routine, in which to train colleagues. Ambassadors were advised to talk during lunch and/or report (10-20 minutes) several times per week to enable optimal coverage.	Nursing home managers, registered and licensed practical nurses, and physicians related to the intervention group were invited to participate in a two-day education seminar, which offered a standardized education programme about ACP with patients and families. Nurses attending the education seminar were named COSMOS ambassadors. At least two nurses from each nursing unit, with hands-on experience with patients, were required to attend the education. It included lectures, skills training and role-play.	Nursing home managers registered and licensed practical nurses.	Physician, preferably with an established patient relationship, attended the quarterly meetings.
Agar et al 2017, Luckett et al, 2017 (2, 3) Australia Cluster randomized controlled trial	Facilitated case conferencing organised by PCPCs.	**External facilitation:** NR **Internal facilitation:** One registered nurse was trained as a PCPC in each nursing home working for two days per week or equivalent. Roles included identifying residents, organising case conferences, implementation of palliative care plans and training staff in palliative care.	Education sessions targeted at registered nurses. Training included integration of palliative care resources within care homes, such as establishment of a palliative care room, development of palliative care toolkits; and the introduction of an in-house palliative care team.	Care home staff (nursing, assistant director of nursing, manager, research nurses, allied health staff).	NR
Amador et al, 2016 (4) United Kingdom Mixed methods study	Appreciative inquiry (Social Identity Approach).	**External facilitation:** Facilitated by a palliative care nurse researcher, with experience in Appreciative Inquiry. **Internal facilitation:** NR	Three appreciative inquiry sessions over a six-month period.	Care home staff - all staff members across the three homes.	Appreciative Inquiry meetings included care home staff and visiting health care practitioners, including GPs and district nurses. GPs and district nurses were invited to participate in the intervention.
Ampe et al, 2017 (5) Belgium Quasi-experimental pre-test/post-test study with an intervention and control group	''We DECide', an educational intervention for nursing home staff on shared decision-making in the context of ACP for residents with dementia.	**External facilitation:** Each group was taught by an experienced communication trainer. **Internal facilitation:** NR	Three modules, in the form of two 4 hour workshops and a homework assignment. Each module was designed to train the specific competences that are necessary to complete the corresponding step.	Care home staff - clinical staff, management.	NR

Andrews et al, 2009 (6) Australia Action research	Action research involved semi-structured interviews to staff, residents and family members, resulting in an information package provided to family caregivers.	**External facilitation:** Researcher acted as a facilitator. **Internal facilitation:** NR	Ten meetings, consisting of two registered nurses, one enrolled nurse and two unregulated workers, and family members.	Care home staff - nurses, unregulated workers.	NR
Arcand et al, 2009 (7) Canada Pre-test/post-test study	Educational program and a booklet for staff, and optionally to families.	**External facilitation:** NR **Internal facilitation:** A trained in-house geriatric clinical nurse specialist was designated to help organize the educational sessions and facilitate staff participation.	Educational sessions, lasting 45 minutes, for nursing staff. Physicians were similarly invited to attend a 60 minute session and given a relevant medical article for further reading. A 25-minutes phone interview to family members about the last week of care at least 3 months after the death of the resident.	Nursing/care home staff, head nurses. Relatives	Consciousness raising meetings were organized with physicians, head nurses, other professionals, members of the residents' committee and administrators. Physicians were similarly invited to attend a 60 minute session and given a relevant medical article for further reading.
Badger et al, 2007, Badger et al, 2009, Badger et al, 2012 (8-10) United Kingdom Pre-test/post-test study and qualitative case study	Gold Standards Framework in Care Homes.	**External facilitation:** Care home managers were offered support over the 8 month period of introduction, by a local Gold Standards Framework in Care Homes facilitator and support by the development team, a helpline and conference calls. **Internal facilitation:** NR	Four, one-day externally located workshops, delivered face to face. Following each workshop, staff implemented the programme in their care homes, supported by training materials and local Gold Standards Framework in Care Homes facilitators.	Nursing assistants, registered nurses, care home managers.	NR
Beck et al, 2012, Beck et al, 2015 (11, 12) Sweden Quasi-experimental pre-test/post-test study and semi structured interviews	Circle sessions interspersed with workshops, semi-structured individual interviews.	**External facilitation:** One circle leader facilitated the study circle sessions and the workshops for the respective district. Three facilitators participated in a study circle leader course, a three-day workshop with two follow up days. All facilitators were employed in the respective district, two as registered nurses and one as a specialized, licensed practical nurse. **Internal facilitation:** NR.	Seven, two-hour study circle sessions with three, six-hour workshops in between. The sessions included discussions and reflections of texts or tasks carried out prior to the meeting. A second circle group was formed consisting of all the managers and registered nurses working at the care homes and focused on how to support and guide the nurses. One or two nursing assistants from each study circle group and the manager and/or registered nurse at that facility took part in workshop sessions. The workshops focused on how practices could be changed in line with discussions.	Nursing assistants, registered nurses, managers.	NR
Blackford et al, 2007 (13) Australia Evaluation	Respecting Patient Choices.	**External facilitation:** Two full time project officers assisted the care homes to prepare for the implementation, including engagement of associated community/acute services in sector and engagement and support from GPs. Project officers also provided a two-day training course to selected care home staff to prepare nominated staff to be able to facilitate ACP	A training course to selected staff. GPs were invited to an education session hosted by the local Division of General Practice and received a GP Information Kit on ACP.	Care home staff Residents and family members.	Engagement of associated community/acute services in sector and engagement and support from GPs. GPs were invited to an education session as stated.

		discussions.with residents and families as well as complete appropriate documents related to ACP. **Internal facilitation:** Facilitated discussions by selected care home staff, who attended a two day training to learn how to facilitate ACP discussions with residents and families as well as complete appropriate documents related to ACP.			
Booth et al, 2014 (14) United Kingdom Evaluation of educational interventions	Action learning project.	**External facilitation:** NR **Internal facilitation:** The sessions were facilitated by the group themselves.	A 10 day action learning skills course, with a palliative care taught component typically lasted about 90 minutes each day. The education sessions included PowerPoint presentations, and educational DVD and Social Care TV. Students were given copies of each presentation and further reading, creating a large portfolio of resource material to cascade the learning in their own nursing home.	Managers or deputy managers.	NR
	Six Steps to Success programme.	**External facilitation:** Programme delivered by one facilitator working three days per week over an eight month period. The programme materials were adapted by the facilitator to suit the locality and the needs of the care homes. Visits to the care homes between the sessions were also made for more intensive support in practice. **Internal facilitation:** NR	Programme delivered in ten online study sessions or workshops over two whole days and eight half days. Two additional days of teaching explore key issues in more depth, including ACP. Each care home committed to delegating two attendees to the programme who were expected to attend every session when possible. Each care home was provided with a file containing comprehensive materials, which were added to over the course of the programme.	Care home staff.	NR
	Gold Standards Framework for Care Homes.	**External facilitation:** Programme delivered through the end of life care coordinator team. Between workshops a support session was held in each locality, with homes from each area supported by their local end of life care coordinator. **Internal facilitation:** NR	Training consist of an introductory workshop followed by four workshops to introduce care homes to end of life care standards and best practice. A final workshop looks at consolidation and accreditation. The programme was supported by an introductory DVD, a good practice guide, and a website.	Care home staff .	Collaboration with GPs and specialists.
Brajtman et al, 2012 (15) Canada Pilot study/evaluation	Educational intervention.	**External facilitation:** NR **Internal facilitation:** NR	One module, delivered as self-directed learning about end of life delirium and inter professional practice. Each group participated in a one-hour session comprising a clinical encounter and received a didactic “theory burst” repeated two weeks later.	Care home staff.	NR
Brännström et al, 2005 (16) Sweden Evaluation	LCP.	**External facilitation:** The project principal investigator, the chief nurse for the municipality and the registered nurse responsible for care development held hour-long meetings every third month with the contact nurses to reflect on issues about end of life care. **Internal facilitation:** Facilitated by a contact registered nurse appointed at each care home. Contact nurses completed a 35 hour, online train-the-trainer course.	One three-hour sessions on the intervention. Each contact nurse then taught staff at their respective workplace and acted as a resource person for LCP implementation. A 2 x 3.5 hour course in end of life care for all staff working in residential care homes.	Nursing assistants, registered nurses, contact nurses.	Physicians included in the intervention.

Campion et al, 2016 (17) United Kingdom Implementation study	Education and training including clinical rounds, advice and guidance, communication, and care co-ordination.	**External facilitation:** Team included a palliative care consultant, a palliative care nurse consultant, a palliative care matron and three clinical nurse specialists. Care homes were facilitated by a clinical nurse specialist on the team, who undertake clinical rounds with the nursing home staff, once a month, with extra visits if necessary. **Internal facilitation:** NR	Five, one-hour education sessions. The sessions are repeated in each nursing home until all staff have attended all sessions. Once they have completed all sessions, staff receive a certificate of attendance. The clinical nurse specialists undertake once a month a clinical round with the nursing home staff to help them identify residents who are approaching the terminal phase. Care homes received a resource folder which contained copies of the training sessions and further guidance.	Nursing home staff	Clinical rounds designed to coincide the GP or relative visit.
Chapman et al, 2018 (18) Australia Quasi-experimental design	Palliative Care Needs Round, including monthly onsite clinical meeting.	**External facilitation:** The intervention consisted of a new monthly onsite clinical meeting known as the Palliative Care Needs Round (referred to hereafter as 'needs rounds'). These needs rounds were facilitated by a palliative care nurse practitioner. **Internal facilitation:** NR	The intervention was developed to allow in-house training for the nurse practitioner in conducting the needs rounds. The needs rounds allowed for indirect specialist palliative care clinical input, staff education and support for residential facilities' staff to prioritise residents for ongoing planning.	Facility staff	Ongoing planning discussions for residents ('case conferences') involved residents, their families, residential facility staff, the GP and the nurse practitioner as appropriate.
Chisholm et al, 2017, Hanson et al, 2016, Hanson et al, 2017 (19-21) USA Cluster randomized controlled trial Evaluation	Two-component intervention: a video decision aid about goals of care choices and a structured decision-making discussion with the nursing home care plan team.	**External facilitation:** Research staff provided support to nursing home staff to promote the Goals of Care discussions during implementation. **Internal facilitation:** Facilitated by a facility liaison from the care plan team at each nursing home.	One, one-hour training on the Goals of Care intervention including a printed discussion guide, and a role play of the discussion.	Care home staff	Physicians and nurse practitioners were invited to Goals of Care discussions. Family decision-makers were provided with a copy of the decision aid video and a print discussion guide. Family decision-makers were asked to participate in a care plan meeting with the care home interdisciplinary team.
Cornally et al, 2015 (22) Ireland Focus groups	'Let Me Decide' - advance care-planning programme.	**External facilitation:** Support from the research team. **Internal facilitation:** NR	Staff education on ACP considered focus groups and resources such as patient packs and laminated visual education aids.	Care home staff, clinical nurse managers and directors of nursing.	NR
Cox et al, 2017 (23) United Kingdom Exploratory mixed methods design with pre and post intervention evaluation	End of Life Care toolkit	**External facilitation:** End of life care toolkit designed and delivered by a clinical nurse specialist in palliative care, with support from a researcher and senior lecturer with expertise in communication skills training. **Internal facilitation:** NR	Three training sessions of one hour each were delivered within each care home: an introduction to the toolkit, and a session on compassion; a session on communication and end of life care; and a session considering end of life symptoms. Eighteen training sessions were conducted within the six care homes during a 3 month period.	Care home staff.	The toolkit was designed with an expert steering group (two doctors working in local hospices, two geriatricians, and an academic specialising in cancer and palliative care).

Cronfalk et al, 2015 (24) Sweden Focus groups	Three competence-building programs between specialized palliative care units engaged by the county councils and nursing homes.	**External facilitation:** NR **Internal facilitation:** NR	Education of 1–2 key persons per ward, including three, two-hour seminars, introducing the principles of palliative care. The program introduced role-play as a pedagogical means for learning.	Registered nurses, enrolled nurses, care assistants.	NR
		External facilitation: Seminars followed by a consultation and support visits once a month for a year. **Internal facilitation:** NR	Separate seminars for staff (5 x 2 hours for enrolled nurses and care assistants, and 4 x 2 hours for registered nurses), with a focus on the principles of palliative care and the palliative team, followed by consultation and support visits once a month for a year.	Registered nurses, enrolled nurses, care assistants.	NR
		External facilitation: NR **Internal facilitation:** NR	Three shared seminars (about 1.5 hours) introducing the LCP.	Registered nurses, enrolled nurses, care assistants.	NR
Farrington, 2014 (25) United Kingdom Pre-test/post-test study and semi structured interviews	The 'ABC' course, a blended e-learning programme (face-to-face facilitated workshops alongside online content).	**External facilitation:** Two nurses with significant experience in end of life care delivery and training acted as facilitators. Facilitators led the workshops and meetings, and were available to participants for additional contact via email both during and after the course. **Internal facilitation:** NR	Blended learning component, including six one-hour online modules and followed by five facilitated workshops. The workshops took the format of facilitated discussion led by the ABC course facilitators with reference to online materials, and lasted between 60 and 90 minutes.	Care home staff	NR
Fernandes, 2008 (26) Australia Pre-test/post-test study	The Getting Research into Practice (GRIP) process of the Practical Application of Clinical Evidence System program.	**External facilitation:** Activities facilitated by the study author. **Internal facilitation:** NR	Formal and informal in service, one to one education sessions. Education was provided on different topics related to ACP and management of end of life care. Residents and their relatives were invited to attend one of two separate sessions held on different days at different times. Additionally, residents and nursing staff held 'one on one' meetings with residents/relatives where the advance care plan was the main topic of discussion. Multidisciplinary meetings with a specific emphasis on an advance care plan were held twice weekly with residents and their relatives.	Managers and general staff	Multidisciplinary meetings held twice weekly, included resident's GP, the director of nursing, the deputy director of nursing, nurse educator, physiotherapist, lifestyle coordinator and the registered nurse on duty.
Finucane et al, 2013 (27) United Kingdom Evaluation	Gold Standards Framework in Care Homes.	**External facilitation:** Facilitated by two community palliative care clinical nurse specialists who each spent one day per week working with care home managers, staff and GPs and provided education. Support by phone/in person outside of these meetings as required. Care home staff were encouraged to implement anticipatory care plans from admission. They were trained to use the adapted LCP when residents were identified as approaching death. **Internal facilitation:** NR	Education programme based on the Macmillan Foundations in Palliative Care for Care Homes, provided by facilitator. Staff across all care homes were invited to attend each workshop, and the number of workshops was based on staff need and clinical nurse specialist time. Each workshop lasted 2.5 hours and was facilitated by both nurse specialists. Nine care home staff shadowed a nurse specialist and hospice staff for a day.	Care home staff - care home managers, staff.	Multidisciplinary team meetings, including the nurse specialist and GP.
Frey et al, 2017 (28) New Zealand Pre-test/post-test study and interviews	Supportive Hospice Aged Residential Exchange.	**External facilitation:** Clinical coaching by a specialist palliative care nurse through direct (for complex needs) and indirect (not so complex needs) patient consultation. **Internal facilitation:** NR	Training included clinical coaching by a specialist palliative care nurse through patient consultation, role modelling of ACP conversations and debriefing amongst all staff following a resident's death.	Care home staff – nurses.	ACP conversations and debriefing following a resident's death with GPs.

Garden et al, 2016 (29) United Kingdom Evaluation	Bromhead Care Home Service - Education programme based on the Stop Delirium! Material.	**External facilitation:** Two registered general nurses with extensive experience in care of inpatients with dementia and frailty were seconded to provide for a two-year period, supported by a consultant liaison psychiatrist. **Internal facilitation:** NR	An education programme was developed based on the Stop Delirium! material delivered via small group teaching 6–8 times in each care home to ensure all members of staff had participated. Educational material was developed on eating, drinking and dysphagia. Care homes were given a reference file with the information.	Care home staff	Facilitation supported by a consultant liaison psychiatrist, GPs asked to refer residents to service is approached, and endorse advance care plans.
Giuffrida, 2015 (30) USA Evaluation	Comprehensive palliative care program.	**External facilitation:** NR **Internal facilitation:** NR	Included educating staff about goals of care, educating residents and families about palliative care philosophy, discussions of palliative care in daily morning report on residents whose health was declining.	NR	Establishment of regular meetings of the palliative care committee.
Hall et al, 2011 (31) United Kingdom Evaluation - qualitative methods	Gold Standards Framework for Care Homes.	**External facilitation:** NR **Internal facilitation:** NR	Curriculum includes resources, learning aids and tools with adaptations to meet the needs of local areas. Most staff described some training in end of life care. The extent and type of training varied considerably between homes.	NR	NR
Hasson et al, 2008 (32) United Kingdom Evaluation - qualitative study	Palliative care educational programme and link nurse role.	**External facilitation:** An independent clinical practitioner, specializing in palliative care, delivered initial education to nursing home staff, and provided support to link nurses within each home. A full-time nurse co-coordinator prepared and assisted volunteer link nurses in delivering the educational programme. **Internal facilitation:** Link nurses, who disseminated information from the coordinator into each nursing home. Monthly meetings were held with the facilitator and link nurses to reassess educational needs.	Educational programme, provided to nursing home staff, of facilitated learning for care home staff including expert opinion, a review of the literature, educational courses and the Macmillan Foundations in Palliative Care learning pack. A link nurse assisted in delivering an educational programme consisting of an information pack. Each link nurse was provided with a resource file outlining the palliative care educational programme for registered nurses and other care staff. This also gave details of hospices and other services which nursing homes could access for support and advice.	Care home staff - link nurses.	NR
Hewison et al, 2008 (33) United Kingdom Case study approach / evaluation - qualitative study	Gold Standards Framework for Care Homes.	**External facilitation:** Facilitators were nurses or GPs who had experience of using the Gold Standards Framework. **Internal facilitation:** A Gold Standards Framework coordinator was identified from the home staff to act as a link between the external facilitator and staff.	A one-day launch event followed by facilitators working with small groups of care homes to assist them with the Gold Standards Framework, followed by three one-day workshops.	Care home staff.	NR
Hickman et al, 2016 (34) USA Implementation study	Advanced Care Planning, using a structured interview guide.	**External facilitation:** Facilitated by a full-time specialized palliative care registered nurse developed for the project. Facilitators received training including the End of life Nursing Education Consortium geriatric curriculum, a comprehensive palliative care educational program. Facilitators were supported by six nurse practitioners and a team of geriatricians. Facilitators were trained using an online training module, followed by 8.5 hours of face to face role playing and education. Facilitators also completed additional role-playing activities, and some were trained as certified instructors. **Internal facilitation:** NR	Facilitators provided in service training to nursing home clinical staff. Training included the End of life Nursing Education Consortium geriatric curriculum and the Respecting Choices Last Steps intervention. The program requires independent online training modules followed by 8.5 hours of face-to-face role-playing and education. Educational handouts on selected topics were also used to guide conversations and support informed decision-making. Educational sessions were offered to residents and families.	Registered nurses. Residents and relatives	

Ho et al, 2016a, Ho et al, 2016b (35, 36) China Evaluation	End of life integrated care pathway / Dignity-Conserving End of life Care Model.	**External facilitation:** Facilitated by an interdisciplinary end of life care team consisting of three core members with expertise in social work, nursing and medicine. The end of life care team was shared between all three nursing homes. A project officer with background in palliative nursing was responsible for providing nursing care to all program participants and delivering training to other nursing staff. **Internal facilitation:** The trained staff were encouraged to cascade this training down.	Two module training programs combined to impart an overarching philosophy of holistic care in practice. An annual fieldwork attachment program with overseas palliative care training institutes was developed and provided to managerial staff and senior care professionals of each nursing home. The skills and knowledge obtained were transferred to all formal care workers through a train-the-trainer paradigm. Education talks and seminars were offered to interested residents and their families	Care home staff, nurses, social workers, personal care workers.	An interagency care co-ordination protocol was established with two partnering hospitals to provide acute and convalescent care as well as medical advice and support for terminally ill residents.
Hockley and Kinley, 2016 (37) United Kingdom Intervention audit	Gold Standards Framework in Care Homes.	**External facilitation:** The programme was facilitated by the Care Home Project team. The nurse facilitators visited the care homes every 7–10 days to establish good relationships with staff/ management and to role model aspects of the programme. **Internal facilitation:** Each care home was encouraged to appoint at least two coordinators who would lead the implementation. During the pre-implementation period, these coordinators attended the Foundations in Palliative Care for Care Homes course held in local care homes.	Four workshops. Additional training included an ‘Introduction to palliative care day’ for all new staff, the Macmillan Foundations in Palliative Care (4 days over 2 months) course for carers and nurses, and action learning sets attended by managers every 2–3 months.	Care home staff	Each care home arranged for meetings where staff, external healthcare professionals (e.g. GP) and families were informed about the programme.
Hockley et al, 2010, Watson et al, 2010 (38, 39) United Kingdom Evaluation - qualitative pre/post implementation	Gold Standards Framework in Care Homes and an adapted LCP.	**External facilitation:** Facilitated by an experienced palliative care nurse, who visited each care home every 10–14 days. The nature of the contact included attending monthly register meetings alongside GPs; scenario-based teaching on death, and regular meetings with management/champions, role modelling good palliative care as the opportunity arose and facilitating debriefing sessions following a death. **Internal facilitation:** Two key champions were appointed in each home and were responsible for co-ordinating and embedding changes. Key champions attended four workshops over the year. Key champions attended a four day facilitative learning course ‘Foundations in Palliative Care for Care Homes’ and were encouraged to cascade this training down to their own staff with the help of the facilitator. Champions implemented two main systems: The Gold Standards Framework in Care Homes 'supportive/palliative care register' or the 'adapted LCP'.	One, two-hour scenario based training. All staff were encouraged to attend 2-hour scenario-based training where they practised using the LCP documentation. Each manager organized the training over a two week period.	Care home staff - managers, key champions, all staff.	GPs were invited to attend these monthly meetings alongside the facilitator.
Horey et al, 2012 (40) Australia Action research/ evaluation	Introduction of end of life care pathways.	**External facilitation:** NR **Internal facilitation:** NR	NR	Care home staff, managers.	Care pathways involved GPs
in der Schmitten et al, 2014 (41) Germany	Advanced Care Planning program; “beizeiten begleiten, based on the US “Respecting	**External facilitation:** The research team attended a one-week training course to become certified facilitators and instructors for Respecting Choices. They developed an ACP program tailored to the German nursing homes.	One, 20-hour training course for the two to four facilitators from each care home. Physicians received four hours of training. Education sessions were provided to nursing staff at the care home, nursing staff at the regional hospital; medical and paramedic emergency staff and professional guardians.	Care home staff.	Physicians were offered four optional 1.5-hour meetings over 2 years. Separate information events for nursing staff at care homes and at the

controlled trial - evaluation	Choices” programme.	**Internal facilitation:** Facilitated by two to four non-physician facilitators from each care home.			regional hospital, for hospital and emergency physicians, for emergency medical service paramedical staff, and for professional guardians.
Kataoka-Yahiro et al 2017 (42) USA Evaluation	Palliative and hospice care training palliative and hospice care training.	**External facilitation:** NR **Internal facilitation:** NR	One four hour communication skills workshop and a ten week culturally appropriate palliative and hospice care training. An interactive communication workshop followed the modular sessions that involved lecture and small group sessions. Each session accommodated a majority of employees working on day and evening shifts. Sessions were videotaped for those who were not able to attend the sessions.	Care home staff.	Hospital staff who attended the palliative and hospice care training included both experienced clinical staff from various disciplines and nonclinical staff (administration and education).
Kinley et al, 2014 Kinley et al, 2018 (43, 44) United Kingdom Cluster randomized controlled trial	Gold Standards Framework for Care Homes.	**External facilitation:** A facilitator visited nursing homes two to three times a month along with attendance at four GSFCH workshops. The facilitator helped coordinators to implement the Liverpool Care Pathway (LCP)/integrated care pathway (ICP), providing ongoing induction days for new staff and ongoing training. **Internal facilitation:** Two coordinators were appointed from each nursing home. Coordinators attended a 4-day training on the Macmillan ‘Foundations in Palliative Care for Care Homes’ curriculum.	In the high facilitation and action-learning arm of the study, each nurse manager was asked to attended one, three-hour action learning set every month between the first and fourth Gold Standards Framework for Care Homes workshops. Action learning centred on 'leadership' in relation to implementing the framework programme.	Care home staff, care home managers.	NR
Kinley et al, 2017 (45) United Kingdom Programme implementation and audit, evaluation-audit	Steps to Success programme.	**External facilitation:** Facilitator visited care homes at least twice a month to help implement the programme and role model discussions and care where required. **Internal facilitation:** NR	One, four-day Macmillan Foundations in Palliative Care for care homes training provided to the care home manager and senior carers. Training consisted of half-day seminars and action learning sets. An introduction to palliative care day was run monthly for all new members of staff to the care home.	Care home staff, care home managers.	GPs, district nurses and specialist palliative care teams informed about study. Managers encouraged to attend multidisciplinary team meetings with a GP.
Knight et al, 2008 (46) United Kingdom Evaluation	All Wales Integrated Care Pathway for the last days of life.	**External facilitation:** The project coordinator, a senior nurse, facilitated and funded the study days, in collaboration with the local specialist palliative care teams from across South-East Wales. **Internal facilitation:** The coordinator set up a learning contract with the link senior nurse in individual care homes (usually the matron) which outlined expectations around times, numbers of nurses, participation, venue and various other ground rules prior to providing education.	Education included a standardized Integrated Care Pathway education pack, formal and informal teaching sessions and afternoons, a ‘Train the Trainer’ syringe driver training implemented over a two-year period, informal training and support sessions, including post-death debriefing sessions, study days, covering issues around improving end of life care.	Care home staff – nurses.	NR
Kortes-Miller et al, 2007 (47) Canada	The Palliative Care in Long Term Care curriculum.	**External facilitation:** Facilitators were recognized palliative care providers from the community who had received palliative care education through a train-the-trainer program. Facilitators received an introduction to the course by the course curriculum	Six, 2.5 hour training sessions. Care home staff received PowerPoint slides for each session, group exercise materials, case study exercises, and a list of palliative care resources on the topics covered. The facilitator's package contains additional reading material and resources on each	Care home staff.	NR

Implementation and evaluation		developer, and offered face-to-face meetings, and telephone or email support throughout the course delivery. **Internal facilitation:** A recognized leader within the facility, who had expertise in palliative care, act as a facilitator of the education.	topic, ice breakers, suggestions for group interaction exercises, case studies, suggested questions for group discussions, and a list of available educational videotapes.		
Kortes-Miller et al, 2016 (48) Canada Evaluation	A high-fidelity simulation educational experience.	**External facilitation:** A high fidelity simulation educational experience was facilitated by two of the researchers on two separate occasions. **Internal facilitation:** Two unregulated providers working as research collaborators informed their peers of the simulation learning opportunity and promoted their perception of the benefits.	Two, high fidelity simulation educational experiences lasting 3.5 hours. A participant manual was given to the staff.	Unregulated care providers.	NR
Kuhn and Forrest, 2012 (49) USA Pilot study/ evaluation	Palliative care intervention; including training, consultations and administrative coaching.	**External facilitation:** Facilitated by a project nurse with experience and expertise in dementia and palliative care, who provided weekly and as needed support for nurses and nursing assistants. **Internal facilitation:** NR	Training consisted of 12 hours of interactive sessions at each nursing home, delivered in six modules at times convenient for all shifts, including education booklet provided to all participating family members and staff members. Case consultations by a project nurse with experience and expertise in dementia and palliative care were provided weekly and as needed for nurses and nursing assistants. The administrative coaching component consisted of monthly meetings of ‘‘Comfort Care Advisory’’ committees established at each nursing home.	Care home staff Relatives	One palliative care consultation by physicians from the hospice for all enrolled residents and their available family members. A contractual relationship was formed with a local non-profit hospice to assist with training and palliative care consultations.
Lansdell and Mahoney, 2011 (50) United Kingdom Implementation study / evaluation	End of life care training programme (competency development package), including Principles of End of Life Care course.	**External facilitation:** Facilitated by staff from a local hospice who delivered a competency assessment training day. **Internal facilitation:** Key staff from each care home who participated in the training disseminated the information, through team meetings and through supervision.	Ten, fortnightly one hour sessions with participants from each care home to introduce the study. A five day education course, principles of end of life care.	Care home staff. Relatives	Relationship building between local hospice and care home.
Livingston et al, 2013 (51) United Kingdom Pre-test/post-test study / mixed methods study	End of life care intervention, including interactive training program.	**External facilitation:** Facilitated by a consultant physician and care home senior managers, who were part of the research team. **Internal facilitation:** NR	Ten sessions of a manualized interactive training program.	Care home staff - general nurses, residential and senior care workers.	NR
Lyon, 2007 (52) Australia Pre-post implementation study	Respecting Patient Choices.	**External facilitation:** External assistance was provided by the Manningham Centre, who provided training related to the Respecting Patient Choices Program. **Internal facilitation:** The facility's Palliative Care Best Practice Group supported the project.	Training included a total of 16 contact hours and additional one-to-one assistance with an experienced mentor when holding discussions with residents. Information sessions on ACP were conducted for nursing and medical staff, residents and their families.	Care home staff - general nurses.	Monthly meetings of the Palliative Care Best Practice Group, including GPs and other health professionals. Information kits were prepared for the

					doctors who did not attend the session.
Magee et al, 2017 (53) United Kingdom Pre-test/post-test study / mixed methods study	Namaste Care Programme.	**External facilitation:** The facilitator held a training session for staff and carers to be involved with the programme prior to its commencement. The first session of the programme was delivered by facilitator but was then run by the activity therapist with help from relatives. **Internal facilitation:** NR	One two-hour session to participate in Namaste Care Programme activities with participation of residents, staff and family carers.	Care home staff, managers. Residents and relatives	NR
Mayrhofer et al, 2016 (54) United Kingdom Mixed method study / evaluation	Train-the-Trainer End of Life Care Education Programme.	**External facilitation:** Facilitated by End of Life Care Educators/ facilitators who held various roles including palliative link nurse, palliative care nurse, practice-development nurses for care homes, end of life care specialist and end of life educator. All trainers had completed the ABC training. **Internal facilitation:** The project trained two ‘trainers’ per care home, who subsequently trained six ‘learners’ each. Trainers’ responsibilities included the preparation of on-line and face-to-face teaching sessions, the organisation and facilitation of group discussions, and offering learners bite-size micro-teach sessions in daily practice.	Trainers took six end of life care training modules and three skills training workshops to support their trainer role, including input pertaining to learning and teaching methods, and practice workshops with educators/facilitators. The study aimed to train two ‘trainers’ per care home, who in turn were to train six ‘learners’ each.	Care home staff.	NR
McGlade et al, 2016 (55) Ireland Feasibility study	The ‘Let Me Decide’ - ACP programme.	**External facilitation:** Staff were supported by the research team. During monthly feedback meetings, any issues arising during implementation were discussed and changes were made to the programme to address the needs identified. **Internal facilitation:** NR	Two half-day workshops covering the principles of palliative care, communication skills, bereavement and symptom assessment and management, were delivered to nurses and healthcare assistants.	Care home staff.	NR
Moore et al, 2017 Saini et al, 2016 (56) (57) United Kingdom Feasibility study	Compassion Intervention.	**External facilitation:** The intervention was facilitated by an interdisciplinary care leader, employed full time to work in two nursing homes for six months. The interdisciplinary care leader was present in each care home for three half-days per week and with two nursing homes to provide mentoring, role modelling, advice and training. **Internal facilitation:** Facilitated by two key champions, appointed in each care home. Facilitators were responsible for co-ordinating and embedding changes, and encouraged to cascade this training down to their own staff with the help of the external facilitator.	Formal staff and family training sessions ran by the facilitator, including informal on the job advice and support.	Care home staff, managers.	Weekly core team meetings, including the clinician, care home nursing staff and the interdisciplinary care leader. Monthly wider team meetings consist of the core team plus any local health and social care professionals and specialists, including GPs.
Morris and Galicia-Castillo, 2017 (58) USA Evaluation	CARES Program.	**External facilitation:** NR **Internal facilitation:** NR	One, one hour in-service and online training by the palliative care physicians provided on: basics of palliative care, goals of care, pain, comprehensive assessment of non-pain symptoms, end of life care, and bereavement/self-care.	Care home staff.	

Nilsen et al, 2018 (59) Sweden Evaluation	Educational intervention intended to facilitate the development of an evidence based palliative care.	**External facilitation:** The seminars were led by five registered nurses and researchers and one registered nurse who worked clinically, all with experience from working as nurses in palliative and geriatric care settings. Facilitators provided flexible support to homes, which was individually tailored to the needs of each home, consisting of a one to one visit to each home between each step to provide support. All facilitators also provided additional support and documentation via telephone and email throughout the programme. **Internal facilitation:** The participants were selected by the manager of each nursing home, to continue as seminar leaders for further training of the entire staff at each nursing home.	The educational intervention consisted of five seminars. The seminars combined lecture style presentations and more interactive group discussions. They were provided as an outreach course and took place within nursing homes. The research team developed an educational booklet primarily based on the two knowledge documents, including recommended assignments to do as preparations before each seminar and assignments to complete after each seminar. A list of references for further self-studying was also given in the booklet. The seminar group at each nursing home consisted of 8–10 participants and met approximately once a month over a period of 6 months.	Care home manager, assistant nurses, registered nurses.	The seminar content was determined after the discussions with staff, informal caregivers, and patients representing both hospital and community care.
O'Brien et al, 2016 (60) United Kingdom Evaluation	Six Steps to Success programme.	**External facilitation:** A facilitator delivered the workshops, and provided guidance and continual support to the implementation of end of life care changes in the home. **Internal facilitation:** Nominated care home staff, champions, led the Six Steps programme, they attended the workshops and cascade the information to all home staff.	A workshop format addressing the core phases of end of life care within a six-stage cycle.	Nurses.	Occupational therapists and physiotherapists involved.
Oliver et al, 2009 (61) USA Implementation study / evaluation	Missouri Mortality Risk Index to facilitate goals of care discussions. Predictive model based on the minimum dataset.	**External facilitation:** NR **Internal facilitation:** NR	NR	Care home staff.	Physicians and facility social worker were involved.
Raunker and Timm, 2010 (62) Denmark Evaluation	Care initiative.	**External facilitation:** Teachers employed at a local university. **Internal facilitation:** NR	Training was provided based on a selection of topics as requested by the care home, including clinical knowledge about death, communication, law and ethics and multi professional cooperation, attitudes towards life and death, clinical guidelines, everyday aesthetics.	Care home staff.	Social workers and physicians involved.
Stacpoole et al, 2015, Stacpoole et al, 2017 (63, 64) United Kingdom Evaluation Qualitative focus groups	Namaste Care Programme.	**External facilitation:** Researchers acted as external facilitators. Following the workshop, the researchers visited each care home for a day, within the same week as the training, holding 20-minutes 'teaching huddles' explaining Namaste to as many staff as possible. A further visit the following week included role modelling a Namaste session. **Internal facilitation:** One care worker was allocated responsibility for up to eight residents with advanced dementia in the Namaste space, while others take responsibility for the remaining residents. The Namaste care workers were chosen by their managers because they commanded respect within the care team, based on seniority and/or personality.	A one-day workshop attended by each care home manager and at least two designated Namaste Care workers from each care home. The workshop included teaching about advanced dementia, end of life care, and outlining the theory and practice of Namaste. Each manager received two copies of a book on Namaste and information about their role in the research.	Care home staff.	Meetings with family/friends of a relative

Taylor and Randall, 2007 (65) New Zealand Evaluation	LCP Pilot Project – including process mapping.	**External facilitation:** A LCP facilitator led the process mapping meetings and took responsibility for ensuring that solutions were actioned. **Internal facilitation:** NR	An intensive education programme explaining the use of the LCP in practice was offered to clinical staff. A process mapping meeting was arranged at each facility with members of the interdisciplinary team.	Manager, care manager, senior nurse, local pharmacist.	Local pharmacist
Temkin-Greener et al, 2017a, Temkin-Greener et al, 2017b (66, 67) USA Randomized controlled trial	Improving Palliative Care through Teamwork (IMPACTT).	**External facilitation:** A TeamSTEPPS master worked within the team in each facility. Facilitated by a study nurse interventionist, a geriatric nurse practitioner certified in End of life Nursing Education with significant nursing home practice experience. During the passive phase, the nurse interventionist was available to further coach the team on as needed/requested basis. **Internal facilitation:** NR	Two training-education intervention components: 1. TeamSTEPPS (Strategies & Tools to Enhance Performance and Patient Safety), used to develop palliative care teams. 2. End of Life Nursing Education (ELNEC) - six, one-hour training modules provided ion the facility to all palliative care team members and to all direct care staff. Workshops were taught by the study nurse interventionist. Once staff completed ELNEC training, their facility was provided free on-line access to online modules for a three-year period.	Registered and licensed practising nurses, certified nurse assistants.	Physician's assistants and physicians involved in the development of palliative care teams. Social workers and therapists involved in the intervention.
Unroe et al, 2015 (68) USA Evaluation	Optimising Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC) approach.	**External facilitation:** Facilitated by OPTIMISTIC nurses; seven full-time employed nurse practitioners covered three to four facilities each, coordinated with the internal registered nurses, and complemented the care of primary care providers by providing in-person evaluation and management of residents with acute changes or recent transition from the hospital. **Internal facilitation:** Full-time registered nurses at each nursing facility lead the intervention addressing changes in condition and leading quality improvement efforts.	Training for OPTIMISTIC staff was a 2-week "boot camp" designed to introduce them to the overall project. OPTIMISTIC staff were trained in the Respecting Choices Last Steps Staff also receive the ELNEC curriculum, a train-the-trainer educational program designed to improve palliative care in the long-term care setting.	Registered nurses, facility staff.	Physicians involved in each collaborative care review.
Verreault et al, 2018 (69) Canada Quasi-experimental study	Multicomponent intervention, including training program clinical monitoring of pain, communication with families, and involvement of a nurse facilitator.	**External facilitation:** A local committee composed of an administrator, head nurses, and a physician was formed to facilitate the intervention. **Internal facilitation:** The two local nurse facilitators in the intervention facilities were selected among the regular staff for their interest in end of life care and leadership with colleagues. The facilitators were released from their regular responsibilities for one year in order to work exclusively for the project. They received a 35 hour training in palliative care in advanced dementia. Facilitators helped researchers in organizing the training sessions, provided training to care home staff, acted as a coach for the nursing staff and facilitated communication between nurses, physicians, and family members.	Staff training sessions were completed followed by continuous involvement of a nurse facilitator in the intervention settings (seven hours for nurses and 3.5 hours for nurses' aids). The nurse facilitators trained the nursing staff to use a pain assessment. Three hour training offered to physicians.	Care home staff.	Facilitators provided written information in the form of a booklet entitled Comfort Care at the end of life for persons and organized a meeting between the family member and the physician.
Vis et al, 2016 (70) Canada Evaluation	The INNPUT intervention; a peer-led debriefing intervention to help staff manage their grief.	**External facilitation:** Researchers trained unregulated care providers to become facilitators. **Internal facilitation:** Volunteer unregulated care providers became facilitators.	Two training sessions provided on disenfranchised grief.	Care home staff/ unregulated care providers (front-line staff) - personal support workers, health care aids, nurse´s aids, nursing assistants.	NR

Waldron et al, 2008 (71) United Kingdom Evaluation	Palliative care education programme with link nurses (link nurse model).	**External facilitation:** A palliative care education facilitator coordinated and delivered the training. **Internal facilitation:** Trained link nurses delivered the training provided by the external facilitator to other staff.	Education on the "Foundations in Palliative Care" delivered in-house to link nurses, in central venues using a facilitated pack and a resource file.	Care home staff.	NR
Wickson-Griffiths et al, 2015 (72) Canada Semi structured individual /focus group interviews	Comfort Care Rounds (CCRs) Strategy.	**External facilitation:** A palliative care consultant, comprehensive advanced palliative care education trained nurse, and other CCRs leaders (e.g. nurse managers) were responsible for chairing or co-chairing CCRs with interprofessional staff and palliative care volunteers. Responsibilities included developing an agenda, promoting and advertising CCRs, facilitating discussion, providing education, and disseminating key messages to staff not in attendance. **Internal facilitation:** CCRs leaders (e.g. nurse managers) were responsible for chairing or co-chairing CCRs.	CCRs were scheduled on a monthly basis, for 30 minutes to 1 hour.	All members of the interprofessional team and palliative care volunteers.	Two palliative care physicians from under a medical director contract provided consultation.
Wils et al, 2017 (73) Belgium Evaluation	Conceptual Framework for Implementation of ACP (model of care goals).	**External facilitation:** The educational training sessions were given by one of the researchers who had been trained in ACP. **Internal facilitation:** NR	Two educational training sessions and four debriefing sessions, lasting two hours each. A number of conversations with the residents were filmed and discussed in the intervention group.	Registered nurses.	NR

Abbreviations

ACP - Advance care planning
CARES - Caring About Residents’ Experience and Symptoms
CCRs - Comfort Care Rounds
DNACPR - Do not attempt cardiopulmonary resuscitation
DNAR - Do not attempt resuscitation
ESAS - Edmonton Symptom Assessment
GP - General practitioner
CP - Integrated care pathway
LCP - Liverpool care pathway
LTCF - Long term care facility
MMRI-R - Minimum Dataset Mortality Risk Index – Risk
MOST - Medical orders for scope of treatment
PCPC - Palliative care planning coordinator
VOICES - Views of Informal Carers – Evaluation of Service

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Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3/4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	4
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	4
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary material 1
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	4
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	5
Critical appraisal of individual	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe	N/A

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
sources of evidence§		the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	5
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Page 5/ Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Supplementary material 2
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Supplementary material 3
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	6-9
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	9
Limitations	20	Discuss the limitations of the scoping review process.	10
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	10-11
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	12

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. ;169:467–473. doi: 10.7326/M18-0850

No.	Item	Guide and description	Page number
1	Aim	State the research question the synthesis addresses.	4
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework, which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	6
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	5
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	Table 1
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	5
6	Electronic search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	Supplementary material
7	Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	5
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions)	Supplementary material
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g., for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).	Figure 1
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	N/A
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	N/A
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	5

13	Appraisal results	Present results of the quality assessment and indicate which articles if any,were weighted/excluded based on the assessment and give the rationale.	N/A
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a computer software).	6
15	Software	State the computer software used, if any.	N/A
16	Number of reviewers	Identify who was involved in coding and analysis.	5
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	6
18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	6
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive	6
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation.	Table 4
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	7-10

Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) guidelines.

Appendix E: Collingridge Moore, D., Payne, S., Van Den Block, L., Ten Koppel, M., Szczerbinska, K. & Froggatt, K. (2019) Research, recruitment and observational data collection in care homes: lessons from the PACE study. BMC Res Notes, 12(1), 508.

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BMC Research Notes

RESEARCH NOTE

Open Access

Research, recruitment and observational data collection in care homes: lessons from the PACE study

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Abstract

Objective: Care homes are a common place of death for older adults, especially those with complex health needs or dementia. Representative, internationally comparable data on care home facilities and their residents is needed to monitor health and wellbeing in this population. Identification and collection of data from care homes can be challenging and often underreported. This paper draws on the experiences of the PACE study, a cross sectional mortality follow back study conducted in six European countries.

Results: Multiple challenges were encountered in creating a sampling framework and contacting, recruiting and retaining care homes in the PACE study. Recruiting a randomly identified, representative cohort from a stratified sampling framework was problematic, as was engaging with care homes to ensure high response rates. Variation in the funding of care homes across the six countries involved in the study may explain the additional challenges encountered in England. Awareness of the challenges encountered in England in implementing an international study in care homes can inform the design and implementation of future studies within care homes. Further discussion is needed to determine the barriers and facilitators to conducting research in care homes, and how this is shaped by the focus of the study.

Keywords: Care home, Nursing home, Long term care facility, Palliative care, Observational study, Epidemiology

Introduction

Long term care facilities, or care homes, are becoming a common place of death for older adults [1, 2]. Ensuring that appropriate services are available to meet the health needs of this population will require accurate, good quality data. Research in this area is increasingly complex; in addition to the challenges of conducting research with older adults [3], the difficulties in obtaining ethical approval, accessing care home residents through gatekeepers, gaining informed consent and collecting data from residents have been explored [4–8]. The experiences of involving care homes as facilities in research, rather than residents, is less understood.

The Palliative Care for Older People in care and nursing homes in Europe (PACE) programme of research, centred on improving palliative care in long-term care facilities across Europe [9]. This paper reflects on the experience of setting up and running a cross sectional study of resident deaths within care homes, conducted in six European countries: United Kingdom (England), the Netherlands, Belgium, Finland, Poland and Italy [10]. The study aimed to recruit 48 care homes in each participating country, collecting data on 192 deceased residents, from care home staff members, general practitioners (GPs)/physicians and relatives of the resident, collecting data on patient and family palliative care outcomes [11–15].

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Figure 1 displays the recruitment and response rates for each questionnaire, for each participant per country. The response rates for care homes in England were lower than in the other countries involved in the study. This paper aims to describe the challenges encountered in conducting the study in England to inform the design and conduct of future international research in care homes. It will specifically explore the challenges encountered in developing and piloting the study, creating a sampling framework, contacting and recruiting care homes, conducting research visits and increasing response rates.

Main text

PACE study development and piloting

During the PACE study development, focus was on ensuring questionnaire data collected across countries would be comparable. Country specific questions and terminology were included, where appropriate, to reflect variation in the funding and types of care homes available. In each country, study documentation was piloted to ensure wording and formatting were accessible; in England this included feedback from a public involvement group, staff from two care homes and three GPs. Feedback centred on whether questionnaire respondents were required to provide written informed consent for their answers to be used before returning the questionnaire. It was agreed that return of the questionnaire would imply consent, providing that this was clearly stated in the participant information leaflet. A 3-month delay following the death on sending the relative questionnaire and signposting to bereavement services was also requested. This lag time extended the study cut-off date for returned data in England.

Two ethical issues were identified in study development, which potentially affected all countries involved in the study. The first issue concerned how care homes could provide confidential data on residents without breaking anonymity; to accommodate this the care home

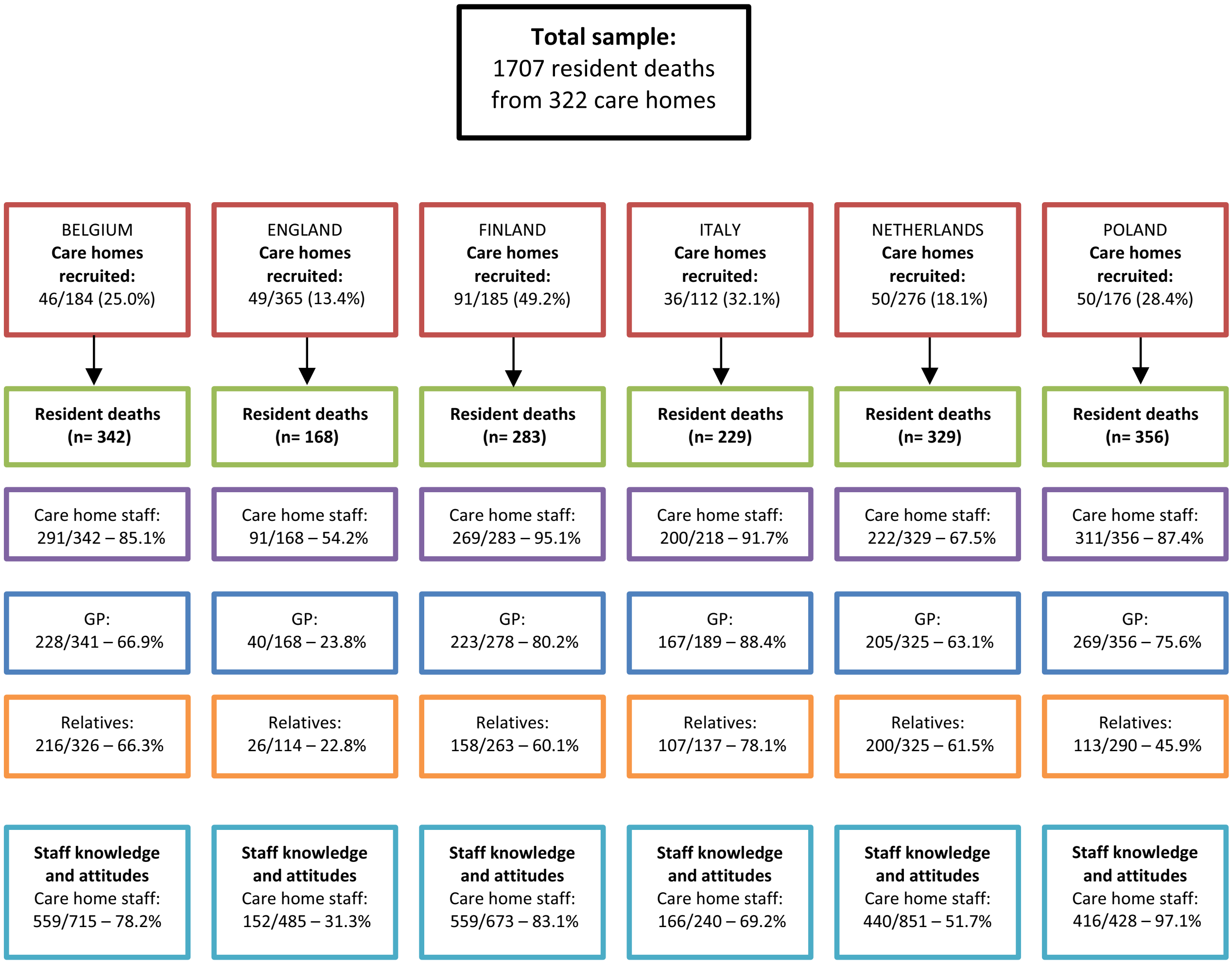

Fig. 1 Recruitment and response rates, by country, in the PACE study

retained all resident identifiable data during the study and posted any questionnaires to recipients. A second ethical issue concerned whether relatives could be confused as to who would see their questionnaire responses, Lancaster University or the care home, which raised questions regarding confidentiality. Changes to the study process or documentation requested during the approvals process in England were often problematic as it reduced comparability with previously agreed documentation from the other countries in the study.

Creating a sampling framework

To identify and recruit care homes, a stratified sample was created for each country based on care home region, type, size and organisational status, using national registers and based on estimated average deaths in each country over a 3 months period. In England, the data from the Care Quality Commission (CQC) was used, including the characteristics, contact details and reports on care quality from around 8000 care homes [16]. The problems encountered in England compared to the other countries in the study may reflect the variation in the long-term care economy across Europe—England has a significantly higher proportion of privately owned, for profit care homes (Fig. 2).

In England, the study excluded 396 local authority and NHS owned care homes as it would not have been possible to apply for local NHS approvals during the study period. In addition, care homes rated as at risk or providing inadequate care during their last CQC inspection were excluded to avoid adding extra work to care homes that were struggling. Quality of care was determined using the care homes most recent CQC inspection report. Forty-eight care homes were randomly selected which met the quota identified in the sampling framework.

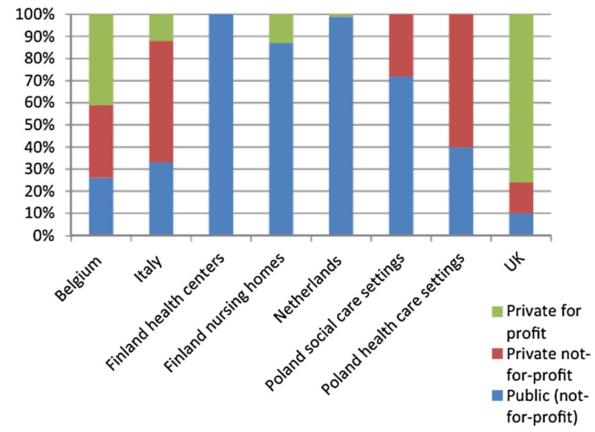

Fig. 2 Care home providers by organizational status in each country involved in the PACE study [10]

Data in the CQC dataset was occasionally out of date. High levels of staff turnover meant that the contact details of managers were sometimes incorrect, and the numbers of beds had changed; care homes which were classed as small in the sampling framework were reclassified as large and no longer fitted into the sampling framework quota, and vice versa. The lag time of 3 to 6 months between CQC inspections the subsequent rating and report being published online meant that the research team were required to review CQC ratings on an ongoing basis.

Contacting and recruiting care homes

Care homes identified in the sampling framework were contacted by post, with a follow up phone call from the research team 2 weeks later. E-mail contact led to substantially more responses than postal contact. Contacting care home managers by telephone was problematic, it took on average three phone calls to a care home before a manager or deputy manager could be reached. Care homes which were unresponsive after five phone calls were not followed up.

Within 3 months, it was clear that the current approach was unlikely to meet the recruitment target within the study period. The research team decided to advertise the study through the Enabling Research in Care Homes Programme (ENRICH) and in care home magazines [17]. The care homes involved in the ENRICH network were classed as 'research ready' and had indicated that they were interested in taking part in research. Nineteen care homes were recruited through the ENRICH network and advertising.

Figure 3 shows the care home recruitment for England. Reasons for decline included being too busy, preparation for an upcoming CQC inspection, managers feeling uncomfortable providing information on a deceased resident and a view that palliative care was not part of the services provided by the care home. There were no statistically significant differences in terms of quality of care between care homes that agreed to take part in the study and those that declined, or between care homes identified through random sampling and those identified through the ENRICH network and advertising.

Conducting research visits

Research visits to the recruited care homes were organised 2 months in advance and confirmed by post. At the research visit, it was common for care home managers to either have forgotten about the study or were not at the care home when the researcher arrived. A reminder call was made by a member of the research team 1 week before the visit to avoid this. As the study progressed, the importance of identifying specific times to visit

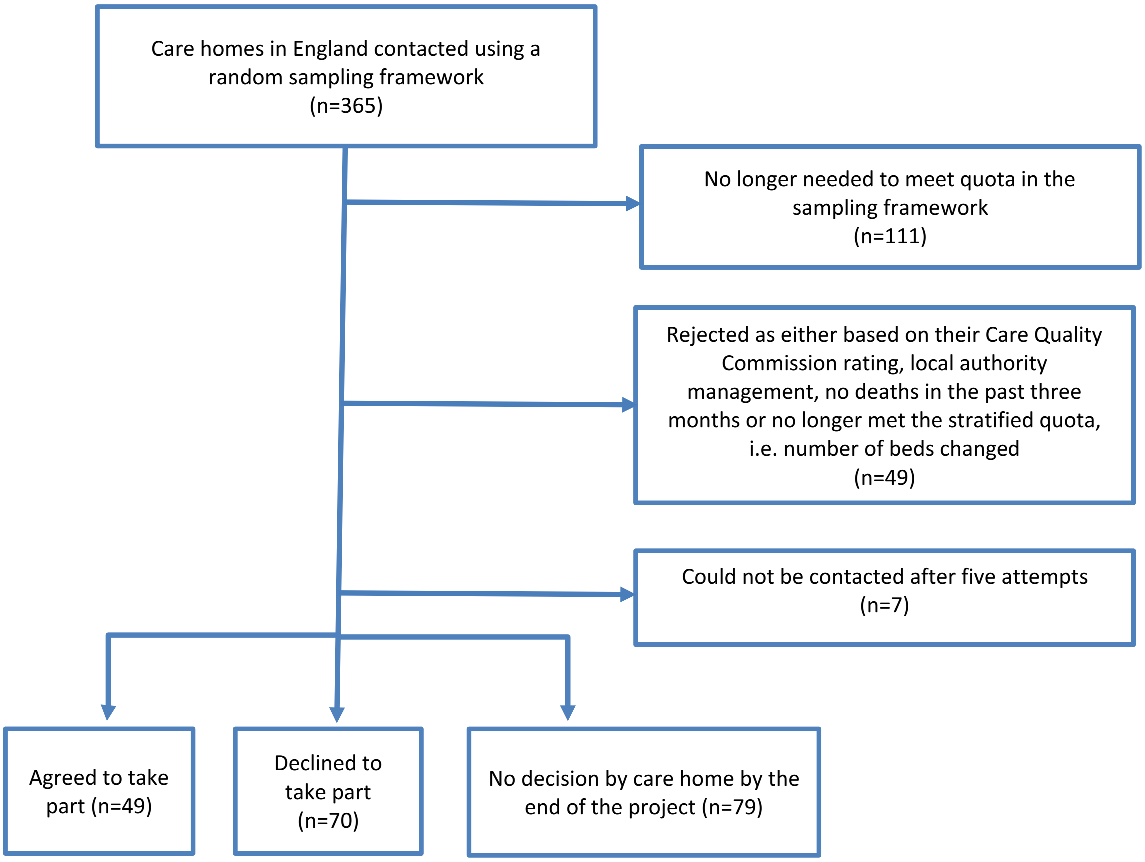

Fig. 3 Recruitment of care homes in England, in the PACE study

care homes, avoiding medication rounds and GP visits, were recognised. As care homes are busy, unpredictable environments focused foremost on providing resident care, it was sometimes difficult to find a quiet, private room to discuss the study with the care home manager.

Accessing information on deceased care home residents was seldom straightforward. The data provided was sourced solely from the care home and relied on the quality of their record keeping. There is no linked computer system across care homes in England; how resident data is collected, updated and stored is locally determined. Some care homes used a paper-based system and care home administrators were asked to source information. Data could be stored in separated places; collated from CQC submissions, medical files and address books. Data on residents who had died in the past 3 months had occasionally been archived, either within or outside the care home. Depending on the number of deaths within the care home, the researcher visit could last up to 5 h.

It was anticipated that on average, there would be at least four deaths per care home over a 3-month period; in practice the number was lower. The average number of deaths across the care homes was three, in care home with nursing this was slightly higher, five deaths compared to two in care homes without nursing. As the visits were conducted between June and December, it is possible that seasonal variation in deaths could explain the discrepancy.

Recruitment/response rates from care home staff, GPs and relatives

At the research visit, care home managers were asked to identify the staff member who was most involved in the resident's care, which in practice was difficult to determine; a senior staff member was often asked to complete questionnaires on more than one deceased resident. Due to high staff turnover, the staff member closest involved in the residents care was sometimes no longer employed in the care home at the time of the research visit. Care home staff found it difficult to complete the questionnaire if a resident had recently been admitted to the facility, if the death had occurred in hospital or if they were asked to complete questionnaires on multiple residents.

In England, all GP care is provided externally to the care home and it is common for a care home to use only one GP practice; this led to GPs receiving questionnaires on multiple residents, potentially leading to questionnaire fatigue. The research team received uncompleted questionnaires from GPs who had only become responsible for the resident shortly before their death and did not feel qualified to complete a questionnaire on their care. Participants were not offered a monetary incentive to complete a questionnaire, and in some cases, GPs requested payment prior to questionnaire completion, which could not be provided.

Questionnaires for relatives of deceased residents were also sent out by post 3 months after the death. In some cases, either a relative could not be identified or it was thought by the care home manager to be inappropriate to contact a relative, i.e. if the relative was in poor health ($n=54$).

Questionnaires on staff knowledge and attitudes to palliative care were only sent out to staff on duty at the time of the visit, therefore night and weekend staff may be underrepresented. One care home manager found it difficult to delimit staff members who were involved in care compared to those who were involved in domestic duties. In some care homes staff took on a number of roles depending on demand and all staff had training in care.

Limitations

The extent to which the obstacles discussed in this paper are intrinsic to care home research, compared to the focus of the study, i.e. palliative care is unclear. In the PACE study, support from the care home manager, enthusiasm among staff and identifying a dependable contact person were imperative in increasing response rates. A major barrier to engagement was that a single research visit to a care home with little prior contact did not allow a relationship with the research team to develop. Initiatives such as ENRICH can enable care home involvement in research; however whether research ready care homes are representative of others nationally is uncertain [17, 18]. The study did not provide any incentives or reimbursements for care home staff, GPs and relatives to take part in the study, which may also explain the low response rate.

The experience of England in the PACE study demonstrates how conducting international studies within the legal, cultural and social norms of each country is challenging. Further research should explore the methodological challenges in this field. Open discussion of these challenges could inform the feasibility and development of research, especially in complex and sensitive areas such as palliative care.

Abbreviations

CQC: Care Quality Commission; ENRICH: National Institute for Health Research: Enabling Research in Care Homes Programme; GP: general practitioner; MDS: Minimum Data Set; NHS: National Health Service; PACE: Palliative Care for Older People in care and nursing homes in Europe.

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Authors' contributions

DCM drafted the manuscript and coordinated the England arm of the study. LVdB was the Chief Investigator of the PACE study. SP and KF were co-investigators for the study in England, and KS was a co-investigator for the study in Poland. MtK coordinated the Netherlands arm of the study. All authors read and approved the final manuscript.

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Availability of data and materials

Not applicable.

Ethics approval and consent to participate

As stated in the PACE protocol "All countries obtained ethical approval from the relevant ethics committee in the country or university, except in the Netherlands and Italy where this is not needed because retrospective data of deceased residents are used (ethical committees were informed in these countries to judge whether or not formal ethical approval is needed and a waiver can be provided". In England, the study was approved by Haydock National Research Ethics Committee (reference 15/NW/0205). Consent for participation was not required for this publication.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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