The presence and intensity and the related changes over time of physical symptoms in the dying phase: A prospective cohort study of residents dying in care homes

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Abstract

Background

Currently 22% of the UK population die in care homes, mostly within 18 months of admission, yet there is little research about the nature of symptoms at the end of life in this population. The limited evidence suggests that the dying trajectory may be different to other populations.

Aim

To describe the presence and intensity of physical symptoms of residents during the dying phase and explore common characteristics that occur over time.

Methods

This prospective cohort study used the Modified Edmonton Symptom Assessment Scale (ESAS) to collate demographic and symptom characteristics from 157 residents during the final days of life in 11 care homes. Descriptive statistics were used to present demographic and clinical characteristics. The presence and intensity of both symptom load and individual symptoms was tested for significance with either ANOVA or Cochran's Q and post-hoc comparisons performed. Finally, an inferential analysis was performed to test for associations between presence and intensity and key characteristics.

Results

The five most common symptoms nearest to death were drowsiness, fatigue, anorexia, unable to respond and shortness of breath with a significant increase in both presence

and intensity of these symptoms towards the time of death. Only a small number of associations between demographics, diagnoses and symptoms were observed.

Discussion

The main symptoms occurring in residents relate to a general deteriorative condition suggesting that dying in care homes is characterised by a gradual decline, with an increased presence and intensity of symptoms towards the time of death. Symptoms can be classified as 'silent' or 'strident', resulting in a typology that has not been previously identified in symptom research in this population. The limited associations between co-variables indicate that despite differences in age, gender, number of diagnoses and length of stay, this cohort is a homogenous group during the last few days of life.

Conclusion

The research findings have implications for end of life care of residents, education and support requirements for professionals and for the wider research community.

Declaration

This thesis has not been submitted in support of an application for another degree at this or any other university. It is the result of my own work and includes nothing that is the outcome of work done in collaboration except where specifically indicated. Many of the ideas in this thesis were the product of discussion with my supervisors Professor Katherine Froggatt and Dr Sarah Brearley.

Excerpts of this thesis have been presented at the following conferences.

Partington, L. (2010) Data from the first 100 deaths. London: National Care Homes Forum *(oral presentation)*

Partington, L. (2010) Collaborative approach to working with hospices and care homes. Liverpool: Academic Palliative and Supportive Care Studies Group *(oral presentation)*

Partington, L. (2010) Methodological challenges of the choice of tool for proxy assessment of symptoms. Nottingham: Nottingham University PhD day for people conducting research at the end of life *(oral presentation)*

Partington, L. (2010) Symptoms at the end of life in residents dying in nursing care homes - a collaborative research project. E-poster: International Palliative Care Network *(poster presentation)*

Partington, L. (2011) A prospective descriptive study to examine the incidence of end of life symptoms in care home residents – 2 specific problems, tool choice and proxy data collection. Lancaster University: Postgraduate Seminar *(oral presentation)*

Partington, L. (2011) Symptoms at the end of life in residents dying in nursing care homes. Bath: National Association for Palliative Care Educators *(poster presentation)*

Partington, L., Froggatt, K., Brearley, S. (2012) Developing a Typology of Dying for Residents in Nursing Care Homes. Norway: European Association for Palliative Care *(oral presentation)*

Partington, L. (2012) Symptoms at end of life in frail older people. London/ St Christopher's Hospice, Celebrating Care Homes Conference *(oral presentation)*

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The word length of this thesis is <mark>68,683</mark> (including footnotes and appendices, but excluding bibliography) and does not exceed the permitted maximum.

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The central focus of this thesis is the residents who died within the care homes while I was undertaking the field work, and it is due to those very special people, along with their families and the staff that this work ever took place. I cannot thank you enough.

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Glossary of Key Terms

Care home	A provider of accommodation and personal care to a wide range of adults, including older people. Also the generic name used to include both homes with personal care and homes with nursing care
Care home with Nursing	As care home (above), also provides nursing care from qualified nurses
Care Quality Commission (CQC)	The independent regulator of all health and social care services in England
Clinical Commissioning Group (CCG)	Clinically led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area in England
Commission for Social Care Inspection (CSCI)	An independent organisation in England and Wales (set up by the Government) to inspect and report on care services and councils including care homes. This body ceased to exist on 31 March 2009, and was replaced by the Care Quality Commission (CQC)
Edmonton Symptom Assessment Scale (ESAS)	An instrument that was developed to assist in the assessment of a number of identified symptoms
End of Life Care (EoLC)	Care of patients in their final period of life (hours, days, weeks, months). Applies to all advanced progressive and incurable illnesses. Has largely taken over from the term 'palliative care', especially in the UK
Liverpool Care Pathway	A document that aimed to improve care of the dying through a standardised approach to end of life care, it was withdrawn in July 2014: and replaced by 'individual care plans for end of life'
Long Term Care	Systems that enable older people, who experience significant declines in capacity, to receive the care and support of others consistent with their basic rights This is a common term used in the USA and Canada as well as some European countries
Minimum Data Set (MDS)	A record-level data system about the care of adults and older people in a variety of settings

SPSS 19   Software package for analysing data and running statistical tests

Abbreviations

ACP	Advance Care Planning
CCG	Clinical Commissioning Group
CSCI	Commission for Social Care Inspection
CQC	Care Quality Commission
DoH	Department of Health
EoL	End of Life
EoLC	End of Life Care
ESAS	Edmonton Symptom Assessment Scale
GP	General Practitioner
KPS	Karnofsky Performance Scale
LTC	Long Term Care
LTCF	Long Term Care Facilities
LCP	Liverpool Care Pathway
MDS	Minimum Data Set
ONS	Office for National Statistics
RGN	Registered General Nurse
SOB	Shortness of Breath
SPSS	Statistical Product and Service Solutions
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

Chapter 1 – Introduction

1.1 An ageing population

The global population is ageing rapidly. In 2012 there were 810 million people aged 60 years or over in the world, 178 million more than in 2002 and, by 2050, it is estimated that 22% of the global population will be 60 or over, amounting to over 2 billion people (United Nations, 2012). A significant feature of the ageing population is the progressive ageing of the older population itself. It is estimated that there will be 425 million people aged 80 years or over by 2050, a 3.5-fold increase (World Health Organization, 2017). Within the UK, there will be an estimated increase in those aged 85 or over, from 1.3 million in 2008 to 8 million in 2050 (Office for National Statistics, 2017)

The increase in the ageing population will bring challenges on many levels from personal to socio-economic due to an increasingly smaller working population having to provide for a non-working older group, both financially and as care providers (Doyle, 2009). The Office for National Statistics (ONS) predict a fall in the demographic support ratio from 3.3 people of working age for every person of pensionable age to 2.9 by 2050 (Office for National Statistics, 2015). This is already evident in Germany which has the third largest oldest population in the world and is facing a 'war of generations', where younger people are required to pay additional taxes for older people's care (Powell, 2012). With people living for longer periods and having fewer children, the need for alternative models of care and support will arise (Powell, 2012).

1.2 Facing illness in old age

As people live longer and older, they are facing longer periods of good health leading to a shorter period of ill health, with increasing needs and more dependency in their final years (Harper, 2017). The numbers of deaths worldwide are set to rise from 57 million in 2015 to 70 million in the next 15 years (Bone et al., 2018). There is a relationship between the number of older people and the number of deaths, as most deaths occur in people over the age of 65 years or older (Costantini & Lunder, 2012), and most will die as a result of serious chronic diseases. In the future, although older people in general are likely to stay healthier for longer (Doyle, 2009), the proportion of people with a long-term limiting illness or disability will increase with age (ONS, 2012); additionally, the last years of life will be accompanied by an increase of illness and disability (Lunenfeld, 2008). This will lead to those who require care within a Long Term Care setting becoming more frail, with higher numbers of co-morbidities and more considerable dependency than those previously cared for (Hallberg, 2006b; Koller & Rockwood, 2013; Murray, Boyd, Hockley, & Sheikh, 2008).

Within the UK, Lievesley, Crosby, and Bowman (2011) established that the average length of stay in care homes in one provider organisation (BUPA) is decreasing. They forecasted that by 2015 the median length of stay for frail older residents would be 265 days; for residents receiving 'dementia care', it would be 367 days. They also highlighted a similar pattern in a decreasing rate of length of stay across Australia, Spain and New Zealand (Lievesley et al., 2011). The World Health Organization has also affirmed that the number of older people dying in care homes is almost certain to increase worldwide (WHO, 2011). This will result in care homes having a higher

turnover of residents who have a shorter length of stay from admission to death, resulting in an increased number of deaths in care homes.

1.3 Care homes in the UK

Within England and Wales, in 2011, 3.2% of the population aged 65 or above live in a care home (with or without nursing care) (Office for National Statistics, 2013). One of the main findings of the ONS report was that the care home population for those aged 65 and over has remained virtually stable since the previous 2001 survey, showing an increase of only 0.3%, despite an increase of 11.0% in the total population of the same age. However, it shows that there has been a change in the age demographic. The numbers of those aged 75 - 84 has decreased while the populations aged 65 - 74 and those of 85 years and over have both increased. This may be an indication of health improvements in the population, which is why there has been an increase in those aged 85 and over but does not explain why the number of those aged 65 – 74 has increased. One key influence on the relative stability of the population within the care home population is likely to be due to an increase of unpaid carers. There were an additional 600,000 unpaid carers in 2011 compared to 2001 (Office for National Statistics, 2013). As this is increasing faster than the population growth, it is helping to prevent care home admissions with more people being cared for in either their own home or a family member's home.

Historically, care homes have always had a higher proportion of females to males, but the gender gap in the care home population is narrowing. In 1983 there were 155 women aged 65 and over for every 100 men of the same age, compared to the current

sex ratio of 130 women for every 100 men for this age group. By 2033 it is projected that the 65 and over sex ratio will have fallen still further to 117 women for every 100 men (Office for National Statistics, 2013). This does differ from provider to provider: for example, The Methodist Homes Association reported that just under a quarter of their care home residents were male, and this proportion was increasing annually (Methodist Homes Association, 2015). The fall in numbers of women entering care is likely to be due to the increase in unpaid carers as previously mentioned on page 3, and particularly to the increase in longevity of men, who are providing support and care for women who had previously lived longer than their spouses and were usually the recipient of care rather than the provider.

Although the number of people who are living in care homes at any one time has not changed significantly over the last 10 years, there are higher numbers of people dying in care homes than ever before. In England, deaths in care homes have increased from 80,000 to 111,000 per annum in the last five years (Public Health England, 2017). This can be explained by the reduction in residents' length of stay. It has been difficult to estimate the average length of stay in care homes as this information has not been a statutory monitoring requirement; however, in 2011, it was reported that the median period from admission to the care home to death was 462 days or 15 months (Forder & Fernandez, 2011). Yet, ten years earlier a study by Bebbington, Darton, and Netten (2001) reported a median length of stay of 19.6 months. From their origins of being long stay residences, care homes are rapidly becoming an important place for end of life care (Public Health England, 2017b) along with an increase in temporary residents[1]

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[1] A temporary resident is defined as a person whose need to stay in a care home is intended to last for a limited period of time and where there is a plan to return home

who are dying in the care homes. End of life care has become a core and vital component of the work of care homes.

1.4 Palliative and end of life care

The term 'palliative care' has been used from around the beginning of the 19th Century, although it has only been employed in its broader sense for the last 25 – 30 years. Traditionally, palliative care was mostly offered to patients with cancer. In 2001, the World Health Organization closely aligned palliative care with cancer and discussed the need to provide it in conjunction with other therapies intended to prolong life, such as chemotherapy or radiation therapy. Although the definition was broadened to embrace life-threatening illness (World Health Organization, 2004), the initial cancer focus still has an impact upon current practice around palliative care.

Palliative care has been defined by the World Health Organization as "an approach that improves the **quality of life** of patients (adults and children) and their families who are facing problems associated with **life-threatening illness**. It prevents and relieves suffering through the **early identification, correct assessment and treatment of pain and other problems**, whether physical, psychosocial or spiritual" (World Health Organization, 2018b)

In the UK, the term 'palliative care' was largely replaced by the term 'end of life care' in 2008, following the publication of the End of Life Care Strategy (Department of Health, 2008). It was identified that people did not fully understand the word 'palliative' and felt the alternative 'terminal care' focussed too much on the final few

hours of life. The concept of end of life care was believed to be broader and was intended to include the last hours, days, weeks, months, and even years. Like the term 'palliative care', it was meant to be inclusive of any illness that was considered life threatening (Department of Health, 2008). Globally, the term 'palliative care' is still commonly in use: Australia (Department of Health, 2018): Canada (Morrison, 2017): USA (Hawley, 2017). Within Europe, there is a similar situation; the European Association for Palliative Care has produced a resource of National Guidelines (European Association for Palliative Care, 2017) which shows that the Netherlands, Germany, Switzerland, the Republic of Ireland and other UK countries such as Northern Ireland and Scotland have guidelines referencing 'palliative care'. This thesis will use the term 'end of life care' as this is now accepted as the main term within England; however, palliative care will still be referred to when appropriate such as for historical references, international discussion or when referring to certain services within the UK. For example, hospices[2] talk about providing 'specialist palliative care' and many Macmillan teams[3] refer to their service as a 'specialist palliative care' speciality.

Three key elements that strongly emerge from the World Health Organization definition (page 5) are the terms 'quality of life', 'life-threatening illness' and the 'early identification, correct assessment and treatment of pain and other problems'.

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[2] Hospice care seeks to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal illness, helping them live as fully as they can.
[3] A Specialist Team that is made up of health professionals who provide support and advice to individuals affected by cancer or other advanced incurable illnesses, and their carers.

The first element, **quality of life** is an often quoted principle of end of life care, yet is accepted to be uniquely subjective to the person experiencing it. However, there is evidence to suggest that there are core factors that are important to many patients and families at the end of life which will enhance quality of life (Steinhauser et al., 2000). These include pain and symptom management, preparation for end of life and promoting relationships between patients, families and health care professionals. Quality of life in end of life care is closely related to quality of death. Regardless of when a person dies or the cause of their death, most people, when asked, want to have a 'good death' (Kelly, 2014; Meier et al., 2016). The End of Life Care Strategy (Department of Health, 2008) highlighted the principles of a good death, and these included being treated as an individual, being free from pain and other symptoms, being in familiar surroundings and being in the company of close family and/or friends. Preparation for end of life was identified as something that can improve quality of life at the end of life. This can be illuminated through two different approaches, both wholly applicable to end of life care:

1. Meeting the patient's needs, wishes and preferences by shared decision making. This can only happen if there is honesty and willingness to discuss future plans on the part of patients, staff and families (Mullick, Martin, & Sallnow, 2013) and to open up discussions early on in the course of the illness.

2. The need to recognise that end of life is approaching. This is a very challenging situation to undertake (Glare et al., 2008), but without timely identification and subsequent communication, opportunities can be lost for the person and their family to say their goodbyes. A report from the Care Quality Commission (2016) identified that people who could benefit from end of life care are not being identified in a timely manner. If it is not recognised that end of life is

approaching, it can lead to inappropriate hospital admissions and an increased risk of dying in hospital. This may not have been that person's choice, given that people in the last year of life will experience 2.28 hospital admissions with an increasing likelihood of emergency admissions in the last 2 weeks of life (Robinson, Gott, Frey, & Ingleton, 2018).

The second element, **the early identification, correct assessment and treatment of pain and other problems,** has become a foundation in the provision of end of life care. Providing relief from symptoms has been long identified as an essential component for end of life care (Wilkie & Ezenwa, 2012). Knowledge of the prevalence of symptoms, together with assessment and management, has become a necessary requirement for the care of all patients (Potter, Hami, Bryan, & Quigley, 2003). This knowledge is not just required of medical staff, but of nursing staff, allied health professionals and, to a lesser degree, of auxiliary care workers and requires a supportive educational approach to promote it. Good symptom control has been associated by those at the end of life with the wish that they do not want to die in pain or distress, rating it as a higher priority than being at home or being with loved ones (Demos, 2013). To be able to treat symptoms effectively, they first need to be recognised (as a symptom) and correctly assessed. While symptom management maintains a high profile in palliative and end of life care, the recognition and assessment of symptoms have a lesser emphasis (although pain does have a higher profile than many other symptoms). To do this effectively, appropriate assessment methods (or instruments) need to also be considered. There is a lack of instruments generally to measure symptoms in an elderly population who are receiving palliative care. (Browner and Smith (2013) reviewed 21 instruments in their study involving an

older palliative population and noted that none of the instruments had been validated for use with geriatrics (elderly population), although they had been used within these populations.

The third element, **'life-threatening illness'**, refers to the extension of palliative care to a wider group of diseases/illnesses that would benefit from this type of approach. Initially, palliative care largely pertained to cancer care; however, in 2004, the World Health Organization recognised the need to expand this definition to include the needs of people living with different serious chronic illnesses who had similar concerns and needs (World Health Organization, 2004).

1.5 End of life care in care homes

The definition of end of life care as discussed above is applicable to care homes with the three elements having the same impact upon residents within care homes as it does to the population in general. This section will consider the place of end of life care in relation to current policy which will be developed further in chapter two: background and context.

Residents living in care homes are some of the most vulnerable people in society, usually presenting with multiple co-morbidities. Residents are likely to have very complex needs. The number of residents with types of dementia, such as Alzheimer's disease, is increasing with nearly two thirds of residents dying with dementia (Public Health England, 2017a). Multiple services may provide care and treatment and decision making involves managing inherent uncertainties. One of those uncertainties

is around the recognition of the end of life phase, both at the earlier stages and later on, when the resident is entering the final days or hours of life. Yet, this uncertainty can reduce the opportunity for the resident and their family to be able to make informed decisions about their care. There is currently a drive to reduce 'avoidable' hospital admissions from care homes thus reducing the number of deaths in hospital (Krueger, 2016). This is seen as a positive move to enhance quality, lower costs and meet people's preferences (Hunter & Orlovic, 2018). NHS Trusts and Clinical Commissioning Groups (CCGs) have been tasked with reducing deaths in hospitals (National Quality Board, 2017) and anecdotally some CCGs, including local Cheshire ones, have identified 'high flyers', that is care homes with the highest hospital admission and death in hospital rates. However, given the increasing ageing population, increasing number of deaths and the wish to prevent hospital admissions, the demand for end of life care provision within care homes is only likely to increase.

1.6 Reflection on the background for this research study

The motivation for this research probably started many years ago. I was an A-level student planning to study home economics when my Mother who was a nurse asked if I would help out in the care of the elderly hospital (as they were known at that time) during my school holidays. I loved it from the first day, so much that I decided to apply for my nurse training. My Mother was not particularly happy at what she had inadvertently set off, and proceeded to include me in all manner of nursing tasks (including my nemesis, cleaning false teeth) but I knew it was what I wanted to do. This foundation gave me my interest in working with older people, something that has remained throughout my nursing career.

After qualifying, I worked in general medical wards and then a hospice, and it felt a very natural progression to work with people, especially older people, at the end of life. After several years working at the hospice, I was given an opportunity to move into an educational post in palliative care. Within my role as an educator/facilitator, I was responsible for a number of initiatives to support nursing homes in delivering end of life care. Many of these allowed me to be able to work directly with nursing home staff, enabling me to start to understand the work that takes place and appreciate both the highlights and the challenges. I was able to use the knowledge that I had built up working within specialist end of life care to support my nursing home colleagues to enhance their own end of life care practices. I could see their frustrations about not always being able to support residents to die in the nursing home and could see the impact that this had upon residents and families. One particular aspect that had started to bother me was in relation to the use of the (now obsolete) Liverpool Care Pathway[4]. The tick-box approach that the LCP was advocating did not seem to fit in with the needs of the nursing home resident. Staff often spent a lot of time requesting drugs to be prescribed for core symptoms and then having to obtain them, yet did not use them. I spent many hours teaching staff how to set up a syringe pump, only for staff to not use one for several months. I felt passionately enough about this to write an article about the use of the Liverpool Care Pathway in nursing homes (Partington, 2006). This was the start of my journey and I was able to secure support to carry out a 'project' to understand this better. I wanted to know more about the end of life symptoms that occur in nursing home residents in order to gain more knowledge to reflect upon and

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[4] The LCP was an Integrated Care Pathway intended to provide a method of recording and measuring outcomes of end of life care (Ellershaw et al, 2001)

influence practice, as I felt that this was an unaddressed issue within the literature that I had read.

I did not start out aiming to be a 'researcher', but I knew that I wanted to be able to do something that would have a positive impact upon the care of residents at the end of life. I also did not set out intending to conduct a positivist research study, but to answer the questions that I was asking, as I appreciated that this was the only viable approach. It is from this background and from my desire to make a difference that I present this research. I will conduct and present the research within a positivist paradigm, along with the rigour and reliability that provides. While I can, and do, accept that knowledge is 'out there', I would also like to explore the possibility of viewing the research through another lens: that of a conceptual model to help to frame the research and make sense of the findings and also help locate it for any potential future researchers to use if they so wish.

The purpose of this research is to determine the presence and intensity of physical symptoms of residents in the dying phase in care homes and explore whether there are changes in symptoms over time and how they relate to specific demographics and other characteristics. It is presented in seven chapters. The aims and objectives of the research and a synopsis of each chapter are presented below.

1.7 A synopsis of Chapters 2 – 6

1.7.1 Chapter 2 – Background and context

This chapter builds on the introduction chapter and continues to set the scene about an ageing population, both internationally and in the UK. Long Term Care/Care home care is introduced within an international perspective and then within the UK. This leads to considering dying in Long Term Care/Care homes and identifies many of the challenges that are currently being faced in this sector. From the care homes, the components of good end of life care are considered and the relationship between symptoms and end of life care is reviewed. This leads into a discussion around symptoms at the end of life for residents in care homes and the role of symptom research from a practical application and a conceptual model.

1.7.2 Chapter 3 – Literature review

By using the PICO framework[5], the literature review seeks to question the prevalence of physical symptoms in residents living in care homes at the end of life. The search strategy is described and the results of the review are presented, followed by a discussion of the literature that was included in the review. The chapter concludes by presenting five gaps in the research as a result of the literature review.

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[5] The PICO framework is a mnemonic used to frame and answer a clinical or health care related question and is described in chapter 3.

1.7.3 Chapter 4 – Methodology and methods

This chapter begins by setting out the aim and objectives of this study and addresses the study's underlying epistemology and ontology. The research study design is presented which leads into detail about the processes that were followed. Data collection is discussed followed by the data analysis plan and the selection of an appropriate instrument. Due to the nature of the study being conducted with participants at the end of life, there is a detailed ethical issues section and concludes with discussions about reliability and validity.

1.7.4 Chapter 5 – Results

This chapter presents the results from the analysis of the data. The objectives of the research are presented, which link into a set of hypotheses to test the objectives. Within the results, an overview of the data sets the scene and provides detail on the complexity of the data. This is followed by a descriptive analysis which describes the presence and intensity of both total symptom load and individual symptom presence and intensity. Testing for significance is followed by pairwise comparisons across three different time points. The next section focusses on an inferential analysis and the associations between presence and intensity of both total load and individual symptoms, and a number of demographic and clinical characteristics. Finally, an overview of the results are provided in the conclusion.

1.7.5 Chapter 6 – Discussion

This chapter begins with presenting the characteristics of the symptoms and leads into a discussion of a typology of symptoms associated with the dying phase. The

discussion broadens and takes into account the changes in symptoms over time and recognition of the dying phase. The strengths and limitations of the study are addressed and conclude with the implications for practice, policy and research.

1.7.6 Chapter 7 – Conclusion

This final chapter summarises the findings from the research by considering the importance of the research. It considers what it has contributed by presenting five key findings. The chapter concludes by providing recommendations for future practice, policy and research.

Chapter 2 – Background and Context

2.1 Introduction

An ageing population is affecting when and where older people live and die on a global level, leading to challenges for the future provision of health and social care (Bone et al., 2018). Over the next 15 years, the numbers of deaths worldwide are set to rise from 57 million in 2015 to 70 million (World Health Organization, 2014). In the UK, (Bone et al., 2018) it has been projected that if current trends continue, the next 25 years will see an increase for the need for end of life care, particularly at home and in care homes. As the demographics change, family structures alter, and people are living longer, with a reduced workforce to care for them, there is a risk in not understanding the needs of the population, which in turn will add more pressure onto already overstretched services. A group of particular interest, due to an increase in prevalence, are people with dementia. Worldwide, the number of people is estimated to double to 65.7 million by 2030 and triple to 115.4 million by 2050 (Wortmann, 2012), while in the UK there are currently around 835,000 people living with dementia which is estimated to increase to over two million by 2050 (Alzheimers Association, 2012). This is because the greatest risk factor for developing dementia is increasing age (Prince et al., 2014). In addition, an increasing number of older adults are living with multiple chronic health conditions. Hung, Ross, Boockvar, and Siu (2011) reported that between 1998 and 2008, the proportion of adults with one or more chronic diseases increased from 86.9% to 92.2% revealing a connection between increasing age and co-morbidities.

Given the increase in older frail people and people with dementia, care homes have increasingly become a place where people are living and dying, meaning that an

understanding of care homes and the care home population is essential to meet both current and future health needs and to support the services providing this care. This chapter will begin with the concept of Long Term Care/care homes/nursing homes and defining the terminology, and by building upon the overview provided in chapter one will consider the development and role of end of life care within care homes. Good end of life care is synonymous with quality of life and this is closely linked with the quality of a person's dying, so the relationship to these concepts will be explored. One key attribute is that of a 'good death', and that has been related to being free of burdensome symptoms. However, to manage symptoms, they firstly need to be identified and quantified, so this aspect will be discussed. This will lead to an examination of the concept of symptoms, what they are, and how they are measured. Finally, the symptoms experienced by older people living in a care home at the end of life will be considered.

2.2 Long Term Care – The international perspective

Long Term Care covers a very broad range of settings and not just care homes; these included facility-based long-term care, continuing care retirement communities, assisted living, adult day service programs, meal programmes, senior centres, home healthcare aides, and transportation services (Technavio, 2017). During a World Health Assembly in 2016, 194 countries agreed that all countries should have a system (World Health Organization, 2018a). However, it was identified that few countries have systems that can effectively meet the care needs of their populations. Despite this, Technavio (2017) predict a global growth of 6.5% for the need for Long Term Care during the period of 2017-2023 highlighting a high level of inequity in the provision of Long Term Care internationally. Institutional care for older people is more common

in developed countries having primarily evolved due to a lack of informal care within families (Seale, 2000). In western countries, the trend in service development is that only older people with significant needs receive institutionalised care (Brazil, Brink, Kaasalainen, Kelly, & McAiney, 2012; Eun-Young, Cho, & June, 2006; Hasson & Arnetz, 2009; McCann, O'Reilly, & Cardwell, 2009; Raikkonen, Perala, & Kahanpaa, 2007).

Increasing numbers of older people are living and dying in care homes and other long-term care settings (Froggatt & Reitinger, 2013), yet the organisation and structure of Long Term Care vary greatly both within Europe and worldwide. To address this, a European Association of Palliative Care (EAPC) taskforce was established in 2010 to review the ways in which palliative care is developing in Long Term Care settings and adopted the following definition of Long Term Care settings: "….collective institutional settings where care is provided for older people who live there and care is provided for 24 hours a day, 7 days a week for an undefined period of time" (Froggatt & Reitinger, 2013 :p.6).

To provide further clarity, the International Association of Gerontology and Geriatrics and The Foundation for Post-Acute and Long Term Care Medicine (Sanford et al., 2015) developed a survey to assist with an international consensus on the definition of a nursing home and provided a similar definition to that of the EAPC taskforce: "A nursing home is a facility with a domestic-styled environment that provides 24-hour functional support and care for persons who require assistance with ADLs and who often have complex health needs and increased vulnerability" (Sanford et al.,

2015 :p183). The main difference is the reference to complex health needs, however, this could be explained by the difference between the broader Long Term Care setting definition and that of a nursing home.

On a wider international basis the systems of long-term care are very diverse across different countries and these are likely to strongly influence the care provided (Albers et al., 2012). In the Netherlands and Norway, Long Term Care is well established, while in South Europe, care is developing with family carers giving much of the care. Further afield, Australia, the USA and Canada have well established systems, but with very different funding arrangements. In an attempt to understand international differences around the approaches to the Long Term Care of older people, McCormack, Roberts, Meyer, Morgan, and Boscart (2012) set out to explore different models of care. The authors found a wide variation of approaches, from an institutional model of care, to one that recognises and celebrates the older 'person' (as a unique individual), and although they conclude that recognising the concept of personhood is crucial to continuing to improving and developing Long Term Care, there is a wide difference of approaches around the world.

Internationally, there are many examples of initiatives to increase knowledge around the needs of older people in care homes. In the US, the National Care Home Study is a continuing series of nationally representative sample surveys of US care homes, including their services, staff, and residents. The last full study was undertaken in 2004, but aspects of care have been reviewed and updated with the most recent occurring in 2011 (CDC, 2013). Other European countries have also identified issues.

In Norway, Selbaek et al. (2007) questioned the increasing practice of prescribing of psychotropic drugs with residents but concluded that it reflected the needs of people with dementia in nursing homes. In the Netherlands, Zuidema et al. (2007) examined symptom clusters of nursing home residents with dementia reporting a prevalence of at least one symptom in 85% of residents. This concurs with the findings from Shah et al. (2010) UK study that residents are likely to have high clinical needs across international settings, so the focus will now move to consider the situation in the UK.

2.3 Long Term Care - Care homes in the UK

Within the UK, the majority of care homes provide services for older people, but a few offer services to children and to people with mental or sensory impairments. This study will be considering care homes for older people only. Using the definition from the EAPC taskforce, above, care homes for older people in the UK are divided between two categories:

1. The first offers personal care only and is called a **'care home'** (although formerly would have been referred to as a residential home). This type of care home is run by staff who are trained to support residents, but are usually not Registered Nurses.

2. The second type of care home was traditionally called a nursing home, but are now referred to as a **'care home with nursing'**. These have Registered Nurses on duty 24 hours per day and they are supported by Health Care Workers.

Within the UK, care homes are run by voluntary organisations, local councils, health authorities and private agencies. All care homes must be individually registered,

inspected and listed by a relevant authority, which in England and Wales is the Care Quality Commission (CQC). There are currently 11,300 care homes in the UK providing care for around 410,000 residents with 95% of beds being provided by the independent sector (Competition and Markets Authority, 2017). This study uses the generic term of 'care home' throughout unless referring to historic literature where the terms 'nursing home' and 'residential home' will be utilised.

While care homes would have always cared for older frail people, there is a change in dependency of residents. On average older men towards the end of life now have 2.4 years with substantial care needs and women 3.0 years, and although most will live in the community, it is anticipated that if dependency and care home proportions remain static in the future, a further 71,215 places will be needed by 2015 (Kingston et al., 2017). There is another group of people that are also requiring additional care: it is estimated that 70% of people in care homes have dementia or severe memory problems (www.alzheimers.org.uk, 2017), the number of which is increasing and will have an effect on the number of care home places that are required. As a result, projections of future demand in relation to providing care for those with dementia indicate that the current number of care home places will need to increase by 82% between 2010 and 2030 to cope with the extra demand (Jagger et al., 2011).

2.4 The importance of understanding care homes and residents

There is a lack of robust information on residents in care homes in terms of their diseases and progression of illness. The last major study that was carried out regarding individual residents across a broad number of care homes was in 2000, when the focus

of the survey was on the health of older people and "provided a general overview of the characteristics of care homes in England and of the socio-demographic and health profiles and social participation of care home residents aged 65 and over" (Health Survey for England, 2000 : p.8). This survey involved 544 care homes and interviews with 2,493 residents, although 51% were interviewed in proxy involving either families or care home staff. Through the knowledge of the demographic status of those living in care homes, it has was identified that older people living in the care homes had high levels of physical dependence and health care use (Bajekal, 2002). Yet, according to Shah et al. (2010), there was limited information regarding the clinical characteristics of this population, meaning that despite growing numbers, there are not any consistent sources of data to support future planning or organisation of care needs. In an attempt to resolve this lack of information about care home residents, Shah et al. (2010) identified older care home residents through a national cross sectional analysis of a primary care database. They found high clinical need, especially with dementia and stroke prevalence, but incomplete recording of other expected diseases suggesting inequity of care for care home residents compared to their counterparts living in their own homes, with the latter group more likely to be on GP frailty or vulnerability registers. Shah et al. (2010) also reported little difference between the clinical needs of residents living in care homes compared to those living in their own home, which indicated that high levels of disease and frailty is no longer limited to nursing care home residents.

2.5 Death and dying in care homes

2.5.1 Dying in care homes – The international perspective

The role of palliative care within Long Term Care was specifically identified as being a requirement to meet the needs of older people during the 2016 World Health Assembly (World Health Organization, 2018a) yet as described, Long Term Care in many countries is minimal. Within other countries, however, Long Term Care has been a constant with palliative care being a stable feature. A significant proportion of people die in Long Term Care settings: ranging from 13% in Austria, 20% in England to 39% in Canada (Hall, Kolliakou, Petkova, Froggatt, & Higginson, 2011).

New Zealand has advocated a palliative care approach for a number of years and Nolan, Featherston, and Nolan (2003) reinforced the benefits of applying palliative care principles to develop end of life care in care homes. Within Sweden, there were reservations indicating that more research is required to adapt this care for older people (Hallberg, 2006a). The domain of specialist palliative care had taken the initiative to try and improve end of life care within care homes. At this time, extensive work was also being carried out in Australia (Parker, Grbich, et al., 2005) and Canada (Goodridge, Bond, Cameron, & McKean, 2005) and the USA (Reynolds, Henderson, Schulman, & Hanson, 2002).

A number of developments in the provision of end of life care took place in Long Term Care settings at international level, so to describe the level and type of interventions occurring Froggatt et al. (2006) undertook a literature review between 2000 and 2004. The review found that the development of end of life care was clearly being addressed

in published literature with its strength lying in the extent to which researchers and practitioners were attempting to engage with the complexity that surrounds this area of care. However, it was found that the nature and form of developments tended to be descriptive, small scale and limited. It was recommended that there was a need to engage in further developments, particularly around interventions that attempt to address the complexity of care in Long Term Care settings. This review shared comparable conclusions to a similar review carried out by Cartwright (2002) between 1990 and 2000, who also found that interventions were mainly descriptive in nature and that there was a lack of evidence-based strategies for recognising common symptoms at end of life with staff often lacking knowledge about how to assess and manage symptoms.

2.5.2 Dying in care homes – The UK perspective

Care homes, both care and care with nursing, play a crucial and growing role in the delivery of care towards the end of life for older people. In the UK in 1990, approximately 13% of people died in nursing or residential homes (Field & Cassel, 1997). By 2005, this was 16% (76,977 people) increasing to 22% (101,203) in 2014 (Centre, 2017). An even higher proportion will receive part of their care in a care home before their death as approximately one third of people (28,892) living in care homes die elsewhere, predominantly in hospital. There is significant variation by Clinical Commissioning Group (CCG) in the proportion of people aged 75 years and older who die in care homes in England, varying from 10% to 43% (Centre, 2017). If the recent decline that has been experienced in hospital deaths is sustained, the annual numbers

of people dying at home and in care homes is estimated to almost double by 2040 and care homes will become the most common place of death (Bone et al., 2018).

Prior to 1995, palliative care was not seen as a requirement within the care home setting, as it was frequently regarded as a type of care that was given to people dying with cancer. It was also viewed as care that needed to be given in hospices. As already noted, people spent longer living in care homes, there were fewer deaths and when death occurred it was often viewed as something that just happened and there was an acceptance that death was a natural event. This view of death being incidental is supported by the observation that there were no research studies carried out in care homes around death and dying until after the mid-1990s. The Calman-Hine Report (1995) promoted the provision of a palliative care approach that could be offered in all care settings and this appeared to coincide with the acknowledgement of palliative care in care homes. However, initially the notion that end of life care could be offered in care homes was slow to establish and this is reflected in the increasing number of deaths that now occur within care homes and a more widely accepting attitude towards them.

The first large UK study of dying in care homes was undertaken in 1997, when Sidell, Katz, and Komaromy (1997) studied the way that death and dying were dealt with in different types of care homes in England. Their research indicated that the palliative care concept was not very widely understood in care homes, and they often failed to recognise the need for end of life care at the end of life. Most homes reported feeling isolated and unsupported when caring for dying residents. Furthermore, care home

managers often identified pain as a major cause of suffering, but without any appreciation of other symptoms. This may be linked to palliative care having strong associations with cancer care and the emphasis on pain management. Following the publication of the Sidell et al. (1997) study, other UK studies subsequently emerged which studied the definition and practice of end of life care in care homes. The findings from these studies continued to reveal that end of life care was often not seen a priority in care homes. These early studies also started to recognise that those who support the development of end of life care in care homes needed to understand the nature of care in care homes and the different ways in which older people die (Froggatt, 2000; Katz, Komaromy, & Sidell, 1999b).

The profile of end of life care in care homes increased and although there were pockets of recognising the need to develop end of life care, many were initiated by external sectors, particularly specialist palliative care. This was confirmed by an European Association for Palliative Care taskforce report (Froggatt & Reitinger, 2013) when they mapped exemplars of good end of life care initiatives across different countries, including the UK, but noted that the drivers came externally rather than from the care homes themselves, for example, Froggatt's study looking at palliative care education in care homes found that education was provided for the care homes rather than by the care homes (Froggatt, 2000). Subsequently, Froggatt put forward the explanation that palliative care may operate from a different paradigm from care home philosophy and that the care homes may have their own 'successful' ways of accommodating dying residents' needs (Froggatt, 2001). It may have also been due to residents having different needs when dying which were not visible, especially to specialist palliative care with their cancer focus. While outside bodies such as the hospice movement

recognised the growth of palliative care, the care home sector itself and its regulatory body, The Commission for Social Care Inspection (CSCI[6]), appeared to be progressing the development of end of life care much more slowly. It is possible that a more enquiring approach as to why care homes did not feel the need to adopt this practice would have achieved a better understanding.

In 2005, a Social Care Institute for Excellence (SCIE) briefing paper identified a lack of detailed standards governing the provision of terminal care to older people in care homes, especially for conditions other than cancer (SCIE, 2005). Despite the acknowledged need to improve end of life care within care homes, there was little support for homes to do this and SCIE reported that the principal source of documents containing practice recommendations came from The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) and (SCIE, 2005) – a body set up to provide support and advice to hospices and other specialist palliative care services and but not to care homes.

More recently, there has been a greater investment to enable care home residents to stay in the care home up to the point of death, particularly in relation to the support of staff and the provision of additional education and training. In the North West of England, the 'Six Steps' end of life care programme for care homes has been developed and demonstrated improved quality of end of life care outcomes (Brien et al., 2014;

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[6] Commission for Social Care Inspection (CSCI) began operating on 1 April 2001, to be replaced by the Care Quality Commission (CQC) in October 2009.

Martin & Martin, 2018). A further programme review is currently underway to continue to support care home staff to care for residents (www.sixsteps.net)[7].

Increased investment has taken place for a number of reasons: an increase in the autonomy and choice of individuals and the right to make decisions around their own care which recognises that most people wish to die in their 'usual place of residence', i.e., the care home. It has also been found that residents do not fare well in acute care facilities (Wowchuk, McClement, & Bond Jr, 2007) increasing the need to prevent hospitalisation. Given the financial climate in health care, it could also be considered a cost effective investment. Within the UK, there has been a drive to reduce the number of hospital deaths generally, and specifically, in the case of care home residents, inappropriate hospital deaths (National Quality Board, 2017).

This impetus to facilitate more residents to die in the care home means that evidence-based end of life care, which has been slow to be established, must advance to ensure that the resident has the best possible death, but also prevents last-minute hospital admissions due to ineffective care or care failure. There may be a number of potential barriers or aspects of care that impede the delivery of good end of life care and these must be addressed to prevent poor experiences around death and dying for residents and their families. However, external support provided to care homes may be at odds with the support they actually require as much of the support is based on a model of care required for the 'cancer trajectory' (Seymour, Kumar, & Froggatt, 2010). The

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[7] The Six Steps programme is a North West initiative based on the NHS Improving Quality Route to Success and aims to enhance end of life care through facilitating organisational change and supporting staff to develop their roles around end of life care.

cancer trajectory, originally defined by Lynn and Adamson (2003) involves a deep and rapid decline towards death. An alternative trajectory identified by Lynn and Adamson which would be more appropriate for this group is the 'frailty decline'. This is a slow low level decline leading to death. The cancer trajectory is often more familiar to those who provide support to care homes, such as Macmillan Teams, because it is one they associate with the type of death they are more familiar with.

The End of Life Care Strategy (Department of Health, 2008) was a key driver in changing the focus of end of life care delivery and research in the UK and has been described as the "publication which significantly changed the focus of EoL care delivery and research in the UK" (Spacey, Scammell, Board, & Porter, 2018 : p182). While this is accurate in many ways, reviewing the literature shows that things did start to change prior to that. Although the Calman-Hine Report (NHS Executive, 1995) had a focus on cancer services, it brought palliative care to the fore and established the ground for much of the work that was done with care homes after that. However, by reviewing the most current literature, it can also been seen that there is still much room for improvement (Forbat, Chapman, Lovell, Liu, & Johnston, 2017; Martin & Martin, 2018; Spacey et al., 2018), so the next section will consider what makes good end of life care in general and then within care homes.

2.6 The components of good end of life care

The End of Life Care Strategy (Department of Health, 2008) was a change agent in many ways as it opened up discussions around end of life care, many of these with the general public as well as health and social care professionals. Despite the strategy

promoting good quality end of life care, it also underlined that this was not happening for everyone. As a result, there was an intense engagement process with the general public and 'What's important to me. A Review of Choice in End of Life Care' was published (The Choice in End of Life Care Programme Board, 2015). This review brought public views together and presented seven key themes about what people want:

> "Many people told us that they wanted choice over their place of care and death; others told us that they wanted choices over other aspects of their care, such as pain control and involvement of family and those close to them" (The Choice in End of Life Care Programme Board, 2015 :p.3)

End of life care has been attributed with ensuring that death is not just treated as a medicalised event, but considers a broad range of aspects in addition to the physical ones (Lloyd, White, & Sutton, 2011), yet while the authors highlighted six characteristics of a good death, the second most important one was 'the control of pain and other symptoms' which suggested that despite not wanting a medicalised death, physical comfort is a high priority for many people. The End of Life Care Strategy (Department of Health, 2008) put forward a comparable version consisting of five domains that are particularly pertinent to the last phase of life, with the first reported element being 'preferences for care and treatment' (p.5)

When considering the characteristics of older people's choices around end of life care, they wish to have a similar experience and do not request to 'give up' or receive less care than their younger counterparts. Although a prolonged dying trajectory can make

it difficult to determine whether they are living with or dying from a disease (Gott, Small, Barnes, Payne, & Seamark, 2008). Lloyd-Williams and Payne (2002) and Mathie et al. (2012) found that older people's views of dying remained similar to those of the wider population with concerns regarding end of life issues such as how they would die. Meier et al. (2016) reported similar findings when they compared patient perspective articles which included an equal representation from individuals over the age of 60 years with those under 60.

There is a relationship between what people want at the end of life in relation to their quality of dying and what has been termed as a 'good death' and a 'bad death'. The 'What's important to me' report very clearly stated that:

> "Patients are so often afraid of a **'bad death'** - pain, nausea, fear and other symptoms - they need reassurance and promises they will receive help with these." (The Choice in End of Life Care Programme Board, 2015 :p.23)

Much has been written about the notion of a 'good death' (Granda-Cameron & Houldin, 2012; Kelly, 2014; Lloyd et al., 2011; Meier et al., 2016; Sherwen, 2014; Steinberg, 2012), and it has been identified as the ultimate goal of palliative care although given people's lack of desire to talk about death and dying, it may be that a 'good death' is implied rather than an explicit statement. Scarre (2012) argued that a 'good death' is an oxymoron and since a death is always the loss of a human life, the claim can only be a philosophical one, and patients can only die "as well as possible" (p.1084). Since dying cannot be avoided, Scarre suggested that a person would be best to assure themselves a 'peaceful' death. Steinhauser et al. (2000) may be more

insightful when they observed that there is no single definition of a good death commenting that quality end of life care is a dynamic process that is collaborated between patients, families, and health care professionals. As an example of this, Saunders, Ross, and Riley (2003) described a young man who died following an accident and was perceived to have died an awful death by healthcare professionals, but contended that he himself may have considered it to have been good, as he died fighting for his life. This emphasises the individuality of the interpretation of what a good or bad death entails.

Steinhauser et al. (2000) carried out a study with patients, families, and health care practitioners and found that the key issue was freedom from pain and good symptom management. As with the example given above, a 'good death' can be seen as different things by different people making it crucial to understand it from the point of view of the person who is dying, although this may not always be possible if someone is unable to communicate through poor condition or lack of capacity due to dementia. Within the provision of end of life care, this can impact upon the measurement of symptoms, especially when others need to report by proxy. It can also influence families' experiences, which can affect the way that they may report symptoms post death, during an interview, for example. A literature review by Meier et al. (2016) set out to define a good death. They worked with three stakeholder groups (patients, families and health care professionals) and identified 11 core themes of what a good death looked like. The most common three themes from across all of the groups were preferences for a specific dying process, i.e. choice of place of death (94%), pain-free status (81%), and emotional well-being (64%), highlighting again the importance of symptom measurement leading to symptom control for people at the end of life.

There are challenges in supporting a person to have a good death but care homes need to ensure they are equipped to do so, as do the external organisations that are championing them. Current evidence suggests that practice in care homes can be unsystematic (SCIE, 2005), which results in disorganised care. The quality of death cannot be separated from care practices given within end of life care (Brazil et al., 2004; Chapman & Ellershaw, 2011), so these must be attended to. Staff working in care homes would have a better understanding of patients' physical needs at the end of life to be able to optimise quality care if symptoms were more effectively characterised (Hui, Santos, Chisholm, & Bruera, 2015). In a study with patients in the terminal phase of dementia, it was identified that quality of life and comfort were enhanced by good symptom assessment and management (Lloyd-Williams & Payne, 2002). This was further supported by findings by Munn et al. (2008) who identified physical and psychological symptom management as one of the components of a good death. The importance and value of symptom assessment and management in promoting a good death has been clearly indicated and its role within end of life care will be expanded upon in the next section.

2.7 The meaning of symptoms in end of life care

As identified in the introduction chapter and the previous section, the relationship between good end of life care and the management of symptoms has been identified, To manage a symptom firstly requires its' recognition which is closely linked to symptom assessment and this will be considered in more detail in section 2.13. However a further dichotomy will be considered, which is the meaning and use of signs and symptoms. This needs to be discussed as current clinical practice favours an

interchangeable use of the terms 'symptom' and 'sign' reflecting an unclear understanding held by practitioners and researchers. The clarity of this definition is central to the positioning of the research question within a positivist epistemology. The evidence regarding symptoms is constantly being revised, with new knowledge being built upon. In the following section the role of signs and symptoms in a good death will be explored.

Derived from the Greek word, sumptÕma, symptoms are defined as subjective health related experiences (Cook, Sousa, Matthews, Meek, & Kwong, 2010) or the subjective evidence of disease or physical disturbance (Sheppard et al., 2013). Symptoms were initially distinguished from signs in the 1800s, where a symptom was identified as an alteration determined by the sense of the person, and a sign is a change in the function of the affected parts (Armstrong, 2003).

A symptom is the "subjective evidence of disease or physical disturbance observed by the patient" (Merriam Webster, 2015 www.merriam-webster.com/ dictionary/ symptom). However, if this definition of symptom is applied, it is a subjective experience which in turn is a construct that requires methods of appraisal (Fayers, Hand, Bjordal, & Groenvold, 1997; Wilkie & Ezenwa, 2012). Within this definition, there is a firm emphasis on "subjective experience", which could be argued to sit more resolutely within an interpretivist paradigm (Trochim, 2008). A subjective experience would require the person who has the symptom to be able to report on their experience, yet this will present challenges in end of life care research with participants who are unable to self-report due to the nature of dying. As such, according to definitions, what

are being measured within this research study are not symptoms, but signs. A sign comes from a different aetiological perspective and defined as an indication of a condition which is directly observable and measured objectively (Merriam Webster, 2015 www.merriam-webster.com/dictionary/sign). This definition aligns more closely with a positivist paradigm and will lead onto a discussion about the objective measurement of a sign. Despite these conceptual differences, many studies have been carried out retrospectively and thus rely on a researcher who translated a third party's notes and/or records (Forbes et al., 2011; Hendriks, Snmalbrugge, Hertogh, & van der steen, 2014; Steindal, Ranhoff, Bredal, Sorbye, & Lerdal, 2012). These studies are not gaining a subjective experience (nor do they purport to) yet they use the term symptom and it is this term that is most commonly utilised throughout studies and has gained common acceptance in the sense of language, particularly for health care professionals. It is not common for a person who is in the dying phase to be able to self-report, so the observer is relied upon to measure the occurrence, incidence and prevalence of a 'sign' rather than a 'symptom', which becomes an objective reality aligning more closely with a positivist approach. However, this study has elected to adopt the term symptom as it reflects its universal acceptance and its common use in practice, even though it would have been technically more precise to have used the term sign. The linguist Ferdinand de Saussure argued that language and labelling is not neutral and identified that the names of things and the labels that are used to form knowledge are a product of culture (Joseph, 2012). This philosophy has a parallel to the use of the term symptom, which has developed to encompass a range of meanings for the medical professions despite a clear dictionary definition.

At the end of life when a person is no longer able to communicate, it does not mean that symptoms are no longer present, so to ensure good quality care, there becomes a need to rely on the observation of possible signs. Signs would be observed versions of symptoms yet there are some symptoms that are strongly classified as subjective experiences, such as pain or fatigue. Another boundary between symptoms and signs may be the 'value' that is placed on a sign. If a sign is the existence of an undesirable situation, a sign that would reasonably be expected at the end of life, such as drowsiness, be considered too unpleasant so it is not observed for or measured.

If good pain and symptom management can be so closely identified with the concept of promoting a good death, more clarity of what a symptom is within the literature would be expected due to the level of importance placed on them, yet this remains a relatively under-stated area. A better understanding of what symptoms are needs to be explored, prior to the consideration of recognition and measurement which impacts upon the subsequent ability to provide symptom management.

2.8 Multiple symptoms

The assessment and interpretation of symptom clusters has become more widespread over the recent years with increasing literature featuring multiple symptoms or symptom clusters (Kim, McDermott, & Barsevick, 2014; Linder et al., 2015; Moens, Siegert, Taylor, Namisango, & Harding, 2015). Furthermore, it was contended that symptom cluster research should be theoretically led (Laird et al., 2011; Molassiotis, Farrell, Bourne, Brearley, & Pilling, 2012) so in other words, having a structure or a framework helps to make sense of what is happening for both multiple and cluster

symptom research but also for single symptom research, an issue that will be considered later in this chapter.

Although not clearly defined systematically, a symptom cluster relates to an aggregate of symptoms that are related to each other in a predictable manner, although Dodd et al. (2000) argue whether they share a common aetiology. Understanding how symptoms present in relation to each other will help increase awareness of the impact upon the person, particularly the older person with co-morbidities. However, before moving to a conceptual view, symptoms at end of life in care home residents will be considered. Single symptoms have been a subject of some research studies and many of these within a single disease group, such as cancer, Chronic Obstructive Pulmonary Disease (COPD) or heart failure. Viewing symptoms as a singular entity imposes a reductionist line, which supposes that the relationships between symptoms can be understood by looking at each one individually and restricts understanding and limits the development of practice (Aktas & Walsh, 2010).

People with multiple conditions often experience a complex range of symptoms (National Institute for Health and Care Excellence, 2015a). When patients' conditions become complicated due to multiple diseases, they are often excluded from research due to complexities of measuring and portraying symptoms (Mercer, Smith, Wyke, Dowd, & Watt, 2009), yet these are likely to be the patients that have the greatest symptom burden and would benefit the most from input. Furthermore, research that focussed on older persons is scarce, with older people often excluded from studies

because it has not always been an area of interest and, even now, remains relatively under researched (Van Lancker et al., 2013).

2.9 Symptoms at the very end of life for residents in care homes

As discussed, care homes have not always been seen as a place for dying and it was not until the mid-1990s that literature about end of life care, and particularly related symptoms, became more widespread. In the USA, a study by Ferrell (1995) on pain evaluation and management in care homes in the USA only briefly mentioned the applicability to those near the end of life. End of life care in care homes in the UK achieved more prominence when Avis, Greening Jacson, Cox, and Miskella (1999) piloted a project to improve end of life care in nursing homes with the goal of "extending hospice standards of end of life care…to people with a terminal illness" (p.33), emphasising the application of general end of life care approaches. Avis et al. discussed end of life symptom management, but made the assumption that knowledge gained from other end of life specialties, such as cancer care, was applicable to residents in the care home setting. The focus of other studies conducted around the same time took a strong focus on pain management, with less attention given to other symptoms (Katz, Komaromy, & Sidell, 1999a; Parker & De Bellis, 1999). Katz et al. (1999a) made a broad reference to the use of syringe drivers being a necessary part of symptom management in care homes, which has been more recently challenged by Kinley and Hockley (2010) when they argued that symptoms frequently did not require the use of a syringe pump[8] due to the late presentation and transient nature of the presence of symptoms.

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[8] Syringe drivers are now called syringe pumps since the old type 'driver' was replaced by a 'pump' device for safety reasons in 2007

By the mid-2000s several articles had been published considering symptom prevalence and management in care homes. This literature had started to focus on a wider range of symptoms, although there was a great diversity across the literature (Brandt et al., 2005; Brandt, Ooms, Deliens, van der Wal, & Ribbe, 2006; Brechtl, Murshed, Homel, & Bookbinder, 2006; Brookfield, 2002; Caprio et al., 2008; Cartwright, Hickman, Perrin, & Tilden, 2005; Goodridge et al., 2005; Hanson et al., 2008; Koopmans, van der Sterren, & van der Steen, 2007; Reynolds et al., 2002; Solloway, LaFrance, Bakitas, & Gerken, 2005). Care homes have now become more widely recognised as the final place of life for the people who live there, and coupled with government directives impelling that people are able to die in their usual place of residence, (Department of Health, 2008), the significance of understanding what experiences take place have been seen as important. In general, research has vastly increased knowledge of symptoms and their impact, especially ones associated with cancer. However, these are more typically involving younger people, which has not been helpful to develop clinical practice and an evidence base, especially for older people. The manifestation of symptoms usually distinguish a shift in health status (Henly, Kallas, Klatt, & Swenson, 2003) and, in the instance of end of life care, this can coincide with the onset of the dying phase. As symptoms are unpleasant sensations which have a severe impact upon a person's quality of life and places a great burden on families (Karabulu, Erci, Ozer, & Ozdemir, 2010; Pautex, Berger, Chatelain, Herrmann, & Zulian, 2003), it is crucial for professionals to understand both singular and multiple symptom presence and intensity to enhance symptom management.

2.10 Identifying symptoms

The recognition and identification of symptoms can be further complicated as care home residents have a number of reasons that make it challenging for care professionals to ensure that death and dying is well planned for, and to ensure that the resident is able to die in the care home. Most residents now living in care homes are in their 80s and 90s and will have multiple co-morbidities. There is around a 70% possibility of residents having dementia, with those with dementia having the shortest life expectancy (Agüero-Torres, Fratiglioni, Guo, Viitanen, & Winblad, 1999). Death is not easily 'predictable', with a slow decline masking the residents approaching death (Froggatt, 2001) meaning staff have to work with the 'uncertainty' while still providing care (Goodman, Froggatt, Amador, Mathie, & Mayrhofer, 2015). Prognostication is a challenge for care professionals: despite most residents estimated to have a life expectancy of 15 months following admission (Forder & Fernandez, 2011), they are often not identified as being at the end of their lives. Hov, Hedelin, and Athlin (2013) recognise that identification of approaching death is a complex process due to the vague prognostic signs that could signal either recovery or death. As a result, there is a lack of meaning placed on end of life symptoms, partly because of the lack of recognition of the resident being in the terminal stages, and partly because the most commonly observed symptoms, such as pain, nausea, agitation, and shortness of breath (from an end of life cancer focussed evidence base) may not actually present in residents dying in care homes. It is also important to consider that although many end of life symptoms are termed physical symptoms, they may allude to broader psychological symptoms such as depression or anxiety.

2.11 Symptom presence in care home residents

The symptoms that are most commonly looked for in care homes have been identified in studies that have been carried out in more disparate care settings such as hospices or hospitals (Brandt et al., 2006), although Hui, Dev, and Bruera (2015) contest that there have been insufficient studies carried out on symptom prevalence during the last few days of life in the general population either. Estabrooks et al. (2015) subsequently state that there are few published studies that describe end of life symptom burden in older adults in nursing homes. This has led to much of the knowledge about symptoms being based upon previous research from other settings, despite the lack of applicable evidence to the care home setting. For example, syringe pump training is normally seen as a core part of education for Registered Nurses working within care homes (Mukoreka & Sisay, 2015), yet Kinley and Hockley (2010) found that syringe pumps were rarely used in care homes and when used, only required for less than 1.5 days prior to death. This suggests two things: there are fewer symptoms present than in other populations and importantly, that when symptoms do occur, they are present for a restricted amount of time. It also suggests that this education may not be appropriate, given the limited time that staff have for training, and that there could be more appropriate education provided which is more appropriate to resident care and making better use of staff time. In a study by Gorlen, Gorlen, and Neergaard (2013) staff participants reported problems with administering medications, yet this study used the guidance from the Liverpool Care Pathway, which identified an expectation that a syringe driver will be required rather than testing out whether there was a need. As well as medication issues, there has also been reported a lack of evidence-based strategies for recognising common symptoms at end of life in care homes (Cartwright, 2002; Eicher et al., 2016; Hallberg, 2006a; Parker-Oliver, Porock, Zweig, Rantz, &

Petroski, 2003; Van Lancker et al., 2013; Wowchuk, McClement, & Bond Jr, 2006), with care staff lacking knowledge on the assessment and management of symptoms (Katz, 2003), resulting in poor symptom control (Seymour et al., 2010).

2.12 Symptom research in end of life care

End of life care research has been described as slow, expensive and often failing to produce useful results (Department of Health, 2008) with Higginson et al. (2013) observing that treatments in end of life care are hampered by poor research.

Symptom research will require a quantification of the symptoms, however symptom research has been described as being, in the majority, cross-sectional and descriptive (Brant, Beck, & Miaskowski, 2010). As already noted, end of life care research requires future development and to do this, two areas will be considered: 1) the measurement of symptoms and 2) the location of the research within a conceptual framework.

2.13 Measuring or assessing symptoms

Measurement and assessment are different constructs, although they are often used interchangeably. Surprisingly, there is little in health related literature to differentiate between the two with some literature using assessment measures. An example of this can be observed in a paper by McColl (2004): the title of the paper is best practice in symptom 'assessment' but this quickly progresses to 'measuring' symptoms with no intervening discussion. However, there does appear to be a distinction even if it is not

made explicit. To explore this further, adopting terminology that is defined in the educational field can add some clarity. '**Assessment** is the process of gathering information to observe progress and make decisions if required' while '**Measurement** relates to the process to which the attributes or dimensions of an object are determined' (Zemlyanskaya, 2016).

Despite their differences, there are also associations between the two with an assessment being necessary to produce a measurement, or as identified by Ajayi (2018), again from science education, measurement provides a technique to capture changes through the assessment process in a two-step process. By taking this a step further, it may be applied to health science as something that translates the phenomena, from the gathering of information (assessment), into a representative set of numerical variables (measurement). Within health science, tools are used to assess and measure using the two-step process, but with the ultimate goal of producing a representative set of information. This process is not mutually exclusive to either using the information for clinical means (e.g., as part of a needs assessment) or for research purposes, but for both, it has the end goal of presenting reliable and valid results.

It is the intention to use the term 'measurement' within this study as it aligns with the research question to reflect the positivist paradigm in which it sits and to reflect the way in which the assessment translates into measurement.

2.13.1 The measurement of symptoms

The MORECare statement (Higginson et al., 2013) stated that outcome measures require similar properties for both clinical practice and research, in that they should be short, responsive to change and used in both areas. A crucial part of measuring symptoms, for either research or clinical practice in carrying out symptom research is the measurement of a symptom. This is important because symptoms directly affect a person's distress and quality of life. Measurement is a prelude to successful symptom treatment, however it is complex because of the evolving nature of disease, and interrelationship between the person's phase of life and symptoms.

Depending upon the research question, symptom research can be conducted with quantitative or qualitative methods, and sometimes a combination of both. The MORECare statement identified five areas of contention to consult upon. 'Outcomes' was one of these areas which was subsequently reported by Evans et al. (2013), who identified the importance of 1) robust measures, 2) data collection time points and 3) proxy reporting guidelines. These findings concurred with work by Armstrong (2014b) who recommended that factors such as the severity, distress and rate of change of symptoms over time needed to be taken into consideration when conducting symptom research.

Symptom measurement has become more complex, or it could be that there has been a new recognition that symptoms are not single entities that occur at a single point of time. For the measurement of symptoms to be meaningful given that studies are now including multiple concurrent symptoms and temporal aspects, locating symptoms

within a conceptual model or framework will not only strengthen the research process by offering more clarity, but help to make the research and its processes more transparent for other researchers. The terms model and framework are often used synonymously in general literature, but this cross-over in definition and purpose also demonstrates why they are used interchangeably as elements of both can be required in any research study. They can both used to describe processes, however a framework provides a big picture overview of various descriptive categories and how they may relate to one another, while a model is commonly used to describe the process of translating research into practice (Crockett, 2017), making it more appropriate for the purpose of this study. A further advantage of the use of a model is that it can help to inform choices of instruments that align with this clearer and more transparent vision. As discussed in the introduction, it was not the intention to use a model or framework for the research study, but to apply it retrospectively to help to frame the research and make sense of the findings.

2.14 The use of a conceptual model

It is often difficult to tell if a particular piece of symptom research has utilised a conceptual model as it is often not reported explicitly within the literature. Because a model provides a way of thinking and organising a subject or an area, a lack of a defined model can result in a lack of structure, and reduce consistency within the bigger picture of symptom research with studies becoming unconnected, thus potentially reducing opportunities for transferability and for meta-analysis studies. Furthermore, the location of symptom research within a positivist paradigm may allow the lack of a conceptual model to go unchallenged due to a universal (but unspoken)

acceptance of this positivist worldview. While this may be a well-founded decision, it raises the possibility that symptom research could be enhanced by the use of a model, or a framework, to make sense of the findings and that allows itself to be refined for use in future symptom research.

To investigate the use of a conceptual model, it was noted that within positivist studies there were a lack of either symptom research models or frameworks. As this study intended to take a positivist approach, a conceptual model that could be applied to review the study and the findings, but in a balanced way, was required. Given a lack of appropriate models for positivist symptom research, both models and frameworks that were allied to symptom research were reviewed. During the review of these publications it became apparent that many of them did not present either a model or a framework, but rather comprised of a set of recommendations for symptom management research. Following the review, six symptom management models and frameworks were located (Brant et al., 2010; Brant, Dudley, Beck, & Miaskowski, 2016; Cashion & Grady, 2015; Corwin, Meek, Cook, Lowe, & Sousa, 2012; Finnegan, Shaver, Zenk, Wilkie, & Ferrans, 2010; Parker, Kimble, Dunbar, & Clark, 2005; Teel, Meek, McNamara, & Watson, 1997). Table 2.1 summarises each of the publications and their proposed model or framework.

Table 2.1 A summary of research management models and frameworks

Author(s) and date	Summary
Brant et al, 2010	A model that aims to incorporate symptom clusters and symptom interactions to allow researchers to have an expansive view of the multitude of symptom related variables.
Cashion et al, 2015	The model is an investigative sequence involving description of complex symptoms, phenotypic characterisation, biomarker discovery and clinical application.
Corwin et al, 2014	The model embraces the use of common measures, symptom trajectories. Advocates a registry of CDEs (common data elements) and sophisticated analytic techniques.
Finnegan et al, 2010	A framework for guiding symptom research around symptom cluster experience and are based on five cardinal symptoms
Parker et al, 2005	A framework to provide a conceptual perspective to understand the underlying mechanisms of symptom pairs and clusters. Plans to help to translate research findings into practice rather than inform symptom research.
Teel et al, 1997	Introduces the symptom interpretation model, which is based on an illness representation model. Aims to understand the individual nature of symptoms in a behavioural context.

The focus of all of the models and frameworks were initially intended for use with symptom management research; however, this may not be appropriate for all types of symptom research, so further deliberation took place. Brant et al. (2010) identified that new developments need new models. While this was largely in reference to a paradigmatic shift within other studies such as work emerging on symptom clusters, temporal studies and patient outcome measures (reported or proxy), many of these involved using the findings for symptom management. However, there are other changes in practice that may require different approaches to gain new understanding and knowledge. Rather than always extending knowledge within new practices, it is also recognising that changes taking place can lead to gaps that are appearing in current knowledge. One such change is in place of death. As a shift is occurring to support

people to die in their usual place of residence, it means that populations are dying in different places than previously and new knowledge about symptom experience in this population and setting is required. While the scope of symptom research management models needs further development, knowledge around symptom presence also needs to be kept up to date and this will require different models and frameworks to capture it.

Ultimately, Brant's model was the only model to address the requirements for symptom research. Their own system, 'the components and criteria of the characteristics of an ideal model or theory for symptom management research' (see Appendix i) proved a useful tool to review the content of all of the models and frameworks, but it did show that others were limited in relation to their focus (i.e. symptom clusters), their representation (behavioural aspects), or their application (chemical changes in symptoms) so using the review criteria by Brant et al. did not give them an unfair advantage but merely emphasised the inappropriateness of other models.

Brant et al. (2010) developed their New Symptom Management Model as the result of a comparison and contrasting exercise of four existing models or theories which ultimately led to proposing their own model. In 2016, it was renamed the Dynamic Symptoms Model as it had been used beyond the sphere of symptom management (Brant et al., 2016). Since 2010, the model has been used in a number of ways such as addressing the complex nature of symptoms, co-occurring symptoms and longitudinal changes of symptoms over time (Brant et al., 2016). It was broad enough to meet a number of different uses, but also it has been used with different disease groups which

have included cancer but other chronic diseases as well. Figure 2.1 shows the New

Symptom Management Model.
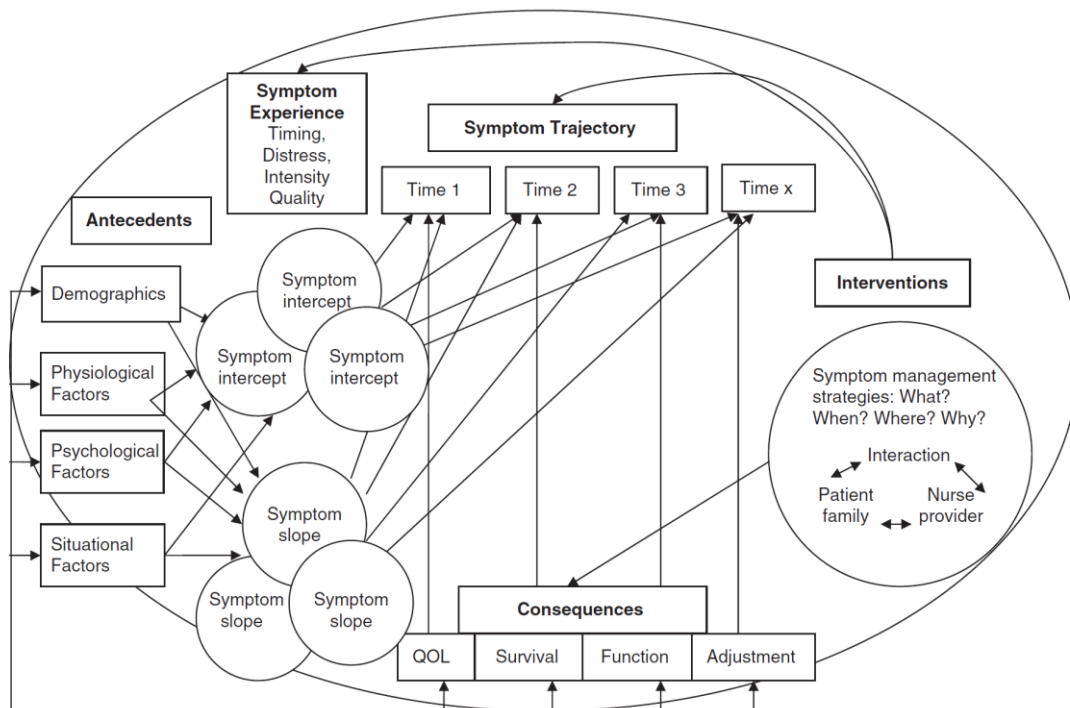
Figure 2.1 The New Symptom Management Model (Brant et al., 2010) (Reproduced with kind permission by Jeannine Brant)

The model by Brant et al (Brant et al., 2010 has a focus on symptom management but has utility to be applied to other aspects because of its comprehensive overview. It shows the potential chain reaction of symptom events, starting on the left hand side of the diagram, moving towards the right. On the left hand side, are the antecedents; these are factors that influence symptoms, both in the way that they present, i.e., through different characteristics and demographics, or the way in which the individual experience may influence them. These can affect the symptom intercept (when symptoms may occur together) or the symptom slope (the level or intensity of the symptom). These are influenced by temporal factors (the symptom trajectory over time). Interventions are carried out (at the right hand side of the diagram), leading to

consequences in terms of quality of life, survival, function and adjustment which go full circle and lead back to the symptom being managed or not. The application of the model will be further discussed in relation to this study and its findings within the discussion chapter. The New Symptom Management Model also highlights the challenges of differentiating between a model and a framework as discussed in section 2.13.1. As a model it does facilitate the description of a process (of symptoms) to help translate research into practice (through the breakdown and explanation of the different elements), however it also, in parts, meets the requirements for a framework in that it describes categories and their relation to one another.

2.15 Conclusion

Care homes are increasingly caring for a population that is becoming older and frailer, with multiple comorbidities and who are living for shorter periods of time in the care home before they die. As the length of stay shortens and place of death shifts from hospital to care homes, they are delivering end of life care much more frequently. Quality of life is strongly linked to knowing that a good death will happen and one core element of a good death that is important to people is the control of symptoms. However, to be able to provide symptom control, there needs to be an understanding of the type and nature of symptoms that this population will be affected by.

As identified by the introduction in chapter one and reinforced by this chapter, there is a need for research in this area, not only to improve the dying experience for residents in care homes, but to provide an evidence base to support staff to be able to deliver good end of life care and to add new knowledge to influence practice and policy. There

has been work done in this area, but in order to look for gaps in knowledge and methods, a systematic literature review was carried out to understand the nature and types of symptoms observed in residents in nursing care homes near the end of life.

Chapter 3 – Literature Review

3.1 Introduction

Providing relief from symptoms has been long identified as an essential component for end of life care (Wilkie & Ezenwa, 2012). End of life care practice and research in residents in care homes has identified an interest in symptoms from measurement to management, and knowledge of the prevalence of symptoms is necessary for the care of all patients (Potter et al., 2003). As discussed in the previous background/context chapter, there is an increasing ageing population with chronic diseases, with associated symptoms requiring appropriate measurement and management. (Chang, Hwang, Thaler, Kasimis, & Portenoy, 2004). Good symptom control has been identified by people at the end of life with the wish that they do not want to die in pain or distress, rating it higher than being at home or being with loved ones. (Demos, 2013). Little is known about symptoms at the end of life in the care home population, in terms of which symptoms occur and the presence and frequency of those symptoms. This review seeks to survey current and previous literature and to identify areas for future development in relation to current knowledge around end of life symptoms for residents in the final days of life, in the care home setting. A narrative or traditional literature review is a comprehensive, critical and objective analysis of the contemporary knowledge on a topic and helps to establish a theoretical context of the research (Onwuegbuzie, 2016). Onwuegbuzie (2016) define four common types of narrative reviews and this review will take the form of a general literature review, which is further defined as:

> "A review of the most important and critical aspects of the current knowledge of the topic. This general literature review forms the introduction to a thesis or

dissertation and must be defined by the research objective, underlying hypothesis or problem or the reviewer's argumentative thesis (Onwuegbuzie, 2016, p.24-25).

This type of systematic approach to reviewing has been widely discussed in other literature (Booth, Papaioannou, & Sutton, 2012; Hawker, Payne, Kerr, Hardey, & Powell, 2002; Khan, Kunz, Kleijnen, & Antes, 2003). The specific data extraction and evaluation methods presented by Hawker et al (2002) that are intended to aid researchers who are planning to undertake a systematic review of disparate material was adopted. This method was selected because, although the traditional method of systematic review is well accepted in health-related research, this method has the capacity to reduce large quantities of data into palatable pieces for digestion, particularly if there is qualitative research incorporated in the review (Dixon-Woods & Fitzpatrick, 2001). While the general approach to a systematic review identified by Booth et al (2012) was utilised to support the overall process, a step wise approach, using five steps identified by Khan et al. (2003) was incorporated as this provided an explicit and comprehensive framework.

Step 1 - Framing questions for a review

Step 2 - Identifying relevant work

Step 3 - Assessing the quality of studies

Step 4: Synthesising the evidence

Step 5: Interpreting the findings (Discussion)

3.2 Framing the research question

To construct the search strategy, the PICO Framework (Huang, Lin, & Demner-Fushman, 2006) was used to articulate the research question (P - patient, problem or population; I - intervention; C - comparison, control or comparator; O – outcome), which supports an improved query formulation and better search. Although there can be a risk of losing the subtle relationships between concepts with this method, the use of PICO may be given a broader application by combining the most relevant items. Table 3.1 highlights the use of PICO to formulate the research question.

Table 3.1 Construction of the research question using PICO

PICO	Related area
P - patient, problem or population	End of life care for older residents in care homes in the final days of life
I – intervention	Observation
C - comparison, control or comparator	None
O – outcome	Knowledge of symptom prevalence in terms of presence and intensity

As a result, the research question was developed – 'What is the presence and frequency of symptoms in residents dying in care homes during the final days of life?'

3.3 The search and search strategy

3.3.1 Search methods

The electronic databases searched from January 1990 to April 2014 were PubMed, CINAHL (Cumulative Index to Nursing and Allied Health), BNI (British Nursing Index), AMED (The Allied and Complementary Medicine Database), EMBASE, Web

of Science and the NHS Evidence database. An updated search was conducted in January 2018. A three-part search strategy was established based on headings from the Medical Subject Headings (MeSH) of the National Library of Medicine and identified key words (Table 3.2).

Table 3.2 - Search strategy keywords

Search term part 1	(("Assisted Living Facilities" [MeSH term] OR "Nursing Homes" [MeSH term] OR "Residential Aged Care" [MeSH term] OR "Homes for the Aged" [MeSH term]) OR "Long Term Care" [MeSH term]) OR ("Care Home*" [Key word] OR "Nursing Home*" [Key word] OR "Long Term Care*" [Key word] OR "Long Term Care Facilit*" [Key word])) AND
Search term part 2	(("Palliative Care" [MeSH term] OR "Terminal Care" [MeSH term] OR "Hospice Care" [MeSH term] OR ("Advanced" [Keyword] OR "Life Limiting" [Key word] OR "Hospice" [Key word] OR "Palliative" [Key word] OR "Supportive" [Key word] OR "End Stage" [Key word] OR "Severe" [Key word] OR "Terminal" [Key word] OR "Death" [Key word] OR "Dying" [Key word])) AND
Search term part 3	(("Outcome Assessment" [MeSH term] OR "Measurement" OR "Assessment" [MeSH term] OR "Symptom" [Key word] OR "Symptoms" [Key word]))

The search was supplemented by reviewing the reference list of the identified studies for any further relevant citations not obtained from the electronic databases. A cited literature search was completed using Web of Science on the final articles that were included in the review. Finally, a grey literature search was performed through a search of conference abstracts, dissertations and theses and appropriate websites. All references were saved to EndNote®. The titles and abstracts of the studies were reviewed against inclusion and exclusion criteria (Table 3.3) and studies excluded that were not relevant. If there was doubt about the content of a study due to an incomplete or unclear abstract, the full study was obtained and reviewed. Finally, the full text of

studies were obtained and reviewed on the basis of their relevance to the inclusion criteria. The reasons for excluding any studies were recorded for the sake of transparency and subsequent reporting. The review was carried out by the researcher (LP).

3.3.2 Inclusion and exclusion criteria

The inclusion and exclusion criteria were established to identify studies involving the reporting/observation of symptoms in residents in the final days of life in nursing/care homes (Table 3.3). The nature of the study around end of life presented a particular challenge and the inclusion/exclusion criteria needed to be sensitive enough to represent this. A difficulty when studying end of life is that end of life can only be identified after it has occurred, so has to also identify aspects that could lead to end of life. This is a similar issue when trying to identify end of life symptoms, however, it is possible to include symptoms that did not result in death, i.e., preventable events that did not lead to the person dying.

Table 3.3 – Inclusion and exclusion criteria

Inclusion	Exclusion
Language - English	Language - Non-English
Care/Nursing Homes	Acute/Hospital, Primary Care, Hospice
Age ≥ 65	Age < 65
Symptoms[9] during events in final days of life	Symptoms[7] during events not resulting in death, such as urinary tract infections, or falls
Empirical studies	Review articles
January 1990 – to date	

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[9] A symptom was not pre-defined for the literature review in order to capture the potential breadth and range of different symptoms. Had certain symptoms been named and searched for specifically, there was a risk that some symptoms may have not been captured. Any paper which included symptoms (as defined by the paper) and met other criteria was included.

3.3.3 Study characteristics

The database searches, along with hand searching and grey literature yielded 1685 potentially relevant articles after duplicates were removed. This resulted in 25 articles being included in the review. See PRISMA flow diagram (Figure 3.1) and Table 3.4 for the list of articles.
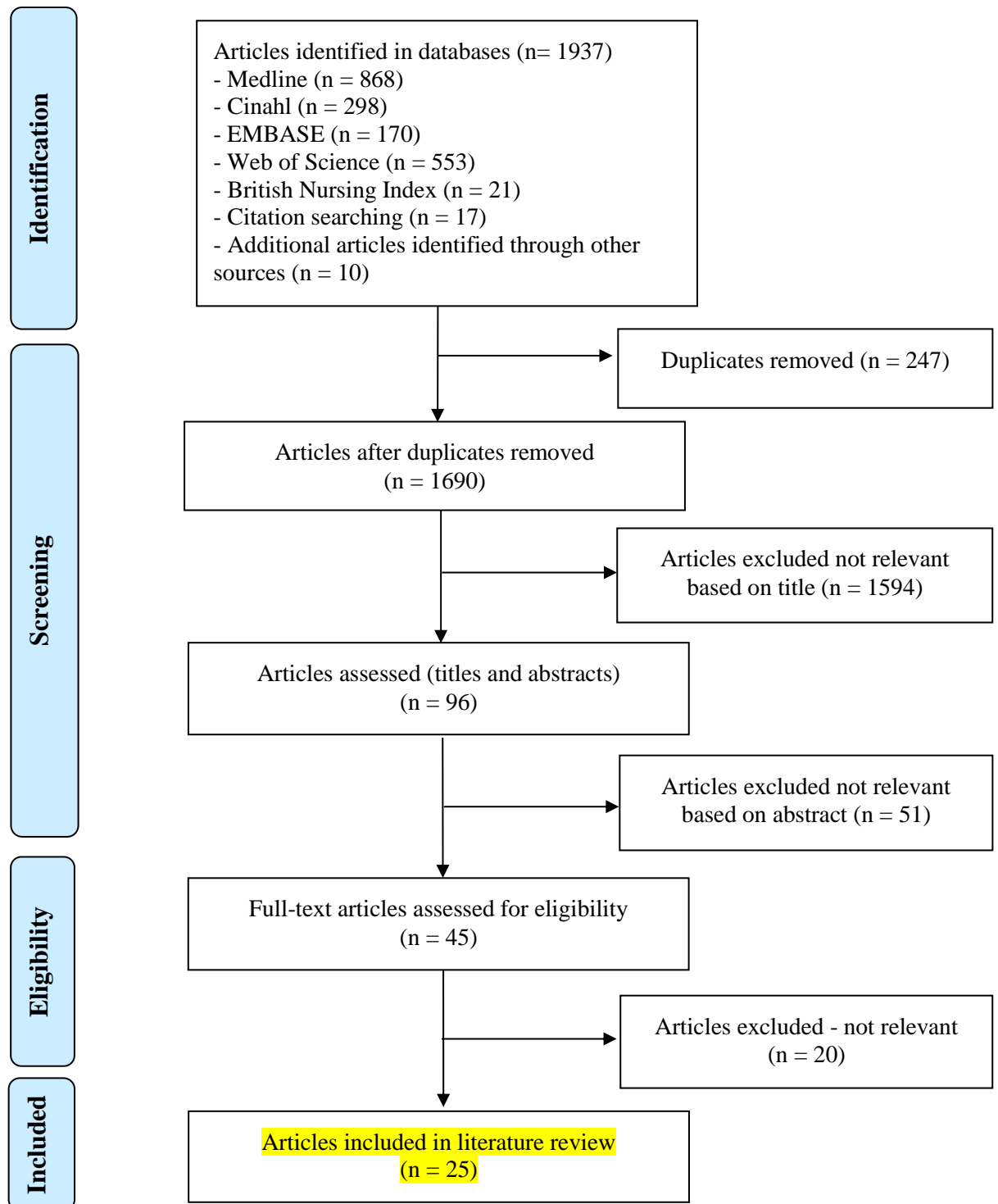
Figure 3.1 – PRISMA flow diagram (Moher, Liberati, Tetzlaff, & Altman, 2009)

3.4 Assessing the quality of the studies

The 25 final selected studies were reviewed to ensure that they met the research question and the selection criteria. The selection criteria included the minimum acceptable level of design (empirical studies). The studies were then subjected to a quality assessment, using the Hawker et al (2002) review framework. This framework permits the appraisal of either qualitative or quantitative studies, or specifically, a combination of both, as it was anticipated that dual type articles were likely to be found. Additionally the quality appraisal enabled consideration of heterogeneity across the studies and whether a meta-analysis would be possible. It also helped to identify the strength of the studies to understand their value when making recommendations for future research.

During data extraction each study was reviewed using the appraisal tool by Hawker et al. (2002) (see Appendix ii). This was utilised to support a consistent approach to the review of the evidence. This also included a scoring protocol (see Appendix iii). The latter was applied to calculate a total score for each article. There were a total of nine questions with marks to be allocated as 10 (very poor), 20 (poor), 30 (fair) to 40 (good), which would result in each article being allocated a total out of 360 marks. The scores for the studies within this literature review ranged from 160-340 the scores can be found in Table 3.4.

3.5 Synthesising the evidence

Narrative reviews have a wide scope and non-standardised methodology, therefore their breadth, depth and time range will vary and do not follow an established

procedure. To enable transparency, the process undertaken to synthesise the evidence will be described here before moving on to present an overview of the findings prior to the discussion.

The final selected studies were read in full several times for familiarisation. Once this had been completed, each articles was scrutinised further, and notes were made about each study within an Excel spreadsheet. These notes were also able to incorporate the notes that had been made during the quality review. This enabled common themes to be observed, recorded and compared across the different articles/studies. The themes had to be revised several times and articles had to be revisited and revised to assess how they fit in with any new emerging themes. An early observation of the evidence showed a lack of homogeneity within the literature, which consisted of both clinical and methodological diversity leading to statistical heterogeneity meaning that a meta-analysis could not be carried out (Eysenck, 1995; Russo, 2007). A meta-synthesis approach was also considered as this would enable qualitative methods to synthesise existing qualitative studies to create meaning through an interpretative process (Erwin, Brotherson, & Summers, 2011). However, the lack of consistency between qualitative and quantitative methods within the literature also prevented this. As a result, rather than presenting a meta-analysis or a meta-synthesis, each study was analysed and presented individually to investigate how the clinical and methodological aspects of studies related to the research question (Higgins et al., 2019). Thus the common elements of the studies were presented as themes and are listed below and will be presented in the following section:

- Geography and demographics

- Care contexts

- Nature and type of studies

- Data collection time period and time points

- Data collection instruments/methods

- Data sources

- Type and prevalence of symptoms

- Influence of associated diagnoses

The 25 articles resulting from the literature review can be found within a summary table (Table 3.4). This table provides an overview of the literature including author, year, country of origin, setting, study size, type of respondent, overview, aim of study, study design, the number of symptoms reported on, and the overall score derived from Hawker et al. (2002) critical appraisal tool.

Table 3.4 – The studies included in the literature review and an overview of the articles

Author, year, country	Setting	Study size (*N*)	Respondents	Overview/aim of study	Study design	Time points of data collection	No of symptoms reported	Score (out of 360)
Brandt et al (2005) The Netherlands	Nursing Homes	516	Nursing Home Physicians	To identify resident characteristics, symptoms, direct causes and incidence of terminally ill NH residents	Prospective observational cohort study	1 time point within 6 weeks of death	26 (plus one open)	310
Brandt et al (2006) The Netherlands	Nursing Homes	463	Nursing Home Physicians	To identify the direct causes of death and to evaluate the presence of burdensome symptoms in last 2 days of life	Prospective observational study	2 time points within 2 days of death (0 - 24hrs and 24 - 48hrs)	15	330
Caprio et al (2008) United States	Nursing Homes and Residential Care	325	Family and staff care givers	To evaluate the relationship between pain, dyspnoea (sic) and family perceptions	Retrospective interviews	1 time point within 1 month of death	2	300
Cartwright et al (2005) United States	Private Home, Nursing Home, Hospital	25	Family members	To identify EoL symptom experience of residents	After death in person interviews	1 time point within 1 week of death	11	260
De Roo (2014) The Netherlands	Long-term Care Facilities	233	Families and physicians (Physicians only for symptoms)	To describe if people with dementia die peacefully and which characteristics are associated	Prospective and retrospective data analysis	1 time point. Unspecified period of time	9	330
Di Giulio et al (2008) Italy	Long-term Care Institutions	141	Clinical and nursing records	To describe the last month of life and clinical decisions in the management of EoL events	Retrospective exploratory study	1 time point within 1 month of death	12	320
Estabrooks et al (2015) Canada	Nursing Homes	3647	Minimum Data Set information	Compare symptoms at EoL for those with and without dementia and look at care home contextual	Retrospective analysis of longitudinal data	Up to 4 time points within 12 months of life. The final time point was within 3 months of death	6	310
Goodridge et al (2005) Canada	Nursing Home	15	Registered Nurses and Healthcare aides and family members	To examine perspectives of last 72 hours of life	Exploratory descriptive retrospective interviews	1 time point within 3 days of death	3	250
Hall et al (2002) Canada	Long-term Care Facilities	185	Nursing records	To focus on the last 48 hours of life of residents	A retrospective chart audit	1 time point within 2 days of death	9	270

Hanson et al (2008) United States	Nursing Home, Residential Care	674	Staff and family	To describe EoL symptoms of nursing home and residential care	After death interviews	1 time point within 1 month of death	4	300
Hendriks et al (2014) The Netherlands	Nursing Home	330	Physicians	To look at prevalence and course of pain, agitation and SOB in residents with dementia	Retrospective after death reports	1 time point within 1 week of death	3	330
Hermans et al (2017) Belgium	Nursing Home	109	Nurses and nursing assistants	To describe palliative care needs and symptoms and compare for those with and without dementia	Prospective cross sectional study	1 time point with 12 months of death	1 (plus 'others')	300
Jordhoy et al (2003) Norway	Hospital, Home & Nursing Homes	55	Physicians	To explore characteristics associated with death	Analysis of prospective data collection	Up to 6 time points within 6 months of death (1 time point within 1 month of death)	9	290
Kayser-Jones (2002) United States	Nursing Homes	117	Residents, staff and family	Investigate process of providing EoLC to residents dying in NH	Participant observation ethnographic study	Unknown	1	250
Klapwijk et al (2014) The Netherlands	Long Term Care Facilities	24	Elderly Care Physicians	Describe symptoms and treatments when death is expected in LTC facilities	Prospective longitudinal observational study	Up to 4.3 time points within 5 days of death	23	300
Knight (2007) United Kingdom	Nursing Homes	263	Nursing staff	Audited the use of an EoL Integrated Care Pathway	Retrospective pre-audit and post-audit	1 time point within "few hours" to 14 days of death	4	160
Mitchell (2004) United States	Nursing Homes	2492	Minimum Data Set records completed by Registered Nurses	Describe and Compare EoL experience of groups with/without dementia	Retrospective data analysis	1 time point within 120 days of death	12	340
Parker & De Bellis (1999) South Australia	Nursing Homes	45	Registered Nurses	To describe profile of dying resident	Retrospective case note review with staff who had completed them	2 time points (a varied 'initial' assessment and 'final' assessment, no specific times given)	5	240
Pinzon (2012) Germany	Home, Hospital, Palliative Care Units, Nursing Homes	125	Families	To assess symptom prevalence of chronically ill	Retrospective random cross sectional survey	1 time point within 2 days of death	16	330

Reynolds et al (2002) United States	Nursing Homes	80	Nurses and Certified Nursing Assistants	To describe the pall care needs of dying NH residents	Retrospective structured interviews	1 time point within 3 months of death	9	300
Rodiguez et al (2010) United States	Nursing home	303	National Nursing Home Survey (NNHS)	To evaluate prevalence of under-treatment of non-pain symptoms and factors	Retrospective cross sectional data analysis	1 time point within day of death	5	330
Sandvik et al (2016) Norway	Nursing Home	134	Registered Nurses and Licenced Practical Nurses	To determine signs of imminent dying and change in symptom intensity during pharmacological treatment	Prospective Trajectory Study	2 time points (last year before death and day of death)	14	330
Sloane (2008) United States	Nursing Homes and Residential Care	581	Nursing staff and families	To understand the experiences and potential unmet need	After death interviews	1 time point within 1 month of death	5	300
Van der Steen et al (2009) The Netherlands	Nursing Homes	48	Dyads of nurses and staff	To compare ratings of symptoms	Retrospective questionnaires (families) and interviews (nurses)	1 time point within 3 months of death	14	330
Veerbeek (2007) The Netherlands	Hospital, Nursing Home, Home Care	102	Medical and nursing records and nurses	To measure the burden of symptoms, medical and nursing interventions	Retrospective note review and questionnaire (for symptoms)	1 time point within 3 days of death	11	320

3.5.1 The geography and demographics of the different studies

There were 25 articles included in the review, and the majority of these were carried out in the United States ($n = 8$) and the Netherlands ($n = 7$). Apart from Canada ($n = 3$), and Norway ($n = 2$), all other countries (Belgium, Italy, Germany and South Australia) only had one published study each. The only study published in the UK was carried out in South Wales. The studies were published between 1999 and 2017: there were no studies published between 2017 and January 2018, when the search was updated. There was a cluster of studies published between 2002 and 2010 ($n = 18$) equating to 70% of the total; however, from 2010 to the updated review in January 2018, there have only been a further seven published studies despite the comparable time periods. In relation to the location of publication, 11 studies were published in journals with a gerontological focus, nine were published in those with a palliative care focus, and the remaining five in general publications (for example, general medicine and cancer care). Although 18 of the publications were in internationally orientated journals, half of those ($n = 9$) were in American publications, possibly reflecting the higher proportion of American studies included in the literature review.

The range of ages within the study populations were 76.8 - 88 years with the mean across all studies was 83.5 years. The proportion of females outweighed males in every study except one (Veerbeek, van Zuylen, Swart, van der Maas, & van der Heide, 2007) with a median percentage of 66.5% (range 45 - 81%).

The length of time spent in the care home was only reported explicitly in eight studies and ranged from 1.2 years to 4 years (mean 2.79 years).

3.5.2 Mixed care contexts

Three studies (Cartwright et al., 2005; Pinzon, Claus, Zepf, Fischbeck, & Weber, 2012; Veerbeek et al., 2007) present comparison studies and identified a mixed population from a number of different settings. These were included as the care home results were reported on separately from the other settings, enabling the care home data to be extrapolated from the wider results.

3.5.3 Nature and type of the studies

All studies focussed on the observation of symptoms although this was not always the primary purpose that the study had set out to achieve. For example, one study was an ethnography to observe end of life care in nursing homes (Kayser-Jones, 2002) while another was investigating the possibility of being able to determine imminent dying (Sandvik, Selbaek, Bergh, Aarsland, & Husebo, 2016). As a result, they can be classified broadly into three types of approaches:

1. Primary measurement/observation of symptoms for the purpose of the study

2. Where the measurement/observation took place within a broader context, so that the purpose of the study was not primarily concerning symptoms, but still included a direct observation

3. Indirectly collected data that used data to provide information about symptoms

This links closely to whether the data in the studies were collected prospectively (at the same time as the resident was dying) ($n = 7$) or retrospectively (following the death) ($n = 17$). One study (De Roo et al., 2014) included both retrospective and prospective

data collection, with physicians collecting information both before and after death, although families were sent questionnaires to complete only after the death occurred.

In the eight studies that collected data prospectively (although one of these studies collected both retrospectively and prospectively), there were processes set up to systematically collect data about residents in the final period of life, and track them until death. Six studies utilised a direct reporting system (Brandt et al., 2005; Brandt et al., 2006; De Roo et al., 2014; Klapwijk, Caljouw, van Soest-Poortvliet, van Der Steen, & Achterberg, 2014; Sandvik et al., 2016) with physicians completing agreed protocols for data collection. Kayser-Jones (2002) used an ethnographic approach, and reported on one observed symptom from the fieldwork (pain). Jordhoy et al. (2003) extrapolated data from a study that prospectively recorded symptoms using the EORTC QLQ-C30 questionnaire, and Estabrooks et al. (2015) used a Minimum Data Set with prospectively recorded data. There appears to be a trend in the mode of data collection as five of the most recent six studies have used prospective data while the older studies mainly use retrospective data.

Eighteen studies presented data that had been collected retrospectively (as mentioned, one included retrospective and prospective data). Eight of these used interviews with staff or family members as a method of data collection, five used case notes or medical records reviews, and five interrogated existing data sets for their information. Two mixed-methods studies were conducted, with van der Steen, Gijsberts, Knol, Deliens, and Muller (2009) utilising questionnaires for families and interviews for nurses and

Veerbeek et al. (2007) presenting a case note review which incorporated a questionnaire for nurses to ask for their recall on the symptoms.

3.5.4 Proxy data collection

All studies were informed by data collected from proxies who were either professionals or families, or through established data sets, such as Minimum Data Sets or case notes. No study was devised specifically to collect symptoms on residents at the end of life.

3.5.5 Data collection instruments/methods

Across the 25 studies, eleven studies reported that they had used existing instruments to collect data, and 14 had developed alternative approaches. These alternative approaches included producing a list of symptoms, adapting an existing instrument by adding questions or undertaking interviews (Table 3.5). Of those who had used existing instruments (Table 3.6), their psychometric properties were mentioned in nine of the ten studies; however, this was very brief and usually limited to one or two lines. The focus of the instruments varied: some were concerned with measuring symptom experience through symptom assessment (ESAS: Brandt et al. (2006)) whilst others (QOD-LTC: De Roo et al. (2014), EORTC QLQ-C30: Veerbeek et al. (2007)), collected symptoms as a method of measuring quality of life. This may contribute to a variation within the results from the studies. Some studies overstate the properties of the instrument, such as reports of the instrument being 'reliable and valid' despite the instrument not having been validated in care home settings (Brandt et al., 2006; Cartwright et al., 2005; Jordhoy et al., 2003; Sandvik et al., 2016). However it should

be acknowledged that word limitations in a journal may have prevented any detailed

discussion.

Table 3.5 - Studies that did not use existing instruments for data collection

Study	Measure used
Brandt et al (2005)	List of 25 symptoms developed for study plus one 'open' symptom
Di Giulio et al (2008)	Collected from records when recorded
Estabrooks et al (2015)	Collected from records when recorded
Goodridge et al (2005)	Semi-structured interviews – thematic analysis
Hall et al (2002)	Audit tool developed for study
Hanson et al (2008)	Interview that included a question about four identified symptoms
Hendriks et al (2015)	Physician assessments
Kayser-Jones (2002)	Observation, followed up with interviews
Knight (2007)	Items from the Integrated Care Pathway (ICP)
Mitchell (2004)	Various instruments specific to MDS (symptoms are an 'item' on the MDS)
Parker & De Bellis (1999)	An assessment instrument was developed by the research team for study
Reynolds et al (2002)	Interview questions developed for study following a literature review which generated closed ended questions
Rodiguez et al (2010)	Reviewed symptoms and medications from existing data set of data (National Nursing Home Survey)
Sloane (2008)	Interview questions developed for study

Table 3.6 - Studies that used existing instruments for data collection

Study	Instrument used	Discussion of psychometrics
Brandt et al (2006)	Edmonton Symptom Assessment Scale (ESAS) & Resident Assessment Instrument MDS – Palliative Care (RAI-MDS-PC)	Not discussed although refers to ESAS as "validated" – not referenced to NH setting
Caprio et al (2008)	Quality of Dying in Long-Term Care (QOD-LTC)- a uni-dimensional measure for psychosocial aspects of the quality of dying plus 2 identified symptoms (pain and dyspnoea)	Describes QOD-LTC as a psychometrically sound for psychosocial aspects
Cartwright et al (2005)	28 - item guide, Family Memorial Assessment Scale-Global Distress Index (FMSAS-GDI)	Describes FMSAS-GDI as reliable and validated – not referenced to AL setting
De Roo (2014)	Quality of Dying in Long-Term Care (QOD-LTC) – a uni-dimensional measure for psychosocial aspects of the quality of dying plus Symptom Management – End of life Dementia (SM-EOLD)	Not discussed – not referenced to LTC
Hermans (2017)	Palliative Outcome Scale	Refers to validation studies in specialist palliative care in the UK
Jordhoy et al (2003)	European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire (EORTC QLQ-C30)	"Practical and valid in measuring quality of life in patients with advanced disease"
Klapwijk et al (2014)	Mini-Suffering State Examination (MSSE), End-Of-Life in Dementia-Comfort Assessment in Dying (EOLD-CAD), DS-DAT, PAINAD	Some discussion
Pinzon (2012)	Adapted the Hospice and Palliative care Evaluation (HOPE) by adding symptoms	Original instrument validated for use in evaluation of symptom intensity in pall care setting, however, no testing has been done since adaptation
Sandvik et al (2016)	Edmonton Symptom Assessment Scale (ESAS), Cognitive Staging Tool (CDR), Karnofsky Performance Scale (KPS), Mini-Suffering State Examination (MSSE), Mobilization-observation-behavior-intensity-dementia-2 Pain Scale (MOBID-2), Physical Self-Maintenance Scale (PSMS), Residents Assessment Instrument for Palliative Care (RAI-PC)	Each item briefly discussed

Van der Steen et al (2009)	End of Life in Dementia (EOLD) Scale which includes: Satisfaction with Care (SWC) Symptom Management (SM) and Comfort Assessment in Dying (CAD)	Discusses good psychometric properties when completed by nurses using interviews
Veerbeek (2007)	Adapted from European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire (EORTC QLQ-C30) – 6 symptoms, then added additional 5 "because these symptoms are common"	Validity of adapted questionnaire was evaluated in face to face interviews with 4 nurses

5.5.6 Time periods and time points of data collection within the studies

The timeliness of the data collection within the studies were seen in two different aspects: the time period over which the data were collected and whether the studies collected single or multiple episodes of symptom prevalence.

All studies set out to consider symptoms towards the end of the resident's life. As discussed in the background chapter, and as expected, the terminology was different across the studies and included "terminally ill", "last days of life", "dying", "end of life care" and "when death is expected". However, the period of time that was captured also varied from study to study with no concurrence as to what period of time constitutes the end of life. These time spans ranged from a few hours (Knight and Jordan, 2007) up to the last year of life (Estabrooks et al., 2015; Sandvik et al., 2016). Within four studies, the period of assessment time was unknown or unclear as the time frame was not specified (Kayser-Jones, 2002; Rodriguez, Hanlon, Perera, Jaffe, & Sevick, 2010) or the study referred to "final days" (Cartwright et al., 2005) or "end of life" (De Roo et al., 2014). Only four studies (Brandt et al., 2006; Estabrooks et al., 2015; Jordhoy et al., 2003; Klapwijk et al., 2014; Parker & De Bellis, 1999; Sandvik et al., 2016) carried out longitudinal studies, to capture data at different points of the resident's dying trajectory to compare changes over time. However, the gaps between data collection points were varied and few captured data consistently either over the final few days of life, or within the final hours of life. Klapwijk et al. (2014) was the only study to have collected data at multiple time points over the final days of life with a mean number of observations of 4.3 (SD 2.6). Sandvik et al. (2016) took a broader approach and followed residents during the first year after admission and in their last

days of life (day perceived as dying and day of death). To emphasise this variation, Table 3.7 uses a timeline to show the time span where data collection occurred within the studies. Not all studies provided this information and within some studies, generic terminology such as "few hours" or "end of life" were used and these can be found at the end of the table.

Table 3.7 – Time periods and time points of data collection across the studies

Study	Studies with a single time point									
	1 day	2 days	3 days	5 days	1 week	4 weeks	6 weeks	3 month	6 month	12 month
Brandt et al (2005)							x			
Caprio et al (2008)						x				
Cartwright et al (2005)					x					
Di Giulio et al (2008)						x				
Goodridge et al (2005)			x							
Hall et al (2002)		x								
Hanson et al (2008)						x				
Hendriks et al (2014)					x					
Hermans et al (2017)										x
Mitchell (2004)									x	
Pinzon (2012)		x								
Reynolds et al (2002)								x		
Rodiguez et al (2010)	x									
Sloane (2008)						x				
Van der Steen et al (2009)								x		
Veerbeek (2007)			x							
	Studies with multiple time points									
	1 day	2 days	3 days	5 days	1 week	4 weeks	6 weeks	3 month	6 month	12 month
Brandt et al (2006)	x	x								
Estabrooks et al (2015)						x		x	x	x
Jordhoy et al (2003)						x	x	x	x	
Klapwijk et al (2014)	x	x	x	x						
Sandvik et al (2016)	x									x
	Not specified									
De Roo (2014)	Not specified (One time point - "End of Life")									
Kayser-Jones (2002)	N/A (Ethnographic study)									
Knight (2007)	Not specified (One time point - "Few hours to 14 days")									
Parker & De Bellis (1999)	Not specified (Two time points - "Initial assessment" and "final assessment")									

3.5.7 The range of different symptoms reported within the studies

Across the 25 studies, a total of 90 different symptoms were identified and reported upon. Table 3.8 presents the range of most frequently reported symptoms across all of the 25 studies. When a symptom was reported upon in three or more studies, it is included in the list in the table below. Each symptom has the reported presence from the study in column three and this is presented as a summarised range, i.e., the highest and lowest reported presence from a study to demonstrate the wide variation within studies. When a symptom is called by a different name, but are clearly referring to the same symptom, they have been grouped together, but only where there is an undoubted defined relationship (using NHS symptom definitions), e.g., 'difficulty swallowing' and 'dysphagia'. If the reported symptoms were potentially different, e.g., 'nausea/feeling sick' and 'nausea/vomiting', they have been included separately. Symptoms that are reported on in one or two studies have been listed in the lower section of the table.

Table 3.8 – The most frequently reported symptoms from all studies

Symptom	Reported in no of studies (out of 25)	Reported prevalence of symptoms (%) across studies (lowest/highest)
Pain	23	9 - 80
Dyspnoea/shortness of breath/difficulty breathing	19	8.2 - 93.3
Anorexia/loss of appetite/lack of appetite	10	10.4 - 94.8
Anxiety	9	2.8 - 54
Constipation	9	8.1 - 60
Fatigue/lack of energy/tiredness	9	52 - 99
Agitation/restlessness	8	3.2 - 71
Depression	7	9.1 - 48.6
Difficulty swallowing/dysphagia	6	5 - 73
Fever	6	3.1 - 64
Nausea	6	0.9 - 30
Pressure ulcer/decubitus ulcer	6	3.8 - 47

Nausea/vomiting	5	0.9 - 38
Drowsiness	4	19 - 97.5
Lung aspirations/troublesome mucus production/ noisy breathing/respiratory tract secretions	4	1.8 - 39
Vomiting/emesis	4	0.9 - 18.8
Choking	3	0.7 - 16
Diarrhoea	3	1.9 - 30

Symptoms only reported in two studies: Calm, Crying, Dry mouth, Fear, Gurgling, Little/no nutrition intake, Moaning, Need for help with ADLs, Peace, Problems with cleanliness, Serenity

Symptoms only reported in one study: Bed sores, Behavioural symptoms, Bleeding, Cachexia, Coma, Cough, Discomfort, Decreased activity, Dehydration, Difficulty coughing, Discomfort, Financial impact, General weakness, Hallucinations, Incontinence, Infections, Insomnia, Invasive action, Irritability, Malnutrition, Medication not successful, Myoclonus, Nervousness, Oedema, Overburden of family, Patient gives up, Pneumonia, Problems with organization of care, Refusal of food, Refusal of liquid, Refusal of medication, Restiveness to care, Sadness, Screams, Seizures, Severe somnolence, Skin breakdown, Somnolence, Sleep disturbance, Sub-coma, Suffering, Tension, Unstable medical condition, Weight loss, Weakness, Well-being, Worry

Five studies presented an undefined category where the symptom was not named - "other symptoms" or "rare symptoms"

Table 3.8 has presented the wide range of symptoms reported across the 25 studies and this highlights the differences within the studies. The number of symptoms within a single study ranged from 1 - 27, with a mean of 9.1 symptoms across all studies, however the mode figure was one (with 37 symptoms only being reported upon once and 12 symptoms reported upon twice) resulting in a mean of 2.1 symptoms across all studies. Furthermore, four studies reported on 'other' or 'rare' symptoms, but did not name the symptom, although this may have been an unknown category taken from the original data source. Consequently, a wide spread of symptoms were presented, yet with little consistency between the studies. For example, pain was represented in 23 out of 25 studies. Despite it being considered an important symptom to include in the overarching majority of studies, there was no explanation as to why it was omitted in other two. Equally, there was little discussion in most studies as to why any of the symptoms were included or excluded.

Pain was reported as the most prevalent symptom in the studies ($n = 23$), and in the study by Kayser-Jones (2002) and Hermans, Cohen, Spruytte, Van Audenhove, and Declercq (2017), it was the only reported symptom, although Hermans et al. did include an 'other' category. Dyspnoea was reported under three different, but consistently defined terms (dyspnoea, shortness of breath, difficulty breathing) ($n = 19$) and presented with a wide range of reported prevalence. Anxiety was included in nine studies and had the lowest variation in range of prevalence (2.8 – 54%). Anorexia (loss of appetite/lack of appetite) was presented in 10 studies and had the narrowest gaps when it was measured within the same study. Fatigue (lack of energy/tiredness) occurred in nine studies and was found to have the widest variation in reported prevalence of between 3.2 - 92%. Within the symptoms that were less frequently reported upon the variations in the ranges get smaller (but this is most likely due to there being fewer studies to report on); however, drowsiness, which was only found in four studies had a wide variation of prevalence of between 19 - 97.5%.

When reviewing the literature, a picture of great disparities started to become apparent. There was a wide variation of reporting within the studies, not only within the reported prevalence rate but also the range of symptoms included. In addition, some studies had included symptoms but had not documented the rates of occurrence (De Roo et al., 2014; Estabrooks et al., 2015; Kayser-Jones, 2002; Reynolds et al., 2002; van der Steen et al., 2009). To demonstrate this heterogeneity further, pain as the most frequently reported symptom across the studies is considered and this permitted some of the noteworthy differences across the studies to be identified.

Pain had a reported variation in prevalence of between 11.5 - 86% within the 23 studies that included pain as a symptom. Some studies measured at more than one time point leading to a count of 27 different measurements/reports of pain. In addition, to the range of 11.5 – 86%, the mean was 43.72, the median was 44 and the mode 58. A standard deviation of 19.06 shows a wide spread of prevalence.

At the upper end of the range, Reynolds et al. (2002) found that 86% of residents experienced pain, and although they report that this is undertreated in dying residents, their study used retrospective data from interviews regarding residents in the last three months of life, meaning that pain may have been present, but does not indicate for how long, how frequent or how near the very end of life it occurred. Parker and De Bellis (1999) measured two different time points prior to death, but there was no consistency between residents, making a comparison even between the individuals in the study not possible. They reported the presence of pain in 80% of residents but they went on to state that the nurses reported it as 'usually' controlled. This makes it difficult to convey whether the nurses were potentially over-assessing/over-treating residents as the study also identified that pain was a great source of conflict between nurses and GPs. Towards the lower end of the reported prevalence of pain, Mitchell, Kiely, and Hamel (2004) found that 11.5% of residents with dementia experienced pain during the 'dying' phase, again, there was no specific time-point of measurement. Knight and Jordan (2007) conducted an audit examining the use of an Integrated Care Pathway (ICP). Their pre-audit prior to use of the ICP reported 17% of residents had pain; however in their post implementation audit, this dropped to 9%. As their project to implement the ICP also involved an educational element within care homes, this

finding may reflect by an improved awareness and assessment of residents' pain, or a more regular recording of symptoms.

3.5.8 The influence of diagnosis

The main diagnosis of particular interest across the studies is dementia with eight studies (De Roo et al., 2014; Di Giulio et al., 2008; Hendriks et al., 2014; Hermans et al., 2017; Klapwijk et al., 2014; Mitchell et al., 2004; Sloane, Zimmerman, Williams, & Hanson, 2008; van der Steen et al., 2009) having a specific focus on it. Hermans et al. (2017) and Sloane et al. (2008) compared residents with a dementia diagnosis against those without and both found no differences between those who died in terms of pain; Sloane et al. (2008) reported less shortness of breath but an increased need for sedative use, while Hermans et al. (2017) reported fewer physical (unspecified) symptoms. Diagnosis alone does not impact upon the diversity of findings as both Sloane et al. (2008) and Mitchell et al. (2004) reviewed residents with dementia, yet presented different findings for shortness of breath/dyspnoea (50.2 v. 8.2%).

The diagnosis of cancer is incorporated into several studies, although only one study (Jordhoy et al., 2003) specifically focuses on it. This study compared those with cancer in a nursing home with other care settings, but found symptom prevalence similar to other end of life care home studies, including those that did not specifically identify cancer. This is supported by Veerbeek et al. (2007), who showed little difference in symptom prevalence between those with cancer and those without.

3.6 Discussion - Interpreting the findings

This literature review identified 25 studies and despite being very specific with inclusion and exclusion criteria, located a very diverse group of studies. There are a number of reasons that are liable for this finding. These are variations in the definition of symptoms; different time periods and time points of data collection; different data sources; different instruments used for data collection; variations in the nature and type of symptoms included in the studies, and different countries of origin of the research. The following section will explore these reasons while discussing the articles that have been reviewed.

3.6.1 Data points within the data collection period

Symptom prevalence over a time period needs to be a consideration in addition to one-off incidents, to help understand the process of dying in the older person rather than viewing it as a one point measurement. Any changes or fluctuations in symptoms are as important as the incidence and the patterns can help establish trends to assist with symptom management. Some will be recorded from notes, 'as it happened'; others will have only considered if a symptom was present at the time of completing a quarterly report (for example, when using Minimum Data Sets). This could result in a resident experiencing a symptom constantly for a month, but if they were symptom-free at the time of reporting, it would have been missed. Conversely, a resident may have experienced a symptom on a single occasion, but has been assumed as 'present' for that person for the whole period.

Knowing when to commence data collection requires the interpretation of when end of life care commences. Again, this review highlighted a wide range of data collection points. This varied from a single point in 19 studies to six studies that had between two and six data points. Even when reviewing the studies with multiple data points there was a wide variation in relation to the time before death that these were collected, ranging from within the final 24 hours to within the last 12 months of life. Notably, there appears to be a changing trend to conduct studies with time point data with three out of the four most recent studies (Estabrooks et al., 2015; Klapwijk et al., 2014; Sandvik et al., 2016) taking this approach. Time point data collection, especially when aiming to collect data within the very final few days of life, adds an additional difficulty around recognising the point at which to start data collection. This is more evident in frail older residents whose dying trajectory may be a slower decline over a period of weeks and months or sometimes longer in residents with dementia. The difficulty in prognostication may be one reason why it is difficult to collect regular data on symptoms. The review included studies focussing on the last period of life which has 'cut off' residents at earlier points of life where greater differences may have been found. It is also likely to be a reason why prospective data collection is more difficult and why fewer studies employed this approach.

Retrospective data collection methods were used in 18 studies (one study used both). This can reflect the challenges of collecting information prospectively, but the challenge then becomes how the symptoms are identified after the event. Retrospective data collection relies on impeccable measurement at the time, and well-documented notes from which to be able to extrapolate the information afterwards. In the case of interviews, a reliable memory of events is needed when interviews are carried out up

to several weeks or months after a death. This results in secondary data, with a further level of interpretation by the researchers. Fewer prospective studies are carried out, yet these can avoid certain potential bias.

3.6.2 Different types of data sources

Across the studies, there was a variety of different data sources which utilised either data collected directly from respondents or derived from records, with one study (Veerbeek et al., 2007) using both. Six studies used data from records, these included Minimum Data Sets (Estabrooks et al., 2015; Mitchell et al., 2004), National Nursing Home Survey (Rodriguez et al., 2010) and the others accessing nursing and/or medical records for information. The majority of studies used healthcare professionals within either prospective or retrospective data collection. The most common way of gaining this information was from interviews for retrospective data and direct observation for prospective data. The studies that involved families all used retrospective data, which apart from one study (Pinzon et al., 2012) involved interviews with invited participants. When family members are asked to opt-in for research purposes, there is potentially an element of self-recruitment of people who have experienced more emotive situations; for example, those who perceived that their family member died in distress or in pain may be more likely to participate and add bias to the overall results.

All studies used proxy reporting - with no study using self-reporting methods. This is less surprising given the timing of the research at end of life even though symptom experience has a high level of subjectivity. However it is unclear whether some of the data from data sets may have been self-reported, especially in the studies that were

collecting data several months prior to death. Proxy reporters were either professionals or families. Although families can contribute as a reliable proxy for the resident, professionals can provide consistent assessments especially for the measurement of physical symptoms.

Another difference across the studies was the method of measurement of the symptoms. Eleven studies used validated instruments (although not validated with a care home population) and 14 used other measures. Of the 11 studies using instruments, four used between two and seven different instruments (with seven using just one). Furthermore many of the instruments had been modified for the purpose of the study: as an example, Caprio et al. (2008) and De Roo et al. (2014) both used the QOD-LTC (Quality of Dying in Long-Term Care) instrument, but while Caprio et al. (2008) added two symptoms, De Roo et al. (2014) added six symptoms. This has an impact upon any validation of instruments; however, as identified earlier, the psychometric properties of instruments were not discussed in detail within the literature. It can be noted, though, that care home research has few high quality instruments to improve comprehensive assessment of symptoms (Ellis-Smith, Higginson, Daveson, Henson, & Evans, 2018; Etkind et al., 2015) resulting in the reliance on instruments validated with other populations, if and when these are used. The most recent study of the review, Hermans et al. (2017), used the Palliative care Outcome Scale (POS) (Cicely Saunders Institute, 2018). The POS was originally validated in 1999 (Hearn & Higginson, 1999) and has been used extensively and validated in many settings, disease groups and languages. Although Hermans et al. (2017) identified that it is suitable for evaluating palliative care needs and symptoms of people with and without dementia, it was not validated in a care home population

even though up to 75% of residents are likely to have dementia in care homes (Public Health England, 2017a). The POS is also available in a version to be completed by staff, although this was not used by Hermans et al. (2017), which may have been an appropriate approach given the population and lack of ability of residents to self-report. Sandvik et al. (2016) in the second most recent study, used the Edmonton Symptom Assessment Scale (ESAS) (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991) which was also used by Brandt et al. (2006). The ESAS had been used and validated for proxy-rating but had not been used with dying patients with dementia (Murray, Sachs, Stocking, & Shega, 2012) despite its use in their study.

3.6.3 Variations in the definition of a symptom

Within the literature review, 90 different symptoms were identified across the 25 studies, although with many of them occurring only once or twice. There appeared to be a lack of consensus to what constitutes a symptom, which in turn leads to a wide number of potential symptoms included in studies resulting in a lack of harmony in measuring and reporting methods. Furthermore, it means that a meta-analysis of studies becomes unfeasible due to these variations. All studies included symptoms individually but did not look at overall symptom load. If this approach had been utilised in studies, it may have facilitated a type of meta-analysis or an assimilation of findings to have been carried out.

Symptoms when considered individually and in their broadest sense, may be physical, psychological, spiritual and social and many studies addressed a core set of physical symptoms, but a range of other symptoms were included that often did not seem to fit

the usual expectations. Reviewing the list in Table 3.4, some examples of these symptoms include overburden of family, problems with organisation of care, patient gives up, need help with ADLs (Activities of Daily Living). As well as this broad interpretation of a symptom, some items that appeared to be more concept-like were included, such as peace and serenity. Certain symptoms do have a universal application, such as pain, although 'discomfort' could be considered a variation of pain. Others such as shortness of breath, may have obviously allied medical terminology i.e., dyspnoea. Some symptoms are much less apparent in their meaning, such as wellbeing, tension and serenity. There are particular challenges in assessing some of these concepts and even more so in reaching a consensus. Even when symptoms were consistent in their presence across studies, there was no consensus over the frequency and intensity. For example, pain was included in most studies, yet had one of the widest reported ranges. As a result, defining the symptoms alone is not enough and requires agreement about the application of the definitions as well.

The range of symptoms reported did not appear to be related to the study design nor the size of the study population. Potentially, a larger number of symptoms may have had to be collected when reviewing notes retrospectively due to the need to broadly interpret notes or records, but this has not ensued as prospective studies presented with a range of symptoms from 1 - 26, while retrospective studies offered a range of symptoms from 3 to 16. Prospective studies faced with real life decisions may have found it harder to categorise the symptoms, hence the increased range of symptoms. There is a link between the symptoms and the instrument used for the study and this will be addressed later. Despite the wide range of symptoms that were addressed, the

majority of symptoms reported upon did have a physical focus and these will be discussed in the next section.

3.6.4 Variations in the type and nature of symptoms

The most commonly reported upon symptoms were predominantly physical ones. Pain was included in 23 studies and dyspnoea was reported in 19 studies. There was a big gap between the next group of symptoms with anorexia included in ten studies and anxiety, constipation and fatigue found in nine. Another influence on the type of symptoms may have been due to the profession of the person conducting the data collection. Most measurements were conducted or supported by medical personnel and physical symptoms may have been viewed as a priority, but may also be considered easier to measure, given that residents were at the end of life, and usually unable to self-report. Physical symptoms may also have been measured more frequently as management pathways are viewed as clearer and the response to the management can be monitored more readily.

The types of symptoms that are assessed are often based on those that may be commonly expected to be seen in acutely ill residents. This could be because cancer care has had a high profile within recent years and as a result, many symptom assessment instruments have their origins in cancer care. These symptoms, such as pain, have a very high profile and a high emotional value, which often places it in the forefront of the mind of the professional (and the public). This is supported by Kirkova, Rybicki, Walsh, and Aktas (2012) who report that pain is well studied and characterised, and that a better understanding of other symptoms is required. This can

be further highlighted by considering the four symptoms that were identified in the Liverpool Care Pathway (LCP) specifically for end of life care. Although the LCP is no longer in use, three of the four symptoms that were included other than pain, i.e., nausea, agitation and secretions have not had a high presence reported within the studies in this literature review. The symptoms within the LCP, although there is no literature to discuss why these symptoms were included, were likely to have been influenced by its introduction into palliative care through hospice care, so had a strong cancer diagnosis emphasis.

3.6.5 Effect of country of origin of the study

The system of Long Term Care in different countries can influence the provision of care within care homes/Long Term Care facilities and have a potential impact upon the studies that emerge. The largest number of studies were carried out in the USA ($n = 8$), followed by the Netherlands ($n = 7$) and the demographic profiles of residents reported across the studies have a great deal of similarities, suggesting that there is parity between residents from different countries despite the studies having a fairly broad international spread. One explanation for the greater numbers of studies coming from the USA and the Netherlands could be a higher presence of medical staff/physicians as many of the articles that originate from there are authored by physicians. The Netherlands is the only country to have nursing home medicine as a specialty and the USA has a level of care that is closer to hospital provision with in-house medical support for residents resulting in a higher level of medicalised care.

As with several other countries there was noted to be a paucity of literature that emerged from the UK with only one study authored by nurses (Knight & Jordan, 2007) being included in the review. Care homes in the UK have a less well integrated service and are supported by GPs with considerable input from nursing professionals. This is reflected by findings from Goodman et al. (2016) whose literature review from the UK showed less published research about medical management than most other topics.

3.7 Limitations

This review was carried out in a systematic way to ensure that no studies were missed. Only studies published in the English language were included, which potentially excluded other relevant studies. There was a specific focus on care homes, so other studies that involved older people at the end of life were excluded. The literature review was conducted by a single researcher (LP) and although an additional reviewer is not mandated, working with a second reviewer may have added additional rigour to the process.

3.8 Conclusion

Due to the lack of homogeneity in inclusion criteria, study design, use of instrument, sample size and characteristics of the participants across the studies, the studies included within the literature review did not meet the criteria for a meta-analysis (Eysenck, 1995; Russo, 2007). However, it was possible to examine the relationships between some of the key characteristics of the studies and be able to address the research question.

This literature review has identified five gaps in the research in symptom prevalence in care home residents at the end of life:

1) Many studies have adopted a retrospective approach, although prospectively collected data are seen as the gold standard. There are challenges in recognising the start of the dying process for prospective studies, which makes retrospective data collection easier to manage. However, this relies on data collection after the occurrence of symptoms, sometimes by many months, and routinely uses notes recorded by a third party.

2) The data are typically collected without using any form of instrument or data collection tool, or if instruments are used, they are frequently generic and unvalidated and are not specific to the purpose of assessing end of life symptoms in this population.

3) There is a wide variation in which end of life symptoms are included across the different studies, resulting in inconsistent knowledge about the symptoms. Studies need to be able to capture the end of life symptoms that are most relevant for the care home population, yet there is little agreement as to what those are. The main two symptoms that are reported upon in the majority of studies are pain and shortness of breath/dyspnoea. While these are important symptoms, there are a number of others that are commonly associated with end of life, such as consciousness, delirium, anorexia, fatigue and tiredness that are frequently unaddressed. In addition to the variation of symptoms that are

addressed within the literature, symptoms are only measured singularly and no studies attempted to consider overall symptom load or burden.

4) The temporal aspects of symptom prevalence have received little attention in all but six studies, and even those do not have a wide span of time points. It is important to understand what happens with symptoms over time leading up to the time of death, including how often the symptoms occur, the levels of symptoms, and any changes in the levels over time.

5) Finally, only one study was carried out in the UK (Knight & Jordan, 2007), which highlights a gap in UK-based research around symptoms in the care home population at the end of life.

Symptoms are subjective experiences and there are many challenges to be faced in measuring symptom prevalence. However, the number of older people dying in care homes is increasing and there is a need to be able to understand the symptom experience to support the care at the end of life for residents, to offer evidence-based practice development for the staff caring for them and to consider the broader implications for practice and policy. There is a need to understand more about the care home population at the end of life in relation to the prevalence; that is the presence and intensity of physical symptoms, not only at the very end of life but at the time leading up to death. The following chapter will lead with the aim and objectives for this study and discuss the methodology and methods that will be utilised in order to address these.

Chapter 4 – Methodology and Methods

4.1 Introduction

4.1.1 Aims and Objectives

Aim

The aim of this research study is to describe the presence and intensity of physical symptoms of residents in the dying phase in care homes, and explore whether there are common characteristics that present over time.

Objectives

1.   To measure the presence, intensity and associations between physical symptoms during the dying phase of people who are resident in a care home.

2.   To identify the longitudinal changes in, and intensity of, the most commonly presenting physical symptoms during the dying phase.

3.   To propose a typology of symptoms associated with the dying phase derived from the population characteristics and the longitudinal changes over time.

The purpose of this study is to describe the presence and intensity of symptoms in the final days of life in residents dying in care homes. By increasing knowledge of what the symptoms are and how and when they occur through time will lead to a greater understanding for professionals who are caring for these residents. This ultimately will aim to increase the quality of life and hence the quality of dying for residents (Miyashita et al., 2010). Chapter three identified five gaps as a result of the literature

review regarding research on symptom prevalence in care home residents at the end of life. Firstly, there was a lack of consensus over the types of symptom being measured, concluding in a consistent lack of knowledge about symptom prevalence. All studies looked at symptoms singularly, and did not consider overall symptom load. Secondly, temporal aspects of symptoms received little attention, both in terms of frequency of prevalence and in changes in intensity over time. Thirdly, most of the studies collected data retrospectively, increasing the risk of bias through either recall bias or second hand data reporting. Fourthly, many studies collected data without using purposeful instruments so were unable to measure end of life symptoms in this specific population. Finally, there has only been one UK-based study that has researched symptoms at the end of life in the care home population.

Epistemologically, this research study adopts a positivist approach which will be introduced and rationalised in the first section of this chapter. Next will follow a critical examination of the benefits and limitations of adopting a positivist stance in relation to the study of end of life symptoms. This section will lead into a discussion of the measurement process and the process of choosing a standardised measurement instrument. The final part of the chapter focuses on the research methods including population, recruitment, data collection, data analysis and ethical issues.

4.2 Underlying epistemology

The study aims to describe presence, intensity and associations between physical symptoms during the dying phase of people who are resident in a care home. This

presents a number of aspects to be considered when selecting the epistemological focus of the research.

Positivism is referred to as a scientific method and is viewed as a rationalist, empiricist philosophy which indicates that causes determine effects or outcomes (Luchins, 2012; Mackenzie & Knipe, 2006). This signifies that there is firstly an objective truth/reality and this reality can be identified, observed and measured (Bruce, Pope, & Stanistreet, 2008) and that secondly, the researcher's findings are absolute and verifiable (Rosenthal & Rubin, 2013). The positivist philosophy encompasses a set of principles that will identify prediction and control (Leary, 2009) to discover the patterns of cause and effect. If the cause and effect can be ascertained they can be predicted, and if they can be predicted, they can be controlled, leading to a greater understanding of the reality or truth. Another concept regards observations and/or measurements as reliable to provide accurate information to understand the truth (Hammond, 2013). Finally, there is the belief that an objective understanding is achieved provided that a rigorous protocol is adhered to (Cohen, Leviton, Isaacson, Tallia, & Crabtree, 2006). Much of health and social science research has been influenced by positivism and the most important characteristic of positivism is empiricism (Parahoo, 2006) where empiricism is deemed to consist of that which can only be observed by human senses. To be able to link these key characteristics of positivist research to practice, observation and measuring data needs to be conducted resulting in the support or adjustment of theory (Coolican, 2004).

There are critics of positivism who have challenged the idea of an objective reality and reason that knowledge is built by accumulatively piecing together different types of theories and observations; however, this can be argued as lacking structure and being too flexible (Silverman, 2013). While phenomena such as personal meaning and experiences are considered as being outside of the scope of positivism (Denzin & Lincoln, 2011), being able to investigate natural order is necessary to make sense of certain features of natural laws.

The debate between philosophers will continue (Trochim, 2008), but primarily the choice of the most appropriate epistemology should depend upon on what is being examined which in turn will lead to the most appropriate approach to apply (Silverman, 2013; Trochim, 2008).

4.2.1 Using a positivist paradigm in relation to end of life symptoms

When attempting research in a field with a dominant paradigm, it may have been easier for the researcher to unquestioningly adopt the same approach even though those within positivist research may not always engage with the ontological and epistemological underpinnings. In addition, where a dominant discourse is regularly employed, the reception and acceptance of the research may ultimately depend on the use of similar approaches to be acknowledged within the field. Despite this, a clear rationale is required as to why a positivist philosophy is judged the most appropriate for this research and this is closely linked with the measurement of symptoms, but specifically those at end of life.

The study sets out to report the presence and intensity of symptoms in residents at the end of life. Positivism requires approaches that employ empirical methods to use quantitative analysis (Al-Habil, 2011), and during the measurement of a symptom, including those at the end of life, the methods utilised are mainly positivist in nature, i.e. they use instruments. Instruments are frequently employed within health and social care as an attempt to standardise measurement. In this study, this is particularly important because the participants will be at the end of life, so highly likely to be unable to self-report which will necessitate an assessment by proxy.

The first ontological assumption of positivism is that there is an objective reality and that it can be measured (Bruce et al., 2008). The reality in the practice of the measurement of end of life symptoms is that they are viewed as absolute i.e., a person has pain or he/she does not have pain. If the person has pain, they may have varying levels of pain; however, this still sits with the belief of an absolute truth, because they are measured as pain being *present* or *absent.* If pain is present, however, it can be present in varying degrees, but a person cannot *maybe* have pain. The presence of this symptom, pain, will become a variable and orders the dynamics into patterns (Schrag, 1992). This enables the elements of the research question – presence and intensity to be captured in a uniform manner. Equally the conditions in which it can occur (e.g. prevalence with a particular diagnosis) can also be specified and through testing, correlations and causal explanations can be established or rejected.

One of the key characteristics of positivism is that the researcher positions themselves objectively so the findings are unaffected by emotion or personal bias (Davey, 2001).

This necessitates the need to minimise the risk of biased reporting of the researcher (or the observer) demonstrating the relationship between a positivist philosophy and methodology. Portraying these entities can pose problems: Boudreau, Gefen, and Straub (2001) argue that the concept is straightforward when the appropriate choice of a valid measure is made. However, the use of valid measures within end of life symptom research, as seen in chapter three, are particularly challenging with many of the studies either not using a validated instrument or using no instrument at all. This was particularly evident as many of the studies considered used retrospective data, which had not been collected in a uniform format. The most appropriate instrument would facilitate an impartial and objective measurement that allows for repeatability over time to reliably capture the dynamic nature of symptoms, something that has lacked in previous studies (Brant et al., 2010).

The second ontological assumption of positivism is that the researcher's findings can be absolute and verifiable. This means that not only do the phenomena have an objective reality, but that this reality can be captured in an accurate and representative way. To be absolute and verifiable brings into consideration the position of detachment that is required between the researcher and that which is being measured. One way in which this is achieved is by the use of a validated measure to support this approach, which in turn prevents the researcher's role shaping the inquiry. Positivists are required to keep a distance from their subjects under inquiry or at least neutral observations (Al-Habil, 2011). Although critiques of positivism assert that a pluralist approach, using mixed methods, are more able to ascertain an objective reality (Denzin & Lincoln, 2011), it can be counter-argued that merging different paradigms, such as within post-positivism, makes neither functional and weakens both (Phoenix et al.,

2012). If what is to be measured is determined by qualitative methods, it will conflict with the very strength of using instruments to measure objective realities.

4.3 Methods

This section aims to provide a documented process of the research design, population, recruitment, data collection, data analysis and ethical issues of the study.

4.3.1 The research study design

The study design is a strategy to control and influence variables to provide an answer to the research question that is underpinned by a set of hypotheses. This research seeks to report the presence and intensity over time (point and period prevalence) in dying residents in nursing care homes. The study design selected was a prospective cohort study. A prospective cohort study is appropriate because it enables a more complete set of data to be collected even though it is considered a less easy option than a retrospective data collection obtained from notes or records (Ghei, 1995). It is less prone to differential measurement error (Antal, Grasela, & Smith, 1989; Sedgwick, 2013) and reduces measurement bias due to poor recall (White, Hunt, & Casso, 1998). A challenge for prospective data collection is that it may suffer from seasonal variations if a study period is a relatively short one (Ghei, 1995). The study was designed to collect data measurements through time as a sequence of data points. This enables variables from the data to be compared at different points in time conveying the dynamic nature of symptoms. The data collection took place over a staggered 12 month period to avoid seasonal variations.

Given the nature of the data, an outcome measure was required and the clinical setting for data collection by the care staff meant that the measure had to be relatively undemanding and straightforward to administer. To ensure all factors are considered, the 'five Ws (and one H)' who/where/what/how/when was considered (Angelo, 2011) (Figure 4.1). Once the factors had been prioritised, a review of the available instruments was carried out and the factors mapped into the instruments to come up with the best counterpart measure.
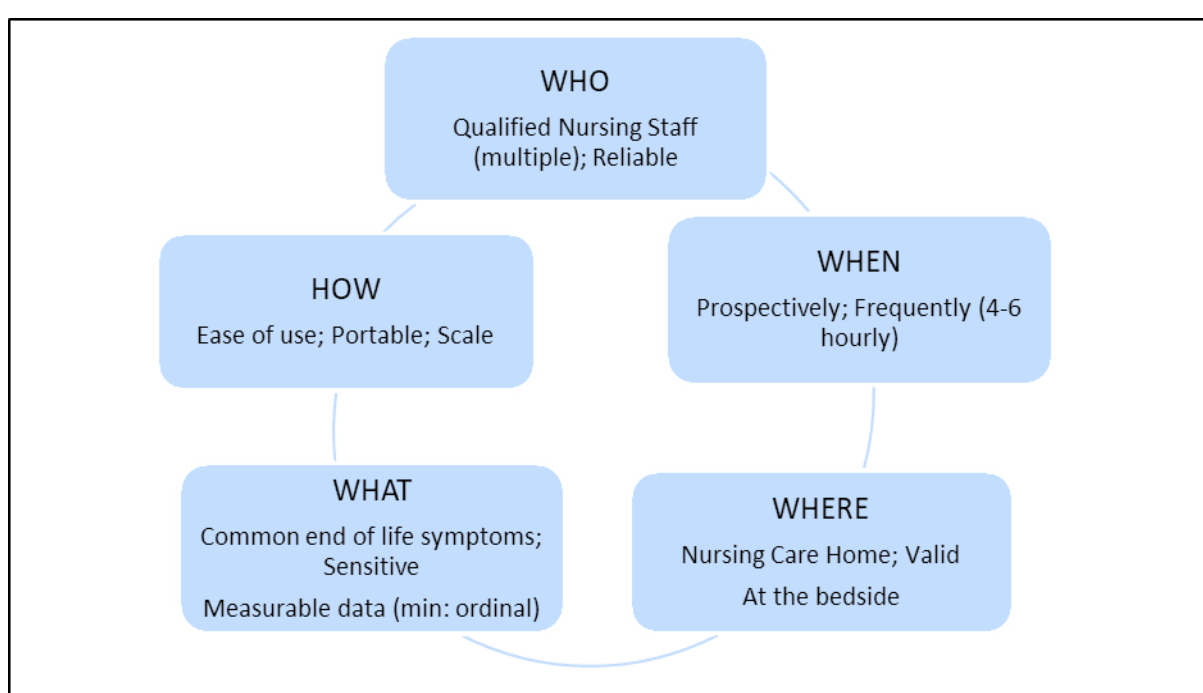
Figure 4.1 - The requirements of an instrument

4.4 Period of data collection

The study took place in the care homes over a twelve month period in two phases. This enabled data to be collected over a 12 month calendar period which avoided any seasonal dips or peaks. Phase one involved the recruitment of five care homes and ran from February 2009 – October 2009 (inclusive). Phase two recruited six care homes and ran from May 2009 – January 2010 (inclusive).

4.5 Sample size for a non-interventional study

For interventional and non-interventional studies (NIS), an 'adequate' sample size is required. However, for non-interventional studies, it is not feasible to apply a power calculation, due to the lack of pre-defined clinical relevance (Schremmer, 2017). As a result, a justification of the sample size will be discussed here. The average number of deaths in care homes in the geographical recruitment area was approximately 16 - 20 per care home per year (Partington, 2008). It was therefore anticipated that a care home would have approximately 13 - 17 deaths over the 9-month period that the research would occur. Having completed the literature review, and comparing with other prospective studies, it can be seen that other studies have a range of the total number of participants between 24 – 516: however, no other studies had a time-sequenced data collection along the lines of this study which increased the number of data points and size of the data. In order to achieve a representative proportion of resident deaths, a sample of eleven homes was selected to yield data on approximately 117 - 153 resident deaths in total. As an observational study, the goal is to collect data on the characteristics of the participants (Lee-Johnson, 2012), but even allowing for a small proportion of hospital deaths (on which data was not collected), it was with assurance that data on a minimum of 120 resident deaths would be achieved. The length of a so-called confidence interval which was calculated from the data measured precision. The higher sample numbers led to smaller confidence intervals which corresponded to more reliability and accuracy of the estimation.

4.5.1 Sampling

The population consisted of a purposive non-random sample in which participants are specifically sought out; that is, the total number of residents who were dying within the care homes during the period of the study.

4.6 Participants

The participants for the research study were residents dying in care homes. To be able to involve the participants, care homes had to be recruited to the study and then the residents from the recruited care homes were considered for participation in the study. The recruitment of the care homes is described and then the participants (residents).

4.6.1 Recruitment of care homes

Eleven care homes were approached to participate in the research study. The homes were purposively selected as a representative range of different types and sizes of care homes from within a geographical area. The area encompassed two Primary Care Trusts (which now form three Clinical Commissioning Groups or CCGs[10]). A meeting was held with each care home manager which provided details and requirements of the study. Each manager was provided with an information leaflet prior to the meeting (Appendix v). Following the meeting a consent form was provided with the request for it to be completed and returned to the researcher (Appendix vi). Consenting managers were required to gain permission from head office (if part of a large chain) or the care home owner depending on the status of the home.

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[10] CCGs were formed after the passing of the Health and Social Care Act 2012, which transferred a range of commissioning responsibilities to CCGs from primary care trusts (PCTs).

4.6.2 Purposive selection of care homes with inclusion/exclusion criteria

The following inclusion/exclusion criteria were used to recruit care homes into the study (Table 4.1). Each care home was required to have achieved a rating of two stars or more during their most recent CQC (Care Quality Commission) inspection as care homes with fewer stars were usually experiencing adverse issues and involving them in a research project was not considered to be in their best interest or would provide the best research site. To meet the inclusion/exclusion criteria, it was necessary for care homes to have a formal system in place to identify residents who were at the end of life. All the care homes taking part in the study were either using an Integrated Care Pathway/Liverpool Care Pathway (ICP/LCP) for care in the final days of life or were able to identify dying residents through their organisational care planning documentation. The ICP/LCP[11] was an integrated care pathway that was used to improve the quality of the dying within the last hours and days of life. It was developed to transfer best quality for care of the dying from the hospice movement into other clinical areas, to provide an equitable model of care (LCP, 2010). The ICP/LCP incorporated a flow chart to identify if a resident is in the final days of life. Finally, at least one member of staff needed to have undergone additional palliative care education within the last 12 months. By providing education for staff helped to demonstrate a level of commitment from the home to support good end of life care.

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[11] In July 2013, an independent review into the Liverpool Care Pathway (LCP) highlighted several failings and recommended that the Government replace it with individual care plans by 14 July 2014.

Table 4.1 - Inclusion and exclusion criteria for selection of care homes

Inclusion criteria	Commission for Social Care Inspection (CSCI)[12] star rating of 2 stars or above[13]
	There is managerial support and/or organisational support (depending on care homes' organisational structure)
	There is current use of an Integrated Care Pathway/Liverpool Care Pathway or equivalent and/or means of identifying dying residents
	At least one member of staff has undergone additional palliative care education within the last 12 months.
Exclusion criteria	CSCI star rating of less than 2 stars
	No managerial/organisation support
	No use of Integrated Care Pathway/Liverpool Care Pathway and/or ways of identifying dying residents
	If there are no staff who have undergone additional palliative care education within the last 12 months.

4.6.3 Inclusion/exclusion criteria for participants

A clear inclusion/exclusion criteria for recruitment of participants was developed (Table 4.2). A resident needed to be in the final days of life to be eligible to be part of the research study. The trigger would be when the resident commenced an ICP/LCP or was identified as dying by the care home care planning documentation. If the resident improved in condition, they were withdrawn from the research, although they could be re-entered if they further deteriorated within the time period of the study. The death must have taken place in the care home, so the symptoms could be measured until the point of death. The presence of selection bias has been noted to be a potential problem in prospective cohort studies (Bookwala, Hussain, & Bhandari, 2011), but this research aimed to include all residents who were dying, which involved no specific

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[12] CSCI were an independent organisation (who were set up by the Government) to inspect and report on care services and councils including care homes. They ceased to exist on the 31st March 2009 to be replaced by the Care Quality Commission (CQC).

[13] This indicates that at the most recent inspection, care homes have received a quality rating of 'good' (2 stars) or 'excellent' (3 stars).

selection of the participant, other than the recognition of impending death, eliminating the risk of selection bias.

Table 4.2 - Inclusion and exclusion criteria for selection of residents

Inclusion	Commenced on a Care Pathway (an expected death within next few days) AND Death took place in care home
Exclusion	Care Pathway discontinued as condition had improved OR Death took place in hospital

4.7 Recruitment, consent, opting out and withdrawing from the study

The following section will consider the methods used for recruitment. In this study, consent is closely linked with recruitment and the choice to opt out or withdraw, so these will be addressed in the same section. The ethical issues that could potentially arise as a result of some of the decisions made within the study will be later addressed in section 4.14.

4.7.1 Recruitment

Once a care home had been recruited to the study (section 4.6.1), and an initial period of induction had taken place, a start and completion date which spanned a nine month period of participation within the study was agreed. Once the study period was commenced, all residents, as identified in the inclusion and exclusion criteria for participants, who were considered to be in the final days of life, would form part of the study.

4.7.2 Providing information to participants

To do this required full and open information giving, the opportunity to opt out of the study before the participant became involved and a method to withdraw once a resident was involved.

It was very important to for all residents and families to understand that the care home was taking part in a research study and it was therefore essential to provide clear and precise information for potential participants and their families. As residents and families have individual ways of engaging with the care home, different mechanisms needed to be employed. A laminated A4 poster was displayed on all notice boards or common space in every care home as advocated as good practice (McMurdo et al., 2011). (Appendix vii) The poster was phrased carefully to avoid upset to any potential readers, but it was also necessary to ensure that the approach and purpose of the study remained transparent. The study chose to use the words 'end of life' to avoid any ambiguity that other more palatable phrases used in other studies such as "becoming more unwell" may invite (Gibbins et al., 2012). The poster assured anonymity to residents and re-iterated that information would be treated with the greatest of respect. It provided information about the researcher and included a photograph. Families and residents were also informed of how to opt out of the research study on the poster.

Dissemination of the study information also occurred through resident/family meetings. Seven care homes held these regularly and the researcher attended meetings in three care homes, with the managers discussing the study in the other four care home meetings. The remaining four care homes had regular newsletters and the poster information was paraphrased (for consistency across care homes) as an article within

the newsletters. In addition, an information leaflet was made openly available in a display stand within the care homes to residents and family members who wanted additional information about the study. (Appendix viii)

During the research study period, the researcher and/or research administration assistant visited/contacted each care home at least once per week to support the data collection and increase compliance with the measures.

4.7.3 Opting out of the research study

There needed to be an opportunity for an individual resident's data not to be included in the research study. If a resident or family required more information, the researcher would meet with any resident or relative who wished to discuss the research study further. (This would be offered either jointly with a staff member or individually). As the researcher was a qualified nurse with a wide experience of dealing with residents/patients and their families concerning emotive and difficult topics, the meeting dealt with these in an appropriate and sensitive manner. If a resident or their family opted out, care notes were marked with an identifying label.

4.7.4 Withdrawing from the research study

If a resident or family, whose information was in the process of being collected, requested to withdraw, the nursing staff destroyed the forms being completed and reported the code number to the researcher on a specific form (Appendix ix), so it did not appear as 'missing data' at the end of the study. Once data had been collected and

the forms collected by the research team, families had to be informed that it was then not possible to withdraw as the collected data were totally anonymous and therefore unable to be identified at this stage. This process was adopted to ensure and protect an anonymous status in this study.

4.8 Data collection

The next part of this chapter will describe the variables that were measured and how the measurement was achieved. There were two types of data collected by care home staff. The first was demographic and the second was the measurement of symptoms through observation. Figure 4.2 illustrates the process in a visual flow chart. A copy of the chart was also provided to every member of care staff working in the care home for their own information.

RESEARCH PROJECT ON SYMPTOMS EXPERIENCED BY RESIDENTS AT THE END OF LIFE
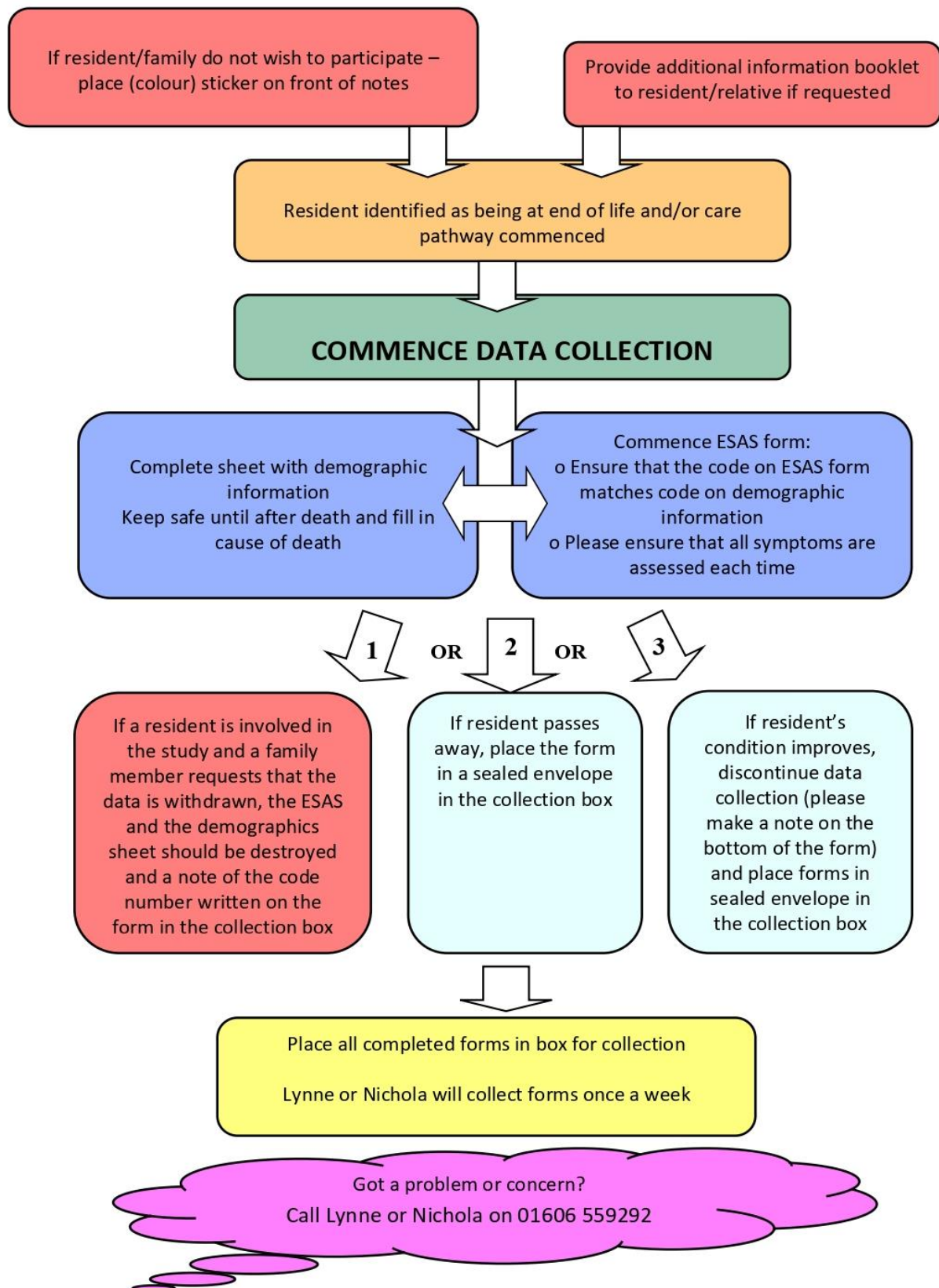
Figure 4.2 - Flow chart showing data collection process

To interpret and understand relationships and correlations between the demographics and the symptoms and the changes over time required the variables to be classified as independent or dependent. Within this study, the independent variables were the demographic elements such as age, gender, diagnosis and co-morbidities as well as a 'through time' period (i.e. the period of time between the recognition of death and death). A prospective approach was adopted to support 'real-time' reporting, facilitating a consistent collection of maximum data and reducing recall error and bias. The next section explains the methods of data collection and analysis.

4.8.1 Independent variables

Data were collected on the following variables: age, gender, diagnosis, co-morbidities and the length spent living in the care home. The data were added to the data collection form on the day the resident entered the study, i.e. at the point of recognition of death. Information regarding age and gender were taken from the nursing notes and the diagnosis and co-morbidities were taken from the medical assessment form within the notes by the nurse commencing the form. The date that the resident entered the home was added to the data collection form which enabled the length of time the resident had lived in the care home to be calculated. No information was collected that would personally identify the resident, to ensure that the resident's identity remained anonymous.

Symptoms were measured each day at 4 hourly intervals from the time of recognition that the resident was dying [the point of recognition] until the time of death. Due to the challenge of forecasting an actual time of death, the last measurement that was

taken before death occurred became the last one in the series [point of death]. Measurements took place at 6am, 10am, 2pm, 6pm and 10pm. A 2am measurement was not carried out to avoid any unnecessary disturbance of the resident.

4.9 The measurement of symptoms

The model identified in chapter two was utilised to form a structure in which to conceptually frame the symptoms. The measurement of symptoms is a challenging area, as symptoms are difficult to define and consistent parameters for symptom measurement is hard to achieve (Chang et al., 2004). In addition, the end stage of an illness is highly dynamic (Nauck, 2001) and people may experience different symptoms than previously presented.

In order to measure concepts, social scientists have created scales to increase the validity and reliability of measurement processes (Luchins, 2012), although the use of these risk losing sight of the importance of the original concept of individual symptoms. A number of instruments have been developed for symptom measurement within the end of life care setting. Some instruments have been designed to measure specific symptoms, while others focus on a wider range of symptoms or different patient groups. In addition, there are Quality of Life (QOL) instruments that are multidimensional constructs. QOL instruments may (and often do) include symptom measurement, but symptom instruments are primarily designed for the single purpose of measuring symptoms. As discussed in chapter four, assessment and measurement are closely linked, with the instrument supporting the 'capture' or measurement of a symptom. They enable the gathering of information (assessment), into a representative

set of numerical variables (measurement) to either allow the assessment of patient's needs or the use of the data for research purposes.

To develop a "gold standard" of symptom measurement, Ionova (2006) identified three principles, comprising of six elements, that are required to formulate an effective instrument (Table 4.3). Firstly, patient (self) rating is an principal feature (although this may not always be feasible, especially around end of life or if a person lacks capacity (Nekolaichuk et al., 1999)). The second requirement is that it is simple and brief; however, this may be too optimistic given the often dynamic nature of symptoms, particularly if there is a requirement to measure symptoms over a period of time. Thirdly, the instrument should be psychometrically validated. This is the ideal, and there are instruments that are validated in specific populations, but given the potential multiple variations between disease groups, demographic groups, and different cultures means that a 'fit for purpose' instrument does not exist for many of these groups. The psychometric properties of instruments are a fundamental aspect, but their selection also needs to meet specific clinical and research needs (Zimmerman et al., 2015).

Table 4.3 - The "gold standard" of symptom measurement (Ionova, 2006)

Simple
Brief
Easy for interpretation
Multiple items but not necessarily multiple scales
Psychometrically validated (published info about reliability and validity)
Appropriate for clinical trials and clinical practice

Using an appropriate instrument provides the opportunity to follow guidance to make the measurement. Although it relies on a measure of judgement, that judgement is of

the parameters of the instrument, not of the assessor. By ensuring that an appropriate instrument is in place and used correctly, it removes the onus of interpretation of the symptom and standardises the response.

During a systematic review of symptom measurement tools, Kirkova et al. (2006) concluded that there is no ideal instrument available, due to the wide range of instruments that reflect different needs of symptom measurement and they recommended that additional research is required. Kirkova et al. (2006) also devised a list of considerations when looking for a suitable instrument to use which has similarities to the one developed by Ionova (2006). Ionova's standards were used as a checklist to support the selection of instrument for this study and to ensure that it met the required outcomes of the study in a thorough and comprehensive manner.

4.9.1 Measurement by proxy

For this study, it was necessary to consider the use of proxy data collection. The participants in the study, due to their proximity to death, were unlikely to be in a position to self-report. In situations where the patient is unable to respond, such as in dementia care, the role of healthcare professionals and families as proxies is an area of considerable interest (Chang et al., 2009). In other disciplines, such as paediatrics, it has also been identified that objective measurement is rarely possible, with a reliance on parents or families to provide information (Bisgaard, Pipper, & Bønnelykke, 2011).

It was not a feasible option to ask families to provide regular and frequent information regarding the symptoms, so in this study data were collected through the use of

qualified nurses as proxy raters. The frequency of monitoring needed to be approached with caution as Forbes et al. (2011), in their study, suggested that 12 hourly recording was onerous for staff working in an acute area. To overcome this issue, the rationale of four-hourly recording was explained to staff so they understood the purpose. Four-hourly recording was deemed appropriate by staff because this fitted in with their usual pattern of observation, which meant that no addition tasks were required. To promote consistent recording, qualified nurses were selected as the proxy raters because they had the relevant clinical knowledge to carry out the assessment as well as being familiar with the resident, as they oversee their care on a daily basis. (Snow, Cook, Lin, Morgan, & Magaziner, 2005). Average nurse ratings are more likely to closely agree with patient ratings than medical colleagues (Nekolaichuk et al., 1999), even though they may still be lower than patient ratings for some symptoms. Some symptoms, for example, psychological symptoms such as depression, may be even more difficult to measure accurately by a proxy (Kutner, Kassner, & Nowels, 2001) and a more sensitive tool may be required. However, the more measurement methods used, the wider the discrepancy (Snow et al., 2005), reinforcing the use of a single instrument rather than multiple methods. To be suitable to assess the multiple symptoms experienced at the end of life, the instrument needs to include multiple items but not necessarily involve multiple scales (Ionova, 2006). The use of a single instrument is also supported by Bruera and Portenoy (2001) who identify the use of a single tool as being less demanding for those involved with measurement.

4.10 Selecting an appropriate instrument

The International Association for Hospice and Palliative Care produced a comprehensive list of pain and palliative care assessment and research instruments (IAHPC, 2008) which listed instruments broadly used for symptom measurement. This list was cross referenced with three other systematic reviews (Brown University, 2008; Kirkova et al., 2006; Medicine, 2001) to ensure that no other relevant instruments had been overlooked. This resulted in 22 instruments being reviewed for consideration of use.

A two stage review process was devised to identify the most suitable instrument for this study. First, all instruments were scrutinised to confirm their general suitability in line with the identified requirements of this study based on the research outcomes, and the criteria identified by Ionova (2006) in Table 4.3. This process enabled unsuitable instruments to be appropriately filtered out, e.g., if they were aimed at different populations, such as care-givers or paediatrics or if they were intended to be single symptom only instruments. For the purposes of transparency, Table 4.4 provides an overview of the first stage of this process with a brief rationale to state why a particular instrument was included or excluded.

Table 4.4 - Stage one – a review of instruments for measurement (IAHPC, 2008)

Instrument	Include √ or Exclude x	Rationale
Brief Fatigue Inventory *(Cleeland & Ryan, 1994)*	x	N/A* – Measures fatigue only
Edmonton Functional Assessment Tool (EFAT) *(Kaasa, Loomis, Gillis, Bruera, & Hanson, 1997)*	x	N/A – Assesses functional performance in patients with advanced cancer
ECOG Performance Status *(Oken et al., 1982)*	x	N/A- Assesses functional performance in patients with cancer

Edmonton Symptom Assessment System (ESAS) *(Bruera et al., 1991)*	√	Assesses a range of symptoms in patients
Edmonton Staging System *(Bruera, MacMillan, Hanson, & MacDonald, 1989)*	x	N/A – A clinical staging system for cancer pain
FAMCARE Scale *(Kristjanson, 1993)*	x	N/A – Scale to assess family satisfaction of care
Geriatric Depression Scale *(Yesavage, 1988)*	x	N/A – Measures depression only
Grief Resolution Index *(Remondet & Hansson, 1987)*	x	N/A – Measures grief only
Hamilton Depression Rating Scale *(Hamilton, 1960)*	x	N/A – Rating scale for depression
Herth Hope Index *(Herth, 1992)*	x	N/A – Hope assessment scale
Karnofsky Performance Scale *(Karnofsky, Abelmann, Craver, & Burchenal, 1948)*	x	N/A – Classifies patients as to their functional impairment
MD Anderson Symptom Assessment System *(Cleeland et al., 2000)*	√	13 symptom self-assessment scale measures severity and interference
McGill Quality of Life Questionnaire *(Cohen, Mount, Strobel, & Bui, 1995)*	x	N/A – Scale to measure quality of life at end of life
McGill Pain Questionnaire *(Melzack, 1975)*	x	N/A – Assesses pain only
Memorial Symptom Assessment Scale *(Portenoy et al., 1994)*	√	24 symptom self-assessment scale
Mini Mental State Questionnaire *(Vertesi et al., 2001)*	x	N/A – Screening instrument for cognitive impairment
Palliative Outcome Scale *(Hearn & Higginson, 1999)*	√	An outcome measure instrument to assess physical, psychological, practical and existential aspects of quality of life
Palliative Performance Scale *(Anderson, Downing, Hill, Casorso, & Lerch, 1996)*	x	N/A – Modified Karnofsky Scale assessing functional impairment
Pediatric Pain Profile *(Hunt et al., 2004)*	x	N/A - Measures paediatric pain only
Rotterdam Symptom Checklist *(Hardy, Edmonds, Turner, Rees, & A'Hern, 1999)*	x	N/A – Developed for cancer patients
Support Team Assessment Schedule *(Higginson & McCarthy, 1993)*	x	N/A – Includes factors such as family anxiety and service needs
Wong-Baker FACES Pain Rating Scale *(Wong & Baker, 1988)*	x	N/A – Assesses pain only

* N/A – Not Applicable

From stage one, four instruments were selected:

- Edmonton Symptom Assessment Scale (ESAS) (Bruera et al., 1991)

- MD Anderson Symptom Assessment Scale (Cleeland et al., 2000)

- Memorial Symptom Assessment Scale (MSAS) (Portenoy et al., 1994)

- Palliative Outcome Scale (POS) (Hearn & Higginson, 1999)

The second stage evaluated the four selected instruments by using the specific criteria identified by Ionova (2006) (Table 4.3). All instruments except the MD Anderson were relatively easy to use due to the length and number of questions. All instruments had been validated for general use and were deemed to be accurate and reliable (Bausewein et al., 2005; Chang et al., 2004; Okuyama et al., 2003). No instrument had been previously validated in the care home population, suggesting that additional studies in other populations are needed. (Watanabe, Nekotaichuk, Beaumont, & Mawani, 2008). All instruments except the POS included a variation in the number of symptoms included, from 11 to 32. The POS only rated pain and 'other' symptoms (Hearn & Higginson, 1999). Finally, the ESAS and the POS were the only two instruments that had been validated for use by proxy assessment (Nekolaichuk et al., 1999). This decision is supported by a review of instruments to measure symptoms in elderly cancer patients receiving palliative care (Browner and Smith (2013). Of the 21 instruments reviewed, and the four finally selected, three mirrored the instruments reviewed by this study (ESAS, MD Anderson and MSAS) and one was a cancer specific outcome measure (European Organization for Research and Treatment of Cancer's Quality of Life Core Questionnaire: EORTC QLQ-C30.). As with this study, they also noted none of the instruments had been validated for use with geriatrics (elderly population), although, they had been used within these populations.

A final decision was made to use the Edmonton Symptom Assessment Scale (ESAS) (Bruera et al., 1991) as it was the only instrument that fulfilled all of the six required criteria based on the gold standards for symptom measurement (Ionova, 2006) Table 4.5 provides a summary of the criteria of the four instruments.

Table 4.5 – A summary of the rationale for the use of the Edmonton Symptom Assessment Scale

Criteria	ESAS	MD Anderson	Memorial	POS
Simple	√	√		√
Brief	√		√	√
Easy for interpretation	√	√	√	√
Multiple items but not necessarily multiple scales	√	√	√	√
Psychometrically validated	√	√	√	
Appropriate for clinical trials and clinical practice, including proxy-rater use	√			√

4.11 The Edmonton Symptom Assessment Scale

The Edmonton Symptom Assessment *System* (ESAS), although now usually referred to as the Edmonton Symptom Assessment *Scale*, was designed for the monitoring of patients' symptom experience in a palliative care unit in Canada (Bruera et al., 1991). The original version of the ESAS used a visual analogue scale from 0 - 100mm to measure the intensity of each of eight symptoms (pain, activity, nausea, depression, anxiety, drowsiness, appetite and well-being) with 100mm being the most severe symptom distress. Since then, there have been a number of revised versions; different symptoms have been added or removed, visual analogue scales have been replaced with numerical rating scales, and the frequency of assessment has varied from four-hourly to daily in in-care settings or weekly to monthly if being used in clinics or out-patient settings. It has also been translated into over 20 languages (Bruera et al., 1991;

Hui & Bruera, 2017). Yet despite its widespread use, it has been recognised that the diversity of ESAS modifications has made cross-study comparisons difficult and reinforces the need for a standardised instrument and administration processes. Nevertheless Watanabe, Nekolaichuk, Beaumont, and Mawani (2008) defend its continued use as no faultless instrument exists, and the ESAS has had its use justified in systematic identification and monitoring of symptoms.

The ESAS has been validated with several different populations primarily within cancer in-patients (Nekolaichuk, Watanabe, & Beaumont, 2008; Nelson et al., 2001; Strömgren, Groenvold, Pedersen, Olsen, & Sjogren, 2002; Yesilbalkan, Ozkutuk, Karadakovan, Turgut, & Kazgan, 2008), and has had significant use within nephrology (Davison, Jhangri, & Johnson, 2006; Flythe et al., 2015) and cardiology (Shah et al., 2013; Udeoji, Shah, Bharadwaj, Katsiyiannis, & Schwarz, 2012). It has also been found to be useful as an audit instrument for palliative symptom control (Dudgeon & Harlos, 1999; Rees, Hardy, Ling, Broadley, & A'Hern, 1998). Hui and Bruera (2017) attribute the widespread use of the ESAS due to it being a pragmatic patient-centred symptom assessment tool that is easy to administer, interpret, and report. It has the ability to assess 10 symptoms making it multi-dimensional and able to identify symptom clusters and concurrent symptom presence. Although it has been psychometrically validated by multiple groups (Hui & Bruera, 2017), it has had few validation studies in non-cancer populations and it has not been validated in the Long Term Care setting population such as nursing care homes. Brandt et al. (2006) utilised the ESAS, as identified in the literature review, and found it to be an effective tool for this population in relation to proxy data collection and for patients with non-cancer diagnoses. More recently it has been used within a study into end of life symptoms in

Norwegian nursing homes (Sandvik et al., 2016), although post data collection of this study, it was reported to be the only end of life care instrument with a relevant symptom list to assess change in symptom intensity by a continuous scale.

Due to the anticipated nature of the population in this study, a prime factor for selection of the ESAS is that it can be completed by the patient or by proxy if self-reporting is not possible Bruera et al. (1991), so while the ESAS is intended to capture the patient's perspective on symptoms, in cases where the patient is unable to self-report, the source of information may come from a proxy (such as a carer). There has to be a degree of caution with this as Garyali et al. (2006) reported errors in some types of symptom intensity (for sleep and appetite) when used for self-assessment against proxy assessment. Another challenge that arises, particularly when using proxy assessment rather than self-assessment, is the measurement of psychological symptoms such as anxiety and depression. This is considered to be methodologically challenging, particularly at the very end of life (Kozlov et al., 2019) and they are considered to be burdensome to both the patient and the care giver; however, attempts to measure and manage these throughout the illness trajectory are still necessary. A benefit of using regular staff to assess patients is that they have prior knowledge of the patients and are able to use that to inform their clinical assessment.

The scales were presented horizontally which made the ESAS simple to use. However, the direction of the visual scale (horizontal or vertical) may have an influence on measurement. Other scales such as the Wong-Baker scale have reported that vertical scale increases validity (Wong & Baker, 1988). Other studies have reported largely positively when the ESAS was used by patients (Baba, Fransson, & Lindh, 2007;

Watanabe, Nekotaichuk, et al., 2008), although the study by Watanabe, Nekotaichuk, et al. (2008) found that patients found some of the medical terminology difficult to understand.

Some of the reported limitations of the use of the ESAS have included difficulty in completion and its completion being time consuming (Rees et al., 1998). Although the ESAS has been found to be a feasible and useful instrument for palliative care nurses, less well qualified nurses found it more difficult to use indicating that the level of training of staff may influence its perceived ease of use (Watanabe, McKinnon, Macmillan, & Hanson, 2006), so this study purposely selected qualified nurses to overcome that potential issue.

Taking the above into consideration, a modified version of the ESAS was selected for this study, and this was considered for a number of reasons:

The modified version contains 12 items, compared to the usual 10. This gave a greater breadth of symptom measurement. It also omitted a symptom that had been previously included - 'well-being'. This symptom had received criticism that it was only a surrogate marker for an overall score of symptom distress due to a lack of consensus of what it really meant. To balance this in a more useful way, the modified ESAS contains an equally weighted summation of scores that may estimate a construct of total symptom distress, which in turn is related to palliative goals and quality of life (Richardson & Jones, 2009). It has a four-hourly numerical rating scale (the previous version had a six-hourly scale) which was found to be simple and valid within a longitudinal assessment (Davison et al., 2006). Unlike other versions, there was a

stratification for symptom severity. This avoided staff having to assign a numeric value to rate the symptoms, and thus reducing the number of options available and adopted a rating of mild, moderate, or severe. There was an anomaly in that eight symptoms were assessed on an observer-rated score between 0 - 3 (0 = None, 1 = Mild, 2 = Moderate, 3 = Severe), but four were required to be rated as present or absent.

4.12 Dependent variables

Data were collected regarding 12 symptoms. The symptoms were: pain, tiredness (fatigue), drowsiness (sleepiness), depression, anxiety, nausea, anorexia, shortness of breath, secretions, constipation, unable to respond and delirium.

4.13 Completion of the research study

At the end of the nine month data collection, either the researcher or research assistant visited the care home and collected any completed forms and the research study box. At the same time, information posters were removed and new posters (Appendix xiii) were provided to each care home to let all staff know that the data collection was over and to thank them. A letter of thanks (Appendix xiv) was sent to each manager with a short descriptive summary of the data from the first deaths from their care home, once 100 deaths in total had been achieved, once the information was collated. A more detailed summary of findings (from the first 100 deaths) from all care homes (anonymised) was completed and sent to all care homes within 12 weeks of the end of data collection.

4.14 Ethical issues

Ethical norms in research have an important role. They not only promote the practice of effective and respectable research, but act to consider and protect those involved in the process. When conducting research with human beings, research ethics considers the minimisation of harm and the maximisation of benefits a key requirement (Shamoo, 2009). Two points of reference are used to guide and discuss the ethical decision making within this study. These are the four principles of ethics (Beauchamp, 2013) and the Economic and Social Research Council (ESRC) Framework for Research Ethics (ESRC, 2015). By applying the principles addressed in the two frameworks, all aspects in relation to this study will be addressed.

4.14.1 Ethical approval

The study went through a full process to gain ethics approval. Applications were made to the local Primary Care Trust REC and the regional NHS National Research Ethics Service (NHS NRES) committee with both responding that an ethical review was not required for this study. An application was made to the Division of Health Research Ethics Committee at Lancaster University, which received full approval in February 2009. Table 4.6 lists the process and decisions and provides links to the documents located within the appendices.

Table 4.6 - Ethics approval processes

Description/Appendix no	Notes
Letter of ethics approval from Lancaster University. Issued 28 January 2009 (Appendix xv)	Full ethics approval was granted following IHR Ethics Committee meeting on 11 December 2008.
Letter of ethics approval from Lancaster University. Issued 20 February 2009 (Appendix xvi)	A request was made to the IHR Ethics Committee on 20 February 2009 to increase the number of participating care homes from

	10 to 11. This letter confirmed that it was a minor amendment and the research still met the requirements for ethical approval.
Letter of ethics approval exemption from NHS RES. Issued 29 September 2009 (Appendix xvii)	The project outline (similar to the outline provided to the IHR Ethics Committee) was submitted. The Chair advised that it was considered to be an audit so did not require ethical review by the NHS REC.
Letter of ethics approval exemption from local PCT[14]. Issued 27 August 2008 (Appendix xviii)	The project outline (similar to the outline provided to the IHR Ethics Committee) was submitted. The study did not require PCT Research and Audit approval because the study did not involve PCT staff or patients.

Collecting data on people at the end of life requires additional consideration, particularly around the nature and type of the information. The nurses were reporting on information that was usually collected as part of normal care and was thus classified as 'existing data' by the National Research Ethics Service at the time when the proposal was considered (NHS, NRES 2008). It must also be noted that when the research proposal was approved in 2009, much of the current ethical guidance and requirements for research was predominantly for clinical trials and non-therapeutic medical research (Smith, 2008) and ethics approval for studies such as this one were less frequent and therefore this did not always readily align with guidance. However, reviewing the study by current guidance, it would still not be considered research by the NHS because: the participants in the study are not randomised to different groups, the study protocol does not change treatment or care from the accepted standards and the findings are not generalizable beyond the specific population (Medical Research Council, 2015).

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[14] PCTs (Primary Care Trusts) were part of the NHS and responsible for commissioning primary, community and secondary health services from providers from 2001 to 2013. They were superseded by Clinical Commissioning Groups.

4.14.2 Ethical issues arising in the study

When considering the frameworks of Beauchamp and the ESRC Framework for Research Ethics, the following aspects are relevant to this study, and will be now discussed in more detail: autonomy, beneficence, avoiding harm (non-maleficence), confidentiality, independence and justice. The approach to consent will be discussed further in the next section, but this study utilises 'existing data' and has not been required to adopt the usual 'default' position of fully informed consent. (Boddy, 2010). However, to maintain the integrity of the study, participants were fully informed of the study with the option to either opt out or withdraw at any time during data collection and this will be discussed in relation to ethical principles. The section will conclude with a consideration of the principles specifically in relation to closed institutions.

4.14.3 Autonomy

Respect for autonomy is the first of the four principles of bioethics (Beauchamp, 2013) and calls for a respectful conduct when disclosing information. To make an autonomous decision, requires information giving and a freely given decision (without coercion) to take part in research. Information was provided in all of the care home sites and was openly displayed in public areas as well as featuring in resident and family meetings and newsletters. The researcher was available to meet with residents and families who required further information or clarification.

Consent is a foundation principle of research and is linked closely to the concept of autonomy. It refers to the participation of an individual within a research project (Miller & Wertheimer, 2010). As consent is a procedure, rather than a simple yes or

no, the whole process of the study needs to be considered and the rationale for the way in which consent is obtained needs to be carefully weighed up. The issue of consent within this study needed to be sensitively tailored to the practical, emotional and psychological needs of those involved (Bradburn & Maher, 2005). Due to the nature of the study it was exempt from full informed consent procedures and individual informed consent was not required. This approach to consent has been utilised in several other studies involving similar populations in care home settings (Brandt et al., 2005; Brandt et al., 2006; Brechtl et al., 2006; Solloway et al., 2005). Other studies in similar settings (Lichter & Hunt, 1990; Morita, Ichiki, Tsunoda, Inoue, & Chihara, 1998; Nauck, 2001) have not indicated if or how consent was gained which may indicate some of the challenges involved. A wider example of a similar approach can be seen in a study conducted by Macleod et al. (2000). This required identification of cases through the cancer registry, and then death register and NHS record review. It was done without seeking individual informed consent for data collection, although patients had to be made aware, through leaflets and explanation, that data collection for this purpose was taking place and were invited to comment upon it. The study for this thesis was considered minimal risk (as discussed in section 4.14.2) which supported the decision to not require full informed consent. Firstly, the demographic information collected was non-identifiable, and neither care homes nor participants would be identified within any external reports or publications. Secondly, the observations were non-invasive and formed part of the usual care routine carried out by staff.

Despite the above instruction that fully informed consent was not necessary, the researcher believed that it was important to adhere to the principles that informed

consent obliges i.e. respect for the person, not deceiving or exploiting nor shaming or harming in any way (Boddy, 2010).

4.14.4 Beneficence and avoiding harm (non-maleficence)

Leading on from the discussion of consent above, this was guided by a balance between beneficence and non-maleficence. As this study was prospective in nature, it was not known who would be participating (i.e. dying during the study) until the resident started on their dying trajectory. It would have created a greater risk to consent every person in the care home, as there was a high chance that they would not become a participant but would have had a potentially upsetting discussion if they were to have been individually consented into the study. Given that the situation around imminent death provokes a very personal reaction, it was more appropriate that the information was provided generally and each person had the opportunity (either through the care home staff or the researcher) to gain more knowledge about the study. This was carried out with a degree of caution as some studies have reported findings that professionals believe that research in dying patients is never appropriate (de Raeve, 1994; Hughes, Preston, & Payne, 2013; Preston, Payne, & Todd, 2009). However, also reported is that involvement in research can provide a sense of empowerment, of value and contribution (Bradburn & Maher, 2005).

Within this study it was agreed that participants would not face any harm – that it was considered 'minimal risk research' for a number of reasons. Observations are non-invasive. The 2am observation was not carried to avoid unnecessary disturbance to residents. The only potential impact was that an increased and more thorough symptom

measurement could improve care. While no research that is harmful should be undertaken (Cowan, 2009), being prohibited by gatekeepers may be unethical in itself, in that it denies the residents the best possible care (Parahoo, 2006). This study did not face these challenges (it has already been discussed how the care homes were engaged with which supported this) and as a result no-one chose not to take part in the study or opted out during the data collection.

4.14.5 Confidentiality

Confidentiality was maintained in a number of ways. Study codes were used for both care homes and participants on all completed data forms. The staff completing forms used a unique code for each resident/form completed. The staff kept a separate master document that links the study code to subjects' identifying information locked in an office. Identifying information of the participants was not shared with the researcher. The care homes in the study were dispersed across a wide geographical area meaning it was not possible to identify the individual homes.

All research study data were kept secure at all times. All paper records were kept in a locked cupboard and all computerised records had security codes assigned to them. Data will be destroyed in line with the Lancaster University's Research Data Management Policy which currently states "that all research data will be stored in either electronic or paper form for a minimum of 10 years after the end of a project, unless ethical considerations, participant confidentiality, FOI requirements or external agencies e.g., NHS, specifically request otherwise" (Lancaster University, 2018).

4.14.6 Independence

There were no conflicts of interest identified prior to this research. The researcher was known professionally to the care homes who took part in the study, but was not directly associated with any care home. This raises questions about researcher positionality in a positivist study, however (Jafar, 2018) argues that positionality does not undermine the truth of the research, but rather it marks the boundaries of the research. It is the intention of the researcher to be open and transparent about their involvement and how this may have added to the value of the research.

4.14.7 Justice

Justice is being fair to research participants and although a potentially subjective principle (Pieper & Thomson, 2013), the researcher recognised that a greater evidence base in end of life is needed. Research could only take place in this population as the distinctiveness around end of life care is normally not generalisable to research with people who have curable conditions, therefore if people at the end of life are to be offered the best levels of care, research needs to be conducted within this group (Perkins, Barclay, & Booth, 2007; Seymour & Skilbeck, 2002). Despite some concerns, Gysels, Evans, and Higginson (2012) found, through a systematic review, that the majority of patients would be willing to take part in end of life research.

4.14.8 The principles of ethics in closed institutions

Gatekeeping is when health professionals or families prevent participants from being asked to become involved in research studies in the belief that they are protecting them. (Preston et al., 2009). Gatekeepers are usually health professionals (Alexander, 2010)

and can be potentially paternalistic and tokenistic preventing potential participants from speaking for themselves (Walker & Read, 2011). In this study, there was a risk that care home staff would block the researcher from having access, by either not involving them or failing to comply with data collection. The emphasis on end of life care makes this a greater risk. Knowing the care homes in a professional context is more likely to create a supportive approach (Walker & Read, 2011), however the researcher needs to be aware of the potential influence leading to bias. There needs to be a balance of remaining independent while being able to use the professional relationship to ensure good research outcomes.

Gatekeepers can both facilitate access to participants and bar the way (Emmel, Hughes, Greenhalgh, & Sales, 2007). The research was conducted with care, respect and regard which helped to support a high level of participation with minimal missing data (Gysels et al., 2012). Individual support and supervision optimised the participants' contributions (Beaver, Bogg, & Luker, 1999).

4.15 Reliability and validity

Due to the nature of the study, one feature requiring particular deliberation concerned rigour. Rigour in research normally refers to the way in which integrity and competence are confirmed to enhance the quality of the research (Coryn, 2007; Heale & Twycross, 2015). In quantitative research, this is attained through measurement of reliability and validity. Although these are often treated separately, they are inter-related and form a continuum (Trochim, 2008).

Reliability refers to the consistency and dependability of a measurement, or to the degree to which an instrument measures when repeated in a population of groups or individuals (Bruce et al., 2008). Although reliability cannot be calculated exactly, reliability estimation can be exercised. The main categories of reliability to be discussed are equivalence, stability and internal consistency (Cohen, 2011; Trochim, 2008; Twycross & Shields, 2004).

Firstly, to demonstrate reliability between the pre-test and post-test data, a t-test can applied to demonstrate if the equivalent forms of a test yields consistent results if applied to matched samples (Cohen, 2011). In this study, matched samples using demographic data were shown through a high correlation coefficient and through the means and standard deviations between the two groups.

Secondly, to achieve a level of agreement between the care home staff, who were the observers, a process was identified (Heale & Twycross, 2015). These involved ensuring consistency of interpretation through training and support; and minimising external sources of variation by having agreement symptom definition. Although these second actions were not an estimate of reliability, they would help to improve the reliability between raters.

All of the qualified staff within the care home were provided with an information sheet regarding the study (Appendix x). A pro-forma was provided to each care home to record when the information was given to the member of staff and the member of staff would sign to confirm they had received and understood it (Appendix xi).

All care homes were offered training sessions to support qualified nursing staff with the use of the ESAS using case studies and sample ESAS forms to sustain internal reliability and rigour (Potter et al., 2003). A general overview of the project was provided with the opportunity for questions and feedback. The ESAS was introduced to staff and a facilitated case study based on a fictional resident called 'Maud' demonstrated the use of the scale. This allowed staff to see the ESAS 'in action' and increased inter-relater reliability by checking that raters agreed with the rating scores of the ESAS (Hearn & Higginson, 1999; Zimmermann et al., 2010), but also agreed with each other over the values to be applied. This supported a standardisation of measurement through different conditions. The 'crib sheet' used by the researcher to lead the training sessions can be seen in Appendix xii. The use of a single assessment form enabled staff to become more familiar with its use. The ESAS form was kept with the resident's usual monitoring paperwork and used by staff at the bedside to enable them to make assessments in the same way regardless of the staff member carrying out the assessment (Bruera & Portenoy, 2001).

During the sessions, feedback from staff identified that there was a lack of clarity of the terminology used for labelling symptoms so in response, a process to standardise the definitions was employed. The lack of clarity of the terminology may have arisen due to the origins of the ESAS from the United States as some of the language, although English, felt unfamiliar to the care home staff. The staff needed a greater understanding of the vocabulary used in the ESAS to promote consistency, applicability and to increase inter-rater reliability. The use of a global description was a method adopted by Bisgaard et al. (2011) who recognised that diagnosis and monitoring (in the case of asthma) was confounded by "second-hand description with

inaccurate terminology" (p.1155). Unable to change the second hand reporting, they set about standardising the terminology. Adding extra definitions to the ESAS is supported by Watanabe et al. (2011), who also found that some terms in the ESAS were perceived as confusing. Inconsistency in definitions does matter in gaining a form of consensus for meaningful clinical or research comparisons (Russell, 2015)

As a solution, but to prevent modifying the ESAS beyond its original format, a list of definitions were obtained from NHS choices (www.nhs.uk) and printed on the reverse of every ESAS form. Staff subsequently reported that it clarified the terminology used and helped them to be more consistent in the application of the instrument. The definitions that were used are presented in Table 4.7

Table 4.7 - Definition of terms used in the Edmonton Symptom Assessment Scale (ESAS)

Symptom	Definition
Pain	Pain is an unpleasant physical or emotional feeling. If a person cannot report pain, they may show it in a number of other ways, such as restlessness, agitation, grimacing or groaning
Fatigue (Tiredness)	Fatigue is extreme tiredness and lack of energy, which makes even minor tasks difficult
Drowsiness (Sleepiness)	Drowsiness is when someone feels extremely tired and uncontrollably near to sleep
Depression	Depression is when someone has feelings of extreme sadness, despair or inadequacy that last for a long time
Anxiety	Anxiety is an unpleasant feeling when someone feels worried, uneasy or distressed about something that may or may not be about to happen
Nausea	Nausea is when a person feels like they are going to be sick
Anorexia	Anorexia is a loss of appetite is when a person does not feel hungry or wants to eat
Shortness of Breath	A person may be short of breath, unable to take a deep breath, gasping for air, or feel like they are not getting enough air
Secretions (Y/N)	An excess and/or thickening of respiratory secretions
Constipation (Y/N)	Constipation is when a person passes stools less often than usual, or when they are having difficulty going to the toilet because their stools are hard and small
Unable to respond (Y/N)	When a person becomes increasingly difficult to rouse or in a sleep like state and will be unresponsive
Delirium (Y/N)	Delirium is a severe state of mental confusion and anxiety that may or may not involve hallucinations

4.15.1 Reliability

The purpose of reliability in this form is to measure consistency over time and with similar samples. In this study, this has been achieved through two measures. Firstly, the study used a prospective data collection method. Prospective data sets are usually more complete and are less reliant on memory as they are recorded at the time. Each measurement is made 'in time' which means being able to detect anomalies as they occur, therefore promoting consistency across samples. The study also utilised the ESAS, which has been shown to have reliability in similar populations. The time span of data collection improves stability as a reliable instrument used in similar research will yield similar data from similar participants over time (Cohen, 2011).

Researcher (observer) consistency was improved by the use of triangulation within the methods (Adami & Kiger, 2005). Due to the nature of the data collection period, there were a number of observers. The observers were based in different locations/care homes. In addition, there was an increased number of occasions when the observations were made. These were assessed using a test/retest correlation coefficient such as Spearman, Pearson or t-test (Trochim, 2008).

Internal consistency refers to an agreement of the results for different items for the same construct within the measure. A common way of calculating correlation values is by the use of Cronbach's Alpha (Heale & Twycross, 2015). The study ran this test through SPSS 19 to measure the consistency amongst the items by calculating all split-half estimates from the same sample. This only involves one administration of the instrument.

4.15.2 Validity

While reliability is about the consistency and dependability of a measurement, validity involves the degree to which empirical evidence supports the suitability and relevance of the interpretations of scores, or more simply, the accuracy of the measurement (Kaplan, 2008; Trochim, 2008; Twycross & Shields, 2004). The main types of validity that will be discussed are content validity, criterion validity and construct validity and will be regarded in relation to internal and external validity.

Face validity is the weakest type of content validity, but it does has value in that it helps shape the instrument and helps shape the construct into a strategy (Trochim, 2008). There were a number of elements that gave this study face validity. The instrument had been introduced to the observers, i.e. the registered nurses who were involved with collecting data prior to the study period. As the data that were collected during the study was the same that they would usually collect as part of normal care, they were considered to be a good judge of the suitability of the instrument. Had this been rejected by the observers, it may well have been considered to not have face validity. A more rigorous way to assess content validity was carried out during the selection of the instrument when previous validation studies were reviewed. Key areas to consider were that an appropriate range of end of life symptoms were included as this was a key domain within the research question and that the instrument was able to be used 'over time' due to the longitudinal nature of the research. Although the instrument was not validated in the care homes setting, it was not believed to signify any element of construct under-representation.

Construct validity links the measure and the theory, although there has been a shift from thinking about the validity of the test to the validity of the outcomes (Colliver, Conlee, & Verhulst, 2012). Constructs can be concerning causes, effects and the cause-effect relationship. If the construct is not valid then a test on which it is established will not be valid either (Trochim, 2008). Within this study, the construct may be seen as measurable symptoms; however, within positivism, it is more common to define constructs by their relationship with other constructs (Colliver et al., 2012). Applied to this study, it means that evidence for the construct comes from evidence for the instrument through the wider validation of the ESAS. In addition, construct validity within this study was increased by virtually eliminating selection bias as all participants who died over the study period would be included unless they chose for their data not to be included or they died away from the care home. Another method to increase construct validity is to reduce the risk of type I and type II errors within the results – type I can be addressed by setting levels of significance, type II by reducing the level of significance.

Criterion-related validity is similar to construct validity, but links the test to external criteria such as another test (Heale & Twycross, 2015). Within this study there was a risk of choosing an instrument based on convenience rather than being fit for purpose, thus increasing the risk of criterion errors. However, comparing instruments against each other enabled the best fit for the criterion as well as the most convenient instrument to use. This in turn increases the generalisability and replicability of the study.

4.15.3 Other considerations in relation to reliability and validity within the study

The impact of the involvement of participants through the use of 'inappropriate' consent methods as highlighted by Smith (2008) and Cassell and Young (2002) can impact upon both the reliability and validity of the findings. By excluding difficult to research groups, such as dying patients or those that are unable to give fully informed consent can result in a limited subset of the potential population and may give a false legitimacy to 'successful' studies (Cassell & Young, 2002).

4.16 Managing the data

At the time of data collection, the data were entered into SPSS 19 by an administrative assistant. At the time of input, the data were cross-checked for accuracy against the original data collection forms by the researcher. The data were entered into SPSS 19 by an administration assistant, so the researcher would conduct the data cleaning. A small sample of the data ($n = 8$, 5%) will be re-entered into an empty database and compared with full data set. If any errors are detected, they will be traced back and compared with the original data forms, and fully corrected. Full details of the adjustments will be expanded upon in the results chapter.

4.16.1 Data transformation

Data often requires transformation to enable a data set to resemble a normal distribution by making it fit a normal distribution curve or when the variance of the data is not homogenous. This is done not only to bring it to normality, but to try to meet the assumptions prior to using any type of a general linear model, such as t-test,

ANOVA, regression etc. However this process can also fundamentally transform the nature of the variable making interpretation more complex due to the nature of the transformations (Osbourne, 2002). It is the intention of this research study to utilise non-normal data if necessary and exhaust all analytical options prior to making a decision to transform. A specific section regarding any data transformation required and an explanation for the inclusion of valid non-normal data will be provided at the beginning of chapter five.

4.16.2 Missing data

Depending on the type of missing data, the following options will be considered to determine how to handle the missing values (MacFarlane, Veach, & LeRoy, 2014). Although excluding cases with missing data are common in some disciplines such as psychology and education (Baraldi & Enders, 2010), the software package used in the research study (SPSS 19) has a default option to implement the generation of replacement values. However, the nature of this process needs to be considered in relation to the type and purpose of the missing data. The following methods will be utilised in the event of missing data. If data are 'missing at random', these are likely to be less problematic and not bias the available data. In this case the missing data will be disregarded, with the available data analysed; however, this would depend upon the number of missing data compared to the size of the dataset (Denis, 2015; Higgins & Green, 2008). If data are 'not missing at random' and the reason they are missing is related to the specific characteristics of the participants, then the missing data will become non-ignorable and publishing the available data alone will lead to bias. In this case, the missing data will be imputed with a mean value, and will be treated as if it

had been observed (Denis, 2015; Higgins & Green, 2008). Last Observation Carried Forward (LOCF) is alternative method. In LOCF, the last captured value is carried forward and assumed not to alter over time. This is a popular method but requires that outcomes do not vary when data become missing and that a single data point can be used to approximate the distribution of potential values (Molnar, Hutton, & Fergusson, 2008). Specific details regarding the treatment of any missing data will be provided at the beginning of chapter five.

4.16.3 Statistical methods

Descriptive statistics will be used to describe the study population demographics (both the care homes and the participants/residents), with the results reported as Mean, Standard Deviation (*SD*), Median and Range. Twelve symptoms will be systematically measured and recorded using the Modified Edmonton Symptom Assessment Scale (ESAS) at four hourly time points during the data collection period (see Appendix xiv). Monitoring will take place five times per 24 hours at 06.00 hrs, 10.00 hrs, 14.00 hrs, 18.00 hrs, 22.00 hrs. A measurement of the symptoms at 02.00 hrs was intentionally not included to avoid residents being unnecessarily disturbed at night.

To test the hypotheses, the following methods will be used

Hypothesis one and three: 'there will be an increase in the presence and intensity of the total symptom load between 48 hours, 24 hours and 4 hours prior to death' and 'there will be an increase in the presence and intensity of each individual symptom between 48 hours, 24 hours and 4 hours prior to death'.

To provide an overview of the presence and intensity of symptoms at three time points prior to death (4 hours, 24 hours and 48 hours), descriptive statistics will be used. This will result in four groups: a) total symptom presence load, b) total symptom intensity load, c) individual symptom presence and d) individual symptom intensity. This process is described in Table 4.8.

Table 4.8 The calculation of the presence and intensity of symptoms

Group	Description	Method of calculation
A and B	Total symptom presence load and total symptom intensity load	The mean score of the presence or intensity of each individual participant at a given time point (4 hours, 24 hours, 48 hours) were added together and then divided by the total number of participants – this resulted in a total symptom load score for each time point for both presence and intensity
C	Individual symptom presence	The number of symptoms per participant were calculated by totalling the number of symptoms at each time point (4 hours, 24 hours, 48 hours).
D	Individual symptom intensity	The total intensity score was calculated by totalling the intensity score of symptoms at each time point (4 hours, 24 hours, 48 hours).

These symptom scores will be analysed in the following ways:

1) For the total symptom load scores for presence and intensity (a & b) and the individual symptom score for intensity (d), a one-way repeated measures analysis of variance (ANOVA) will be conducted on the participants for whom there are data available over the three time points ($N = 61$). In this instance ANOVA is used to determine whether there are any statistically significant differences between the means of two or more measures for the same participants. . These will be reported as the F value, degrees of freedom (df), p value and partial theta (η) (an estimation of effect size). Next, post hoc comparisons will be performed. The total symptom load (presence

and intensity) and individual symptom intensity will undergo a pairwise comparison to look for significant differences between the three time points. ANOVA can be used for these data because there are three or more groups and the data are continuous. The distribution of the data must be normal, and standards deviations must be similar for each group (homogeneity of variance). Data will be observed against Maunchly's Test of Sphericity to ensure that the data demonstrate compound symmetry. If the significance value is $p < 0.05$, this assumption is violated. Due to the nature of the data collection instrument, only eight symptoms will be included in the individual symptom intensity, because four of the symptoms (secretions, constipation, unable to respond and delirium) were recorded in the data collection as 'present' or 'not present', so do not have an intensity score.

2) The individual symptom presence score (c) is categorical data because a symptom can only be present or not, so this will need to be treated differently. Cochran's Q test will be used because this is a non-parametric way to find differences in matched sets of three or more groups. These will be reported as the Q value. As previous, post hoc comparisons, in the form of pairwise comparisons will be performed on any that have a significant Q value ($p < .05$) (SPSS does not perform multiple comparisons when the overall test does not show significant differences across samples). Cochran's Q test can be used because there is one dependent dichotomous variable (presence or absence).

All of the scores for a, b, c & d will be reported as uncorrected. A Bonferroni test is the most commonly used test to correct for multiple comparisons however its use needs

to be considered and it should not be used routinely. Consideration needs to be made as to whether (1) a single test of the universal null hypothesis that all tests are not significant is required, (2) it is essential to avoid type I error, and (3) a large number of tests are carried out without pre-planned hypotheses (Armstrong (2014a).

Hypothesis two and four: 'there will be an association between the total presence and intensity of the total symptom load and the key characteristics of residents at 48 hours, 24 hours and 4 hours prior to death" and "there will be an association between the total presence and intensity of individual symptoms and the key characteristics of residents at the time closest to death (within 4 hours)". The presence and intensity of symptoms will positively correlate with older age, a higher number of diagnoses, a longer length of stay and a male gender'.

An inferential analysis will performed to test the hypothesis, and to observe for associations between the symptoms and the participant characteristics. Depending on the distribution, it is planned to use a parametric test of bivariate correlation, Pearson's correlation coefficient, to measure the strength and direction of linear relationships between the variables. To use Pearson's, correlation data are required to be continuous, have an absence of outliers and be normally distributed. The Kolmogorov–Smirnov test will examine if variables are normally distributed. When observing for statistical significance, a significant p value will be reported with the level of significance set at $p > .05$, although smaller values have been reported on where appropriate. However the effect size (in this case the product moment correlation co-efficient) will also be reported to see the strength of the association. It can be argued that a more clinically

4.17 Storage of data and information, data protection

The completed demographical information and the ESAS forms, once completed by staff, were stored in a central point in the home prior to collection by the researcher or administration support person. This was agreed with each home individually, but needed to be in a secure place in the care home. A stock of the research study documents were stored in each home in a brightly coloured box and contained all the documents. The boxes were kept secure in the staff office and easily located for staff completing forms and acted as a 'reminder'. Envelopes were provided for each completed form, which were sealed before placing in the central storage point. All the paper information was kept in a locked filing cabinet in a locked research office at Cheshire Hospices Education (based at St Luke's (Cheshire) Hospice, Winsford). The paper copies will be destroyed at the end of the research study on completion of the thesis. All electronic data were saved on a password-only accessible drive on the network of computers belonging to Cheshire Hospices Education. This system complied with the Data Protection Act, registration number Z6557193.

4.18 Conclusion

This chapter presents the ontological positioning of this study within the positivist worldview, chosen to answer the specific aims and objectives of this study as identified at the beginning of the chapter. The characteristics of this position are identified and how this shaped the study design. Taking a positivist stance to measure symptoms may

require no further discussion as it aligns to a dominant worldview; however, this chapter has demonstrated that this was the most appropriate choice of epistemology. But due to the nature of the study, particularly in relation to the aspects around end of life and the inability of the population to be able to 'experience' symptoms, a positivist approach was the appropriate one to take.

A positivist approach has subsequently influenced the choice of methods in order to measure the incidence and prevalence of symptoms, while gaining that knowledge in a transparent and open manner.

Chapter 5 - Results

5.1 Introduction

This research aims to study the presence and intensity of physical symptoms of residents in the dying phase in care homes and explore whether there are changes in symptoms over time and how they relate to specific demographics and other characteristics.

The objectives of the research are:

1. To measure the presence and intensity of total physical symptoms, and test the associations between key characteristics (age, gender, number of diagnoses and length of stay), during the final 48 hours of life in people who are resident in a care home.

2. To measure the presence and intensity of individual physical symptoms, during the final 48 hours of life in people who are resident in a care home and test the associations between key characteristics (age, gender, number and type of diagnoses and length of stay) during the final 4 hours of life in people who are resident in a care home.

3. To propose a typology of symptoms associated with the dying phase derived from the population characteristics and the longitudinal changes over time.

To be able to test research objectives one and two, the following hypotheses were developed:

1. There will be an increase in the presence and intensity of the total symptom load from 48 hours, to 24 hours and 4 hours prior to death (*Research Objective 1*).

2. There will be an association between both the total presence and intensity of the total symptom load and the hypothesised characteristics of residents at 48 hours, 24 hours and 4 hours prior to death. The presence and intensity of symptoms will positively correlate with older age, a higher number of diagnoses, a longer length of stay and a male gender *(Research Objective 1).*

3. There will be an increase in the presence and intensity of individual symptoms between 48 hours, 24 hours and 4 hours prior to death (*Research Objective 2*).

4. There will be an association between the total presence and intensity of individual symptoms and the key characteristics of residents at the time closest to death (within 4 hours). The presence and intensity of symptoms will positively correlate with older age, a higher number of diagnoses, a longer length of stay and a male gender *(Research Objective 2).*

This chapter presents the findings from the research. First, the sample will be described through the presentation of the organisational and participant characteristics. The data are complex in parts, due to the cumulative nature of recruitment to the study, so these will be described in depth.

The first and third hypotheses will be addressed and met through descriptive and inferential analyses of the data. A descriptive analysis of the occurrence of individual symptoms will be presented and the total presence and intensity of symptoms will be addressed through an inferential analysis of the data utilising a one way repeated measure *ANOVA* and pairwise comparisons at 4 hrs, 24 hrs and 48 hrs prior to death.

The second and fourth hypotheses will consider the association between the total symptom load and individual symptom presence and intensity and the characteristics of age, gender, number of diagnoses and length of stay in care home at 4 hours, 24 hours and 48 hours prior to death.

5.2 Description of the sample

5.2.1 Organisational characteristics

Data were collected from 11 care homes with a mean bed capacity of 60 ($SD = 31$, range 30 - 137). All of the care homes were registered to provide care for both older people and older people with dementia. Fifty-one per cent ($n = 334$) of the total beds ($N = 656$) in the homes were designated for older people and 43% ($n = 282$) for older people with dementia. One care home had a third registration category for mental disorder (6%: $n = 40$ of the total beds). Seventy-three percent ($n = 8$) of the homes were purpose built and 27% ($n = 3$) had converted residential properties for use as a care home. The care homes were located mainly in town or semi-rural locations. Sixty-four per cent ($n = 7$) of the care homes were 'for profit' organisations (see Table 5.1 for a list of the organisations ranked by bed capacity).

Table 5.1 - Organisational characteristics

Care home	No of beds	Registration category			CQC star rating[15]	Type of organisation	Building type and location
		Older person	Dementia over age of 65	Mental disorder			
A	137	30	67	40	3 Star	Part of a not for profit healthcare provider with over 300 care homes nationally	A purpose built home, comprising of five single storey units, located on the outskirts of a city
B	90	39	51	0	2 Star	Part of an independent healthcare provider with three local care homes	A purpose built two storied home with three units, located on the edge of a town
C	69	30	39	0	3 Star	Part of an independent healthcare provider with over 50 care homes nationally	A purpose built single storied home with two units, located on the edge of a small town
D	60	30	30	0	2 Star	Part of a not for profit healthcare provider with 22 care homes regionally	A purpose built two storied home comprising of three units, located on the outskirts of a town
E	55	45	10	0	2 Star	Part of an independent healthcare provider with four local homes	A converted two storied house, with two units, located approximately three miles from a small town
F	49	25	24	0	2 Star	Independent family run care home	A converted two storied country home, located in the countryside, close to three towns
G	48	48	0	0	2 Star	Part of an independent healthcare provider with 730 care homes nationally	A purpose built two storied home, located within a residential area of a town
H	40	20	20	0	3 Star	Part of a not for profit healthcare provider with 22 care homes regionally	A purpose built single story home, comprising of two units, located on the outskirts of a town
I	40	21	19	0	3 Star	Part of a not for profit healthcare provider with 22 care homes regionally	A purpose built two storied home, located in a village
J	38	23	15	0	2 Star	Independent owner managed care home	A converted three storied home, located in a village
K	30	25	5	0	2 Star	Part of an independent healthcare provider with four local homes	A purpose built two storied home in a residential area on the outskirts of a town

[15] Up to 2010, the Care Quality Commission (CQC) used star ratings as part of their quality assessment (0=Poor, 1=Adequate, 2=Good, 3=Excellent). These were replaced by the current system of 'inadequate', 'requires improvement', 'good' and 'outstanding'.

5.2.2 Participant characteristics

The sample (the individuals identified as being in the last phase of life whose data were collected) was composed of 157 participants. The mean age of the sample was 84.80 years ($SD = 7.67$, Range = 58 - 105). Just over two-thirds of the participants (69.4%, $n = 109$) were female. The mean length of stay in the care home prior to death was 111 weeks ($SD = 146$ weeks), with a minimum stay of 2 days and a maximum stay of 707 weeks. The number of medical diagnoses recorded at entry to the study ranged from one to nine per participant, with a mean number of diagnoses of 3.3 ($SD = 1.68$). Forty-eight percent ($n = 76$) of participants had a diagnosis of dementia, 39% ($n = 61$) had cardiovascular disorders, 27% ($n = 43$) had cancer, 20% ($n = 31$) had had a previous stroke and 10% ($n = 15$) had respiratory disorders (see Table 5.2). Two participants were excluded from the study as they made a recovery, resulting in a total of 157 participants.

Table 5.2 - Participant characteristics ($N = 157$)

Variable	
Age (years)	
Mean ± *SD*	84.80 ± 7.67
Median	85
Range	58 – 105
Gender, female, *n* (%)	109 (69.40)
Length of stay (weeks/days)	
Mean ± *SD*	111 ± 146 (weeks), 775 ± 1020 (days)
Median	61 (weeks), 427 (days)
Range	0.30 – 707 (weeks), 2 – 4946 (days)
Number of diagnoses	
Mean ± *SD*	3.3 ± 1.7
Median	3
Range	1 – 9
Diagnosis (Highest 5) *n* (%)	

Dementia	75 (48)
Cardiovascular	61 (39)
Cancer	43 (27)
Stroke	31 (20)
Respiratory	15 (10)

5.3 Defining the complexity of the data

Due to the uncertain nature of recognising impending death, commencing data collection for a participant approaching the end of life presented challenges in recognising the point at which to start data collection. In accordance with the research study protocol, participants were entered into the study at the point impending death was *recognised* by the multi-disciplinary team using criteria defined by the Liverpool Care Pathway[16]. The longest period of data collection prior to death for a participant was 24 days (relevant for one participant) and the shortest period was within four hours of death occurring *(n = 23)*. The difficulties in recognising dying in order to recruit participants resulted in an unbalanced design. This meant participants 'joined' the study at varying stages yielding data of a cumulative nature, but of varying lengths of time. For consistency, all of the time series data charts are shown with the nearest point to time of death at the intersection of the y-axis at the left hand side. Figure 5.1 shows the number of participants who 'joined' the data collection at each time point.

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[16] The LCP was an Integrated Care Pathway intended to provide a method of recording and measuring outcomes of end of life care. Two of the following four symptoms had to be present, and all other reversible causes ruled out. The patient is: 1) bed bound, 2) semi-comatose, 3) only able to take sips of fluids, 4) no longer able to take tablets (Ellershaw et al, 2001)
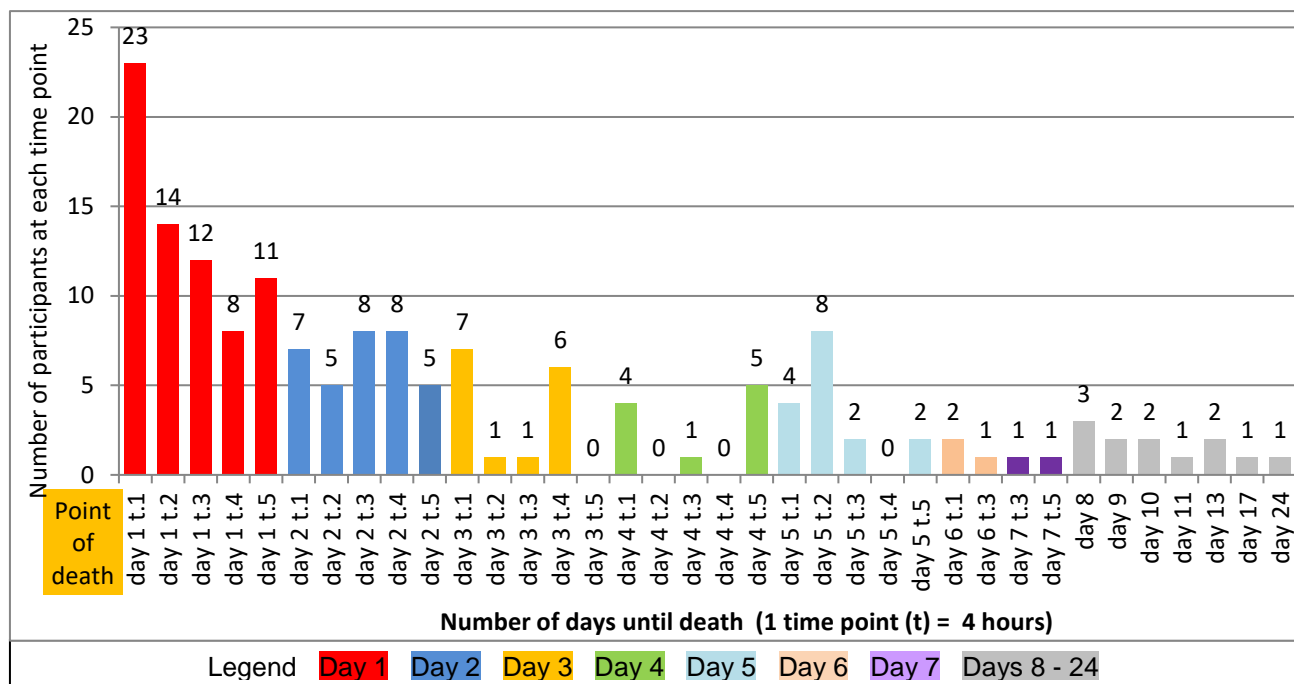
Figure 5.1 - Number of participants recruited to the study at each time point

The nature of the challenge of recognising impending death to recruit to the study is illustrated in Figure 5.2, which shows the cumulative number of participants, and therefore varying volumes of data, from 4 hours up to 24 days.
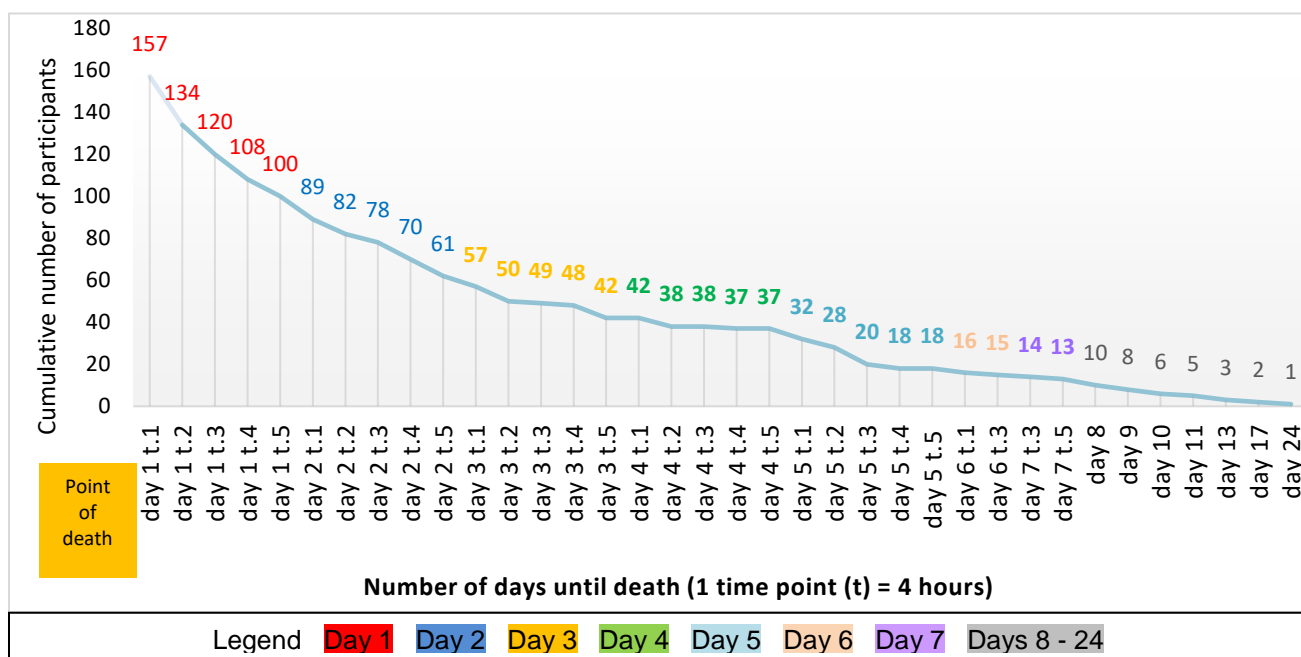
Figure 5.2 - Cumulative total of participants recruited to the study by time point

The data incorporate a range of individual trajectories. These can be described in two ways: firstly, each individual presents a unique set of symptoms where symptoms can be present or not present; when present, they can vary in intensity. Secondly, and importantly, the symptoms can be combined to represent the full research population and this will be addressed as this chapter develops.

5.3.1 Individual participants' trajectories

In order to give a more detailed illustration as part of this descriptive section, the following figures demonstrate the individuality of participants' trajectories by depicting the symptom profiles of five participants recruited to the study. To demonstrate this, figures 5.3 – 5.7 show 10 consecutive time points of data collection (i.e. the data collected within 48 hours of death) for five participants. The purpose of these charts are to demonstrate the differences across individual residents. These five participants include the first and penultimate participants in the order that the data were collected, plus three other randomly selected participants to represent each quintile. For ease of viewing, the data for each participant are shown in two separate charts. The left hand side chart presents eight symptoms which were assessed as 0 (absent), 1 (mild), 2 (moderate) or 3 (severe) and indicated on the y-axis. The right hand side chart indicates four symptoms, which were assessed as 0 (absent) or 4 (present) and indicated on the y-axis. Each time point is shown as a figure (0 to -9) on the x-axis with zero (0) being the point nearest to death (within four hours of death) and decreasing incrementally in four-hour periods (-1, -2, -3, -4, -5, -6, -7, -8) with -9 being 48 hours prior to death.
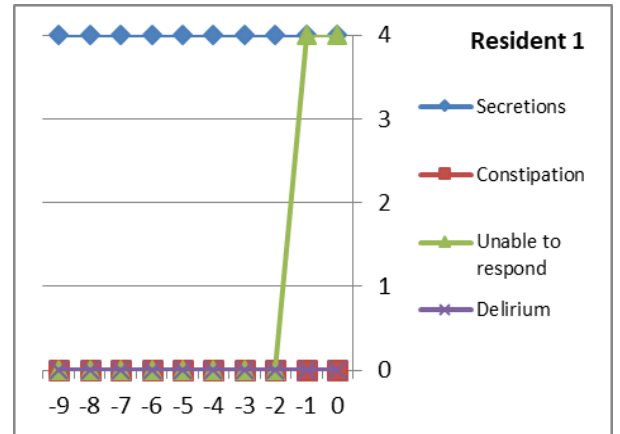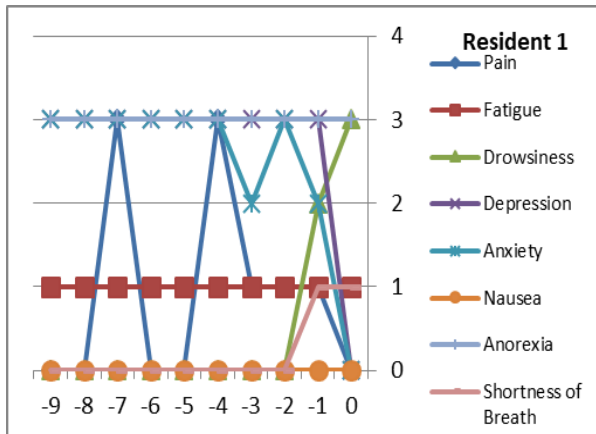
Figure 5.3 Individual trajectory - Participant 1
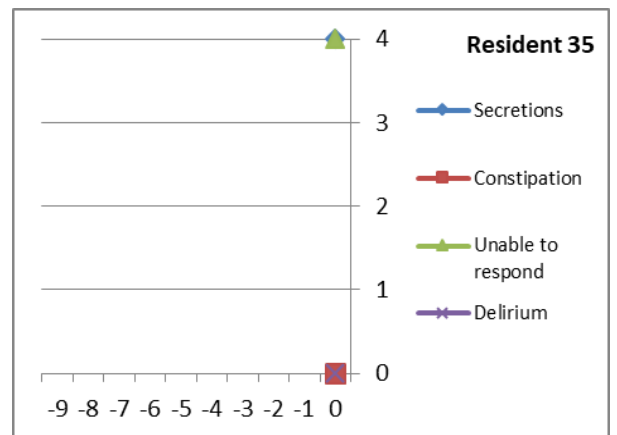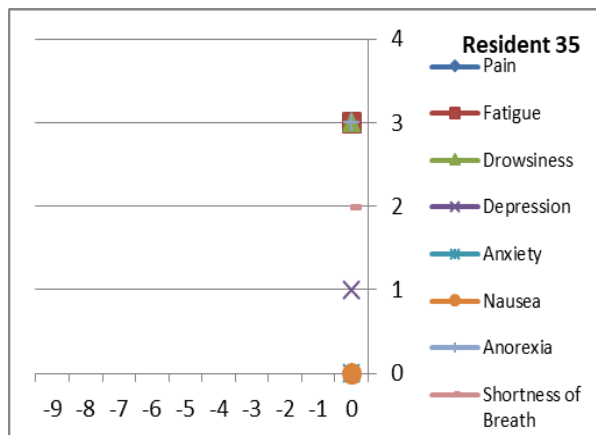
Figure 5.4 Individual trajectory - Participant 35
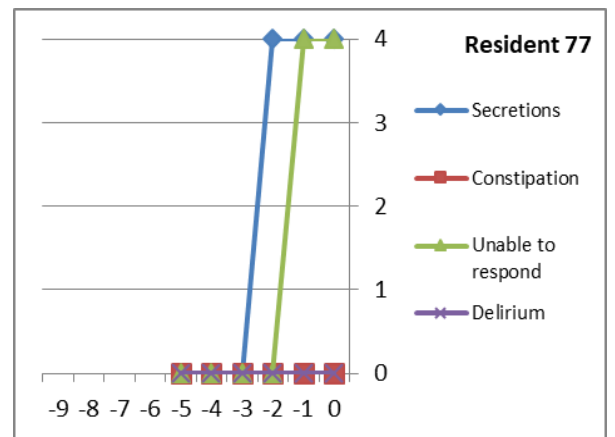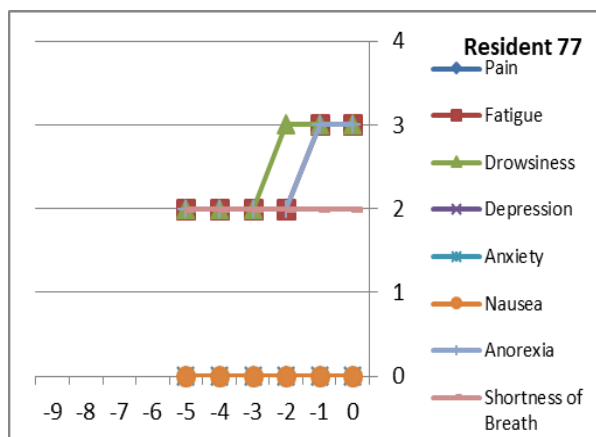
Figure 5.5 Individual trajectory - Participant 77
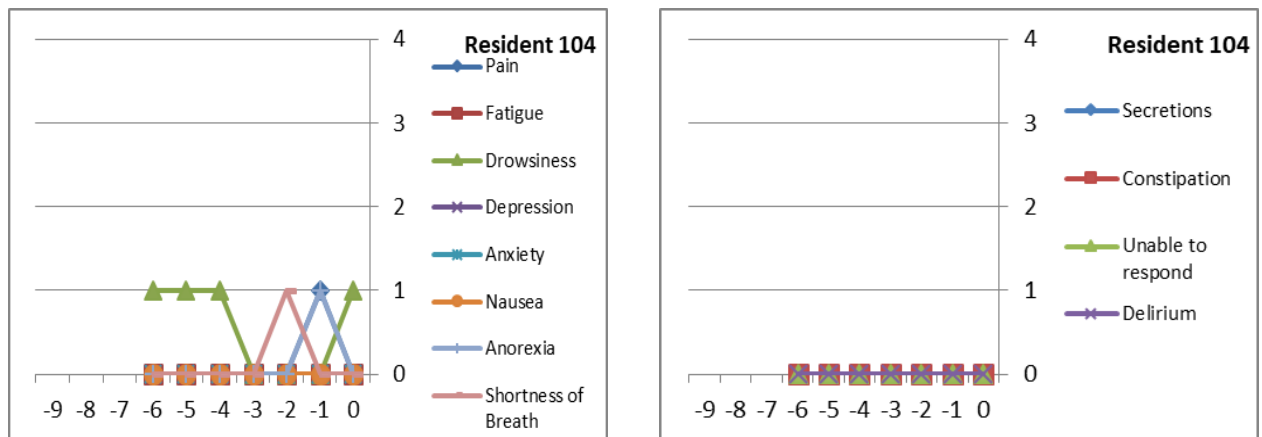
Figure 5.6 Individual trajectory - Participant 104
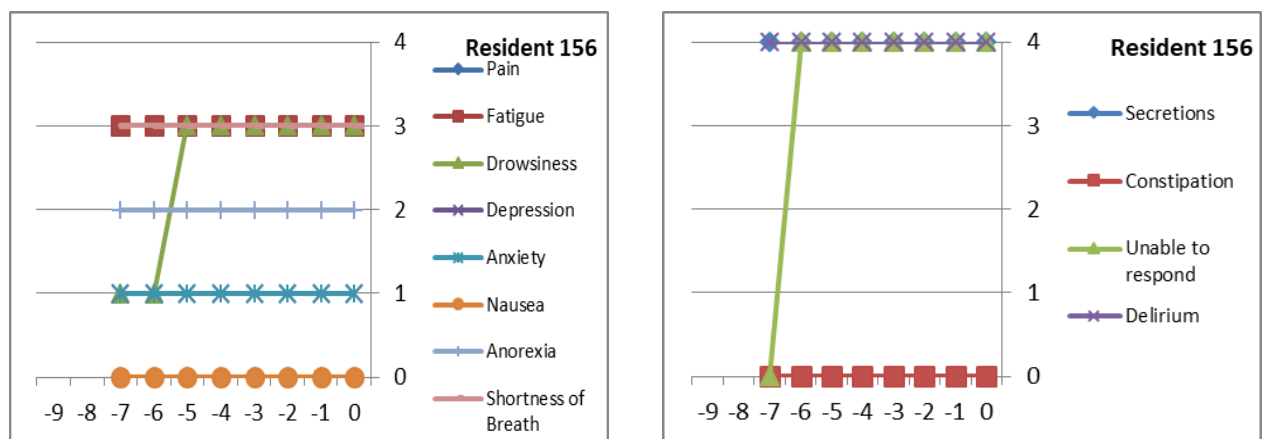
Figure 5.7 Individual trajectory - Participant 156

Using the first two participants as examples (Figures 5.3 and 5.4), they show notably different symptom profiles. Participant one (Figure 5.3) had data collected over the full 48 hour period (or ten different time points). In the left hand figure, regarding the eight symptoms (assessed as 0 - 3), these show that the participant did not have nausea present, they had depression, fatigue and anorexia present at a consistent level, their levels of drowsiness and shortness of breath both increased towards the time of death, their anxiety initially fluctuated and decreased, while their pain levels fluctuated throughout the final period of life. In the right hand figure, regarding the four symptoms (assessed as absent/present), these indicated neither the presence of

constipation nor delirium throughout the final days, a constant presence of secretions and a shift from the absence to the presence of the ability to respond within the final few hours of life.

Participant two (Figure 5.4) presents with only a single time period of data captured, meaning that death was not assessed as imminent until within four hours prior to the participant dying. Six symptoms, namely depression, shortness of breath, drowsiness, fatigue, unable to respond and secretions were all assessed as present at four hours prior to death. The remaining six symptoms were assessed as not present.

While this section has emphasised the variations within individual trajectories, and these have been illustrated above, the aim of this research is to present the symptoms across the population as a whole, and this will be discussed in the following section.

5.3.2 Managing the data

All data were entered into SPSS 19 by an administrative assistant. All data were cross-checked at the time of input by the researcher for accuracy of inputting. Minor errors were detected and corrected. At the time of checking, the assistant's understanding of the data were clarified to reduce the risk of inputting errors. The data were entered into SPSS 19 by an administration assistant, so the researcher conducted the data cleaning. A small sample of the data ($n = 8$, 5%) was re-entered into an empty database and compared with full data set. A very small number of errors were discovered, well within the permissible margin of error of 1.5%. The errors were traced and compared back with the original data collection forms and corrected.

5.3.3 Data transformation

There were no requirements for the need for data transformation as the data met the normality requirements for the tests being performed.

5.3.4 Missing data

The levels of missing data required for the analyses were very low. Of all the variables recorded, there was missing data regarding the length of stay in 1% of participants ($n = 2$) which had not been completed by the staff collecting the data. These two data points, given that they comprised of much less than 10% of the total possible number (Cohen, Cohen, West, & Aiken, 2003), were replaced by mean imputation. Consequently the analysis was carried out on a complete dataset.

5.4 A descriptive analysis of the data

5.4.1 The presence and intensity of symptoms at 4, 24 and 48 hours prior to death

As discussed in the methods chapter, 12 symptoms were systematically monitored and recorded using the Edmonton Symptom Assessment Scale (ESAS) at four hourly periods (see Appendix xiv). Monitoring took place five times per 24 hours, as assessing the resident at 2am was not appropriate to ensure they were not unnecessarily disturbed at night. The next section describes the presentation of symptoms, firstly as an overview of all symptoms and then as a sum of total presence and total intensity to show the overall symptom load on the resident. Overall presence and intensity by symptom will be described later in the chapter.

5.4.2 The presence and intensity of individual symptoms – an overview

Due to the difficulty of predicting impending death, the incremental enrolment of participants to the study meant that the number of participants varied between each time period. The period within four hours of death included all 157 participants, the period within 24 hours prior to death included 100 participants and the period within 48 hours included 61 participants. Within the latter analyses, the participants who had data had across all three time points over the final 48 hours of life are included ($N = 61$) so to start the section with a broad overview, the presence and intensity of each individual symptom within the final four, 24 and 48 hour periods prior to death are presented in Table 5.3. An example to demonstrate how the data have been calculated and presented can be seen in Figure 5.8.

Figure 5.8 An explanation of the data found in Table 5.3

Table 5.3 - Occurrence of symptoms by percentage, within four, 24 and 48 hours of death (symptoms are presented ranked by intensity as scored at the four hour time point)

| Symptom presence | Within four hours of death, $n = 157$ | | | | | Within 24 hours of death, $n = 100$ | | | | | Within 48 hours of death, $n = 61$ | | | | |
| | Yes | Intensity n (%) | | | Mean | Yes | Intensity n (%) | | | Mean | Yes | Intensity n (%) | | | Mean |
	n (%)	1	2	3	$\pm SD$	n (%)	1	2	3	$\pm SD$	n (%)	1	2	3	$\pm SD$
Drowsiness	138 (87.9)	14 (8.9)	39 (24.8)	85 (54.1)	2.21 1.04	86 (86)	15 (15)	30 (30)	41 (41)	1.98 1.06	53 (85.3)	9 (14.8)	19 (29.5)	25 (41)	2.0 1.05
Fatigue	125 (79.6)	15 (9.6)	35 (22.3)	75 (47.8)	1.97 1.18	81 (81)	18 (18)	23 (23)	40 (40)	1.84 1.16	51 (83.6)	13 (21.3)	19 (31.1)	19 (31.1)	1.77 1.07
Anorexia	100 (63.7)	7 (4.5)	18 (11.5)	75 (47.8)	1.71 1.38	69 (69)	7 (7)	18 (18)	44 (44)	1.75 1.31	40 (65.6)	5 (8.2)	10 (16.4)	25 (41)	1.64 1.33
Shortness of breath	75 (47.5)	33 (21)	20 (12.7)	22 (14)	.89 1.10	31 (31)	18 (18)	9 (9)	4 (4)	.48 .82	11 (18)	5 (8.2)	6 (9.8)	0	.28 .64
Pain	31 (19.7)	14 (8.9)	9 (5.7)	8 (5.1)	.36 .81	21 (21)	8 (8)	9 (9)	4 (4)	.38 .82	11 (18)	4 (6.6)	5 (8.2)	2 (3.3)	.33 .77
Anxiety	29 (18.5)	12 (7.6)	10 (6.4)	7 (4.5)	.34 .79	19 (19)	10 (10)	5 (5)	4 (4)	.35 .80	7 (11.5)	2 (3.3)	2 (3.3)	3 (4.9)	.25 .75
Depression	18 (11.5)	11 (7)	4 (2.5)	3 (1.9)	.18 .56	14 (14)	5 (5)	6 (6)	3 (3)	.26 .71	8 (13.1)	2 (3.3)	5 (8.2)	1 (1.6)	.25 .68
Nausea	12 (7.6)	4 (2.5)	6 (3.8)	2 (1.3)	1.4 .53	4 (4)	3 (3)	0	1 (1)	.06 .34	0	0	0	0	0 0
Unable to respond*	96 (61.1)	n/a	n/a	n/a	2.45 1.96	50 (50)	n/a	n/a	n/a	2.0 2.01	23 (37.7)	n/a	n/a	n/a	1.51 1.96

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Symptom															
Secretions*	37 (23.6)	n/a	n/a	n/a	.94 1.70	17 (17)	n/a	n/a	n/a	.68 1.51	8 (13.1)	n/a	n/a	n/a	.52 1.36
Constipation*	11 (7)	n/a	n/a	n/a	.28 1.03	8 (8)	n/a	n/a	n/a	.36 1.15	5 (8.2)	n/a	n/a	n/a	.33 1.11
Delirium*	11 (7)	n/a	n/a	n/a	.28 1.03	8 (8)	n/a	n/a	n/a	.32 1.10	4 (6.6)	n/a	n/a	n/a	.26 1.0

Note: Symptoms were scored as 0 (absent) or 1 - 3 (the higher score = the more intense the symptom). *These four symptoms were scored either as absent or present.

Table 5.3 highlights that there were common features across the three time periods, despite the differing numbers of participants (157 participants at 4 hours, 100 participants at 24 hours and 61 participants at 48 hours). The five most commonly occurring symptoms in the final four hours prior to death were drowsiness, fatigue, anorexia, unable to respond and shortness of breath and this pattern was repeated across all of the three time periods. The most common symptom was drowsiness (the range across the three time points was between 86 - 88%), followed by fatigue (80 - 84%), anorexia (64 - 69%), unable to respond (38 - 61%) and shortness of breath (18 - 48%). For the symptoms that had the widest ranges of presentation (unable to respond and shortness of breath), the percentage of participants experiencing the symptoms was at its lowest in the time periods furthest away from death and increased towards the time of death. The least reported symptoms (nausea, constipation and delirium) varied in their frequency across the three time periods: nausea (range 0 - 8%), constipation (range 7 - 8%), and delirium (range 7 - 8%).

In addition to looking at the occurrence of the individual symptoms at the different time points, the total number of symptoms across the three time points appears to increase towards the time of death.

5.4.3 The total presence and total intensity of symptoms

When reviewing the data in Table 5.3, patterns in changes in symptoms towards the time of death start to become apparent. However to test this more rigorously, further analysis is required. The analysis will be presented from two different aspects. Firstly, the total symptom load in terms of presence and intensity will be explored. The total symptom load scores were computed by calculating the mean score of the presence or intensity of each participant at the given time point (4 hours, 24 hours, 48 hours), then divided by the total number of participants which resulted in a mean score for each time point of presence or intensity. This led on to an examination of each individual symptom for the level of presence and intensity to understand which symptoms present with greater frequency and intensity. Each individual symptom score was calculated by totalling the number of symptoms or the mean intensity of symptoms per participant. Table 5.4 presents the total presence of all symptoms prior to death (Mean, Standard Deviation, Median and Range), and Table 5.5 presents the total intensity of all symptoms prior to death (Mean, Standard Deviation, Median and Range).

Table 5.4 – Total presence of symptoms at 4 hrs, 24 hrs and 48 hrs prior to death

	Time before death ($N = 61$)		
	4 hours	24 hours	48 hours
Mean *(SD)*	4.44 (1.61)	3.97 (1.61)	3.62 (1.46)
Median	5	4	4
Range	0 - 8	0 - 7	0 - 7

Table 5.5 Total intensity of eight symptoms^ at 4 hrs, 24 hrs and 48 hrs prior to death

	Time before death ($N = 61$)		
	4 hours	24 hours	48 hours
Mean *(SD)*	1.00 (.44)	.89 (.42)	.82 (.40)
Median	1	1	.88
Range +	0 – 2.13	0 – 1.75	0 – 1.63

* Four symptoms (secretions, constipation, unable to respond and delirium) were recorded as 'present' or 'not present', so do not have an intensity score
^ The potential range of the intensity of symptoms is between 0 - 3

Tables 5.4 and 5.5 show an increase in the mean of both the total presence and intensity of symptoms between the 48-hour period and the 4-hour period, with a greater presence and intensity at 4 hours, i.e., the time closest to death. The next section will compare these means using a one-way repeated measure ANOVA to determine whether any statistically significantly differences are present across the analysis.

5.4.4 The total presence of symptoms at 4 hrs, 24 hrs and 48 hrs prior to death

In order to test the hypothesis that the total presence of symptoms would increase over the three time periods (for those participants for whom these data were available, $n = 61$), a one-way repeated measure *ANOVA* was conducted using the data displayed as means in Table 5.4. This indicated ($F = 13.82$, $df = 2, 59$, $p < .001$, partial $\eta = .32$) a significant difference in the mean number of symptoms reported over the three time points. While the p value is significant at $< .001$, the effect size of partial η at .32 is considered to be of a large magnitude (University of Cambridge, 2019)[17] making this an important difference. As the analysis involved three levels, post hoc comparisons were performed; these indicated significant (uncorrected) differences between all of the time points when compared pairwise (all $p < .05$) (See Table 5.6).

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[17] Effect sizes for partial η 2 (R-squared in a multiple regression) = 0.01 (small), 0.09 (medium) and 0.25 (large)

Table 5.6 Pairwise comparisons of total presence of all twelve symptoms at 4 hrs, 24 hrs and 48 hrs prior to death *(N = 61)*

Factor	Cross factor	Mean difference	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Presence of symptoms at 4 hours	24 hours	.48***	.13	.22	.73
	48 hours	.82***	.16	.50	1.14
Presence of symptoms at 24 hours	4 hours	-.48***	.13	-.73	-.22
	48 hours	.34*	.15	.04	.65
Presence of symptoms at 48 hours	4 hours	-.82***	.16	-1.14	-.50
	24 hours	-.34*	.15	-.65	-.04

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table 5.6 shows that there was a significant increase in the total presence of all twelve symptoms between 4 hours, 24 hours and 48 hours prior to death with a higher presence of symptoms occurring between 4 hours and 24 hours compared to between 24 hours and 48 hours. This confirmed an increasing presence of the total symptoms towards the time of death, with greater significance between the two final time points (4 hours and 24 hours).

5.4.5 The total intensity of eight symptoms at 4 hrs, 24 hrs and 48 hrs prior to death

The same analysis was applied to test the hypothesis that the total intensity of symptoms would increase over the three time periods (Table 5.5). Again, a one way repeated measure *ANOVA* was conducted. This indicated ($F = 9.76$, $df = 2$, 59, $p < 001$, partial $\eta = .25$), a significant difference in the mean intensity of symptoms reported over the three time points. While the p value is significant, the effect size of

partial η is regarded as large (University of Cambridge, 2019)[18] meaning this is a worthy distinction. The analysis involved three levels, therefore post hoc comparisons were performed; these indicated significant (uncorrected) differences between two of the three time points when compared pairwise (all $p < .01$) (See Table 5.7).

Table 5.7 Pairwise comparisons of total intensity of eight symptoms^ at 4 hrs, 24 hrs and 48 hrs prior to death *(N = 61)*

Factor	Cross factor	Mean difference	Std. Error	95% Confidence Interval Lower Bound	Upper Bound
Presence of symptoms at 4 hours	24 hours	.11***	.03	.06	.17
	48 hours	.18***	.04	.09	.27
Presence of symptoms at 24 hours	4 hours	-.11***	.03	-.17	-.06
	48 hours	.07	.04	-.002	.14
Presence of symptoms at 48 hours	4 hours	-.18***	.04	-.27	-.09
	24 hours	-.07	.04	-.14	.002

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

^ Four symptoms (secretions, constipation, unable to respond and delirium) were recorded as 'present' or 'not present', so were not allocated an intensity score

Table 5.7 shows that there was a significant increase in the intensity of symptoms between 4 hours and 48 hours prior to death with a higher presence of symptoms between 4 hours and 24 hours compared to between 24 hours and 48 hours, demonstrating that symptoms became more intense nearer the time of death.

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[18] Effect sizes for partial η 2 (R-squared in a multiple regression) = 0.01 (small), 0.09 (medium) and 0.25 (large)

5.4.6 The presence and intensity of individual symptoms

When referring back to Table 5.3, the patterns in changes in the individual symptoms towards the time of death were observed. The last section reviewed the changes in total presence and intensity of symptoms, but further analysis to understand how individual symptoms changed over time is required. Table 5.8 presents the presence and intensity of individual symptoms prior to death at the same time points as previous, 4 hours, 24 hours and 48 hours. The presence is reported as the number of participants experiencing a symptom at the given time point, while the intensity is reported by the Mean, Standard Deviation, Median and Range. Due to the nature of the data collection instrument, only eight symptoms are included in the individual symptom intensity, because four of the symptoms (secretions, constipation, unable to respond and delirium) were recorded in the data collection as 'present' or 'not present', so do not have a score allocated for intensity.

Table 5.8 – Presence and intensity of individual symptoms at 4 hrs, 24 hrs and 48 hrs prior to death

| | | Time before death ($N = 61$) | | |
		4 hours	24 hours	48 hours
Pain				
Presence	*n*	10	13	11
Intensity	Mean (*SD*)	.25 (.62)	.35 (.75)	.33 (.77)
	Median	0	0	0
	Range	0 - 3	0 - 3	0 - 3
Fatigue				
Presence	*n*	52	50	51
Intensity	Mean (*SD*)	2.07 (1.11)	1.9 (1.14)	1.77 (1.07)
	Median	2	2	2
	Range	0 - 3	0 - 3	0 - 3
Drowsiness				
Presence	*n*	56	52	53
Intensity	Mean (*SD*)	2.38 (.95)	2.11 (1.07)	2 (1.05)
	Median	3	2	2
	Range	0 - 3	0 - 3	0 - 3

Depression				
Presence	*n*	5	7	8
Intensity	Mean (*SD*)	.15 (.54)	.21 (.64)	.25 (.675)
	Median	0	0	0
	Range	0 - 3	0 - 3	0 - 3
Anxiety				
Presence	*n*	9	8	7
Intensity	Mean (*SD*)	.30 (.78)	.26 (.75)	.25 (.75)
	Median	0	0	0
	Range	0 - 3	0 - 3	0 - 3
Nausea				
Presence	*n*	3	1	0
Intensity	Mean (*SD*)	.12 (.52)	.02 (.13)	.00 (.00)
	Median	0	0	0
	Range	0 - 3	0 - 1	0 - 0
Anorexia				
Presence	*n*	43	43	40
Intensity	Mean (*SD*)	1.93 (1.33)	1.82 (1.31)	1.64 (1.33)
	Median	3	2	2
	Range	0 - 3	0 - 3	0 - 3
Shortness of Breath				
Presence	*n*	26	14	11
Intensity	Mean (*SD*)	.79 (1.07)	.39 (.80)	.28 (.64)
	Median	0	0	0
	Range	0 - 3	0 - 3	0 - 2
Secretions*				
Presence	*n*	17	11	8
Intensity	n/a			
Constipation*				
Presence	*n*	5	6	5
Intensity	n/a			
Unable to respond*				
Presence	*n*	39	31	23
Intensity	n/a			
Delirium*				
Presence	*n*	6	5	4
Intensity	n/a			

* Four symptoms (secretions, constipation, unable to respond and delirium) were recorded as 'present' or 'not present', so do not have an intensity score
^ The potential range of the intensity of symptoms is between 0 - 3

Table 5.8 shows a range of changes across the individual symptoms. Drowsiness, fatigue, anxiety, nausea, anorexia and shortness of breath all increased in both presence and intensity towards the time of death. The presence of secretions, unable to respond and delirium all increased towards the time of death. In contrast, pain and depression reduced towards the time of death, although pain had increased between 48 and 24 hours, but decreased at the fours hour time point. To understand these further, the next section will analyse whether these changes were statistically significant.

5.4.7 Pairwise comparisons of the presence of individual symptoms at 4 hrs, 24 hrs and 48 hrs prior to death

In order to test the hypothesis that the presence of individual symptoms (the number of participants having a symptom) would increase over the three time periods ($n = 61$ as 61 participants had data collected at all three time points). Due to the categorical nature of the data (present or not present) and the measurement of the symptoms over three time points with the same participants, a standardised Cochran's test was conducted using the data from Table 5.8 (see Table 5.9 for these). The Q values are reported in Table 5.9. As the analysis involved three levels, post hoc pairwise comparisons were performed on those that had a significant Q test ($p < .05$) (SPSS does not perform multiple comparisons when the overall test does not show significant differences across samples); these indicated significant (uncorrected) differences in four of the symptoms when compared pairwise (all $p < .05$). (see Appendix xv for full data tables).

Table 5.9 Results of Cochran's Q test of the presence of individual symptoms (N = 61)

Symptom	Q value
Pain	1.27
Fatigue	1.00
Drowsiness	3.56
Depression	2.80
Anxiety	.50
Nausea	.18
Anorexia	6.00*
Shortness of breath	22.24***
Secretions	9.69**
Constipation	1.00
Unable to respond	20.21***
Delirium	1.50

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

The following table (5.10) provides an example of the data on which the Cochran's Q test was run for the symptom of unable to respond at the three different time points. This shows an increasing number of participants had unable to respond recorded as a symptom towards the time of death.

Table 5.10 Unable to respond – a sample of the data

Time point	Present (1)	Not present (0)
4 hour	39	22
24 hour	31	30
48 hour	23	38

The pairwise comparisons tables (see Appendix xv) show that there was a significant (estimated at $p < .05$) increase in the presence of four of the twelve symptoms in the participants, which were anorexia, shortness of breath, secretions and unable to respond towards the time of death. The presence of anorexia increased significantly closer to death between the 48 hour and 4 hour time period and the 48 hour and 24

hour time period, but not between the 24 hour and 4 hour time period. The presence of shortness of breath increased significantly between the time periods of 24 hours to 4 hours and 48 hours to 4 hours, again closer towards the time of death. The presence of secretions increased significantly between the 48 hour and 4 hour time points and between the 24 hour and 4 hour time points. Finally, being unable to respond increased significantly between all of the three time points (The full data can be found in Appendix xvi).

5.4.8 Pairwise comparisons of the intensity of individual symptoms at 4 hrs, 24 hrs and 48 hrs prior to death

To be able to test the hypothesis that the intensity of individual symptoms would increase over the three time periods (for those participants for whom these data were available, $n = 61$), a one-way repeated measure *ANOVA* was conducted using the data from Table 5.8. Due to the number of symptoms being analysed the F value, *F*, degrees of freedom, *df,* and partial theta, *partial η* are reported in table 5.10 below. As the analysis involved three levels, post hoc comparisons were performed; these indicated significant (uncorrected) differences between all of the time points when compared pairwise (all $p < .05$) (see Appendix xv for full data tables).

Table 5.11 Results of a one-way repeated measure ANOVA of the intensity of eight individual symptoms^ ($N = 61$)

	F value	*df*	*partial η*
Symptom			
Pain	.85	2, 59	.29
Fatigue	6.03**	2, 59	.17
Drowsiness	9.04***	2, 59	.24
Depression	1	2, 59	.04
Anxiety	.08	2, 59	.003
Nausea	2	2, 59	.07
Anorexia	6.36**	2, 59	.18

Shortness of breath	11.53***	2, 59	.28

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

^ Four symptoms (secretions, constipation, unable to respond and delirium) were recorded as 'present' or 'not present', so do not have an intensity score

The pairwise comparisons tables (see Appendix xvi) show that there was a significant increase in the intensity towards the time of death in four of the eight symptoms that had intensity levels measured, fatigue, drowsiness, anorexia and shortness of breath. The intensity of fatigue, drowsiness and shortness of breath significantly increased between the time points of 4 hours to 24 hours and 4 hours to 48 hours. The intensity of anorexia increased between all of the time points towards the time of death. (The full set of comparisons can be found in Appendix xvi).

5.5 Inferential analysis

5.5.1 The associations between total presence and intensity of symptoms and certain demographic and clinical characteristics

The next section will look at the relationships between specific variables to test the hypothesis that there will be positive correlations between age, gender, number of diagnoses and length of stay and the two symptoms variables – presence and intensity – over the three time points prior to the time of death.

5.5.2 The associations between the total presence of symptoms and the characteristics of age, gender, number of diagnoses and length of stay in care home at 4 hours, 24 hours and 48 hours prior to death

Table 5.12 Associations between total presence of symptoms and characteristics ($N = 61$)

	Time before death		
	4 hours	24 hours	48 hours
Age	-.10	-.03	.06
Gender	.07	-.04	.00
No. of diagnoses	.09	.06	.05
Length of stay (in days)	-.12	-.27**	-.29*

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

As can be seen in the correlation matrix in Table 5.11, the only significant correlation was in the predicted (negative) direction which related to a shorter length of stay being correlated to the presence of a higher number of symptoms at the 24 hour and 48 hour time points ($r = -.27$ (24 hours) to $r = -.29$ (48 hours), but not at the four hour time point prior to death. These, however, were of a small to medium effect sizes.

5.5.3 The associations between the total intensity of symptoms and the characteristics of age, gender, number of diagnoses and length of stay in care home at four hours, 24 hours and 48 hours prior to death

Table 5.13 Associations between total intensity of eight symptoms^ and characteristics *(N = 61)*

	Time before death		
	4 hours	24 hours	48 hours
Age	-.04	.02	.08
Gender	-.02	-.05	.01
No. of diagnoses	.07	.01	-.04
Length of stay (in days)	-.16*	-.23*	-.29*

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

^ Four symptoms (secretions, constipation, unable to respond and delirium) were recorded as 'present' or 'not present', so do not have an intensity score

As can be seen in the correlation matrix in Table 5.12, the only positive correlation is in the predicted direction (a shorter length of stay, higher intensity of symptoms) over all three time points ($r = -.16$ (4 hours) to $r = -.29$ (48 hours), however these were of a small effect size giving a relatively consistent pattern here across intensity and presence.

The next section will look at the presence of the individual symptoms (all 12 symptoms can be included while looking at presence) at the time closest to death (four hours) as this can include the data from all 157 participants. The mean presence of individual symptoms will be correlated with the demographics of age, gender, number of diagnoses and length of stay in the table (5.13) and with the five most common diagnoses in table 5.14.

5.5.4 The associations between demographics and the presence of individual symptoms at the time closest to death (within the final four hours)

Table 5.14 Associations between demographics and individual symptoms at the time closest to death (within the final four hours) (*N* = 157)

								Symptom				
Variable	Pain	Fatigue	Drowsiness	Depression	Anxiety	Nausea	Anorexia	Shortness of breath	Secretions	Constipation	Unable to respond	Delirium
Age	-.03	.06	.14	-.06	-.03	-.06	.10	-.16*	.14	-.04	.04	-.04
Gender	-.05	-.05	.04	-.03	-.13	-.03	-.03	.04	.19*	.09	.08	.09
No. of diagnoses	.21**	.01	-.08	.09	.19*	.04	.01	.18*	-.02	.14	-.22**	.04
Length of stay	-.16*	-.18*	.02	-.21*	-.08	-.02	-.14	.05	.06	-.04	.10	-.08

Note: * *p* < .05, ** *p* <. 01, *** *p* <. 001

In relation to the number of diagnoses a participant had, the total was significantly correlated with a number of symptoms, those with a higher number of diagnoses were less likely to be unresponsive (*r* = -.22) while they were more likely to have pain (*r* = .21), anxiety (*r* = .19) and shortness of breath (*r* = .18), all of which were of a small effect size.

There is an association of small effect between the length of time a person had been in a care home and the three symptoms of pain, fatigue and depression. These were all negatively correlated (*r* = -.16, *r* = -.18 and *r* = -.21) meaning the longer a person spent in a care home, the less likely these were to be reported.

5.5.5 A post hoc analysis - The associations between the diagnosis of dementia and symptom presence at the time closest to death (within the final four hours)

This final section leads on from the analysis in section 5.5.4 and will consider a specific diagnosis in more depth. The diagnosis of dementia has already been discussed in previous chapters as a diagnosis of specific interest, therefore, it has been decided to include this symptom in a post hoc analysis as it links closely with research objective 2 although was not specified in the original hypotheses. Of the 157 participants with data at the time point closest to death, 75 participants had a diagnosis of dementia, while 82 did not. The analysis will involve the application of multivariate analysis of variance (MANOVA). MANOVA is similar to an ANOVA (as applied earlier in this chapter) but enables the inclusion of several dependent variables. MANOVA permits the testing of the effect of one or more independent variables on two or more dependent variables. The key assumptions to conducting a MANOVA are that the observations are randomly and independently sampled from the population and that each dependent variable has an interval measurement and is normally distributed.

The result of the MANOVA indicated that there was a statistically significant difference in the presence of symptoms between those participants with a diagnosis of dementia and those without, $F (12, 144) = 2.48$, $p < .01$; Wilk's $\Lambda = 0.829$, partial $\eta2 = .17$). On examining the individual symptoms, the diagnosis of dementia had a significant effect on three symptoms: fatigue ($F (1, 155) = 12.76$, $p < .001$, partial $\eta2 = .08$); depression ($F (1, 155) = 8.19$, $p < .01$, partial $\eta2 = .05$); and anorexia ($F (1, 155) = 6.87$, $p < .01$, partial $\eta2 = .04$). This means that having a diagnosis of dementia increased the likelihood of having fatigue, depression and anorexia, but was not linked

to any of the other symptoms. The relationship between fatigue and dementia was highly significant, ($p < .001$) with a large effect size, while the relationship between the symptoms of depression and anorexia were both significant ($p < .01$) with small to medium effect sizes.

As this final set of analyses were performed as a post-hoc test, these results would need replication in further studies but can provide an indication of the relationship between the presence of symptoms in the final few hours of life and a diagnosis of dementia.

5.6 Conclusion

The data were complex due to the cumulative nature of recruitment to the study. Participants were recruited when it could be identified that they were dying: the difficulties with this meant that recruitment to the study ranged from between four hours up to 24 days prior to death highlighting the uncertainty of recognising impending death. Data were collected on 12 individual symptoms (the modified ESAS comprised of eight ordinal and four categorical responses).

Through an initial simple descriptive analysis, the five most commonly occurring symptoms were found to be drowsiness, fatigue, anorexia, unable to respond and shortness of breath and the least reported symptoms were nausea, constipation and delirium. However, to examine this pattern further and address the objectives, a set of hypotheses were developed and a more detailed programme of analysis carried out to test the hypotheses. The total symptom load was first investigated in relation to

presence and intensity and this was followed by an exploration of the presence and intensity of individual symptoms.

When considering the total presence and intensity of all symptoms, there was an increase in the mean of both, showing an increase towards the time of death. Subsequent pairwise comparison testing between 4 hours, 24 hours and 48 hours resulted in statistically significance differences across all of the time periods in relation to presence and in all but one (48 hours to 24 hours showed a mean change, but not a significant change) in relation to intensity. This demonstrated that the total presence of symptoms increased and became more intense the nearer to the time of death.

Taking a similar approach to the previous analysis, but by examining the presence and intensity of individual symptoms, there was found to be a significant increase in the presence of four of the twelve symptoms towards the time of death which were drowsiness, shortness of breath, secretions and unable to respond. The main increases were found in the periods between 24 and 4 hours and 48 and 4 hours. It was only possible to study the change in intensity of eight symptoms (due to the binary nature of the measuring of four of the symptoms) and this disclosed a significant increase in the intensity towards the time of death in four of the eight symptoms; fatigue, drowsiness, anorexia and shortness of breath. Similarly to presence, the main increases were found in the periods between 24 and 4hours and 48 and 4 hours.

Next, associations between the symptoms and demographic variables were tested for in order to look for correlations. The total presence and intensity of symptoms and the characteristics of age, gender, number of diagnoses and length of stay in care home

were tested at 4 hours, 24 hours and 48 hours prior to death. In relation to presence, the only significant correlation was related to a shorter length of stay being correlated to the presence of an increased number of symptoms at the 24 hour and 48 hour time points. This was also the only significant correlation in relation to intensity, when a shorter length of stay was found to relate to a high intensity of symptoms, although only at the 24 hour and 48 hour time points.

Finally, associations between demographics, diagnoses and symptoms were tested for, these were limited and mainly of small effect (r< 0.30). Some key associations were observed including the relationships between the length of stay and different types of diagnoses, and the increased likelihood of having specific symptoms when certain diseases were present.

Summary of the hypotheses in relation to the findings

1. There will be an increase in the presence and intensity of the total symptom load between 48 hours, 24 hours and 4 hours prior to death. *The null hypothesis was rejected and the hypothesis was accepted.*

2. There will be an association between the total presence and intensity of the total symptom load and the key characteristics of residents at 48 hours, 24 hours and 4 hours prior to death. The presence and intensity of symptoms will positively correlate with older age, a higher number of diagnoses, a longer length of stay and a male gender. *The null hypothesis was upheld as there were very few correlations between symptom presence and intensity and the key characteristics. Of the few relationships, all were of small effect.*

3. There will be an increase in the presence and intensity of individual symptoms between 48 hours, 24 hours and 4 hours prior to death. *The null hypothesis was rejected and the hypothesis was accepted.*

4. There will be an association between the total presence and intensity of individual symptoms and the key characteristics of residents at the time closest to death (within 4 hours). The presence and intensity of symptoms will positively correlate with older age, a higher number of diagnoses, a longer length of stay and a male gender. *The null hypothesis was upheld as there were very few correlations between symptom presence and intensity and the key characteristics. Of the few relationships, all were of small effect.*

The results from a descriptive analysis and an inferential analysis of the data have been presented in this chapter. The following chapter will interpret and explain these findings in light of what is already known about symptoms at the end of life in care home residents, and explain new insights into the issue taking the findings into consideration.

Chapter 6 – Discussion

6.1 Introduction

The focus of this study has been the presence of symptoms, because symptom measurement, leading to its subsequent management is a core element of end of life care (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002). Estabrooks et al. (2015) identified that assessing symptoms that lead to managing them is a foundational component, stressing the very active elements of treatment, management and control. The literature review identified five gaps in the research in symptom prevalence in care home residents at the end of life:

1) The lack of prospectively collected data

2) The data were typically collected without using any form of instrument or data collection tool, or if instruments were used, there was no consistency of their use

3) Studies did not capture symptoms relevant for the care home population

4) The temporal aspects of symptom prevalence have received little attention

5) Only one study was carried out in the UK (Knight & Jordan, 2007)

To address these gaps, the research objectives and hypotheses set out to explore the presence and intensity of end of life symptoms at key time points towards the very end of life. This discussion chapter will critically consider the findings, focusing on the presence and intensity of symptoms and the changes over time, and in consideration to certain characteristic and demographics, and outlining a new symptom typology associated with the dying phase in care home residents. This will lead into a discussion

involving the recognition of the dying phase for residents dying in care homes. Finally, the strengths and limitations of the study will be identified, and concluding with the implications for practice, policy and research.

6.2 An overview of the characteristics of symptoms of a resident dying in a care home

The sample was composed of 157 participants from 11 different care homes. The mean age was 84.80 years and comprised of two-thirds females. The length of stay in the care home ranged from two days to over 13 years.

The first part of the simple descriptive analysis found the five most commonly occurring symptoms at the end of life were drowsiness, fatigue, anorexia, unable to respond and shortness of breath and the least reported symptoms were nausea, constipation and delirium. Drowsiness and fatigue were the most common with similar rates of prevalence (drowsiness, range 86 - 88% and fatigue, range 80 - 84%) increasing in intensity closer to the time of death. Other studies in end of life symptoms in care homes residents show similar findings (Brechtl et al., 2006; Hendriks et al., 2014; Sandvik et al., 2016). Although fatigue and drowsiness are often used interchangeably, fatigue is different from drowsiness. Drowsiness is feeling the need to sleep, while fatigue is a lack of energy and motivation (Chamberlain, Houghton, & Gray, 2010). However, a proxy observer may be unable to differentiate between the two, which lead to them being categorised together, particularly at the end of life. This could explain why many studies had considered one or the other (Brechtl et al., 2006; Van Lancker et al., 2013), while only a few studies had used both (Hui, Dev, et al.,

2015). A commonality between the work of Hui et al (2015) and this study was the use of the Edmonton Symptom Assessment Scale (ESAS) which includes both fatigue and drowsiness. As discussed earlier in the literature review, the use of so many different instruments made it very difficult to compare results, thus impacting upon consistency.

As found within this study, drowsiness and/or fatigue were the most common symptoms at end of life, however, this may have been predicted, given the expectation that people will increasingly sleep more within the terminal phase and while this did appear to occur in many studies, as identified above, it did not occur with all. Studies that have been carried out at the end of life with other populations again rank drowsiness and/or fatigue as highly prevalent symptoms (Cheung, Le, & Zimmermann, 2009; Doorenbos, Given, Given, & Verbitsky, 2006; Hui, Santos, et al., 2015; Nauck, 2001). Drageset, Corbett, Selbaek, and Husebo (2014) found that pain was the highest occurring symptom although their study compared cancer related symptoms between residents with and without cancer, rather than focussing specifically on end of life symptoms. This concurs with the work from Ritchie et al. (2013) who found pain to have the highest rate of symptom occurrence in age group 60 – 65 years but when compared with older age groups, they reported that a lack of energy had a higher occurrence than pain. This suggested that there was an age related factor to the occurrence of symptoms, especially when it involved energy and fatigue levels.

As well as considering presence of individual symptoms, this study set out to take a temporal view of changes in the presence and intensity of symptoms, both in terms of overall total symptoms and within individual symptoms.

6.3 The total presence and total intensity of symptoms and changes over time

When considering the total presence and intensity of all symptoms, there was an increase in the mean of both, showing an increase towards the time of death. Subsequent pairwise comparison testing between the 4 hour, 24 hour and 48 hour time periods resulted in statistically significance differences across all of the three time periods in relation to presence and in all but one in relation to intensity. The time period between 48 hours to 24 hours revealed a shift in the mean towards the time of death, but not a significant change. This means that total presence of symptoms increased towards the time of death, so that a participant had more symptoms, and those symptoms became more intense the nearer to the time of death.

6.4 The presence and intensity of individual symptoms and changes over time

Taking a similar approach to the total symptom load, it was necessary to understand whether all symptoms were increasing at equal levels or whether it was individual symptoms that were increasing the total load. Expanding on the analysis further by examining the presence and intensity of individual symptoms, there was found to be an increase in the presence of seven of the symptoms between the three different time points towards the time of death; of these, four were statistically significant, which were drowsiness, shortness of breath, secretions and unable to respond. The main increases were found in the periods between 4 and 24 hours and 4 and 48 hours. There

were a few anomalies within presence; for example, the presence of both depression and pain decreased, which given an increase in the presence of drowsiness may have led to these symptoms being more difficult to assess.

When considering the changes in levels of intensity within the individual symptoms, it was only possible to study the change in intensity in eight symptoms (due to the binary nature of the measuring of four of the symptoms). This disclosed a significant increase in the intensity towards the time of death in four of the eight symptoms, fatigue, drowsiness, anorexia and shortness of breath. Similarly to presence, the main increases were found in the periods between 4 and 24 hours and 4 and 48 hours. These temporal aspects of combined symptom load have not been studied previously in relation to residents in care homes; however, this presentation has a very similar pattern to Seow et al. (2011) who documented the intensity of nine ESAS symptoms in the last six months of life with patients with cancer. They reported that fatigue, poor appetite, drowsiness, shortness of breath, and well-being worsened over time, whereas nausea, depression, anxiety, and pain remained mostly stable.

When looking at groups of signs and how the signs co-occur, there are patterns that begin to emerge when reviewed over time. There were a group of five symptoms (drowsiness, fatigue, anorexia, unable to respond and shortness of breath) that were present at three key points during the final two days of life (at 4 hours, 24 hours and 48 hours). They were ranked in the same order at each of the three different time points prior to death. However, even beyond these three time points, the symptoms were also present in the study population and were the most frequently occurring across the data

collection period across all participants. There was, however, a difference in the intensity to which these symptoms were observed. The intensity of symptoms increased towards the time to death.

All symptoms except pain increased towards the time of death in intensity (although pain reduced very slightly and was not statistically significant). A general decline (one that is with less presence and intensity of acute symptoms) can be seen within this cohort. These are very similar to the findings of Estabrooks et al. (2015) and Echteld, Deliens, van der Wal, Ooms, and Ribbe (2004) who carried out studies in similar populations. However in their studies, the level of pain was reported to have decreased, but this could be due to a lack of ability to express it either due to proxy reporting or could have been masked by other symptoms such as drowsiness.

6.5 A typology of symptoms associated with the dying phase in care home residents

The background for categorisation of symptoms in end of life care primarily comes from the Liverpool Care Pathway (LCP) (Chapman & Ellershaw, 2011; Coackley & Ellershaw, 2008; Ellershaw, Smith, Overill, Walker, & Aldridge, 2001). The LCP included five symptoms and were identified as "key symptoms" and described as the "commonest symptoms in the dying phase". It is not explained why the four "commonest" symptoms (plus one "other problem") were included within the LCP, yet it went on to become a highly influential document to support symptom control through assessment and measurement in end of life care. This was further evidenced by the increasing number of published studies around symptoms that aim to improve

their management. Fewer studies had been carried out to understand the impact of the symptoms without an 'end-goal' in sight. Some symptoms appeared to have been given more value than others. For example, there were large numbers of studies focussing specifically on pain, shortness of breath, and secretions and nausea were included regularly in studies, while symptoms such as fatigue remained relatively under researched and less understood (Judge, Schnitzer, & White, 2015). A type of categorisation was considered by Treusch et al. (2015), who studied behavioural symptoms in dementia and discussed apathy as a 'passive' symptom as opposed to other symptoms such as agitation and aggression. The authors did not discuss why they labelled apathy as 'passive', although they did consider that apathy can be easily overlooked by staff, possibly because it is a quieter or less obvious symptom, in that it usually presents in a low key manner, but its very nature can lead to be less disruptive to staff with less burden to treat and manage. Looking at the symptoms from this study, drowsiness, fatigue, anorexia and being unable to respond all fell into a similar category, in that they were quieter symptoms. As a result, from the findings within this study, a typology of symptoms is proposed that addresses three different dimensions. 1) the classification of symptoms into two principal categories; 2) the prevalence of a range of symptoms taking into account their presence and intensity and; 3) the temporal characteristics of symptoms. Although these will be presented in a systematic manner, the three aspects interconnected with each other and this will be referred to as the chapter develops. A visual representation was developed to illustrate the discussion (Figure 6.1).
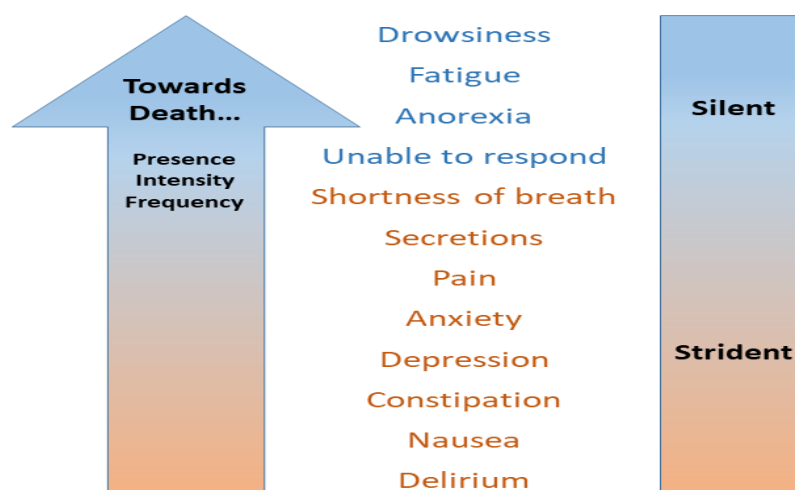
Figure 6.1 A visual representation of the symptom typology

6.6 The classification of symptoms into two principal categories

The implications of the presence and intensity of symptoms will be discussed further on in this chapter, however a key finding of this study concerned the symptoms that were the most prevalent and how they were interpreted. It is proposed that the symptoms can be divided into two principal categories aligning to the symptoms with the highest levels of frequency and intensity. While literature that discussed symptom groupings or clusters or reporting about different levels or intensities is very common, there was a paucity of literature about symptoms themselves being classified. A classification that is used internationally is the ICD-16 (version 16) (World Health Organization, 2016), but this is a disease categorisation codes for reporting diseases and health conditions. It does not describe the symptoms. (Meads & McLemore, 1974) use a similar coding to classify patients symptoms. Stanton, Downham, Oakley, Emery, and Knowelden (1978) identified two different categories of symptoms: major and minor, during a study of terminal illnesses in children. They proposed that major symptoms were those that usually needed a medical opinion on the same day, while

minor did not and observed that many children had non-specific symptoms rather than the physical signs of life-threatening illness that are of major concern to health care professionals. Wilson, Downham, and Forster (1984) expanded upon the work of Stanton in relation to major vs. minor illnesses in children and although they argued that major and minor symptom categories were not sufficiently discriminating enough to use in practice, they still used the same division in relation to those needing same day medical opinions. There are a number of problems with this classification. It is a very medically emphasised classification, which is linked wholly to its degree of life-threatening threat. It does not allow for any individual interpretation as what is major for one person is minor for another.

While searching for any evidence that this had been addressed previously, a forum member on the website/forum Researchgate posted a question in 2014 to ask "Is there any universal symptom classification"? (https://www.researchgate.net/post/Is_there_any_universal_symptom_classification) It was asked whether there were any universal approaches to classify symptoms according to their features. He received several replies to provide him with disease specification classification, but nothing else.

Using the modified Edmonton Symptom Assessment Scale (modified ESAS), this study measured 12 different symptoms: anorexia, anxiety, constipation, delirium, depression, drowsiness, fatigue, nausea, pain, secretions, shortness of breath, and being unable to respond. These symptoms, especially when experienced at the end of life would be difficult to categorise as major or minor, yet when viewed in their ascending order (of most prevalent first), a different classification appears

6.6.1 Silent symptoms

This study had identified that the symptoms that occurred with the highest frequency and intensity were drowsiness, fatigue, anorexia and unable to respond. It is proposed that these symptoms fall under the classification of **'silent'**.

End of life care education often places a strong emphasis on teaching health care professionals how to manage symptoms, particularly around symptoms as reported in the literature review, such as pain, dyspnoea, nausea and secretions. However, many of the symptoms experienced at the end of life, such as the most common ones identified in this study, i.e., drowsiness, fatigue, anorexia and unable to respond, do not require active treatment but rather require recognition of their being part of the dying process. Some symptoms at the end of life may be viewed as 'inevitable' or 'acceptable'. Health professionals may be so attuned to symptoms that must be treated that they do not view these as symptoms. During professional training, there was an emphasis on active symptom treatment, so that the more subtle symptoms received less attention. Fatigue was one such symptom that had traditionally received less attention than others (Haas, Kallen, & Escalante, 2012). It can also be affirmed by the literature review in chapter three, where pain was included in 23 studies, yet fatigue with its high prevalence only in nine. This in turn reduces the symptoms' value in the eyes of those caring for residents with symptoms like fatigue, making certain symptoms appear or seem 'silent'. This invisibility can also be linked to the tenet of treating what can be seen which can be related to the above about viewing them as inevitable. The impact upon moral distress as a result of witnessing symptoms, and ignoring them may have made it easier to bear as human beings which can result in

professionals into thinking that they are not a problem. Every person has an 'internal frame of reference' (Rosendal, Jarbol, Pedersen, & Andersen, 2013), which interprets bodily sensations as either 'normal' or 'threatening' and was moderated by an internal frame of reference based on previous bodily experiences. When caring for older people/dying people the internal frame of reference of the professional may broaden the perception of 'normality' so it becomes accepted without question. The analysis of professionals' practice in palliative care shows how the 'end of life' was constructed in two ways: as a stage of psychological preparation for patients and families (and therefore an object of professional intervention), and as a gradual process culminating in death (Alonso, 2012).

Recognising the worth of silent symptoms could support the earlier identification of dying. Within this study, the silent symptoms increased towards death at the highest rate. This was supported by other studies (Sandvik et al., 2016) who found that increased fatigue and poor appetite were significantly associated with being able to identify the day a person was imminently dying.

6.6.2 Strident symptoms

This study had identified that the symptoms that occurred with the least frequency and intensity were shortness of breath, secretions, pain, anxiety, depression, constipation and delirium. It was proposed that these symptoms fall under the classification of **'strident'**.

Strident symptoms are those that are treated in an active way. Considering the main symptoms that were originally identified in the Liverpool Care Pathway and now are included in individualised care plans[19], they were all symptoms that had a solution or a way of reducing them. In many ways, these are the opposite of silent symptoms because they require attention. While silent symptoms are quiet and insidious, strident symptoms can be more apparent and noisy. They can be less difficult to ignore and can be more demanding of the professional.

There is a risk in taking too much notice of these symptoms at the cost of ignoring silent symptoms. While they do need to and can be managed and can also indicate the end of life, this study found that they did not occur with the same frequency and intensity as the silent ones and they are not as reliable in being used to recognise the very end of life. They may, however, distract the professional from having recognised impending death and shift the focus to acute symptom management, which is when the risk of inappropriate hospital admissions can occur. As professionals who strive to provide good care, especially at the end of life when it may feel like the last chance to get it right, there is often a desire to 'do' something; yet 'being with' someone which is a very real humane response, is often perceived as something more uncomfortable and challenging to do (Speakman, 2018).

The identification of these two categories of symptoms within this study appeared to be novel and has not been identified in any other published work to date. Although

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[19] Individualised care plans are identified in the NICE Guidance document 'Care of dying adults in the last days of life' (March 2017). It was part of the process that superseded the Liverpool Care Pathway

similar rankings of symptoms have been found in other studies, and will be discussed later in this chapter, this previously unrecognised categorisation of silent and strident symptoms is unique.

6.7 Symptoms and different individual characteristics

The purpose of this section of the analysis was to look for symptom modulators; these are variables that are consistently associated with the expression of one or more symptoms. The main variables that were tested for associations were:

Age was included because the average age of residents is increasing, but it is also likely to continue to increase as this proportion of the population are increasing, leading to the oldest people requiring care.

Gender was included as a variable in view of the increasing number of men living in care homes compared to women.

Length of stay was included because of the decreasing length of stay in care homes.

Number of diagnoses were included due to the increasing complexity of residents second to multiple morbidities.

Finally, the five most frequent diagnoses were included: one area of topical interest is dementia, prevalence is increasing generally but also within the literature review, three out of the five most recent studies were carried out with people with dementia.

6.7.1 Associations between total presence and intensity of symptoms and characteristics

Associations between age, gender, number of diagnoses and length of stay and the total symptom presence and intensity were tested for. The main association that was observed was a relationship between the length of stay and total symptom presence and intensity. Regarding total presence, there was a negative association, which meant that the less time spent in the care home, the participant would have a higher number of symptoms, and however this was only statistically significant at 24 and 48 hours. There was a greater association between the total symptom intensity over time and the length of stay, as this was significant at all three time periods, although only with a small effect size. There was no association between any other variables in this study which starts to illustrate a portrayal of more similarities than differences in the dying phase of residents.

6.7.2 The associations between demographics and the presence of individual symptoms at the time closest to death (within the final four hours)

To narrow the focus down on the final four hours prior to death, all twelve symptoms were tested for associations with age, gender, number of diagnoses and length of stay These were found to have overall little associations with the symptoms, with mainly small effect sizes. The most notable association was that of the number of the number of diagnoses and four symptoms (pain, anxiety, shortness of breath and unable to respond), although again, with small effect sizes ($r = -.18$ to $-.22$) indicating an association between a higher number of diagnoses and the presence of symptoms.

Finally, associations between symptoms and five different diagnoses were tested for. Again, there were some correlations, but these were all of small effect size (r = -.18 to -.23), making it difficult to show clear relationships between these variables.

Sometimes, it is more important to consider what the data does not demonstrate rather than what is present. When considering the associations between total presence and intensity of symptoms and characteristics, as well as individual symptoms and characteristics, the study population has very few differences, despite their different characteristics resulting in a very homogeneous cohort of people.

6.8 Recognition of the dying phase

In line with many other studies, this study identified a slow response of staff in anticipating or recognising dying. As discussed in the background chapter 2, end of life care is care that has a very broad application and can apply to a person who has many weeks or months to live. However as this study is focussing on the final days of life, end of life care here is used to apply to that period of time immediately prior to a resident's death (this would have previously be known as 'terminal care, although that term is little used now). The mean time from recognition of death to the point of death in this study was 2.3 days (median 4.5 days), but within a very large range of time (four hours – 24 days). Most deaths, however, occurred shortly after data collection started (when recognition of death took place). Twenty three participants only had a single set of data recorded, so having died within four hours of being identified as dying. Yet their symptoms were only minimally different to those who had longer data collections of a few days. Barclay et al. (2014) identified that while there is a gradual

deterioration or 'dwindling' of older frail people, this is commonly recognised in retrospect. Their study proposed this, having identified four trajectories to death: 'anticipated dying', 'unexpected dying', 'uncertain dying' and 'unpredictable dying', however it was a small study with 23 deaths. As it appeared that all deaths in the participating care homes were captured within this study, it would rule out unexpected dying, so leaves a very fine line between anticipated dying: and unexpected and uncertain dying. As most deaths occurred within a relatively short time of recognition, this study supports the conclusion that most deaths are either uncertain or unexpected, yet the reality is that with the right knowledge and support, care home staff would be able to observe for anticipated dying in many cases. This may also be explained by the work of Cable-Williams and Wilson (2014) who noted that the trajectories of decline associated with chronic progressive diseases in advanced old age have few prognostic markers making it difficult to determine when to start end of life care. Covinsky, Eng, Lui, Sands, and Yaffe (2003) also found a link between frailty and functional decline stating that it was not likely for any of the four measures of frailty to identify a time point prior to death when there was an abrupt decline in function that would signal impending death.

Despite a general awareness in the care homes that death occurs naturally at the end of a long life and/or long illness (Cable-Williams & Wilson, 2014), this serious decline towards death was not noticed or acknowledged until an average of 2.3 days (and much less in many cases) in this study, thus limiting end of life care to very late stages and potentially resulting in reactive rather than pro-active care and subsequently reactive rather than pro-active decisions, which may aid understanding as to why some 'unavoidable' hospital admissions occur. Presence of a symptom does not solely

indicate death within the last 48 hours: participants were more likely to have increased unresponsiveness (but not significantly so) (Pollock, Caswell, Harwood, & Porock, 2014).

6.9 The strengths of the study

6.9.1 A unique approach

This was the first known research study to observe and report a typology of dying and characterise the symptoms into two types. The research aim and objectives were based on a clinically relevant question, so as a result, the findings had meaning about the population that they involved. The study set out purposively to observe and report a range of common end of life symptoms experienced at the very end of life, using prospective methods and direct and consistent measurement procedures.

6.9.2 The use of a systematic measurement tool

The study utilised the Modified Edmonton Symptom Assessment System to assess and measure symptoms. While there was no perfect tool following a comprehensive review of the available tools, the modified ESAS met specific criteria. It fulfilled the requirement of being both a clinical tool, but also met the requirements for being used within clinical audit or research (Nekolaichuk et al., 2008). It enabled a consistent approach to the assessment and measurement of symptoms within a single document, while also allowing a repeated administration over the period of data collection. The goal of the ESAS has been described as simply practical: to identify a few active symptoms using a consistent listing and scoring system across patients (Richardson & Jones, 2009). It was easy to administer and was reported to be easily integrated into

the nurse's daily routines, so much so that several of the care homes continued with its use after the data collection had been completed.

6.9.3 A comprehensive data set

The sample of care homes were purposive due to ensuring that the homes were willing to be involved with the study and stayed engaged throughout the research process. However this purposive sample was a representation of a mix of types and sizes of care homes and a representative sample when comparing the characteristics with other care homes across the area. They were, however, spread across a broad geographical area which meant a significant amount of travelling for the researcher when collecting data sheets.

This study had a relatively small sample size ($N = 157$), although this was comparable and often favourable in line with the other studies in the literature review. The real strength however, came from the richness of the data that were achieved due to the number of time points and residents that were incorporated. This resulted in almost two thousand observations collected through the course of the study. There was very little missing data which meant that missing data computations were not required. Despite the fact that the participants were all at the end of life and that it is a very sensitive time for the residents, families and staff, there were no requests for participants not to take part in the study nor for any withdrawals once data collection was underway. Even though the very end of life phase is very difficult to predict, there were no reports from care homes of not collecting at least one data point from residents who were dying, adding to the comprehensiveness of the data set.

6.9.4 Supportive relationships with care homes

The strengths noted above were supported by the full data set that were achieved during this study. The researcher was known to the care homes professionally through previous professional support (mainly through the provision of education) and this enabled the researcher to be able to work closely with the homes while maintaining a professional boundary. The relationships that developed with the homes (and with the care home manager and senior staff) were key. The relationship was supportive but realistic with its expectations and the requests made of the care homes. It resulted in high quality data and despite the length of the data collection period, there were little missing data.

It has been reported that care home staff, health professionals or family may all act as gatekeepers to ensure that residents do not participate in research that may be burdensome or detrimental to their health and wellbeing (Moore and Hanratty, 2013). Being invited and able to speak with care home staff and with families at family meetings meant there were no residents' families who requested their family member not be involved with the research.

6.10 The limitations of the study

6.10.1 The choice of a systematic measurement tool

At the time of data collection, there was no validated measurement tool currently used in this population to report the end of life symptoms; however, the use of the modified ESAS was the best available for data collection with staff reporting on its ease of use and clarity. The completeness of the data collected also indicates that this instrument

was not burdensome for in use in practice, an aspect that could have seriously impacted upon the study if it had been. The modified ESAS was selected as it provided the best match to the research requirements. However, it comprised of 12 symptoms, and although these were appropriate when selecting the instrument, it limited the range of symptoms to be studied, although having a pre-defined set of symptoms is seem as preferable to having no guide. The modified ESAS also had an anomaly in that eight symptoms were continuous variables with a scale of 0-4 and four symptoms were recorded as categorical (present or absent). This resulted in not being able to measure intensity of these four symptoms as they could only be present or not, and had not been assessed with an intensity score. To overcome this, an option may have been to use an alternative version of the ESAS, for example, one with all symptoms having the ability to be measured as continuous. Staff from the care homes could have been involved in the original choice of tool as their experience of end of life care would have been valuable to inform the decision process. A representative from each of the care homes could have been invited to provide feedback regarding the potential use of the modified ESAS. However, a balance between the utility of a tool and the purpose for data collection for a research project would need to be kept at the forefront. It was also fortunate that the researcher worked within a different care home as a bank nurse and had experience of end of life care at first hand.

Since the study has been carried out, there have been further changes and subsequent studies involving the ESAS to increase reliability and validity. The ESAS-revised retains core elements of the ESAS, with improved interpretation and clarity of symptom intensity assessment. It represents the next generation of development, with

further validation recommended for drowsiness, appetite, and well-being (Watanabe et al., 2011).

At the time the study was carried out, another instrument, the Palliative Outcome Scale (POS) was reviewed and rejected as it did not meet the criteria as well as the ESAS. It now has undergone major changes (now renamed integrated Palliative Care Outcome Scale or iPOS). There are multiple versions for use with different types of diseases and care settings (including proxy-rating) and it has demonstrated construct validity acceptable test/re-test reliability for seven items, and good internal consistency (Collins et al., 2015). However, the iPOS is being primarily used as part of a set of Patient Reported Outcome Measures (PROMS) to capture changes in health status. With this in mind, the advice on using the iPOS is to understand how the symptoms are affecting the individual rather than capturing its presence or intensity. This highlights the challenge of finding an appropriate measurement tool that meets the needs of the patient while being suitable for use in research.

A single tool was used to collect data; as discussed earlier, this was a considered decision to reduce the burden on the qualified nurses in collecting the data. It also enabled consistency with use of the instrument in that staff could become familiar with the instrument and not have a risk of competing instruments causing confusion. However, there is a risk when measuring the prevalence and intensity of symptoms for patients at the very end of life. A single tool may not be sensitive enough to measure psychological symptoms such as depression, especially if they consist of multidimensional aspects affected by emotional, social, and various other elements

(Kajiwara, Kako, & Miyashita, 2019). This will be discussed in more depth in section 6.10.4. In addition, the use of this may have also caused some limitations such as floor or ceiling effects, due to the measurement limitation that occurs when the highest possible score or close to the highest score on a test or measurement instrument is reached, thereby decreasing the likelihood that the testing instrument has accurately measured the intended variable (Denzin & Lincoln, 2011). The four point scale of the ESAS may have contributed to this and using the ten point scale would have widened the floor and ceiling effect.

6.10.2 The use of a systematic measurement tool

Although the use of a systematic measurement tool can be considered a strength, conversely this can also be seen as a limitation. There is a need to ensure full reliability and to use the tool properly. The staff completing the assessment were all qualified nurses. As discussed earlier, all staff had undergone training to understand the rationale for the study and the use of the modified ESAS. A case study was presented to enable discussion to support consistent completion, and definitions of the symptoms were added to the back of the modified ESAS form following feedback from the staff to ensure the use of a consistent definition of the symptoms. Inter-rater reliability between different staff members could have been further enhanced by obtaining information on the staff collecting data, for example, type of qualification (RGN/RMN), how long they had been qualified, what was their first language. This could have been checked against other completed data to see if it was a factor. The modified ESAS form incorporates a space at the bottom for the nurses' initials, so it would have been a straight forward process to add in this extra level. Reliability could

have been further checked by the use of focus groups with staff to promote discussion about the assessment (and if any problems arose). A second method would have involved gaining ethical approval at the beginning of the study to gain access to resident notes or their drug charts which would further acted as a review process.

On reflection, a follow up evaluation could have been carried out to understand what the staff thought of the modified ESAS tool. Informal feedback was gathered throughout the process, but this was done to support the staff, i.e., to be able to pick up on any problems during data collection, but was not done within a rigorous process. The feedback could have been gained by holding a small focus group with representatives from the care homes. Their views on the design, applicability, ease of use and the nature and types of symptoms included would have been of benefit to increase learning about the use of tools at the end of life in care homes, especially as this is very new territory to be exploring.

6.10.3 Lack of missing data

Missing data is another provocative matter. While having minimal missing data is a positive factor, especially with the need to carry out statistical analyses, it also raises the need to consider any consequences that this may have. As discussed above, the data were collected by qualified staff and the completed forms were collected by the researcher or the business administrator. All forms were scanned on collection for gaps, but forms (apart from a few omissions) were complete. Each time point was initialled for verification by the member of staff completing that assessment. While it

is possible that all forms were authentically completed, the initials could have been double checked with the member of staff to ensure this.

A further question to be asked is whether the tool changed the behaviour of the staff? Where there patterns of reporting, i.e., staff following previous assessment rather than looking at the resident? This would have been more difficult to overcome, but holding a focus group with staff following the data collection period could have led to discussion. An alternative way to assess this would be to gather a random sample of completed modified ESAS forms and analyse for patterns, particularly if the staff initials on the forms were used as a comparator.

6.10.4 Proxy data collection and symptom assessment

There was a potential that compliance of the use of proxies to collect data could have limited the completeness of data collection; however, given the ontological approach and the nature of end of life, it has proved to be a very beneficial way to collect data, resulting in a complete set of data. The modified ESAS had been validated for the use of proxy data collection and staff were fully prepared for this role; however, the subjective nature of symptoms still creates challenges during proxy data collection and these have been discussed earlier in the thesis. One aspect that can prove difficult is that of assessment of psychological symptoms. In particular, one of the symptoms included on the modified ESAS is depression. When reviewing the results of the analysis, it was seen that depression was less prevalent towards the time of death. This raises the question as to whether it had reduced, whether it had become less apparent because other symptoms such as drowsiness had increased and masked depression, or

whether the staff assessing were able to adequately measure the symptom. There are specific tools available, e.g., The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), however, the challenge is finding suitable tools for multi-dimensional assessment rather than having to use several uni-dimensional tools for each assessment. Preparation for integrating assessment of multiple symptoms, as well as having the knowledge of individual symptoms is important. In relation to depression this could mean having a knowledge of how to assess, but also self-awareness of staff own beliefs on depression as their views of patient suffering, especially at the very end of life, are relevant given the major role they play. For symptoms such as depression; advice to staff can include to assume the same unless notable changes were observed that could be attributed to the symptom. However, depression is an important symptom and should continue to be assessed. Any form of psychological distress impairs the person's capacity for pleasure, and meaning, erodes quality of life and intensifies pain and other symptoms (Block, 2000) and while pharmacological management may not be appropriate, support and care of the person is paramount.

6.10.5 The challenges in recognising dying

Although the total number of participants was estimated prior to the study and subsequently achieved, the challenge was the care home staff recognising when a resident entered their final days of life. This meant that many residents did not 'join' the study until the final day or hours of life. It resulted in a very complex and large set of data which took a considerable amount of time for data input and the subsequent analysis. By using pairwise comparisons, it enabled the recognition of death as a

variable to be incorporated in the analysis, but longer periods of data collection for individual participants would have further strengthened the analysis.

6.11 The implications on policy and practice

Care homes often operate in isolation from other services and from each other, even when part of a larger corporation, so their position in the wider care provision needs to be considered. To consider this, a typology identified by Froggatt et al. (2017) can be drawn upon. The typology incorporated three levels that need to be considered to be able to implement palliative care delivery and practice in care homes: 1) macro (national/regional/local policy, legislation, regulatory drivers); 2) meso (actions to support development, such as research, education and practice model); 3) micro (the recognition of the very end of life phase and the delivery of palliative care). It could be seen how a cascade effect from the macro level to the meso level would have an effect on the micro level. This typology has similarities with the Organizational Culture Model developed by Edgar Schein (Schein, 2004), who described a series of three layers or sub-cultures, each one affecting and being affected by the next one. Applying this process to the care homes, it becomes apparent that if inappropriate hospital admissions are to be avoided for residents who are dying, the meso level needs to include actions such as education and training, but that there is a macro level that must be addressed to support care homes to be able to put the meso actions in place in order to influence the micro level, or the delivery of palliative care. Wider policy development and implementation can help to shape this. The framework for enhanced health care in care homes (National Health Service, 2016) is attempting to pull together

care homes and services to improve care, while providing much needed support for the care homes.

6.12 The macro level – Policy and planning

There are growing challenges associated with ageing globally and so there is an urgent need to build a robust international comparative evidence base that can inform the development of policies with the goal to improve end of life care in care homes (Van den Block et al., 2016). From the literature review in chapter three, it was noted that there was a lack of published research from the UK around end of life symptoms in care homes, so support is needed to develop research skills to lead these, plus ways of increasing engagement with care homes. In today's climate of staff shortages and financial cut-backs this may be difficult, so the development of regional teaching/research-based care homes that become centres for practice-based research could be one solution (Hockley, Harrison, Watson, Randall, & Murray, 2017). There is a risk, however, that the good quality care and learning and development that has the potential to take place does not come out of these homes/centres but remains in-situ. Another policy implication that has been identified from this study will now be addressed.

6.12.1 Avoiding inappropriate hospital admissions

Although this is could also be considered a meso/practice issue, it is appropriate to position this under the implications for the policy section as it is often a bigger issue that the care homes are unable to influence by themselves.

The correct recognition and identification of the symptoms that signified the very end of life could prevent residents being admitted into hospital when supportive or comfort care provided in the care home would be the best option. It highlights the importance of assessment and measurement, improving pro-active care which can stop things getting out of control. It would also help those people that are not at end of life receive the appropriate medical care they need at a time when care homes are fearful of admitting residents for what could be a very appropriate and timely admission.

6.13 The meso level - supporting development through education and practice model/frameworks

6.13.1 Developing a curriculum for staff working with care home residents at the end of life

The education and support of staff is an important area of development to enhance the care of residents at the end of life. Bone et al. (2018) stressed the importance of education for staff in driving the current increase in care home deaths, and said that if there is no end of life care training and release for training for staff in care homes, the trend in declining hospital deaths will likely reverse as a result by 2023. There are a wide range of professionals who support care homes, beyond the care home staff themselves, and so education and support would be needed for them as well. Based on the findings from this study, it is proposed that it would include the following three key areas: 1. Identification of all types of symptoms (including silent and strident); 2. Recognising the significance of symptoms; and 3., Managing the consequences of 1 and 2. The following table (6.1) describes how these three areas relate to the emerging findings and how they could be incorporated within a curriculum for care home staff.

Table 6.1 A curriculum for care home staff based on the findings of the study

Key area	Emerging finding	Application of findings to a curriculum
1.Identification of all types of symptoms (including silent and strident)	The most prevalent symptoms may not need 'treatment' but care of the resident is still crucial	Not all symptoms need management, but they do require acknowledgement
	There is little difference in symptoms at very end of life regardless of diagnosis	Recognising and addressing pre-conceived ideas about the influence of age/gender/co-morbidities
2. Recognising the significance of symptoms	The four key 'silent' symptoms increase in severity towards death	Spotting the 'trigger' change points of the dying process
	This study has shown that accurate measurement provides relevant information	How to carry out a measurement of symptoms
	Recently, several studies have examined the ESAS predictive validity, although not currently in the care home setting (Hui & Bruera, 2017)	Use of an appropriate symptom measurement/ assessment tool
	Silent symptoms may not be recognised by families as part of the dying process so their significance may need highlighting	Communication with families and others regarding the implications
3. Managing the consequences	This study has shown there are no certainties, but there some indicators that can help with early recognition of impending death Strident symptoms will still be present in some residents and require management	Recognition of needing to work with uncertainty but indicators can alleviate some uncertainty and support decision making
	This study has shown a range of different symptoms can present and all form part of holistic care	All round general symptom management knowledge is required but also need to know when to refer on
		Holistic care planning. End of life care is not just about drugs and syringe drivers (but might be needed) but keeping the person comfortable is the goal
	Complex symptoms require specialist advice or support	How to access to support network of other professionals

6.14 The micro level - recognising dying and the delivery of end of life care

6.14.1 The recognition of imminent death

Symptoms can be monitored in order to manage and treat to promote quality of life and subsequently support a good death, but they can also be observed and monitored for an indication of approaching death. Following this study, it has been shown that both purposes of symptoms can support the provision of good end of life care (Sandvik et al., 2016). This study established that many symptoms are related to a general deteriorative condition, that they generally increase in presence and intensity towards the time of death, and that residents dying in nursing homes have similar symptoms despite different characteristics. The symptoms are less acute than reported in other populations and these symptoms can be divided between 2 different types – silent and strident.

To apply the findings from this study, care home staff can be made more aware of the type and nature of symptoms (as in the curriculum in Table 6.1) and that an increase of symptoms may be an indicator of approaching death (specifically when the silent symptoms are increasing in presence and increasing in intensity). They also need to be aware that the diagnosis of the resident is largely irrelevant to this process but the less time the resident has been in the care home may mean that if they are presenting with more and increasing symptoms, they are more likely to be moving into the dying phase. Residents in care homes have a slow gradual decline (Barclay et al., 2014) which may not be picked up by staff (or relatives) who see the person each day. Adding in an additional assessment, such as the Karnofsky Performance Scale (KPS) (Oken et al., 1982), which is a measure of the patient's overall performance status or ability to

perform their activities of daily living, can help to see decline and make sense of changes in symptoms. The combination of these two approaches, when carried out regularly, may assist staff when making decisions about hospital admission and help to prevent inappropriate and unwanted (on the part of the resident) admissions. This will also help to support Advance Care Planning (ACP):

> "Advance care planning offers people the opportunity to plan their future care and support, including medical treatment, while they have the capacity to do so" (Happ et al., 2002): p.829)

Although ACP should ideally be completed as early as possible, for example, on admission to the care home or soon after. However it often does not get addressed due to apprehension about upsetting the patient or their family, or that patients were not ready for these conversations with only 16% of staff discussing advance care planning at least sometimes (Ottoboni et al., 2019). Patients and families prefer health professionals to initiate the conversation, but professionals often defer the discussion until it is deemed clinically relevant (Hall, Rowland, & Grande, 2019) but can miss the opportunity as the patient deteriorates. By identifying the increasing presence and intensity of symptoms, along with an increasing KPS, may provide a trigger to have conversations about care and hospital admissions before it gets too late.

6.14.2 Targeting the right type of care to the right people

Different models of care are required for people with different illness trajectories (Murray, Dawson, Thomas, & Cebul, 2005), but what this study has shown is that there is a 'type' of trajectory of a slow decline that is common to residents in care homes in

the final few days, meaning it could be possible to identify an appropriate approach to care. Specialist and generalist palliative care are the terms mainly applied, but having an approach that sits somewhere between the two may be more appropriate for residents in care homes. While the specialist skills of a Clinical Nurse Specialist (i.e. Macmillan Nurse) may not be necessary, end of life care does require specific skills to meet the challenges of recognising, and specifically interpreting, end of life symptoms. Within the UK there is a medicalisation of end of life care in older people in care homes that may be unnecessary (Lievesley et al., 2011). Resources may be being invested in the wrong ways. In addition, a clear rationale of what is the role and boundaries of specialist palliative care is required – it does have a role, but it needs a more clearly defined role. This links into the next section regarding the care home culture.

6.14.3 The impact of care home culture

The culture of institutions providing care for older people is increasingly recognised as influential in the quality and nature of the care provided (Killett et al., 2016). As already discussed, (Schein, 2004) describes culture as a dynamic relationship between three levels, with artifacts being the most shallow, espoused values in the middle and assumptions lying at the deepest level. Culture in any setting does not just involve bringing in a 'good' manager or putting a policy on the wall. It is about working with practice issues and aligning them with espoused values. From that practice, assumptions will develop and grow and be influenced through the espoused values.

The findings from this study will not necessarily be able to affect assumptions directly, but it can influence practice and support staff to change culture through changing values which could ultimately shift assumptions. For example, by having a model built on the knowledge, skills and confidence to identify end of life through the recognition of decline and the presentation of silent symptoms, staff may be able to have conversations with residents and their families about end of life wishes and from that, build the confidence to have these conversations earlier (maybe on admission). The willingness to discuss these difficult issues and the resulting openness between staff and residents and families influences values and ultimately can change assumptions. It only needs small steps to do this which leads to an accumulative and much bigger effect.

6.15 Implications for research

Symptom research is a fertile field (Kroenke & Harris, 2001) and there are a lack of studies at end of life, particularly in certain groups such as older people or with certain symptoms such as the silent ones identified in this study. There needs to be consistent ways of researching symptoms utilising best practice guidance. A higher priority should be given to exploring symptoms as a phenomenon in its own right rather than focus on symptoms as part of diagnostic constructs only (Rosendal et al., 2013). This would prevent the focus on a 'fix-it' solution only and place symptom assessment and measurement as a way of understanding how symptoms are utilised more broadly. Three specific aspects in relation to implications for research will now be discussed.

6.15.1 Standardisation of approaches

The philosophy behind the UK Medical Research Council (MRC) and National Institutes of Health Research (NIHR) funded 'MORECare' was to recognise that firstly, end of life care is neglected by medicine, and secondly, that end of life care research is complex and hard to conduct with no common standards (Higginson et al., 2013). As a result, they have produced a guidance statement on the best methods to research end of life care. This study has found that it had aligned itself with several of the MORECare criteria, such as focusing on a period of time, using a number of time points to gain longitudinal information and attempted to support proxy reporting. The MORECare statement offers a practice guide, rather than a model or theory, so the next implication is for the use of a conceptual model.

6.15.2 Use of a symptom research model

Brant's model (Brant et al., 2010) was introduced in the background/context chapter. On reviewing the model further, it becomes apparent that there are some components that are more appropriate to include than others, especially if this model is to be used with a population at the end of life or any other group where self-reporting is not appropriate or possible, and that symptom management is not in question, for example, in symptom research. To isolate the components that are required from the New Symptom Management Model the following steps have been taken. This process has been explained in a set of images and tables and will be described after the process within the following order:

**Figure 6.2 Part of the New Symptom Management Model (Brant et al, 2010)
Reproduced with permission by Jeannine Brant**

The evaluation component, the current criteria and the adaptations that will be applied

to operationalise the model for current use are listed below in Table 6.2.

Table 6.2 – The key components within symptom research in older people in nursing care homes (based on Brant et al criteria)

Evaluation component	Criteria	Using the criteria to operationalise symptom research for older people care homes
Antecedents and/or precipitating factors	Demographics (age, gender), performance status, disease type, individual health and illness factors	Age Gender Number and type of diagnoses/diseases Length of residence in care home
Symptom appraisal	Symptom assessment and evaluation, type, common symptoms, timing, intensity/severity, frequency, interactions with others, situational factors, assessment instruments for measurement	Symptom assessment and evaluation, type, common symptoms, timing, intensity/severity, frequency, interactions with others, situational factors, assessment instruments for measurement
Symptom pair and cluster components	Symptom multiplicity, symptom interactions	Symptoms occurring together
Outcomes or consequences	Cognitive performance, mortality (recognising end of life), morbidity and co-mortalities	Symptoms at point of recognition of impending death/time to death
Temporal components	Temporal patterns, change over time, rate of change, progression of symptoms and disease state	Rate of change Change over time
Intervention components	Different interventions, clinician influences	Objective assessment
Concepts	Identified, well defined	
Relationships	Clearly delineated	
Utility	Useful, generalizable, parsimonious	
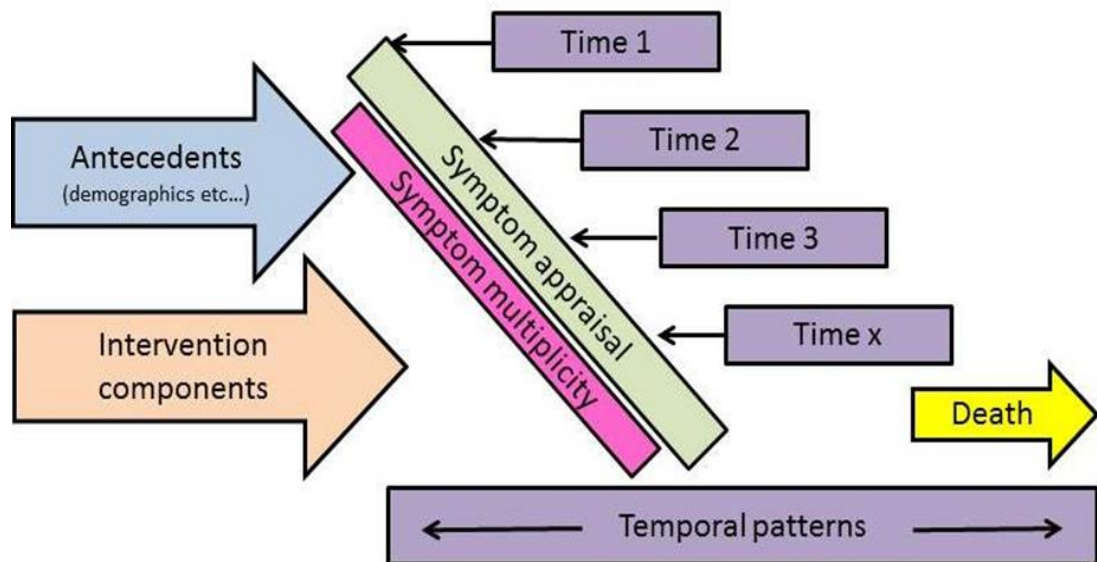
Figure 6.3 – A revised model of Brant et al (2010) model for symptom research (at end of life)

The key features of this application are the temporal aspects, and looking for changes

in symptoms over time. The antecedents are the areas of interest, such as specific

demographics or diseases. In the very middle is the measurement or appraisal of

symptoms and the multiplicity of symptoms. This model helps to inform a

conceptualization of symptoms to develop an understanding how they appear,

particularly in relation to temporal aspects and their relationships with each other. It

also recognises that symptoms may be more or less visible, such as the silent and

strident ones categorised within this study, and that all symptoms are equally

important. The model identifies the key components within symptom research in older

people in nursing care homes, rather than the nature of the symptoms themselves, so

6.15.3 The use of appropriate measurement tools

A further implication of this study is the choice and use of instruments for end of life symptom research. Generally, if an instrument is intended for research purposes alone, there may be a drive to develop complex multi-dimensional instruments that have less practical applications, especially with populations at the end of life. If the instrument is for practical and/or clinical assessment, utility becomes a key factor in the choice of instrument. The main requirements of an instrument are that it has to be comprehensible to diverse groups of staff and fairly quick to apply. It also needs to be considered how it can be used when measuring by proxy due to the likely incapacity of the population to be able to self-report. It will also depend on who will be informing the assessments. If staff are using it for a practical aspect, i.e., measuring, monitoring or improving care, potential training implications need to be considered to ensure reliability as well as validity. A further useful addition to the criteria would be to include the ability to assess multiple symptoms. This is supported by Van Lancker et al. (2013), who, following a systematic review found that many validated instruments existed to assess single symptoms, but none for multiple symptoms. The ESAS was reliable, but it had restricted validity due to the lack of application in the care home setting. In addition, there have been frequent modification of the ESAS raising some uncertainties around its consistency.

6.16 Conclusion

The main findings have been that symptoms tended to relate to a general deteriorative condition suggesting that dying in nursing homes represents a gradual decline towards death. The limited associations between demographics such as disease, age and gender indicate that those dying in nursing homes have similar symptoms despite different characteristics. There are less symptoms than reported in other populations and these symptoms can be divided between two different kinds – silent and strident, concluding in a typology that has not been previously identified in symptom research in this population.

Although many symptom research studies do not explicitly utilise a framework or model, however the use of a model can ensure that all areas of symptoms are considered.

Chapter 7 – Conclusion and Recommendations

7.1 Introduction

This chapter will summarise the findings from the research. First it will outline the importance of the research and why it was important to carry out in this population. Then, it will consider the major contributions of this research. Each finding will be summarised and the implications of these discussed. The contributions of the research are in some places unique, and in others they add to or build on existing knowledge. The implications will be aligned to practical, organisational or policy related domains.

7.2 The importance of this research

This subject of this research was of importance because it was recognised that the number of residents who are dying in care homes is increasing. This population consists of some of the frailest people in society: they live with high levels of disability, they often have multi-comorbidities and they are usually in their final months or years of life. Despite this, there is relatively little understood about the final days of this population's life, so this work was important to be able to contribute to the knowledge of how end of life care can best be provided, as everyone has the right to die with comfort and dignity, in the place of their choosing with appropriate support. It was also important to carry out the research in this setting as staff working in care homes are facing increasing pressures to provide good care, while working in challenging situations with high work-loads, high staff turn-over, reduced funding and often a lack of managerial stability. Working 'with' care homes in the field rather than 'on' care homes can be one way of valuing staff and recognising their expertise, as well as

improving research participation. A key driver for this study was to support and improve the quality of dying for residents in care homes. Improving the quality of dying for residents can improve the experience of the families and loved ones of residents as the perception of a 'bad death' has been linked with a complicated bereavement process (Wilson, MacLeod, & Houttekier, 2015). Furthermore, satisfaction for the care staff providing care can sustain their well-being and lead to increased staff retention (Marcella & Kelley, 2015).

7.3 What has this research contributed?

This research has made a number of contributions to the wider body of knowledge; some are new while there are other findings that add support to what is already known.

Key finding number one was the knowledge that dying was different in this population compared to people dying in other settings. This study has shown that dying in a care homes is a slow and gradual process, but relatively free of acute type symptoms. Residents admitted to care homes are most likely going to die in the care home after an average of a 11.9 month stay (Forder & Fernandez, 2011). This compares with an average hospital length of stay of 5.9 days (Stewart, 2019) and an average hospice length of stay of 15 days (Hospice UK, 2016). Both care settings are for acute care with a very short length of stay. This suggested that care needs to be focused on supporting residents who are becoming increasingly fatigued and drowsy, eating less and drinking less and ultimately becoming unresponsive. Although other causative factors of deterioration need to be excluded, care home staff (and those

working with care homes) should be educated and supported to recognise impending death in residents. These findings were of value on a number of different levels. For professionals, they provided information that has not been previously widely available to influence the way in which care is given. It will confirm what many care home staff have known for a number of years; that is that the residents in their care often 'slip away' peacefully (Fleming et al., 2017). Hospices have cared for dying people for many years and have a very low hospital admission rate at the end of life. Care homes, who have a different demographic, but essentially the same cohort of dying people as hospices, do not always recognise the need **not** to admit to hospital.

Despite Key finding one recognising that dying in care homes is different from other populations, **Key finding two** identified that there were very few differences in symptoms between the different population demographics within the cohort, meaning that dying is also quite similar across different residents. Variables of interest such as age, gender, diagnosis and length of stay in the care home showed little difference in symptoms within the cohort. Although there were some differences in individuals, when looking at this group as a cohort there were mainly similarities. The similarities present within this cohort, regardless of diagnosis, age, gender and length of stay at this very late stage of life, had not been reported on before making this seem to be a unique finding. As the diagnosis of dementia was included in the modelling process, this implies that people with dementia do not seem to have a different death trajectory to people without dementia.

The symptoms were able to be categorised into two different types which creates **Key finding three**. The symptoms that were the most frequently occurring/most intense have been characterised as being 'silent'. Silent symptoms are gradual in their onset, have an observable pattern and increase towards the time of death. The group of four symptoms of increasing drowsiness, fatigue, anorexia and being unable to respond had not been previously specifically identified as being important in relation to impending death. The categorisation of the 'silence' of them had also not been noted in previous literature. This is often because many studies had focused on the reporting of 'strident' symptoms, particularly pain, which was evident in nearly all of the studies that were reviewed in the literature review; pain had also been a solo study outcome in two studies. This suggests that 'silent symptoms' do have value and could be acknowledged for what they demonstrate. It needs to be recognised that not all symptoms have to be 'managed' through medical/pharmacological interventions, but that they are useful signs for the professionals caring for people at the end of life. It matters because it can influence where the emphasis of end of life care in care homes is placed. Teaching care home staff to identify and become familiar and comfortable with these symptoms could be more beneficial to teaching management of a set of acute symptoms that are less likely to arise.

Key finding four showed that residents dying in care homes did not have significantly high numbers of symptoms that required acute symptom management. These symptoms also fell into the silent symptom classification whereas the symptoms that usually required acute management fell into the strident classification. The implications of this is similar to Key finding three, although in addition, when

'strident' symptoms arise, care home staff should know where to go and whom to ask for support.

This study showed that recognising death is very challenging **(Key finding five)**. Although this finding was not unique to this study, as it has been described previously, it had often not been reported upon as part of a symptom research study. In this research, it was detected because participants needed to be recruited at the point of recognition of entering the dying phase and 23 out of the 157 were not recruited until less than four hours prior to death. It is worthy of note that no resident died (in the care home) without having at least one assessment using the ESAS so although death may have been reported as 'unexpected', there were warnings in many cases even if it was less than four hours prior to death. The implications are that although professionals may feel concerned at not being able to forecast dying with any degree of accuracy, the lack of certainty can be used to benefit care. Professionals who work with residents in care homes need to be supported to use approaches to pre-empt this uncertainty. If the care homes engage in thorough Advance Care Planning processes, this can promote choice and decision making for residents and families, one of the things that can help to improve quality of life. To do this, staff need to have excellent communication skills of the type that are often provided to acute clinical staff as they will need to be able to support open, honest and sensitive discussions with residents and their families. If residents are not identified as dying until very late in the dying trajectory, the result can lead to inappropriate care such as hospital admissions or emergency response calls being provided if imminent death is not recognised.

The findings are important when it comes to developing and implementing policy. There is a contradiction in current directives. On one hand, there is a national drive to reduce 'inappropriate' admissions from care homes to hospital, so a resident who is identified as being at the end of life gives a rational decision not to admit. However, there is a fear from care homes that they are not providing essential care if they fail to admit, and fear that they put themselves in line for scrutiny from their regulatory body or managers (National Institute For Health And Care Excellence, 2015b).

7.4 How the research met the study aim and objectives

These have been identified throughout this thesis and are hereby presented as a summary within table 7.1.

Table 7.1 Achievement of the research aims and objectives

Aim	How were these achieved?
Describe the presence and intensity of physical symptoms of residents in the dying phase in care homes, and explore whether there are changes in symptoms over time and how they relate to specific demographics and other characteristics.	Twelve symptoms were assessed: 'Is it there', 'How often is it there for' and 'What level did it occur at' meeting the requirements for presence and intensity. Their common characteristics were explored.

Objectives	How were these achieved?
To measure the presence and intensity of total physical symptoms, and test the associations between key characteristics (age, gender, number of diagnoses and length of stay), during the final 48 hours of life in people who are resident in a care home.	The presence and intensity of the total physical symptoms were tested for significance by pairwise comparison and showed an increase in both presence and intensity towards the time of death. There were very few significant associations.
To measure the presence and intensity of individual physical symptoms, during	The presence and intensity of individual physical symptoms were tested for

the final 48 hours of life in people who are resident in a care home and test the associations between key characteristics (age, gender, number and type of diagnoses and length of stay) during the final 4 hours of life in people who are resident in a care home.	significance by pairwise comparison and showed an increase of several symptoms in both presence and intensity towards the time of death. There were very few significant associations.
To propose a typology of symptoms associated with the dying phase derived from the population characteristics and the longitudinal changes over time.	The typology comprises of two elements: Firstly, it identified a slow gradual deterioration towards death, and secondly, documented a classification of silent and strident symptoms.

7.5 Methodological findings

Although symptoms at the end of life in care home residents was not an area that has attracted extensive research, the range of variations within the reporting of the presence of symptoms across the different studies was considerable. There was little consensus between the reporting of symptoms, although drowsiness was a very commonly reported symptom. Throughout the different studies, there was a very wide range of different ways of obtaining data from observation through to extracting data from residents' records. While the majority of studies used retrospective data, there were far fewer that collect data prospectively. The studies that involved prospective data often did not involve the staff caring for them and, given that the nature of data collection will normally be by proxy, it could be a weakness of any potential study by not involving the staff who know the resident and by utilising records that may not have been fit for purpose when written. Understanding the temporal aspects is a less-researched area. It was not easy to identify when a person is dying, so hence made it difficult to know when to start data collection, especially within a prospective study.

The value of prospective cohort studies need to be recognised. Collecting data for the direct purpose of a study was beneficial as retrospective data were much more open to misinterpretation. Prospective studies do have challenges, but they provided a key method to obtain specific data. The methods of collecting data (by assessing symptoms) and using a standardised instrument could be a lesson learnt from this study, although there were challenges in identifying an appropriate instrument for this study too. The literature review demonstrated that research on symptoms could be more rigorous, more standardised and more joined-up. As studies like this often involve small numbers, having studies that can be consolidated into meta-analyses would be very advantageous. There is a need to have processes for regular and comparative assessment and monitoring of significant symptoms and a way to find a more global description/ assessment of symptoms instead of a qualitative assessment (Bisgaard et al., 2011).

There needs to be a consensus on what are the significant symptoms at end of life. This would lead to a more consistent approach in symptom management. Future research could focus on defining key symptoms to be able to develop consistent data sets going forward. Once core symptoms are agreed and explored, future research could be focussed on other broader issues. Studies that consider the management of symptoms in care homes would add to the knowledge base, and one that is not currently well researched. Some of the symptoms that have been grouped as 'strident', such as shortness of breath, secretions and pain, could be monitored along with their management, providing valuable information to support future symptom management. This study highlighted a group of symptoms which have been grouped as 'silent'. They often receive little attention within research studies, yet are the most prolific within

this cohort. Further understanding of the impact of these symptoms upon residents is required, but also there is also a need to consider why these symptoms remain unacknowledged in some cases.

7.6 Recommendations

7.6.1 Recommendations for future practice

1. All staff working in care homes and with care homes are educated to recognise the signs of impending death and understand the nature of symptoms, particularly in relation to 'silent' and 'strident' symptoms.
2. Care homes are supported to carry out consistent assessment and measurement of symptoms for residents who are at the very end of life.
3. Guidelines that support symptom management are aligned with the new knowledge about the prevalence of symptoms in this population.

7.6.2 Recommendations for future policy

1. Care homes need to be recognised for their contribution to end of life care and involved when policies and guidelines are being developed.
2. More knowledge is required about the influence of culture within care homes and the impact that has upon implementation of practice or delivery systems in the care homes

7.6.3 Recommendations for future research

1. Guidance from the MORECare statement is taken into account when planning research in care homes.

2. Temporal aspects of symptoms are a requirement to understand the changes that occur over a given period of time.

3. ==A matched study looking for silent and strident symptoms in other populations or care contexts==

4. Proxy reporting measures are strengthened and developed further.

5. There is a development of a symptom research model that will provide a lens through which to view symptom research and provide the consistency needed to produce studies suitable for cross analysis.

6. A reliable and valid instrument is available for use with a care home population that captures the appropriate symptoms over a series of time points with the ability to be used by a proxy-rater. The instrument needs to be straightforward in use and is practical and functional for care home staff as well as researchers.

7.7 Conclusion

To conclude this thesis, this positivist study has met the aims and outcomes that it set out to achieve. The importance of understanding the symptoms is not only important from a symptom management perspective, but demonstrates that the effect of not understanding symptoms (and the broader impact of them) can be very wide-reaching. This study, through its findings, will help to improve care for older people dying in care homes through better symptom recognition and their subsequent management

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Appendices

Appendix i - Characteristics of an Ideal Model or Theory for Symptom Management Research

Evaluation components	Criteria
Antecedents and/or precipitating factors	Demographic and sociocultural characteristics Age, gender, marital status, sexual preference, race, culture, role, education, socioeconomic status, developmental stage Psychological characteristics Attitude, motivation, mental ability, mental illness Physiological characteristics Disease type and state, types of treatments, co-morbid conditions, clinical factors Individual health and illness factors Health knowledge, values, attitudes, past experiences, sense of coherence, self-efficacy, motivation, resiliency, risk factors, personal definition of wellness, substance abuse issues
Symptom appraisal	Symptom assessment: location, timing, intensity, quality, exacerbating factors, alleviating factors Symptom meaning: distress, impact, existential meaning Symptom evaluation and response to self-care, pharmacologic, and non-pharmacological interventions Symptom appraisal resulting from interactions with clinicians and the healthcare system
Symptom pair and cluster components	Multiple underlying mechanisms Symptom interactions: physiologic, psychological, sociocultural, behavioural Symptom multiplicity
Outcomes or consequences	Functional performance Cognitive performance Self-care Costs Adjustment to illness Emotional adjustment Cognitive factors Adaptive behaviours Quality of life Morbidity and co-morbidities Mortality
Temporal components	Temporal patterns Change over time Onset and rate of change Patient outcomes over time Resolution Alleviation Enduring symptoms Exacerbation of symptoms Acute versus chronic progression of symptoms and disease states
Intervention components	Self-care Health seeking behaviours Inclusion of different types of interventions Adherence Clinician influences Demographic influences Sociocultural influences Cognitive influences
Concepts	Identified, well-defined, discussed
Relationships	Clearly delineated
Utility	Model is useful, generalizable and parsimonious

Brant, J. M., Beck, S., & Miaskowski, C. (2010). Building dynamic models and theories to advance the science of symptom management research. *Journal of Advanced Nursing, 66*(1), 228.

Appendix ii - Assessment form for data extraction and scoring

Author(s):	Date of Publication:

Abbreviated Title:

Date Assessed:

Study Design ( ) Quantitative ( ) Qualitative ( ) Combination	Location of Study: Sample – Size:	Sample – Description:

Aim:

Research Questions / Hypothesis (If Any):

Method and Analysis:

Intervention (If Applicable)

Results:

Conclusions, Comments, and Issues Raised:

	Good	Fair	Poor	Very Poor	Comments
1. Abstract and title					
2. Introduction and aims					
3. Method and data					
4. Sampling					
5. Data analysis					
6. Ethics and bias					
7. Findings/results					
8. Transferability/generalizability					
9. Implications and usefulness					
Total					

Hawker, S., Payne, S., Kerr, C., Hardey, M., Powell, J. (2002) Appraising the evidence: reviewing disparate data systematically. Qualitative Health Research. 12, (9), 1284-1299

Appendix iii - Protocol for scoring for methodological rigour

1. Abstract and title: Did they provide a clear description of the study?

Good	Structured abstract with full information and clear title
Fair	Abstract with most of the information
Poor	Inadequate abstract
Very Poor	No abstract

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?

Good	Full but concise background to discussion/study containing up- to date literature review and highlighting gaps in knowledge
	Clear statement of aim AND objectives including research questions
Fair	Some background and literature review
	Research questions outlined
Poor	Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background
Very Poor	No mention of aims/objectives
	No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?

Good	Method is appropriate and described clearly (e.g. questionnaires included)
	Clear details of the data collection and recording
Fair	Method appropriate, description could be better
	Data described
Poor	Questionable whether method is appropriate
	Method described inadequately
	Little description of data
Very Poor	No mention of method, AND/OR
	Method inappropriate, AND/OR
	No details of data

4. Sampling: Was the sampling strategy appropriate to address the aims?

Good	Details (age/gender/race/context) of who was studied and how they were recruited
	Why this group was targeted
	The sample size was justified for the study
	Response rates shown and explained
Fair	Sample size justified
	Most information given, but some missing
Poor	Sampling mentioned but few descriptive details
Very Poor	No details of sample

5. Data analysis: Was the description of the data analysis sufficiently rigorous?

Good	Clear description of how analysis was done
	Qualitative studies: Description of how themes derived/respondent validation or triangulation
	Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed

Fair	Qualitative: Descriptive discussion of analysis
	Quantitative.
Poor	Minimal details about analysis
Very Poor	No discussion of analysis

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed
	Bias: Researcher was reflexive and/or aware of own bias
Fair	Lip service was paid to above (i.e., these issues were
acknowledged)	
Poor	Brief mention of issues
Very Poor	No mention of issues

7. Results: Is there a clear statement of the findings?

Good	Findings explicit, easy to understand, and in logical
progression	
	Tables, if present, are explained in text
	Results relate directly to aims
	Sufficient data are presented to support findings
Fair	Findings mentioned but more explanation could be given
	Data presented relate directly to results
Poor	Findings presented haphazardly, not explained, and do not progress logically from results
Very Poor	Findings not mentioned or do not relate to aims

8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?

Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in
	Question 4 (sampling)
Fair	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in
	Question 4
Poor	Minimal description of context/setting
Very Poor	No description of context/setting

9. Implications and usefulness: How important are these findings to policy and practice?

Good	Contributes something new and/or different in terms of understanding/insight or perspective
	Suggests ideas for further research
	Suggests implications for policy and/or practice
Fair	Two of the above (state what is missing in comments)
Poor	Only one of the above
Very Poor	None of the above

Hawker, S., Payne, S., Kerr, C., Hardey, M., Powell, J. (2002) Appraising the evidence: reviewing disparate data systematically. Qualitative Health Research. 12, (9), 1284-1299

End of life in Care Homes:
Research project on symptoms experienced by residents at end of life

THIS INFORMATION LEAFLET IS FOR CARE HOME MANAGERS

Why is this research being done?
Care homes are caring for an increasing number of people at the end of life and generally use symptom management guidance from a range of sources. This can include the Liverpool Care Pathway flow charts or information from the local specialist palliative care teams. It is extremely useful to have this guidance, but much of the current guidance has come from research with people with cancer and there has been little research done looking at the symptoms experienced by residents living in care homes. It would be very useful to be able to get an up to date picture of what is happening with residents at this stage of their life. This would ensure that appropriate symptom management guidance can be provided for residents living in care homes and the staff caring for them.

Who can take part?
A number of homes across the CECPCT/WCPCT area are being asked to take part in a research project
The criteria for inclusion in the research project are:
• There is managerial support and/or organisational support (depending on care homes' policy) for the project to go ahead within the care home.
• There is current use of an Integrated Care Pathway/Liverpool Care Pathway or equivalent and/or ways of identifying dying residents.
• At least one member of staff has undergone additional palliative care training/education within the last 12 months.

What would you be asked to do?
All qualified staff would be asked to record the symptoms experienced by residents (at the end of life – i.e. within the final 48 - 72 hours) on a special form called an ESAS. The ESAS is a recognised tool that has been used in many care settings to monitor the symptoms experienced by people near the end of life. The ESAS will be attached to the Liverpool Care Pathway and the resident's symptoms will be observed and documented at the same time that the care pathway documentation is normally completed. There will be more

information available about the ESAS and I am happy to speak to staff either individually or as a team about the ESAS and how it is completed.

The project will also be collecting some demographic information about the resident, so the (qualified) staff would be asked to complete another form with some basic information such as age, gender, diagnosis, length spent in care home. This form will be completed at the same time as the pathway is commenced. We do not wish to collect any information that could identify the residents, so will not be asking for names, previous addresses, names of GPs etc.

Both of the collection forms will have codes on the top right hand corner. The forms will come as a 'pair' – i.e. the ESAS and the demographic information sheet. Please ensure that the codes on both forms match so the data can be collated at a later date.

All completed forms need to be placed in a sealed envelope (blank envelopes will be provided) and kept in an agreed place, probably the nurses or, if more suitable, your own office. Forms will be collected once a week by one of the research team. Staff will have the opportunity to ask questions or have anything clarified during this visit. The date of next collection/visit will be posted on a note at the collection point.

What will we do with the information you give us?

The data that you provide (i.e., all the information on the forms) will be inserted into a computer, which will enable us to see the occurrence of specific symptoms and any relationship to each other. The data will not be identified to any individual (it will be anonymous) but will build up to provide a bigger picture of what sort of things happen to residents at the end of life.

The completed forms will be always be stored in a safe locked place and the data on the computer will only be able to be accessed with a special password. At the end of the research project, the completed forms will be destroyed.

Consent from residents and families

Although the research project will involve a number of residents, there will be many more that do not get involved with the research project. However, it is important to inform residents and families that a research project is taking place. An information poster has been produced so it can be placed on a notice board for residents and their families to read. Depending on the communication structure of the home, the information may also be discussed at residents meetings or an item placed in the home newsletter. I would be very happy to speak to any resident/family member or member of staff if more information is required.

An extra booklet with more details about the research project will be available for any residents or families who require additional information. Copies of this booklet will be kept in the box where you will place the completed forms. Finally, I would be very happy to speak to any resident/family member or member of staff if more information is required and can be contacted directly by the resident/family or you are welcome to get directly in touch with me.

Any resident or their family can request for their information not to be included in the research project. If a resident or their family member requests not to be involved, there will be some (colour to be inserted once agreed with individual homes) coloured stickers in the collection box. Staff will be requested to stick

one of these on top of the resident's kardex/notes so all staff will know that this data should not be collected. If a resident is involved in the research project and a family member requests that the data is withdrawn, the ESAS and the demographics sheet should be destroyed and a note of the code number put in the collection box. Once the data has been collected (after the death of the resident), it would not be possible for the data to be withdrawn as it will have been anonymised, therefore not identifiable for removal.

<u>What if you change your mind about taking part?</u>
If you say that you want to take part in this project and then you change your mind about it, that is fine – just let us know! You are welcome to change your mind at any time and we will not put pressure on you to continue.

<u>Who are we and how can you contact us?</u>
My name is Lynne Partington and I am a researcher working at St Luke's Hospice. I also work as a Lecturer in Palliative Care at Cheshire Hospices Education.
Nichola Noden (who is an administrator working at Cheshire Hospices Education) will be working with me for one day a week.
I have an honorary contract with Lancaster University for the duration of this project and am being supported by Dr Katherine Froggatt, who is a researcher at the University. This project has been given ethics approval by Lancaster University.

We can be contacted at Cheshire Hospices Education on **01606 559292** or by email at either lynne-p@che.org.uk or nichola-n@che.org.uk

Form of consent for care home to participate in a research project

Title of project: *Research on symptoms experienced by residents at end of life*

I…………………………………………… agree to
involve……………………….
(Subject's full name)   *(Care home name)*
to take part in the above named project, the details of which have been
provided and explained to me.

Signed…………………………………   Date……………………………….
         (Subject)

I…………………………………………….. certify that the details of this project
(Investigator's full name)
have been provided and fully explained to the subject named above and
have been understood by him/her.

Signed…………………………………   Date……………………………….
         (Investigator)

Research project in *(insert name)* care home

We are always looking for ways to improve the care provided to residents at all stages of their stay with us. So we are involved in a research project, which is looking at the experiences of people at the end of life. The research is particularly focussing on what sorts of symptoms (for example, pain or breathlessness) that people may experience at the end of their lives.

Lynne Partington is a lecturer and researcher based at St Luke's Hospice in Winsford. She is particularly interested in care homes and also works part-time as a bank nurse in a care home in another area.

The research involves Lynne collecting information from the staff at the home. The information will be collected from the forms that are usually completed when residents are very poorly so no extra effort is required. The information will be collected with the greatest of confidence and respect and all information will be anonymised so the resident will not be able to be identified in any way. The project has been granted ethical approval from Lancaster University.

If you or your family do not wish your information to be involved in this project, please inform the manager, ** **, or nursing staff
If you would like more information, please speak to the manger or staff, or Lynne can be contacted directly at Cheshire Hospices Education on 01606 559292

Appendix viii - Information leaflet for care home residents and family members

APPENDIX X—INFORMATION SHEET FOR RESIDENTS/FAMILIES

Research project
in (*insert name*) care home

Information sheet
for residents and families

St Luke's Cheshire Hospice · CHESHIRE HOSPICES EDUCATION · LANCASTER UNIVERSITY

Front page

Information about the project

We are always looking at ways in which we can improve the care provided to residents at all stages of their stay with us.

We are involved in a research project, which is looking at the experiences of people at the end of their lives. The main focus of the research is find out what types of symptoms (for example, pain, breathlessness, nausea) that older people may experience at the end of their lives.

The information will be gained from a form that the trained nurses will complete while caring for the resident at the end of his or her life. This information will help ensure that the necessary care is provided and will help inform care and services in the future as well.

The resident will not be interviewed or come into direct contact with the research team.

Page 2

What happens to the information?

The completed forms will be collected by a researcher called Lynne Partington, who will collate all the information together. The forms that are given to Lynne will not have any identifying information on it so the resident will not be able to be recognised in any way.

All information will be treated with the greatest of respect and confidence at all times.

More information?

If you would like any more information about this project, please speak to **** ****, home manager or any of the nursing staff.
Alternatively, if you wish to speak to Lynne, this can be arranged through the care home staff or directly (details overleaf...)

Involvement is voluntary. If you do not wish your Information to be included in this project, please inform the manager or nursing staff. However, in order to preserve total anonymity, it would not be possible to withdraw the data after collection by the research team. This is because the data provided to the research team does not have any information included that would identify a resident.

Page 3

About the research team

Lynne Partington is a Senior Lecturer and Researcher for Cheshire Hospices Education based at St Luke's Hospice in Winsford. Lynne is a qualified nurse and has a great interest in care homes. She also works part-time as a bank nurse in a care home in another area. Lynne has an honorary contract with Lancaster University and this project has been granted ethical approval from Lancaster University.

Nichola Noden works with Lynne at Cheshire Hospices as an administrator and will be supporting Lynne throughout this project.

If you would like to speak or meet with Lynne / Nichola, they can be contacted on 01606 559292 or Email lynne-p@che.org.uk

Back page

Appendix ix - Form to record withdrawn participants

<u>Withdrawing residents</u>

Please use this form if a resident or family wishes to withdraw from the research project AFTER data collection has begun. Please make a note of the code on the ESAS form before it is destroyed. (This help to keep track of the forms)

Thank you

Date of withdrawal	Code on ESAS form

End of life in Care Homes:
Research project on symptoms experienced by residents at end of life

INFORMATION LEAFLET IS FOR QUALIFED STAFF WORKING IN (*NAME*) CARE HOME

Why is this research being done?
Care homes are caring for an increasing number of people at the end of life and generally use symptom management guidance from a range of sources. This can include the Liverpool Care Pathway flow charts or information from the local specialist palliative care teams. It is extremely useful to have this guidance, but much of the current guidance has come from research with people with cancer and there has been little research done looking at the symptoms experienced by residents living in care homes. It would be helpful to be able to get an up to date picture of what is happening with residents at this stage of their life to ensure that appropriate symptom management guidance can be provided for residents living in care homes.

Who can take part?
All qualified nurses working in (*Name*) Care Home are invited to be involved in this research project

What would you be asked to do?
You will be asked to record the symptoms experienced by residents (at the end of life – i.e. within the final 48 - 72 hours) on a special form called an ESAS. The ESAS is a recognised tool that has been used in many care settings to monitor the symptoms experienced by people near the end of life. The ESAS will be attached to the Liverpool Care Pathway and the symptom will be recorded at the same time that you usually complete the care pathway documentation. There will be more information available about the ESAS and I am happy to speak to you either individually or as a team about the ESAS and how it is completed.
We will also be collecting some demographic information about the resident, so will ask you to complete another form with some basic information such as age, gender, diagnosis, length spent in care home. This form will be completed at the same time as the pathway is commenced. We do not wish to collect any information that could identify the residents, so will not be asking for names,

previous addresses, names of GPs etc. to ensure that residents remain anonymous.

Both of the collection forms will have codes on the top right hand corner. The forms will come as a 'pair' – i.e. the ESAS and the demographic information sheet. Please ensure that the codes on both forms match so the data can be collated at a later date.

All completed forms need to be placed in a sealed envelope (blank envelopes will be provided) and kept in (*a collection place to be agreed with the team/home manager*). Forms will be collected once a week by one of the research team. Staff will have the opportunity to ask questions or have anything clarified during this visit. The date of next collection/visit will be available on a note at the collection point.

What will we do with the information you give us?

The data that you provide (i.e. all the information on the forms) will be input into a computer, which will enable us to see the occurrence of specific symptoms. The data will not be identified to any individual (it will be anonymous) but will build up to provide a bigger picture of what sort of things happen to residents at the end of life.

The completed forms will be stored in a safe locked place and the data on the computer will only be able to be accessed with a special password.

Consent from residents and families

Although the research project will involve a number of residents, there will be many more that do not get involved with the research project. However, it is important to inform residents and families that a research project is taking place. An information poster has been produced so it can be placed on a notice board for residents and their families to read. Depending on the communication structure of the home, the information may also be discussed at residents meetings or an item placed in the home newsletter. An extra booklet with more details about the research project will be available for any residents or families who require additional information. Copies of this booklet will be kept in the box where you will place the completed forms. Finally, I would be very happy to speak to any resident/family member or member of staff if more information is required and can be contacted directly by the resident/family or you are welcome to get directly in touch with me.

Any resident or their family can request for their information not to be included in the research project. If a resident or their family member requests not to be involved, there will be some (colour to be inserted once agreed with individual homes) coloured stickers in the collection box. Staff will be requested to stick one of these on top of the resident's kardex/notes so all staff will know that this data should not be collected. If a resident is involved in the research project and a family member requests that the data is withdrawn, the ESAS and the demographics sheet should be destroyed and a note of the code number put in the collection box. Once the data has been collected (after the death of the resident), it would not be possible for the data to be withdrawn as it will have been anonymised, therefore not identifiable for removal.

Who are we and how can you contact us?

My name is Lynne Partington and I am a researcher working at St Luke's Hospice. I also work as a Lecturer in Palliative Care at Cheshire Hospices Education.

Nichola Noden (who is an administrator working at Cheshire Hospices Education) will be working with me for one day a week.

I have an honorary contract with Lancaster University for the duration of this research project and am being supported by Dr Katherine Froggatt, who is a researcher at the University. This research project has been given ethics approval by Lancaster University.

We can be contacted at Cheshire Hospices Education on **01606 559292** or by email at either lynne-p@che.org.uk or nichola-n@che.org.uk.

Appendix xi - Form to record information provided to qualified nurses

Research project on symptoms experienced by residents at end of life

Name of Care Home:

Name of Unit:

I agree that I have been provided with an information sheet regarding the above named research project. I understand my role outlined within the information sheet.

NAME	JOB TITLE	SIGNATURE	DATE

Preparation session for care home staff for end of life symptom research project

- Introduce self

- Discuss background and rationale to research project

- Discuss resident participation (family/resident meetings/posters/info booklets for families & residents)

- Discuss the process (using the colour flow chart)

- How to complete the first page (demographics – complete all boxes). Explain coding system

- How to complete the ESAS – complete all boxes – decide severity of symptom – This is not about checking up on care but if you do have a challenging issue, please pass it on to me/Manager/Key link person

- Presentation and practice of the use of the ESAS with 'Maud' – a case study

- The first 2 weeks will be used as a trial and will then review any issues that have been identified

- Discuss residents who withdraw (withdrawing sheet in box) or destroyed forms

- LP and/or NN to visit weekly. Contact details available. 'Next visit' on top of box.

- How does it fit with the use of the pathway – any questions about ICP/LCP?

- Any questions??

END OF RESEARCH PROJECT

We have now finished collecting information for the end of life research project that *(care home)* has been involved with for the last several months.

Can we thank everyone at *(care home)* for collecting and passing on information for the research project undertaken by myself on behalf of St Luke's Hospice and Cheshire Hospices Education.

Some specific information from the findings will be provided through your Manager within a few weeks and there will be a more detailed report later on. If you need any information or have any questions, please contact Lynne or Nichola on 01606 559292.

Thank you

Lynne Partington & Nichola Noden

Appendix xv - Letter of ethics approval (1) from Lancaster University

Lynne Partington

Cheshire Hospices Education
Queensway
Winsford
Cheshire

28 January, 2009

Dear Lynne

Re: IHR Ethics Committee application for your research project titled "A prospective study to examine the incidences of end of life symptoms in care home residents"

Thank you for sending the revised paperwork relating to your research project. I can confirm, on behalf of the Ethics Committee, that your project has been approved. Best wishes for the rest of your research!

Yours sincerely

Dr Keren Cohen
Institute for Health Research Ethics Committee
Lancaster University

Appendix xvi - Letter of ethics approval (2) from Lancaster University

LANCASTER
U N I V E R S I T Y

Lynne Partington
Senior Lecturer and Researcher
Cheshire Hospices Education
Queensway
Winsford
Cheshire
CW7 4AW

20th February 2009

Dear Lynne

Re: "A prospective study to examine the incidences of end of life symptoms in care home residents"
Many thanks for your letter of 20th February outlining a proposed extension of your project to include 11 rather than 10 care homes. This is a minor amendment and your research still meets the requirements for ethical approval.

Yours sincerely

Anna Daiches
DHR Ethics Committee

Appendix xvii - Letter of ethics approval exemption from NHS

NHS

National Research Ethics Service

Cheshire Research Ethics Committee
Research Ethics Office
Victoria Building
Bishop Goss Complex
Rose Place
Liverpool
L3 3AN

Telephone: 0151 330 2070
Facsimile: 0151 330 2075

29 September 2008

Lynne Partington
Senior Lecturer & Practitioner
Cheshire Hospices Education
St Luke's Hospice
Queensway
Winsford
Cheshire
CW7 4AW

Dear Ms Partington

Full title of project: incidence of end of life symptoms in care home residents.

REC reference: 03/09/08

Thank you for seeking the Committee's advice about the above project.

You provided the following documents for consideration:

- *Project outline dated 29 July 2008*

These documents have been considered by the Vice Chair

I enclose a copy of our leaflet, 'Defining Research', which explains how we differentiate research from other activities. Chair has advised that the project is not considered to be research according to this guidance. Therefore it does not require ethical review by a NHS Research Ethics Committee.

You should check with the appropriate Trusts what other review arrangements or sources of advice apply to projects of this type. Guidance may be available from the clinical governance office.

This Research Ethics Committee is an advisory committee to North West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

This letter should not be interpreted as giving a form of ethical approval to the project or any endorsement of the project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements.

However, if you, your sponsor / funder or any NHS organisation feels that the project should be managed as research and/or that ethical review be a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

Where NHS organisations have clarified that a project is not to be managed as research the Research Governance Framework states that it should not be presented as research within the NHS.

Yours Sincerely

R G Emmett
Committee Co-ordinator

E-mail: rob.emmett@liverpoolpct.nhs.uk

Enclosure: NRES leaflet – "Defining Research"

Appendix xviii - Email of ethics approval exemption from local CCGs

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Lynne Partington, CHE

From:	r.beech@hpm.keele.ac.uk
Sent:	27 August 2008 10:23
To:	lynne-p@che.org.uk
Cc:	liz.saadouni@cocpct.nhs.uk
Subject:	Re: research ethics

Lynne

I am pleased that things are progressing with your project. The meeting that I was referring to was the PCT's Research and Audit Approval Group. I cannot remember the precise details of our converstaion but my view must have been that because your study does not involve PCT staff or patients it will not require formal approval from that Group. However, I thought that they would find your study of interest. Hence, presentation at the meeting would represent an awareness raising exercise.

I'll leave it to you to decide when you are ready to forward details of your project. When you are ready, Liz Saadouni is the person to contact.

Regards

Roger

>
> Hi Roger,
>
> I hope that you are well.
>
> Following our last discussion regarding the research project that I am
> involved with, I have had discussions with Rob Emmett, who following
> discussions with the vice-chair of the Cheshire REC has said that I do not
> need ethical approval from their perspective. I am now in the process of
> taking it through Lancaster University Division of Health Research Ethics
> Committee.
> At our last meeting, you had requested my proposal to be tabled at a
> meeting, but also would not require formal PCT approval. Would you mind
> putting that down in an email/note so I can keep it as a point of
> reference?
> Thank you very much,
>
> With best wishes,
>
> Lynne
>
> Lynne Partington
> Senior Lecturer & Practitioner
>
> Cheshire Hospices Education
> Queensway
> Winsford
> Cheshire
> CW7 4AW
>
> Email: lynne-p@che.org.uk
> Tel: 01606 559292
>
>
>
> Confidentiality: This e-mail and any attachments, together with their
> contents, are confidential unless otherwise explicitly stated in writing
> by the sender of this e-mail and are for the intended recipient only. If
> they have come to you in error you must not take any action in respect of
> them, which includes but is not limited to reproducing, sending or storing
> them, other than to notifying the sender immediately of the mistake, and
> deleting the e-mail, any attachments and any reproductions made by

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Appendix xiv - **Modified Edmonton Symptom Assessment Scale**

Modified Edmonton Symptom Assessment Scale (ESAS) for CARE HOMES

Date																								
Time	2am	6am	10am	2pm	6pm	10pm	2am	6am	10am	2pm	6pm	10pm	2am	6am	10am	2pm	6pm	10pm	2am	6am	10am	2pm	6pm	10pm
Symptom																								
Pain																								
Fatigue (Tiredness)																								
Drowsiness (Sleepiness)																								
Depression																								
Anxiety																								
Nausea																								
Anorexia																								
Shortness of breath																								
Delirium (Y/N)																								
Secretions (Y/N)																								
Unable to respond (Y/N)																								
Constipation (Y/N)																								
Initials of nurse completing assessment																								

Assessment Scale:	None = 0	Mild = 1	Moderate = 2*	Severe* = 3	* requires daily follow-up plus 72 hour follow-up

Appendix xv - **Pairwise comparisons of the presence of individual symptoms at 4 hrs, 24 hrs and 48 hrs prior to death**

Table Append xv (a) Pairwise comparisons of the presence of anorexia at 4 hrs, 24 hrs and 48 hrs prior to death

Factor	Test Statistic	Std. Error
Presence of anorexia at 4 hours v 24 hours	.000	.023
Presence of anorexia at 4 hours v 48 hours	.049*	.023
Presence of anorexia at 24 hours v 48 hours	.049*	.023

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xv (b) Pairwise comparisons of the presence of shortness of breath at 4 hrs, 24 hrs and 48 hrs prior to death

Factor	Test Statistic	Std. Error
Presence of shortness of breath at 4 hours v 24 hours	.197***	.055
Presence of shortness of breath at 4 hours v 48 hours	.246***	.055
Presence of shortness of breath at 24 hours v 48 hours	.049	.055

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xv (c) Pairwise comparisons of the presence of secretions at 4 hrs, 24 hrs and 48 hrs prior to death

Factor	Test Statistic	Std. Error
Presence of secretions at 4 hours v 24 hours	.131*	.058
Presence of secretions at 4 hours v 48 hours	.262***	.058
Presence of secretions at 24 hours v 48 hours	.131*	.058

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xv (d) Pairwise comparisons of the presence of unable to respond at 4 hrs, 24 hrs and 48 hrs prior to death

Factor	Test Statistic	Std. Error
Presence of unable to respond at 4 hours v 24 hours	.131*	.058

Presence of unable to respond at 4 hours v 48 hours	.262***	.058
Presence of unable to respond at 24 hours v 48 hours	.131*	.058

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Appendix xvi - Pairwise comparisons of the intensity of individual symptoms at 4 hrs, 24 hrs and 48 hrs prior to death

Table Append xvi (a) Pairwise comparisons of pain at 4 hrs, 24 hrs and 48 hrs prior to death

Factor	Cross factor	Mean difference	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intensity of pain at 4 hours	24 hours	-.098	.087	-.271	.075
	48 hours	-.098	.098	-.295	.098
Intensity of pain at 24 hours	4 hours	.098	.087	-.075	.271
	48 hours	.000	.107	-.214	.214
Intensity of pain at 48 hours	4 hours	.098	.098	-.098	.295
	24 hours	.000	.107	-.214	.241

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xvi (b) Pairwise comparisons of fatigue at 4 hrs, 24 hrs and 48 hrs prior to death

Factor	Cross factor	Mean difference	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intensity of fatigue at 4 hours	24 hours	.164*	.067	.030	.298
	48 hours	.295***	.085	.124	.466
Intensity of fatigue at 24 hours	4 hours	-.164*	.067	-.298	-.030
	48 hours	.131	.072	-.013	.275
Intensity of fatigue at 48 hours	4 hours	-.295***	.085	-.466	-.124
	24 hours	-.131	.072	-.275	.013

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xvi (b) Pairwise comparisons of drowsiness at 4 hrs, 24 hrs and 48 hrs prior to death

Factor	Cross factor	Mean difference	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intensity of drowsiness at 4 hours	24 hours	.262**	.084	.094	.430
	48 hours	.410***	.097	.215	.605
Intensity of drowsiness at 24 hours	4 hours	-.262**	.084	-.430	-.094
	48 hours	.148	.084	-.020	.315

| Intensity of drowsiness at 48 hours | 4 hours | -.410*** | .097 | -.605 | -.215 |
| | 24 hours | -.148 | .084 | -.315 | .020 |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xvi (c) Pairwise comparisons of depression at 4 hrs, 24 hrs and 48 hrs prior to death

| Factor | Cross factor | Mean difference | Std. Error | 95% Confidence Interval | |
				Lower Bound	Upper Bound
Intensity of depression at 4 hours	24 hours	-.066	.057	-.179	.048
	48 hours	-.098	.069	-.236	.040
Intensity of depression at 24 hours	4 hours	.066	.057	-.048	.179
	48 hours	-.033	.040	-.113	.048
Intensity of depression at 48 hours	4 hours	.098	.069	-.040	.236
	24 hours	.033	.040	-.048	.113

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xvi (d) Pairwise comparisons of anxiety at 4 hrs, 24 hrs and 48 hrs prior to death

| Factor | Cross factor | Mean difference | Std. Error | 95% Confidence Interval | |
				Lower Bound	Upper Bound
Intensity of anxiety at 4 hours	24 hours	.033	.096	-.160	.225
	48 hours	.049	.125	-.200	.298
Intensity of anxiety at 24 hours	4 hours	-.033	.096	-.225	.160
	48 hours	.016	.076	-.135	.168
Intensity of anxiety at 48 hours	4 hours	-.049	.125	-.298	.200
	24 hours	-.106	.076	-.168	.136

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xvi (e) Pairwise comparisons of nausea at 4 hrs, 24 hrs and 48 hrs prior to death

| Factor | Cross factor | Mean difference | Std. Error | 95% Confidence Interval | |
				Lower Bound	Upper Bound
	24 hours	.098	.069	-.040	.236

Factor	Cross factor	Mean difference	Std. Error	Lower Bound	Upper Bound
Intensity of nausea at 4 hours	48 hours	.115	.067	-.018	.248
Intensity of nausea at 24 hours	4 hours	-.098	.069	-.236	.040
	48 hours	.016	.016	-.016	.049
Intensity of nausea at 48 hours	4 hours	-.115	.067	-.248	.018
	24 hours	-.016	.016	-.049	.016

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xvi (f) Pairwise comparisons of anorexia at 4 hrs, 24 hrs and 48 hrs prior to death

Factor	Cross factor	Mean difference	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intensity of anorexia at 4 hours	24 hours	.115**	.041	.032	.197
	48 hours	.295***	.082	.131	.459
Intensity of anorexia at 24 hours	4 hours	-.115**	.041	-.197	-.032
	48 hours	.180**	.055	.071	.290
Intensity of anorexia at 48 hours	4 hours	-.295***	.082	-.459	-.131
	24 hours	-.180**	.055	-.290	-.071

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table Append xvi (g) Pairwise comparisons of shortness of breath at 4 hrs, 24 hrs and 48 hrs prior to death

Factor	Cross factor	Mean difference	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intensity of shortness of breath at 4 hours	24 hours	.393***	.094	.205	.582
	48 hours	.508***	.111	.286	.731
Intensity of shortness of breath at 24 hours	4 hours	-.393***	.094	-.582	-.205
	48 hours	.115	.088	-.061	.290
Intensity of shortness of breath at 48 hours	4 hours	-.508***	.111	-.731	-.286
	24 hours	-.115	.088	-.290	.061

Note: * $p < .05$, ** $p < .01$, *** $p < .001$