

Nursing Home Staff's Experience of Moral Distress when Caring for Residents at the End of Life

AMANDA YOUNG

BSc (Hons) Community Nursing

MSc Professional Studies in Nursing. Nurse Education

Faculty of Health and Medicine

Lancaster University

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD programme

August 2015

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

ProQuest Number: 11003594

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest 11003594

Published by ProQuest LLC (2018). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code
Microform Edition © ProQuest LLC.

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

CONTENTS

CONTENTS..... 1

TABLES..... 5

FIGURES..... 5

BOXES..... 5

APPENDICES 5

ACKNOWLEDGEMENTS 7

ABSTRACT 9

CHAPTER 1 INTRODUCTION 11

1.1 THE IMPORTANCE OF THE TOPIC..... 11

1.2 THE SIGNIFICANCE OF THE TOPIC 12

1.3 CONTEXT FOR THE RESEARCH..... 13

1.4 BACKGROUND OF THE RESEARCHER 13

1.5 WHERE THE RESEARCH was CONDUCTED 13

1.6 AIMS AND OBJECTIVES..... 14

1.7 ORGANISATION OF THE THESIS 14

CHAPTER 2 BACKGROUND 17

2.1 INTRODUCTION 17

2.2 LONG TERM CARE PROVISION FOR OLDER ADULTS 17

2.3 END OF LIFE CARE FOR OLDER ADULTS 19

2.4 ETHICS AND END OF LIFE CARE FOR OLDER PEOPLE 21

2.5 A GOOD DEATH 22

2.6 VALUES..... 23

2.6.1 VALUES IN CARING 24

2.7 MORAL DISTRESS 25

2.7.1 MORAL DISTRESS LITERATURE..... 27

2.8 MORAL DEVELOPMENT..... 31

2.9 CONCLUSION..... 32

CHAPTER 3 LITERATURE REVIEW 33

3.1 AIM OF THE REVIEW 33

3.2 LITERATURE REVIEW METHOD 33

3.2.1 FOCUS OF REVIEW 34

3.2.2 SEARCH PROCESS 34

3.2.2.1 Identification of the search terms 34

| | |
|--|----|
| 3.2.2.2 Hand searches | 35 |
| 3.2.2.3 Inclusion and exclusion criteria | 35 |
| 3.3 OVERVIEW OF THE INCLUDED PAPERS | 36 |
| 3.4 APPRAISAL OF THE LITERATURE..... | 36 |
| 3.5 CRITICAL REVIEW OF THE LITERATURE | 38 |
| 3.5.1 SAMPLING STRATEGIES..... | 39 |
| 3.5.2 DATA ANALYSIS AND FINDINGS | 39 |
| 3.5.3 MORAL DISTRESS IN NURSING HOMES..... | 40 |
| 3.5.3.1 Definitions | 40 |
| 3.5.3.2 Measurement of moral distress | 41 |
| 3.5.3.3 Intensity of Moral Distress | 41 |
| 3.5.4 CONTRIBUTORY FACTORS TO MORAL DISTRESS | 43 |
| 3.5.4.1 Conflict..... | 43 |
| 3.5.4.2 Organisational constraints..... | 45 |
| 3.5.4.3 Resources | 47 |
| 3.5.4.3.1 Staffing levels..... | 48 |
| 3.5.4.3.2 Education and knowledge | 49 |
| 3.5.4.3.3 Hospice care | 50 |
| 3.5.4.4. Complexity of patient issues..... | 51 |
| 3.5.4.4.1 Dementia | 52 |
| 3.5.4.4.2 Futile care | 53 |
| 3.5.4.4.3 Symptom management | 54 |
| 3.5.4.4.4 Dying trajectory | 54 |
| 3.5.4.5 Communication | 55 |
| 3.5.4.6 Emotional work | 57 |
| 3.6 FURTHER IDENTIFIED ASPECTS OF CARE..... | 59 |
| 3.7 LIMITATIONS | 59 |
| 3.8 CONCLUSION..... | 60 |
| CHAPTER 4 METHODS AND METHODOLOGY..... | 61 |
| 4.1 EPISTEMOLOGY | 61 |
| 4.2 METHODOLOGY | 62 |
| 4.2.1 INTERPRETIVE DESCRIPTION | 63 |
| 4.3 METHODS..... | 66 |
| 4.3.1 POPULATION | 66 |
| 4.3.2 SAMPLE | 67 |

| | |
|--|-----|
| 4.3.3 RECRUITMENT | 67 |
| 4.3.4 DATA COLLECTION | 68 |
| 4.3.4.1 Critical Incident Technique | 68 |
| 4.3.4.2 Semi-structured interviews | 70 |
| 4.3.5 DATA ANALYSIS | 71 |
| 4.3.5.1 Familiarisation with the data | 73 |
| 4.3.5.2 Generating initial codes | 73 |
| 4.3.5.3 Searching for themes | 75 |
| 4.3.5.4 Reviewing themes | 75 |
| 4.3.6 CREDIBILITY AND RIGOUR | 76 |
| 4.3.7 ETHICAL PROCESSES | 77 |
| 4.3.7.1 Consent | 77 |
| 4.3.7.2 Duty of care to residents | 77 |
| 4.3.7.3 Staff safety | 78 |
| 4.3.7.4 Confidentiality and anonymity | 78 |
| 4.3.7.5 Power dynamics and the researcher's role | 79 |
| 4.4. CONCLUSION | 80 |
| CHAPTER 5 FINDINGS | 81 |
| 5.1 INTRODUCTION | 81 |
| 5.2 DEFINING AND NAMING THEMES | 81 |
| 5.3 ADVOCATING | 86 |
| 5.3.1 ACHIEVING RESIDENTS AND RELATIVES END OF LIFE WISHES AND CHOICES | 86 |
| 5.3.2 FEAR OF CONSEQUENCES | 91 |
| 5.4 CARING | 92 |
| 5.4.1 MANAGING SYMPTOMS | 95 |
| 5.4.2 THE LINGERING DEATH | 98 |
| 5.4.3 CARE AFTER DEATH | 99 |
| 5.5 COMMUNICATING | 100 |
| 5.5.1 COMMUNICATING WITH RELATIVES AND RESIDENTS | 100 |
| 5.5.2 COMMUNICATING WITH INTERNAL AND EXTERNAL COLLEAGUES | 101 |
| 5.6 RELATING | 104 |
| 5.6.1 INSIDE THE NURSING HOME | 104 |
| 5.6.1.1 Residents | 104 |
| 5.6.1.2 Colleagues | 107 |
| 5.6.2 OUTSIDE THE NURSING HOME | 108 |

| | |
|--|-----|
| 5.6.2.1 Relatives | 108 |
| 5.6.2.2 GPs..... | 110 |
| 5.6.2.3 Hospital staff..... | 111 |
| 5.6.2.4 Hospice staff | 112 |
| 5.7 ADDITIONAL FINDINGS | 112 |
| 5.7.1 PARTICIPANT ROLES AND EXPERIENCE | 112 |
| 5.7.2 PARTICIPANT CULTURE | 114 |
| 5.7.3 PARTICIPANT RELIGION..... | 114 |
| 5.8 CONCLUSION..... | 114 |
| CHAPTER 6 DISCUSSION..... | 117 |
| 6.1 INTRODUCTION | 117 |
| 6.2 PARTICIPANT VALUES..... | 118 |
| 6.2.1 GOOD DYING VALUES | 119 |
| 6.3 PRACTICE ELEMENTS OF END OF LIFE CARE | 121 |
| 6.3.1 ADVOCATING | 121 |
| 6.3.2 CARING..... | 123 |
| 6.3.3 COMMUNICATING | 125 |
| 6.3.4 RELATING | 126 |
| 6.4 IDENTIFYING MORAL DISTRESS..... | 128 |
| 6.5 EMOTIONAL DISTRESS | 129 |
| 6.6 MORAL DISTRESS IN NURSING HOMES..... | 129 |
| 6.7 CONSEQUENCES OF MORAL DISTRESS | 134 |
| 6.8 REDEFINING MORAL DISTRESS..... | 136 |
| 6.9 REFLECTIONS ON THE RESEARCH PROCESS | 137 |
| 6.10 CONCLUSION..... | 139 |
| CHAPTER 7 CONCLUSION..... | 140 |
| 7.1 INTRODUCTION | 140 |
| 7.2 EMPIRICAL FINDINGS | 140 |
| 7.3 THEORETICAL IMPLICATIONS..... | 141 |
| 7.4 LIMITATIONS | 143 |
| 7.5 RECOMMENDATIONS FOR PRACTICE AND FUTURE RESEARCH | 145 |
| 7.6 CONCLUSIONS..... | 146 |
| REFERENCES | 149 |

TABLES

Table 1 Schwartz's basic values and their contents (1994) Revisions in *italics* Schwartz (2012) 24

Table 2 Contributory factors to moral distress 28

Table 3 Kable et al. (2012) 12 steps for literature review 33

Table 4 Databases and search terms 34

Table 5 Inclusion and exclusion criteria 35

Table 6 Overview of participant numbers 38

Table 7 Application of Braun and Clarke's (2006) five stage analytical process for thematic analysis 72

Table 8 Final elements 83

Table 9 The elements contributing to the experience of end of life care in nursing homes 84

FIGURES

Figure 1 Flow chart of search process 38

Figure 2 The relationship between epistemology, methodology, and method (adapted from Carter and Little 2007 p1317)..... 63

Figure 3 Process of recruitment..... 68

Figure 4 Incident categories (developed from Webster and Mertova 2007)..... 74

Figure 5 Good dying values 82

Figure 6. Model of the experience of moral distress in nursing homes 115

BOXES

Box 1 Case Report 1 90

Box 2 Case report 2 91

APPENDICES

Appendix 1 Summary table of the studies included in the literature review 170

Appendix 2 Appraisal tool..... 178

Appendix 3 Letter of ethical approval 180

Appendix 4 Letter of introduction to home managers..... 181

Appendix 5 Participant information sheet..... 182

Appendix 6 Consent formError! Bookmark not defined.

Appendix 7 Number of incidents per participant..... 185

Appendix 8 Interview guide 187

Appendix 9 Interview summary contact sheet 189

Appendix 10 Interview transcript with 'other' and 'incidents' identified..... 190

Appendix 11 table of seperated incidents and first stage of coding 196

Appendix 12 Step 2 of analysis initial codes 202

Appendix 13 Step 2 of analysis codes aligned to moral distress literature..... 203

Appendix 14 Step 4 of analysis challenges and positive aspects of end of life care..... 207

Appendix 15 Protocol for the reporting of unsafe practice 208

Appendix 16 Demographic details of participants 211

Appendix 17 Step 5 of analysis condensing themes 212

Appendix 18 Step 5 of analysis main themes and sub themes..... 214

Appendix 19 Step 5 main themes defined 215

Appendix 20 Step 5 of analysis practice themes as main themes 216

Appendix 21 March 2013 reflections from themes so far 217

ACKNOWLEDGEMENTS

This study would have been impossible if not for the nursing home staff who gave their time freely to be interviewed and whose valuable contribution have enabled me to use their stories to answer my research question.

Undertaking this study part time, whilst working full time, requires that I thank a very large number of people without whose support and assistance this study would never have been completed. First of all thanks have to go to my exceptionally tolerant family, Patrick my husband who was able to magic the children away from the house when silence and space were needed to meet deadlines. My children, Max, who was 10 when I started and is now taller and bigger than me at the age of 15 and who has now embarked on his GCSEs. Esme, whose childhood has been most affected by my hours of study as she was only 6, and is now 11, and who has encouraged me by providing pictures and drawings to keep me going, which adorn the walls of my office, and in the downstairs bathroom.

The hours of study have also required additional childcare support and tolerance from my parents Theresa and Ray, my sister Angela, my child minders Kathleen and Christopher, and my in laws, Maire, Susan, Richard, Rachel, Pete, Val and Paul. Then there are my amazing friends: Stacey, Tony, Jane, Russell, Libby, Emma, Tim, Trudie, Ed, Sarah, Danny, Patrick, Justine, Debbie, Sally, Jacqui, Leah, Sonya, Jo and Kim and many more whose unending support and tolerance have been greatly appreciated.

The first cohort of distance learning students undertaking the palliative care PhD have been amazing and the journey we have shared has been turbulent, sometimes difficult, but great fun. However, without the support, encouragement, laughter and academic prowess of my fellow students, I would never have got this far so I thank them all: Jackie, Ann, Lynn, Katrina, Deborah, Fiona, Alison, Shirley and Andrea, and not forgetting Stephen, Jean and Gary who were there for so much of the time. Also thank you to Debbie Smith, Lee Chester, my manager Linda, for her support and to my colleagues Debra, Suzanne, Sharon and Lynn from North East London Foundation Trust.

The team of lecturers within the Division of Health Research at Lancaster University who ran units of study in the taught components of the programme, and as personal tutors provided great support and information. Thanks also must go to the tolerant administration staff who yearly solved fee issues and autumn academics, library staff and the technical staff Steve and Anthony, without whom I would not have discovered so much about technology, which has saved me so much time and effort.

Finally, and probably most importantly, my thanks must go to my exceptionally patient and knowledgeable supervisors, Professor Katherine Froggatt and Dr Sarah Brearley whose thousands of comments and hours of telephone tutorials have kept me on track. They have motivated me at my least motivated times and were always positive when all I felt was negative. Without them I would definitely not have achieved what I have.

ABSTRACT

Eighteen percent of the older population die in nursing homes in the United Kingdom (UK). Moral distress in healthcare professionals has been linked to end of life issues but there has been a lack of investigation of the concept in the nursing home context and how staff in this environment experiences it.

The aim of the study was to understand how nursing home staff experienced moral distress when they cared for residents coming to the end of life.

The study used an interpretive descriptive design, which utilised the critical incident technique to collect data from 16 participants from nursing homes using semi-structured interviews. The interviews focused on positive and challenging incidents the staff experienced when caring for residents at the end of life. Data were analysed using a thematic analysis approach.

The staff were found to hold values about 'good dying' which influenced their practice of advocating, caring, communicating and relating with residents, relatives, GPs, and colleagues, when a resident was on the journey through the complex living and dying trajectory. Incongruent values with others contributed to the staff not being able to 'do the right thing' leading to 'powerlessness' which was found to be the characteristic of their moral distress. Participants were found to experience moral distress because the incongruent values could lead to care decisions which staff felt contributed to 'bad dying' or a 'bad death'.

Nursing home residents are vulnerable and the staff need support to provide good quality end of life care. Understanding the experience of moral distress by staff

working in this environment will inform and improve the appropriateness of the support I can offer them as an end of life facilitator for care homes.

CHAPTER 1 INTRODUCTION

The profile of palliative and end of life care in the United Kingdom (UK) has been significantly raised in the last year since the Leadership Alliance for the Care of Dying People (LACDP) published its findings on the use of the Liverpool Care Pathway (LACDP, 2014). This report instigated a House of Commons Health Select Committee (HCHSC) to review end of life care in the UK in all care settings, as they found inequalities of care provision and a lack of a competent workforce (HCHSC, 2015). Access to 24 hour palliative care in all care settings was recommended with more focus on research in palliative care being required to improve end of life care (HCHSC, 2015). Areas identified for research included palliative care provision to avoid crisis, sustainable training for staff to improve standards of care, the benefits of advance care planning and how to support people with a life-limiting non-cancer diagnosis (HCHSC, 2015).

1.1 THE IMPORTANCE OF THE TOPIC

Demographic and policy changes in the UK have had an impact on nursing home care provision, and 18% of deaths occur in English nursing homes (National End of Life Care Intelligence Network, 2012). Palliative care research in this environment has focused on interventions to improve practice of end of life care, rather than exploring how staff cope with the challenges of caring for residents with complex disease trajectories (Froggatt et al., 2006).

The Health Select Committee (HCHSC, 2015) specifically noted that the quality of end of life care in hospitals for older people was less than ideal with patients experiencing a lack of dignity and a lack of honesty regarding their health status.

Afzal et al. (2010) found that people with dementia received a different level of palliative care than older adults who were not cognitively impaired. Preventing inappropriate admission of people with end stage dementia is just as important as improving the quality of care provided (Chapman, 2011). A third of avoidable hospital admissions at the end of life are from nursing homes and preventing these admissions could be beneficial to residents and their relatives (Abel et al., 2009). Shanley et al. (2011) discussed that to prevent hospital admissions from nursing homes community support is required.

1.2 THE SIGNIFICANCE OF THE TOPIC

Nursing home staff have been criticised for admitting residents to hospital when they are coming towards the end of life but there are challenges that influence this decision: medical decisions, relative anxiety, and the risk of criticism for doing the wrong thing (Purdy, 2010, Kalvemmark et al., 2004). Residents admitted to nursing homes have a plethora of diagnosis which nursing home staff are expected to be familiar with so that they can provide quality care to meet the physical, mental and psychological needs of the resident with little outside support (Fossum et al., 2011, Royal College of Nursing, 2010).

End of life care has been found as a contributory factor to the experience of moral distress (Corley et al., 2005). Nursing home staff care for older people at the end of life and to date there has been no investigation of how these staff experience moral distress in the UK. This is relevant to the nursing home staff population because moral distress can lead to 'burnout', higher sickness levels and more staff resigning from their positions (Corley et al., 2001).

1.3 CONTEXT FOR THE RESEARCH

Moral distress research has been focused in acute care settings where care provision and experiences are very different to those providing long term care. Moral distress is a new concept in the UK and further investigation will contribute to the knowledge about it to improve the practice of end of life care in nursing homes. Identifying the factors which contribute to the staff experience will contribute to appropriate support being given. Addressing moral distress by the provision of support has been found to improve staff retention, sickness levels and improvements in the quality of care provision (Pendry, 2007) and these areas have been acknowledged as problematic which require support to improve (Royal College of Nursing, 2010).

1.4 BACKGROUND OF THE RESEARCHER

I have been a qualified nurse for 30 years and I am currently an end of life care facilitator providing support and education for 17 nursing homes with a total of 900 beds. I was previously a nurse lecturer used to providing a curriculum based model of education, the process of which does not involve the learning needs of individuals but of a profession. To provide appropriate support for nursing homes staff it is important to identify the challenges they face when providing end of life care, rather than me as the educator deciding what education would benefit them on their behalf. Exploring their experience of end of life care and how this contributes to moral distress will inform the development of support which they will find beneficial and addresses the issues they identify.

1.5 WHERE THE RESEARCH WAS CONDUCTED

The research was carried out in six out of 17 nursing homes in the London Borough in which I work, as this provided me with knowledge of the locally challenging aspects

that staff face. Conducting the research locally also allowed easier access to participants, as accessing nursing homes for research can be problematic due to the culture of consistent inspection and the ability of managers to release staff for purposes other than care provision (Luff et al., 2011).

1.6 AIMS AND OBJECTIVES

The aim of the study was to understand how nursing home staff experienced moral distress when caring for residents coming to the end of life, to inform the provision of appropriate support.

The objectives of this study are:

1. To explore how staff experience end of life care in the nursing homes
2. To identify and understand the factors influencing the experience of moral distress in nursing home staff when caring for residents at the end of life.

1.7 ORGANISATION OF THE THESIS

Chapter two gives the context to the research. It provides the demographic data on older people and long term care provision in the UK, and explores end of life care for this population. It considers values related to caring and nursing building on work by Schwartz (2005), and links these to morals and moral and ethical issues in nursing, then in older person care before discussing the concept of moral distress and its key dimensions.

Chapter three is the literature review, the aim of which is to identify nursing homes staff's experience of caring for residents at the end of life, with specific reference to moral distress. Literature was searched systematically and the process explained, including search terms, and inclusion and exclusion criteria. A dearth of literature

identified prior to undertaking the review required that the identified contributory factors to moral distress were used to extend the scope of the review. An overview of the literature is given, prior to an appraisal and critical review of the included studies using the contributory factors of conflict, organisational culture, resources, complexity of patient issues, communication and emotional work, to organise them. The review concludes that there is a gap in the literature of UK nursing home staff's experience of moral distress when caring for residents at the end of life.

Chapter four initially explains the choice of interpretivism as the epistemological stance for this research because of the recognition of external influences to personal experiences. It identifies interpretive description as the qualitative research design and the three stages within it. Firstly a practice orientated goal is identified, which is the provision of appropriate support for the staff in nursing homes when caring for residents at the end of life. The second stage is the literature review which provides the scaffolding for the study and, thirdly, in depth analysis and interpretation of the data to answer the research question.

The settings for this study were the 17 nursing homes in the London Borough in which the researcher works as the end of life facilitator. To obtain the minimum number of 50 critical incidents required for a study (Flanagan, 1954), six nursing homes were randomly selected and managers approached to ask if staff from their homes could take part and 16 staff consented to participate. Critical incidents were collected by undertaking semi-structured interviews focusing on end of life care of residents. The data were analysed using thematic analysis to identify patterns and themes within the identified incidents.

Chapter five explores the themes identified from the analysis which inform the findings. The identification of the participant's values on 'good dying' was found to influence their experience of end of life care. The practice elements of advocating, caring, communicating and relating were also influenced by participants' values. When the staff values were congruent with others involved in the care of residents, staff believed that the resident had a 'good death' as they were able to 'do the right thing'. When incongruent values concerning care for residents at the end of life existed, staff experienced moral distress due to being powerless to 'do the right thing' and to influence care decisions which could result in a suboptimal death.

Chapter six presents a model of the experience of moral distress in nursing homes and critically considers the findings from this research with literature from the background and literature review chapters and new literature. The identified practice elements provided the basis of the discussion for linking together the 'good dying values' and 'doing the right thing' and 'powerlessness' and moral distress which contributed to the staff experience of end of life care in nursing homes.

Chapter seven concludes with the empirical findings that nursing home staff experience moral distress when incongruent values on 'good dying' exist between them and relatives, General Practitioners (GPs) and colleagues. The theoretical implications identify the new knowledge as well as concurrent knowledge found in this study. The limitations of the research and recommendations for practice and further research are also presented prior to the final conclusion.

CHAPTER 2 BACKGROUND

2.1 INTRODUCTION

This chapter provides the context for this research study by discussing the demographic background information related to older adults in the UK specifically related to long term care provision. End of life care in this population will be initially discussed. Then the ethical issues in end of life care for older adults, and how these relate to a 'good death' will be considered. Values related to care will then be discussed and these will be linked to the literature on moral distress which has been scoped to explore the concept of moral distress to contextualise the research.

2.2 LONG TERM CARE PROVISION FOR OLDER ADULTS

In the UK there are over 11 million people over 65 years of age, with life expectancy at an all-time high of 79.3 years for men and 83 years for women (Office for National Statistics, 2014). Advances in medical science, and the improvement in public health in the developing world have contributed to this population increase (Gomes et al., 2011). The number of people over the age of 65 is predicted to reach 23% of the population (16.9 million) by 2035, and 17% of these will be over the age of 85 (Office for National Statistics, 2014). There has been a fivefold increase in the number of centenarians in the last 30 years (Office for National Statistics, 2011).

Longevity, unfortunately, can mean a higher risk of having multiple health problems, the levels of which can also increase with age (Gomes et al., 2011). Dementia is one such health problem, where the prevalence increases with age and is higher in those aged over 80 years old (Matthews et al., 2013). Long term conditions have become more of an issue in this age group than disability related to limiting functionality,

such as eyesight and mobility, due to improved medical management of long term conditions and technological advances in surgery (Martin et al., 2011). In UK care homes, dementia is the most frequently occurring long term condition (Lievesley et al., 2011) with an estimated 89% of residents possibly affected (Lithgow et al., 2012). Heart disease, arthritis and diabetes are the next three most prevalent long term conditions in the over 75 age group in care homes (Lievesley et al., 2011). Cancer incidence has also increased in those aged over 75 years, with a third of all cancers diagnosed in those over the age of 65 years (Office for National Statistics, 2012).

Caring for older adults who may be affected by more than one long term condition can be challenging (Bedlin et al., 2012), with many being admitted to care homes with highly complex health needs that are unable to be met in a person's own home (Lievesley et al., 2011). In the UK, care homes with nursing provide 24 hour registered nurse support (Orellana, 2014), and for the purpose of this study are referred to as nursing homes. Nursing homes, as a place of care at the end of life, are increasing as the population continues to age and the deaths in the older population are predicted to increase with societies demographic changes (Gomes et al., 2011). The British United Provident Association (BUPA) census of care homes reinforces the view that nursing homes are moving away from being an alternative form of housing for frail older people, towards a location of last resort for individuals with high support needs near the end of life (Lievesley et al., 2011).

Nursing homes in the UK provide care for 16% of those aged over 85 (Age UK, 2013) and 4% of those aged between 75-84 years old. There were 4,676 nursing homes in the UK in 2014 (Care Quality Commission, 2014), which employed approximately

276,000 members of staff (Skills for Care, 2013). Currently 18% of deaths in the UK occur in nursing homes (National End of Life Care Intelligence Network, 2012). The anticipated demographic rise alongside an increase in the number of older people dying over the next 15 years (Gomes et al., 2011) is likely to increase the impact on the human and physical resources required to care for this population (Gomes and Higginson, 2008, Royal College of Nursing, 2010) including the increased need for palliative care in nursing homes (Froggatt et al., 2006).

2.3 END OF LIFE CARE FOR OLDER ADULTS

Palliative care provided in the last year of life is defined as end of life care in the UK (The National Institute for Health and Care Excellence, 2011 (NICE)). End of life care is the term also used in UK policy (Department of Health, 2008) and research (Skilbeck and Payne, 2005, Froggatt and Payne, 2006) but it has not been well defined in either (Nolan and Mock, 2004), but will be the term used to include palliative care in this study.

Historically palliative care was provided for people with a cancer diagnosis (Clark, 2006), which would be limited to 4.2% of the population over the age of 75 (Ruth and Verne, 2010). Palliative care definitions did not address the complexities of caring for people without a cancer diagnosis (O'Conner, 2008), but recent definitions have encompassed all life limiting health conditions which are non-curative (European Association for Palliative Care, 2010). Radbruch et al. (2009) explain that using a palliative care approach fundamentally provides basic, holistic, quality, co-ordinated care to affirm life, and alleviate suffering. Seymour (2012 p 10) however simply states 'end of life care *is* care of older people'.

Dying with conditions other than cancer has contributed to the older population having unequal access to palliative care (Seymour, 2007) which is contributed to by the unpredictable dying trajectories (Hart et al., 1998). The National Service Framework for Older People (Department of Health, 2001) and the End of Life Care Strategy (Department of Health, 2008) had both identified the need to improve the provision of end of life care for older people with life-limiting illness in all care settings, as long term conditions and frailty have been identified as the main cause of death in the over 75 age group (World Health Organisation, 2011). The medical management of co-morbidities in any age group is difficult but with frailty and cognitive deficits increased in the older population, care becomes multifaceted and more complex (Larkin and Hegarty, 2011, Cornwell, 2011). In addition, access to specialist palliative care services, which provide care for those dying with more complex needs, has been found to be inequitable for those of older age (Gott and Ingleton, 2011, Holloway, 2009).

The quality standard for end of life care states that all people should be offered 'palliative care' in a timely fashion wherever they are being cared for including nursing homes (NICE, 2011). The terminology used to describe the care provided in the last year of life can be confusing. End of life care, hospice, terminal and palliative care are used interchangeably within the literature and this contributes to the confusion (Froggatt et al., 2006). In Froggatt and Payne's (2006) study of nursing home managers, end of life care was found to be associated with the act of dying rather than the approach to care. The lack of clarity contributes to difficulties in identifying which older adults could benefit from additional timely palliative care

support (Pugh, 2009, Gott et al., 2008a, Addicott and Ashton, 2009, Lorenz et al., 2007, O'Conner, 2008).

2.4 ETHICS AND END OF LIFE CARE FOR OLDER PEOPLE

The timely referral and accessibility of palliative care services is just one of the ethical issues facing nursing home staff when caring for residents at the end of life (Vallis and Boyd, 2002). Practice issues in end of life care contribute to the ethical issues associated with older people; over, under or withdrawal of treatment, futile care (Seymour and Gott, 2011) and poor symptom management resulting in patient suffering (Georges and Grypdonck, 2002) have all been identified. Dementia compounds these ethical problems due to the inability of people to communicate their choices effectively (Alzheimer's Society, 2011, Hughes et al., 2007). Improvement in end of life care for people suffering from dementia is required, with the palliative care approach being recognised as beneficial for this group of patients (Hughes et al., 2007) as well as being recommended in the End of Life Care Strategy (Department of Health, 2008). Hydration, feeding, and resuscitation are the main contributory factors to ethical dilemmas, but advance care planning discussions can be beneficial and improve care outcomes (Hughes et al., 2007, Moriarty et al., 2012).

Ethical issues specifically related to end of life care in the frail elderly were investigated in Scottish geriatric care settings, including nursing homes (Vallis and Boyd, 2002). Medical and nursing staff identified decision making at the end of a resident's life as challenging as well as suggesting that the principle of a 'good death' was fundamental to the decisions made (Vallis and Boyd, 2002). However 89% of residents in care homes have dementia and may be reliant on family or staff to make decisions on their behalf (Lithgow et al., 2012) which contribute to the ethical

dilemmas that staff face. Vallis and Boyd's (2002) study discussed the four principles of healthcare ethics in relation to the decision making capabilities of residents: respect for autonomy, beneficence, non-maleficence and justice. They argued that these principles were medical in nature rather than being care focused and as such were not appropriate for residents who were unable to make their own decisions. Instead they proposed alternative ethical principles, such as 'protective responsibility'; preventing harm, 'responsibility for narrative integrity'; defence of best interests due to knowing residents well and 'candour'; and 'complete truth and honesty' (Vallis and Boyd, 2002).

Individualised care can be affected by the ethical climate and practice environment of organisations (Suhonen et al., 2014). The organisational influence on care has been highlighted by older people themselves as rarely being reflective of the values of society because of the lack of resources available (Franklin et al., 2006). These resources can refer to people, equipment or environments lack of which can cause ethical and moral dilemmas within this care setting (Vallis and Boyd, 2002) affecting the quality of care (Spilsbury et al., 2011) and the ability of staff to facilitate a 'good death'.

2.5 A GOOD DEATH

The principle of a 'good death' was explored with a small number of terminally ill people whose expectations were diverse and did not always fit with the normative expectations of healthcare professionals (Goldsteen et al., 2006). Individualised care underpins the principle of a 'good death', but it must also be recognised that people's expectations of death are not the same (Vallis and Boyd, 2002, Goldsteen et al., 2006, British Geriatric Society, 2011).

Death is given a high status by healthcare professionals, with set values pertaining to death which some people may not achieve, possibly contributing to stress for the dying person and feelings of failure for staff (Goldsteen et al., 2006, Costello, 2006). Older people with heart failure were asked their opinion of what a good death would be and they identified symptom management, to be with whom they chose, openness about impending death, control and choice, and care for those that were left behind (Gott et al., 2008b). Palliative care principles hold the same ideals (Payne et al., 2004) and are what healthcare professionals strive for when caring for the dying (Lloyd et al., 2011). Achieving a 'good death' for residents should be based on the needs and wishes of each resident (Vallis and Boyd, 2002). It is, however, important to recognise that staff have their own values about death and dying, as well as there being organisational ones (Lloyd, 2004) or societal ones (Hart et al., 1998) which could be in conflict with personal ones.

2.6 VALUES

Values are beliefs that influence specific courses of action or behaviours which contribute to a standard that guides attitudes towards situations, judgements, evaluations, or decisions (Rokeach, 1973). Values are formulated in childhood, shaped by culture, society, personal experiences and influenced by organisations and professions in later life (Rokeach, 1973). They motivate action to achieve goals and serve as standards against which every day decisions are made (Rokeach, 1973). Schwartz (1994) identified 10 basic human values: power, achievement, hedonism, stimulation, self-direction, universalism, benevolence, tradition, conformity and security (Table 1 Schwartz, 1994). In 2012, these were revised and caring and dependability were added to the value of benevolence (Schwartz et al., 2012).

Table 1 Schwartz's basic values and their contents (1994) Revisions in *italics* Schwartz (2012)

| Value | Conceptual definitions in terms of motivational goal |
|---|---|
| Power <i>Dominance</i> <i>Resources</i> | Societal prestige and controlling others <i>Power through exercising control over people</i> <i>Power through control of material and social resources</i> |
| Achievement | Personal success and competence according to social norms |
| Hedonism | Pleasure and satisfaction of sensual needs |
| Stimulation | Excitement, novelty and challenge in life |
| Self-direction <i>Thought</i> <i>Action</i> | Independent action and thought, making one's own choices <i>Freedom to cultivate one's own ideas and abilities</i> <i>Freedom to determine one's own actions</i> |
| Universalism <i>Concern</i> <i>Nature</i> <i>Tolerance</i> | Understanding, tolerance and protection for the welfare of all people and for nature <i>Commitment to equality, justice and protection for all people</i> <i>Preservation of the natural environment</i> <i>Acceptance and understanding of those who are different from oneself</i> |
| Benevolence <i>Caring</i> <i>Dependability</i> <i>Humility</i> | Protecting the welfare of close others in everyday interaction <i>Devotion to the welfare of the in-group members</i> <i>Being a reliable and trustworthy member of the in-group</i> <i>Recognizing one's insignificance in the larger scheme of things</i> |
| Conformity <i>Interpersonal</i> <i>Rules</i> | Restraint of actions, inclinations and impulses likely to upset or harm others, or violate social expectations or norms <i>Avoidance of upsetting or harming other people</i> <i>Compliance with rules, laws, and formal obligations</i> |
| Tradition | Respect, commitment and acceptance of the customs and ideas that one's culture or religion impose on the individual |
| Security <i>Personal</i> <i>Societal</i> <i>Face</i> | Safety, harmony and the stability of society, of relationships and of self <i>Safety in one's immediate environment</i> <i>Safety and stability in the wider society</i> <i>Security and power through maintaining one's public image and avoiding humiliation</i> |

2.6.1 VALUES IN CARING

Schwartz (2007) stated that five of his human values were moral in nature benevolence, universalism, conformity, tradition, and security. These all have an interpersonal rather than a personal focus and link to thinking of others before oneself (Schwartz, 2007, Rokeach, 1973). The values of nurses focus on the needs of the person who is suffering rather than the needs of the nurse, which enables them to be empathic and provide good care (Naden and Eriksson, 2004). Receivers and providers of care can have different opinions of what good care should be or look like (Tronto, 2010) but the cornerstone of good care, is to enable the alleviation of a person's suffering and maintain their dignity (Naden and Eriksson, 2004). Values are important in maintaining the dignity of the person being cared for as well as for the

personal dignity of the carer and if values are violated then a lack of dignity can be the result (Naden and Eriksson, 2004). Watson's caring values (2012) hold human life in high regard, but are also non paternalistic as they allow patient autonomy, honour the individual's lived experience of a situation and places a high value on the relationship that exists between the nurse and other.

Caring is considered to be the moral nature of nursing and is underpinned by values (Watson, 2012) which when they are personally committed to, become morals (Jameton, 1984). Beagan and Ells (2007) found that the values that matter to nurses are helping others, caring and compassion, making a difference, patient-centeredness, integrity, holistic care and sharing knowledge for patient empowerment. When there is a conflict of values or an inability to make a difference this causes nurses to feel frustrated and distressed (Beagan and Ells, 2007). Feelings of anxiety and guilt can also be experienced if these personally held values are violated (Rokeach, 1973) or when the appropriateness of a care intervention can be called into question. This often provides a challenge to the healthcare professional's moral beliefs (Rowe, 2013) which could lead to moral distress (Jameton, 1984).

2.7 MORAL DISTRESS

The literature on moral distress was scoped to provide definitions and identify key issues in order to give context for this study. The concept of moral distress was first alluded to by the philosopher Jameton in his book on nursing ethics (1984). He described three types of ethical dilemmas that nurses face. Moral uncertainty when there is a lack of understanding of which moral principles apply to a situation, or a lack of understanding of what the moral issue might be. Moral dilemmas, when two or more opposing principles apply to a situation, result in different courses of action

and hence outcomes. Moral distress, which is when a nurse knows the right course of action to take but, due to organisational constraints, is prevented from carrying out the action (Jameton, 1984).

Wilkinson (1987) explored the link between moral distress and the quality of patient care, concluding that those nurses who were most sensitive to moral issues e.g. patients suffering harm or dehumanisation, resulting in moral distress, were more likely to leave their jobs than others. The experience of conflict of a moral issue which nurses were unable to resolve contributed to nurses feeling psychological disequilibrium (Wilkinson, 1987). The number of morally distressing situations contributed to nurses coping strategies failing and affecting the quality of patient care (Wilkinson, 1987).

Jameton (1993) extended his definition of moral distress taking Wilkinson's (1987) work into consideration to include two phases of distress. Initial distress which occurs as a situation unfolds and is associated with feelings of anger; frustration and anxiety directed at the organisational constraints. Reactive distress, which can occur after initial distress when there is inaction over the cause of the initial moral distress (Jameton, 1993) causing harm to patients and organisations.

Epstein and Hamric (2009) suggest that initial distress is moral distress and what Jameton (1993) refers to as reactive distress should be considered to be moral residue (Epstein and Hamric, 2009). Each morally distressing situation has a crescendo effect when it is at its worst, which abates leaving behind feelings which contribute to moral residue. These feelings contribute to subsequent morally distressing situations resulting in stronger and stronger reactions, which can

contribute to the healthcare professional becoming numb to morally distressing situations, and can influence care delivery and the health and well-being of the nurse (Epstein and Hamric, 2009). Huffman and Rittenmeyer's (2012) systematic review on hospital nurses experience of moral distress concluded that there were four themes which categorised these experiences: human reactivity including powerlessness and stress reactions, institutional culpability which were the constraints on healthcare, patient pain and suffering and unequal power hierarchies.

Dilemmas identified in end of life care in nursing homes (Lloyd et al., 2011) link with general everyday ethical issues (Bolmsjo et al., 2006) as well as being intrinsically linked with those identified by nurses who provide palliative care (Georges and Grypdonck, 2002). These dilemmas have also been identified to contribute to moral distress (Lerkiatbundit and Borry, 2009, Wiegand and Funk, 2012). End of life care has been identified as the area of care, which provokes ethical dilemmas, by poor communication, conflict of opinions, patient suffering and lack of resources (Pavlish et al., 2011). These ethical issues are very similar to those that contributed to healthcare staff experiencing moral distress (Huffman and Rittenmeyer, 2012, de Veer et al., 2013, Austin et al., 2008).

2.7.1 MORAL DISTRESS LITERATURE

Moral distress research has been focused on American nurses working in acute care settings such as intensive care (Corley et al., 2005, Fenton, 1988), but has expanded to other health professions and in more countries, Japan (Ohnishi et al., 2010), Norway (Forde and Aasland, 2008), Canada (Austin et al., 2005a). A validated moral distress measurement tool (Corley et al., 2001) has been used in quantitative studies, to measure the level of moral distress in: critical care (Mobley et al., 2007), with

nurses (Zuzelo, 2007), and non-nursing university students (Range and Rotherham, 2010), and psychiatric nurses (Ohnishi et al., 2010). These studies found that conflict with relatives, colleague competence, communication, futile care and lack of resources contributed most to the experience of moral distress. Intensive care physicians experienced moral distress related to futile care when relatives wanted to prolong life support or due to poor communication of colleagues which affected the quality of care (Hamric, 2012). A large postal survey of Norwegian doctors concluded that the lack of strategies to resolve ethical dilemmas, which assist in decision making, increased the experience of moral distress (Forde and Aasland, 2008). A study with psychologists concluded that moral distress was an issue mainly due to organisational demands and conflicts (Austin et al., 2005b). More recently an investigation into moral distress was undertaken across 2,700 healthcare professionals from all disciplines and although intensity of moral distress was greater in nurses it was present in all participants (Houston et al., 2013). Three studies on moral distress have been carried out in nursing home settings, one specifically on end of life care (Piers et al., 2012), one on job characteristics associated with moral distress (de Veer et al., 2013) and one that looked at the responses to initial moral distress in long term care (Edwards et al., 2013). These studies are reported on more fully in chapter three.

There are common contributory factors to moral distress visible across the literature on moral distress. These contributory factors have been used to inform this study's literature review due to moral distress in nursing homes being an under researched area. The identified contributory factors are: conflict, organizational culture, resources, complexity of patient issues, communication and emotional work, (Table

2). An explanation of how these contributory factors will be interpreted in the literature review is given in Table 2.

Table 2 Contributory factors to moral distress

| Factor contributing to moral distress | Description |
|--|---|
| Conflict Austin, 2012, de Veer et al., 2013, Lerkiatbundit and Borry, 2009, Eizenberg et al., 2009, Pavlish et al., 2011 | Conflict with relatives or colleagues related to decision-making on care, internally or externally. |
| Organizational constraints Huffman and Rittenmeyer, 2012, Corley and Minick, 2002, de Veer et al., 2013, Kalvemark et al., 2004, Lützén and Kvist, 2012, Ohnishi et al., 2010, Jameton, 1984, Fenton, 1988 | Culture of internal and external organizations, processes and procedures influencing the care residents received. |
| Resources Huffman and Rittenmeyer, 2012, Corley and Minick, 2002, de Veer et al., 2013, Kalvemark et al., 2004, Lützén and Kvist, 2012, Ohnishi et al., 2010, Jameton, 1984, Fenton, 1988 | Resources included staff, time, finances access to equipment/additional support, education and knowledge. |
| Complexity of patient issues Corley, 2002, Corley and Minick, 2002, Corley et al., 2005, Brazil et al., 2010, Ferrell, 2006, Lerkiatbundit and Borry, 2009, Mobley et al., 2007, Nathaniel, 2006, Pavlish et al., 2011, Wiegand and Funk, 2012 Kalvemark et al., 2004 | Complex patients in nursing homes include residents with dementia who were unable to make decisions for their own care. Residents who receive what is considered to be futile care such as hospital admission or artificial nutrition, and residents who have a long dying trajectory, or uncontrolled symptoms causing pain and suffering. |
| Communication Brazil et al. 2010, Corley et al. 2005, Lerkiatbundit and Borry, 2009 | Communicating internally, externally with relatives, residents or colleagues both verbally and in writing |
| Emotional work Austin, 2012, Austin et al., 2005a, Brazil et al., 2010, de Veer et al., 2013, Ferrell, 2006, Wilkinson, 1987, Lerkiatbundit and Borry, 2009, Lützén et al., 2003 | Positive and negative emotions associated with end of life care. |

The findings from the identified studies on moral distress are similar. The consequences of moral distress have been identified as ‘burnout’ and job leave (Corley, 2002, Epstein and Delgado, 2010, McCarthy, 2010, Austin, 2012). Burnout has been described as a multidimensional stress response of exhaustion, cynicism and detachment from the job (Maslach et al., 2001), which links with the idea of moral residue (Epstein and Hamric, 2009). Burnout leads to staff leaving their jobs in intensive care units (Mobley et al., 2007) or changing careers. This could be

particularly relevant to nursing homes as staff turnover is very high (Tilden et al., 2012, Royal College of Nursing, 2012).

Although researchers are in agreement that moral distress exists, there is a lack of clarity about how it is defined and addressed in the practice setting (Hanna, 2004, Lützén and Kvist, 2012, McCarthy, 2010, Pauly et al., 2012, Johnstone and Hutchinson, 2013). Some authors use moral stress and moral distress interchangeably (Canadian Nurses Association, 2008). Stress has been identified as a response to a stimulus on the body from the social environment (Selye, 1973) and can be motivational as well as contributing negatively to health issues. Lützén et al. (2003) suggest that moral stress has similar characteristics as moral distress but the emphasis of moral stress is on staff recognising the ethical issue which underpins the initial problem, which they argue is missing from some of the moral distress literature. They argue that if the stress experienced by staff has a moral component then staff are morally sensitive and could experience moral stress (Lützén et al., 2003). Nurses may also feel emotional distress when caring for patients but the situation might not be because of a clash of morals or values but as the result of being upset (McCarthy and Deady, 2008).

Moral distress, however, is a negative response to the work environment which can contribute to psychological distress (Corley et al., 2005). An attempt to clarify the concept was made by Varcoe et al. (2012a p 59) when they defined moral distress as:

‘...the experience of being seriously compromised as a moral agent in practicing in accordance with accepted professional values and standards. It is

a relational experience shaped by multiple contexts, including the socio-political and cultural contexts of the workplace environment’.

A more recent explanation of what moral distress is: ‘a challenge that arises when one has an ethical or moral judgement about care that differs from that of others in charge’ (Peter, 2013, p 298), this will be used alongside Varcoe et al.’s (2012a) definition as the lens through which the data from this study will be viewed.

2.8 MORAL DEVELOPMENT

Austin (2012) discusses healthcare professionals as working in an ethical climate where momentous decisions are made on patient care on a regular basis. These decisions have become more intense with more ethical awareness of situations and increased technological advances. Austin (2012) advocates that environments should be moral communities where the values and morals of professionals are recognised within a safe environment to make ethical decisions.

Decision making in healthcare is complex and it is suggested that there are different stages of ‘cognitive moral development’ which contribute to decision making based on Piaget’s (1932) theory of moral development, which is extended by Kohlberg (1977). He suggests that there are three levels of moral development. Pre-conventional, when a person does not understand that actions are immoral and they act out of fear of punishment within an organisation. Conventional, where an employee conforms to the behaviour within the group they belong rather than make an individual decision. Post-conventional, when morals are understood and independent decisions are made about ethical dilemmas which follow the ethical principle of justice (Kohlberg and Hersh, 1977).

Unawareness and 'following behaviours' can contribute to organisational cultures that can be harmful to patients, such as at Mid Staffordshire National Health Service hospital (Gallagher, 2010). Moral courage to speak out when staff knew what they were doing impacted on care was lacking in the hospital. The courageous ones were ignored and the consequence was poor quality care, arguably resulting in staff experiencing moral distress and moral residue (Gallagher, 2010, Francis, 2010). The provision of high quality care relies on organisations at all levels starting with the individual through to the global level to maintain moral integrity (Rodney, 2013).

2.9 CONCLUSION

In practice there are many moral and ethical issues to contend with in caring for the vulnerable population living in nursing homes. Against a backdrop of an ageing population, increased demands for care with less resources, nursing homes remain the right place for frail older people to receive end of life care.

The contributory factors of moral distress, and the complexities associated with caring for residents in nursing homes theoretically link together suggesting that moral distress exists in the nursing home environment.

CHAPTER 3 LITERATURE REVIEW

Chapter two demonstrated that moral distress exists but there is little known about the staff experience when providing end of life care in nursing homes. This chapter will adopt a systematic approach to searching and identifying literature in order to understand what is known about moral distress in nursing home staff caring for residents at the end of life. The conclusions from this literature review inform the design, and research question of this study.

3.1 AIM OF THE REVIEW

To identify what is known about nursing home staff’s experience of caring for residents at the end of life, with specific reference to moral distress and to answer the following question, *‘how do nursing home staff experience moral distress when caring for residents at the end of life?’*

3.2 LITERATURE REVIEW METHOD

A systematic approach to the search strategy was undertaken based upon Kable et al.’s (2012) 12 step approach to searching the literature for systematic reviews, where they use 12 steps when carrying out a literature search and review (Table 3).

Table 3 Kable et al. (2012) 12 steps for literature review

| Kable et al. steps (2012) | Adapted for this study | |
|---|-----------------------------|----------------------------------|
| 1. Provide a focus for the review | Focus of review | |
| 2. Document the databases and search engines | Search process | Search terms |
| 3. Identify the search terms and limits (including hand searches) | | Hand searches |
| 4. List inclusion and exclusion criteria | | Inclusion and exclusion criteria |
| 5. List search terms | | |
| 6. Document search process for each search engine | | |
| 7. Assess retrieved articles for relevance using inclusion and exclusion criteria | | |
| 8. Document a summary table of included articles | Overview of papers | |
| 9. Specify number of retrieved articles | | |
| 10. Conduct quality appraisal of retrieved articles | Appraisal of the literature | |

| Kable et al. steps (2012) | Adapted for this study |
|-----------------------------------|-----------------------------------|
| 11. Critical review of literature | Critical review of the literature |
| 12. Check reference list | Carried out but not reported on |

3.2.1 FOCUS OF REVIEW

The focus of this review is to explore the literature on the experiences of nursing home staff on caring for residents at the end of life in relation to moral distress.

3.2.2 SEARCH PROCESS

Searches for this study were undertaken in May 2013 and repeated in January 2015 to update the review using the following search strategy.

3.2.2.1 Identification of the search terms

The search terms in this search needed to reflect and amalgamate the areas under investigation: end of life care, moral distress, and nursing homes to answer the review question. To ensure that the right literature was identified (Kable et al., 2012), associated words were identified in consultation with a subject librarian and from previous readings and work (Table 4). These terms were checked in each database and words were truncated to ensure the inclusion of plurals and associated terms (Kable et al., 2012).

Table 4 Databases and search terms

| Search strategy | Search terms used |
|---|--|
| Electronic databases searched CINAHL, MEDLINE, BNI, PsycINFO, EMBASE and AMED | nursing home*"OR "care home*" OR Geria*OR age*OR "aged care fac" "old* people" OR "old* person*", OR resident* OR elderly OR Geria*OR age AND "end of life" OR death OR dying OR 'palliative care' OR terminal OR hospice distress "moral distress" OR "moral action*" OR AND "moral matrix" OR ethic* OR reason*, "moral response" OR "moral choice" OR "moral concept" OR moral* OR judg* OR conflict* OR "moral constraint" OR "moral case deliberation" AND between dates 1984-January 2015 |
| Science Direct (from 2005) Limited from 2005 Title abstract and keyword | 'moral distress' AND nursing homes' 'care homes' AND 'moral distress' 'palliative care' AND 'nursing homes' |

| Search strategy | Search terms used |
|--|---|
| Nursing and Health professions journals | 'palliative care' AND 'care homes' 'end of life care' AND 'nursing homes' 'end of life care' AND 'care homes' |
| Electronic Journal search terms used for specific journal searches | |
| Nursing Ethics | aged OR geriatrics AND care facilities AND end of life care AND moral distress |
| Journal of Bioethical Inquiry | moral distress AND nursing homes AND palliative care |
| Ageing and Society, Palliative and Supportive Care, Primary Health Care Research | old', 'end of life' 'moral*' 'nurse*' home' |
| The Journal of Medical Ethics | moral* AND 'end of life'/dying AND age* |

3.2.2.2 Hand searches

Following Kable et al.'s (2012) recommendations the reference lists of all retrieved studies were scrutinised to ensure that all relevant literature was included.

3.2.2.3 Inclusion and exclusion criteria

The inclusion and exclusion criteria (Table 5), provided a framework that ensured that articles focusing on the purpose of the review were included (Kable et al., 2012).

The search process and numbers of papers for inclusion can be viewed in Figure 1.

Table 5 Inclusion and exclusion criteria

| Inclusion criteria | Exclusion criteria |
|---|---|
| Empirical papers of qualitative or quantitative, mixed methods design. | Non-empirical papers: Position papers Policy papers Theoretical papers Grey literature Clinical case studies |
| Written in English | |
| Relate to community and institutional care settings where nursing care is provided (care homes, care homes with nursing, geriatric hospital wards, residential care settings) | Papers that relate only to institutional settings other than care homes e.g. acute hospital care, mental healthcare settings. |
| Focus on patients or residents ≥65 years old | Papers related to populations <65 years old residing in nursing homes. People over the age of 65 with learning disabilities (currently different care settings in UK). |
| Papers focused on staff experience (nurses, care assistants, social carers, managers, and administrators). | Papers focused on experiences of staff not employed within the nursing home e.g. primary care staff, specialist palliative care staff. |
| Papers examining end-of-life care (defined in this study as dying/ or death) AND OR papers related to moral distress/moral conflict/ethical decision making | Bereavement studies. |

The time frame of the search was limited from 1984 as the concept of moral distress was not discussed until 1984 (Jameton, 1984).

Titles and abstracts were used in the initial stage of literature identification prior to selecting the full text versions of papers for more in depth appraisal. To achieve the aim of this review and due to the lack of literature available, findings from the studies which met the inclusion criteria were categorised to the identified contributory factors to moral distress. This ensured that the included studies contained the contributory factor to moral distress and as such could conceptually be linked to study participants potentially having experienced moral distress (see Appendix 1).

3.3 OVERVIEW OF THE INCLUDED PAPERS

Forty studies met the inclusion criteria for this study with 20 from America or Canada, nine from the UK or Ireland, seven from Scandinavian countries, two from Australia, and one each from Belgium and Austria. Twenty-three of the included studies used qualitative approaches, 11 used mixed methods, and six used a quantitative approach and 12 were over 10 years old. An overview of the number of participants involved can be seen in Table 6 and a more complete summary of how the literature was aligned to the factors contributing to moral distress, discussed in chapter two, can be seen in Appendix 1.

3.4 APPRAISAL OF THE LITERATURE

This review identified studies with different methodological approaches, the majority of which were qualitative in nature. Standardising the appraisal of qualitative and quantitative literature can be complex in nature, making the process of review less rigorous (Hawker et al., 2002). To ensure that a consistent approach to appraisal for

both qualitative and quantitative studies was undertaken an appraisal tool was adopted for all studies, see Appendix 2 (Hawker et al., 2002). This initially was utilised to eliminate studies which did not meet the inclusion criteria. Studies which did meet the inclusion criteria were then appraised for quality by allocating scores between 1 (poor) and 4 (good) against each of the following criteria:

- Abstract and title
- Introduction and aims
- Method and data
- Sampling
- Data analysis
- Ethics and bias
- Findings/results
- Transferability/generalizability
- Implications and usefulness

The scores enabled the assessment of quality; however no studies were excluded based on the scores. It was felt that the paucity of literature meant that an inclusive approach as possible needed to be adopted as there could be relevance to the review question despite methodological issues (Dixon-Woods et al., 2006).

Ethical processes or considerations were often not mentioned within the papers, which contributed to lower scores being attributed. However, undertaking research with staff members does not always require ethical approval, including in the UK (Department of Health, 2011).

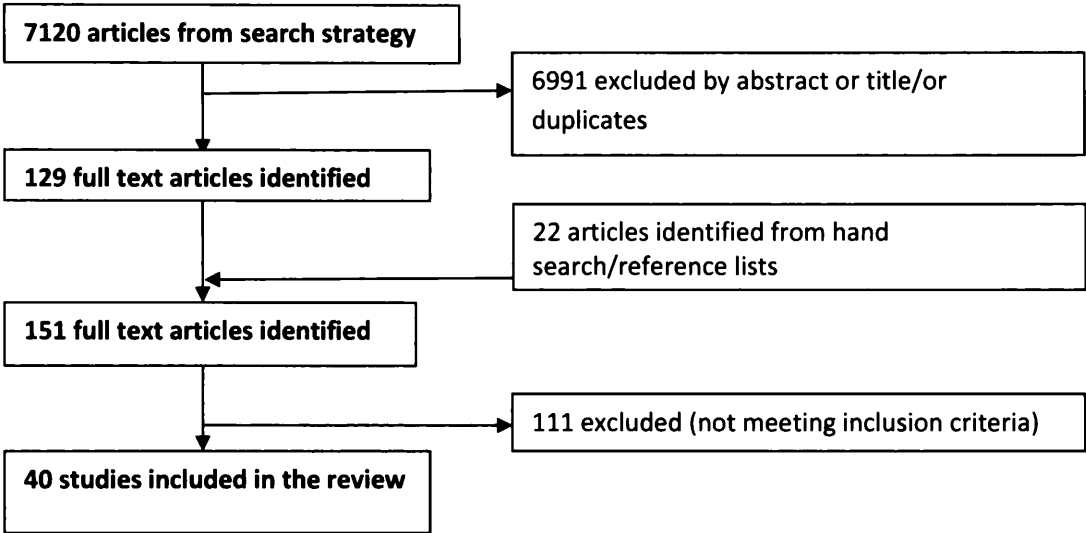


Figure 1 Flow chart of search process

Table 6 Overview of participant numbers

| Participant numbers | Authors |
|---------------------|--|
| <20 | Lopez, 2007, Miskella and Avis, 1998, Porock and Parker-Oliver, 2007, Edwards et al., 2013, Funk et al., 2013, Dreyer et al., 2011, Dreyer et al., 2010, Hockley et al., 2005 |
| 20-50 | Burack and Chichin, 2001, Forbes, 2001, Osterlind et al., 2011, Rice et al., 2004, Beck et al., 2012a, Dwyer et al., 2009, Froggatt, 2001, Goodridge et al., 2005, Reitingering and Heimerl, 2014, Schaffer, 2007, Waldrop and Nyquist, 2011 |
| 51-100 | Casey et al., 2011, Enes and de Vries, 2004, Hanson et al., 2002, Trotta, 2010, Seymour et al., 2011 |
| 101-200 | De Bellis and Parker, 1998 Lacey, 2005, Raudonis et al., 2002 |
| 201-300 | Ersek et al., 1999, Piers et al., 2012, de Veer et al., 2013 |
| 301-500 | Brazil et al., 2006, Gjerberg et al., 2010, Katz et al., 2001, Komaromy et al., 2000 |
| >501 <2000 | Mitchell et al., 2011, Munn, 2006, Stillman et al., 2005, Whittaker et al., 2007 |
| >2000 | Zheng and Temkin-Greener, 2011 |

All the studies, which had engaged residents in their studies, had the appropriate ethical approval, study scores are noted in Appendix 1.

3.5 CRITICAL REVIEW OF THE LITERATURE

The sampling strategies and processes of data analysis of the literature were reported prior to the studies being critically reviewed. Firstly, the papers which had

moral distress as their focus were reviewed. The remaining studies were discussed in the context of the contributory factors to moral distress, conflict, organisational constraints, complexity of patient issues, communication and emotional work.

3.5.1 SAMPLING STRATEGIES

Sampling strategies varied but most studies access potential participants by first seeking agreement from home managers (Dreyer et al., 2011, Casey et al., 2011). Accessing all potential participants was achieved by using a participant observation approach (Froggatt, 2001, Schaffer, 2007, Hockley et al., 2005). Interviewing all staff on duty on a specific date was found to allow better access to potential participants (Osterlind et al., 2011). Purposive sampling was the main method used in the majority of the studies, especially those using questionnaires as the method of data collection. Two exceptions to this were Zheng and Temkin-Greener's (2010) and de Veer et al.'s (2013) studies which amalgamated two larger data sets to obtain only participants who had responded to two separate questionnaires, the results of which were analysed together to answer a different research question which was relevant to this review. Stillman et al. (2005) also compared two data sets but from using the same questionnaire which had been carried out a year apart.

3.5.2 DATA ANALYSIS AND FINDINGS

The process of data analysis was either brief or completely lacking in a third of the papers (e.g. Ersek et al., 1999, Lacey, 2005) which also affected the rigour and transferability of the results. The more recent papers included in this review had better explanations of the methodological process that had been undertaken (Beck et al., 2012, Funk, 2013, Edwards et al., 2013, de Veer et al., 2013). Qualitative studies evidenced their findings with verbatim quotes from interviews or written

accounts, but if analysis was not fully explained it was difficult to see how researchers could justify their results without this explanation (Komaromy et al., 2000). Quantitative studies published tables of statistical data to present findings, with explanations of the statistical tests they used to get results (Piers et al., 2012).

3.5.3 MORAL DISTRESS IN NURSING HOMES

Three studies addressed moral distress in nursing homes (Piers et al., 2012, Edwards et al., 2013, de Veer et al., 2013), with only one alluding to end of life care as a contributory factor to moral distress prior to data collection (Piers et al., 2012). The aims of these studies were to identify contributory factors to moral distress (Piers et al., 2012), the responses to initial moral distress (Edwards et al., 2013) and the job characteristics associated with moral distress (de Veer et al., 2013) in a variety of settings where older people were cared for, including nursing homes. All three had identified a dearth of literature on moral distress in care settings of this nature and the majority of the moral distress research had been carried out in acute care settings such as intensive care (Corley et al., 2001). These three studies all found that moral distress did exist in the nursing home setting and ethical situations were identified as contributing to moral distress.

3.5.3.1 Definitions

De Veer et al. (2013) and Edwards et al. (2013) both explore the concept of moral distress and offer an explanation of where they are positioning their research in relation to this. Jameton's (1993) revised definition of moral distress and discussion of initial and residual distress, informs Edwards et al. (2012) study along with the Canadian Nurses Association (2003) definition of moral distress, which was provided to each of their participants at interview. De Veer et al. (2013) utilises Kalvemark et

al.'s (2004) extended definition broadening the scope of moral distress to include individual as well as organisational factors which can cause negative stress responses to ethical situations. Piers et al., (2012) refers to Kalvemark et al. (2004) but does not offer a definition of moral distress but positions it with Corley et al.'s (2001) work.

3.5.3.2 Measurement of moral distress

Moral distress was measured using differently formatted tools, Corley et al.'s (2001) validated tool to measure moral distress informed the quantitative study by Piers et al (2012). This tool was based on the original work by Jameton (1984), the work on values by Rokeach (1973) and House and Rizzo's role conflict theory (1972) and has been found to be valid and reliable (Corley et al., 2001).

De Veer et al. (2013) developed a tool from the literature and validated it locally, with additional measuring tools on associated issues used for correlating data on moral distress, including 'Maslach Burnout Inventory', as burnout had been purported to be one of the consequences of moral distress by Corley et al. (2001) and Piers et al. (2012). Job satisfaction was measured by a shortened version of the 'Masstricht Work Satisfaction Scale Healthcare (MAS-GZ)' to measure job satisfaction (De Veer et al., 2013) with a variety of validated job characteristic measures to identify which job characteristics increased the risk of moral distress. All measures were reported independently as well as when correlated.

3.5.3.3 Intensity of Moral Distress

Analysis of the frequency and intensity of moral distress identified that there was a difference between acute and nursing home settings, with futility of care most frequent in the acute care setting, and cost saving in the nursing home setting (Piers et al., 2012). The intensity scores were comparable across both settings and found

that working with incompetent colleagues, ignoring caregiver abuse and futile care causing the most moral distress. Intensity scores in de Veer et al.'s (2012) study however found that when there was disagreement between the wishes of patients and their families most moral distress occurred, as it did in nurses, when medical staff ignored patient's wishes. Edwards et al.'s (2013) findings are in agreement with these as interventions against resident's wishes, especially by relatives, was the predominant issue causing moral distress with lack of resources being the second. The product of the intensity and frequency of moral distress in Piers et al. (2012) study also found that the carrying out, of what nurses considered, futile care, requested by relatives, as contributing to moral distress.

Piers et al. (2012) found less moral distress in the chronic care settings, but when nurses had higher levels of personal accomplishment and emotional exhaustion with less opportunity to have ethical debate an increase in moral distress was experienced. De Veer et al. (2013) found that staff who worked less than 30 hours a week, or who had less job satisfaction, experienced higher levels of moral distress. When collating the data on moral distress and job characteristics they found that job related stress was statistically significant with moral distress closely followed by poor quality of care, lack of career opportunities, instrumental leadership, and not having enough time to carry out care (de Veer et al., 2013). The findings in both of these studies indicate that organisations could benefit from recognising moral distress to reduce 'burnout' and staff leaving.

Edwards et al. (2013) found leadership influenced how nurses responded to initial moral distress. The nurses in this study valued the coming together of the team to

discuss the ethical situation, including looking for help outside of the organisation. It identified that this required good leadership, and mechanisms of support to facilitate this. In most of the homes, however, the nurses did not feel they worked in a supportive environment and therefore their moral distress lingered, leading to lingering distress (Edwards et al., 2013). The situational context contributed to the response to moral distress i.e. conflicting values, pre-existing relationships, time and the nurse's confidence to do 'the right thing' (Edwards et al., 2013). The Canadian code of ethics for nurses highlights the ethical and moral situations that nurses may encounter, and advises them of their responsibility to address them with team members (Canadian Nurse Association, 2008), which may have contributed to the findings of Edwards et al.'s (2013) Canadian study. The results clearly indicate that internal or external support can reduce the moral distress that nurses experience.

3.5.4 CONTRIBUTORY FACTORS TO MORAL DISTRESS

The contributory factors to moral distress were collated from the moral distress literature under six headings as identified and described in chapter two: conflict, organisational constraints, resources, complexity of patient issues, communication and emotional work.

3.5.4.1 Conflict

Conflict has been identified as a contributory factor within the moral distress literature in a variety of studies (Deady and McCarthy, 2010, Austin et al., 2005b, Eizenberg et al., 2009).as well as an issue in nursing homes. Forbes (2001) found conflict to be the multifaceted pattern that influenced communication, quality of life, staff education, teamwork, and the work environment. Schaffer (2007) also found that when residents were unable to make their own decisions, conflict could be

experienced. Conflict in Mitchell et al.'s (2011) study, was mainly found to be between relatives, which staff found difficult to resolve when a resident was dying, corresponding with relative conflict found by Ersek et al. (1999). Kapp (2003) also found family conflict problematic in nursing homes because staff were afraid of litigation when a resident was at the end of life. This fear was also found in Lacey's (2005) study specifically related to the decisions made for residents with dementia. The fear staff felt could result in more aggressive interventions being carried out, which staff may not necessarily have agreed with as it conflicted with their care values (Kapp, 2003). Over treatment of residents was also found to contribute to the conflict experienced by the staff in Lopez's (2007) study and Gjerberg et al.'s (2010), where families were seen as the main decision makers.

Conflict between relatives and staff, or between colleagues, could result in delayed referral to palliative care (Forbes, 2001, Enes and de Vries, 2004, Funk et al., 2013). Conflict between colleagues could be experienced when care decisions were made to prolong life, which the staff member disagreed with, when they knew the resident well and believed this went against the resident's wishes (Dreyer et al., 2011, Enes and de Vries, 2004, Forbes, 2001, Schaffer, 2007, Edwards et al., 2013). Ersek et al. (1999) identified that care decisions which a staff member disagreed with could cause feelings of anger towards the colleague who had made the decision. The lack of competence of staff to communicate or provide quality end of life care was also found to contribute to the conflict staff experienced leading to moral distress (Piers et al., 2012, Varcoe et al., 2012b). The conflict between the ideal level of care provision and the reality of what could be done within the constraints of the care

setting was also found to be a threat to the dignity of residents as well as contributing to the distress of staff (Dwyer et al., 2009).

The conflict in these studies could prevent staff providing the care they would like, or they perceive to be morally correct for the resident. The inability to carry out the care that the staff would like links directly to the concept of moral distress.

3.5.4.2 Organisational constraints

Organisational constraints are identified as the main cause of moral distress by Jameton (1984). Although his definition has been adapted and developed, these constraints are still identified in the literature. These constraints have been identified as relating to the structure and processes of the organisation, routines, and leadership of organisations. Structurally homes with more than 100 beds were found to negatively affect the quality of end of life care provision (Brazil et al., 2006). Organisational routines and the expectation to work as normal when someone was dying contributed to the staff experience of end of life care (Casey et al., 2011, Porock and Parker-Oliver., 2007). Organisational leadership and how staff experienced support could have reduced moral distress especially when staff were provided with a forum to discuss ethical issues and concerns by a supportive manager whose focus was on relationships and people, rather than tasks (de Veer et al., 2013, Reitingger and Heimerl, 2014). Good leadership influenced good team working which could have provided support and made a difference to care outcomes (Forbes, 2001, Hockley et al., 2005). Edwards et al. (2013) found that managers of nursing homes were often in a position between staff and the organisation where conflicting values might have existed which could have contributed to the type of support that the managers were able to offer.

A general lack of support was found in the following studies: Ersek et al., 1999, Burack and Chichin, 2001, Katz et al., 2001, Munn, 2006, Varcoe et al., 2012b and Whittaker et al., 2007. Some managers, although they were aware that caring for the dying was emotionally draining, did not provide specific bereavement support for the staff (Katz et al., 2001, Funk et al., 2013, De Bellis et al., 1998, Goodridge et al., 2005). The reviewed literature also identified that some staff were fearful of caring for the dying and the deceased, which does not relate to moral distress but identifies the need for additional support (Burack et al., 2001 Osterlind et al., 2011). Managers did not always listen to staff, and in Dwyer et al.'s (2009) study on the dignity of staff and residents in nursing homes, found this could contribute to a culture of mistrust. Organisational processes and communication issues were also found to contribute to a lack of trust affecting team work and collaboration (Dreyer et al., 2011).

Katz et al., (2001) identified that there was a lack of organizational policies related to end of life care which could support how staff provided, and made decisions about, the care for their residents. Waldrop and Nyquist (2011) also recognised the importance of policies both internally and externally as affecting the staff experience. The move to a more target focused healthcare system could affect outcome measures when a resident in a nursing home was dying, which can contribute to other healthcare problems such as a pressure sore, affecting the statistical information that the home is required to publish (Waldrop and Nyquist, 2011). Developing protocols, which help to recognise the transition from living to dying, could be beneficial in reducing negative results being published (Waldrop and Nyquist, 2011).

The culture of caring for the dying as well as the living within the same environment could make care provision problematic and isolating for residents (Froggatt, 2001). Separating residents who were dying in inadequately sized spaces was also found to be problematic for staff in Komaromy et al. (2000) and Miskella and Avis's (1998) studies. The ability of organisations to be suitable for both the living and the dying was a difficult balance to achieve in these nursing homes, although it was not found to be the case in the acute geriatric care settings (Piers et al., 2012).

3.5.4.3 Resources

Resources were reported negatively related to finances, staffing, knowledge and education and positively to residents, GPs, hospice care and healthcare assistants. The allocation of adequate resources was found to influence the quality of end of life care in nursing homes (Munn, 2006). The lack of financial resources had been identified as a contributing factor to moral distress in the moral distress literature (Zuzelo, 2007, Huffman and Rittenmeyer, 2012) and financial constraints impacting on staffing levels were identified by Gjerberg et al. (2010) and Rice et al. (2004). Lack of end of life education could directly affect a resident's dying, knowledgeable staff were able to provide good end of life care which could allow the resident to die in peace, with their symptoms well managed, facilitating what is perceived to be a 'good death' (Munn, 2006, Hanson et al., 2002, Trotta, 2010).

Residents were recognised as a valuable resource when they were able to provide clear guidance on their wishes and choices (Froggatt, 2001), as well as GP's who could improve end of life decisions related to symptom management and family discussions (Seymour et al., 2011, Komaromy et al., 2000). Healthcare assistants were found to be a valuable asset in nursing homes as they spend twice as much

time with residents than nurses and are the main staffing group in this environment (Zheng and Temkin-Greener, 2010).

3.5.4.3.1 Staffing levels

Lack of staff was problematic for end of life care in nursing homes as the time staff could spend with dying residents was reduced (De Bellis and Parker, 1998, Brazil et al., 2010, Komaromy et al., 2000). This lack of time prevented staff from providing the quality of care they felt they were capable of (Rice et al., 2004). Beck et al. (2012a) found that a lack of time for care assistants, who were familiar with palliative care, made them feel out of control when they were unable to provide the care they knew they could give. Staff believed that it was unethical to leave a dying person alone when there was not enough staff on duty, or time to stay with them, which distressed staff (Gjerberg et al., 2010).

It was not just the numbers of staff available, but staff recruitment and consistency (Dwyer et al., 2009, Munn, 2006, Rice et al., 2004). Part time physicians in Dreyer et al.'s (2011) study contributed to a lack of consistency and care coordination at the end of a resident's life even though all the staff were motivated to provide high quality care, the hours these doctors worked were a barrier to this. Inadequate staffing levels contributed to moral distress resulting in staff resignation, as discussed by Piers et al. (2012), perpetuating the problems of recruitment and retention of staff in this environment. Unskilled staff at weekends (Gjerberg et al., 2010) and reduced numbers of staff on night duty (Komaromy et al., 2000) also contributed to the challenges that staff faced when a resident was dying. The deficient numbers of staff on duty out of normal service delivery hours had an impact on the care residents received and on the levels of distress experienced by staff (Seymour et al.,

2011). Out of hours, GP services negatively contributed to staff experience of end of life care as hospital admission was usually the chosen course of action when a resident was unknown to the GP (Mitchell et al., 2011).

3.5.4.3.2 Education and knowledge

Education and knowledge were identified as a valuable resource within the papers (e.g. Waldrop and Nyquist, 2011). However deficits in knowledge related to end of life care, symptom management and communication were found within nursing homes (Enes and de Vries, 2004, Ersek et al., 1999, Hockley et al., 2005, Lopez, 2007, Trotta, 2010, Rice et al., 2004, Whittaker et al., 2007). It was recognised that where staff whose first language was not English (Ersek et al., 1999) or where the ethnicity ratio of staff to residents was unequal (Zheng and Temkin-Greener, 2010), there could also be deficiencies in knowledge and education on end of life care. The lack of education could contribute to staff experiencing distress due to poor understanding of dying, and the ethical issues related to treatment decisions (De Bellis and Parker, 1998, Casey et al., 2011, Goodridge et al., 2005, Hanson et al., 2002, Kapp, 2003, Miskella and Avis, 1998, Munn, 2006, Seymour et al., 2011). Education was found to improve communication between staff and relatives which enhanced the staff experience of caring for terminally ill residents as well as improving care outcomes (Hockley et al., 2005, Ersek et al., 1999).

Access to end of life care education was highlighted as needing improvement in Miskella and Avis's (1998) and Edwards et al.'s (2013) studies. Stillman et al. (2005), however, found that the provision of an education intervention did not make a difference to the staff knowledge of palliative care a year after an educational intervention. Arguably this study was flawed in how the interventions were

measured because in the intervening year the majority of staff trained initially had left. There was some variation over the importance of education as the managers in Katz et al.'s (2001) study believed that education on caring for the dying was not as good as having the actual experience of caring for residents at the end of life, which the staff disagreed with. Miskella and Avis (1998) found that staff were expected to learn whilst doing the job, but they also identified that there was a need for palliative care education.

Staff competence was seen as a resource linked to knowledge and education and was found to be ethically challenging (Gjerberg et al., 2010), whereby incompetent colleagues could cause moral distress (Piers et al., 2012). Staff competence was not measured, in any of the reviewed studies but improving the working knowledge of specific areas of end of life care was found to have a positive effect on staff (De Bellis and Parker, 1998, Ersek et al., 1999, Forbes, 2001, Goodridge et al., 2005, Kapp, 2003, Komaromy et al., 2000, Miskella and Avis, 1998, Rice et al., 2004, Seymour et al., 2011, Trotta, 2010). Provision of education was recognised as one way of improving end of life care in nursing homes (Waldrop and Nyquist, 2011, Osterlind et al., 2011) with the need for symptom management training specifically identified by Raudonis et al. (2002) after they undertook an assessment of the knowledge of nursing home staff on end of life care.

3.5.4.3.3 Hospice care

Referral to hospice care or services was identified as a positive resource (Forbes, 2001, Zheng and Temkin-Greener, 2010). In the United States of America (USA) provision of hospice services requires contracts with hospice providers, which was found to positively affect care provision through the provision of additional support

for residents and relatives (Rice et al., 2004). The palliative care approach used within hospice care was identified as improving communication, advance care planning, symptom management and support for residents and relatives in nursing homes (Mitchell et al., 2013, Rice et al., 2004). Munn's (2006) participants valued hospice care in nursing homes but reported that they also wanted the opportunity to provide end of life care for their residents rather than all the care being provided by the hospice. Some staff, who lacked palliative care knowledge, believed that hospice care caused disruption by changing how care was provided (Rice et al., 2004). Kapp (2003) found that involving hospice services reduced the risk of litigation for nursing homes, which he discussed as being on the increase in the USA.

The majority of studies included in this review discussed the allocation of resources which, when lacking can contribute to moral distress as staff can be prevented from providing the standard of care that they know they can give.

3.5.4.4. Complexity of patient issues

Patient complexity was the least identifiable factor contributing to moral distress in the reviewed literature. This is likely because moral distress research has focused on intensive care settings, where patients have very complex medical needs, requiring complex life and death decisions. In the nursing home literature in this review, complex issues have been interpreted to relate to treatment decisions made for residents with dementia, the instigation of futile care, complex symptom management, and the dying trajectory in frail older adults. These complex issues are interrelated with other contributory factors to moral distress, especially communication and conflict.

3.5.4.4.1 Dementia

Residents with a diagnosis of dementia or who suffered with cognitive impairment were considered complex because of the difficulties staff experienced when residents were unable to make their own decisions about care (Enes and de Vries, 2004, Lacey, 2005, Seymour et al., 2011). Lacey's (2005) exploratory study among social service staff caring for this client group at the end of life, investigated their perceptions on tube feeding and hospitalisation at the end of life. It identified that there was a discrepancy in the opinion from the staff about treatment and the recommendations about palliative care treatment for people with end stage dementia (Lacey, 2005). This concurs with Seymour et al.'s (2011) results, which identified that the experience of end of life care in people with dementia was not as positive as people with cancer, as they received more aggressive treatment, which staff believed increased the residents suffering.

Feeding tube placement in residents with end stage dementia caused staff to experience the most distress (Reitinger et al., 2014), in particular the contribution of relatives as the surrogate decision maker requesting this level of care which was considered to be futile (Enes and de Vries, 2004, Ersek et al., 1999, Lopez, 2007, Mitchell et al., 2011, Gjerberg et al., 2010). Complexities in a resident's care could also occur when relatives were found to be in conflict with other relatives and/or with the team caring for the resident, over treatment and care decisions (Dreyer et al., 2011). The associated treatment decisions were found to affect the staff experience of end of life care depending on their own values and beliefs (De Bellis and Parker, 1998, Dreyer et al., 2010). The ultimate decision to treat or not was a

medical one although inconsistencies in decision making were identified most frequently when relatives demanded hospitalisation (Lacey, 2005).

3.5.4.4.2 Futile care

Futile care in this review related to inappropriate admission of dying residents to hospital for active treatment. Poor recognition that a resident was coming to the end of life could result in a hospital admission or inappropriate treatment (Burack and Chichin, 2001, Dreyer et al., 2010, Dreyer et al., 2011, Gjerberg et al., 2010, Kapp, 2003, Porock and Parker-Oliver, 2007). This was perceived to be distressing for the residents of nursing homes and could cause distress, (Dreyer et al., 2010, Lopez, 2007, Enes and de Vries, 2004, Piers et al., 2012, Ferrell, 2006) or moral distress (Piers et al., 2012, Edwards et al., 2013, Funk et al., 2013, de Veer et al., 2013) for the staff. Conversely, there was also evidence of moral distress amongst staff when active treatment was not provided (Piers et al., 2012).

These multifaceted issues and differences of opinion demonstrate how complicated end of life care in a nursing home can be for the staff, residents, and their relatives (Waldrop and Nyquist, 2011, Trotta, 2010, Seymour et al., 2011, Schaffer, 2007, Munn, 2006). Inadequate communication skills and strategies to advocate on behalf of residents contributed to staff feeling uncomfortable with decisions being made (Lopez, 2007). This could act as a barrier to the provision of good quality end of life care for residents (Dreyer et al., 2011, Ersek et al., 1999, Forbes, 2001, Lopez, 2007). Porock and Parker-Oliver (2007) identified that staff felt unable to prevent medical interventions at the end of a resident's life which would contribute to them feeling that they were not providing good quality care. Piers et al. (2012) also identified this

powerlessness as a central theme related to a lack of respect for the nurse's expertise in caring for older adults, which contributed to moral distress.

3.5.4.4.3 Symptom management

Piers et al. (2012) found that inadequate pain control caused moral distress. Pain was one of the palliative care symptoms identified as not being well managed or diagnosed for older people in nursing homes (Enes and de Vries, 2004, Ersek et al., 1999, Forbes, 2001, Mitchell et al., 2011, Munn, 2006, Waldrop and Nyquist, 2011, Goodridge et al., 2005, Varcoe et al., 2012b). Care assistants in Whittaker et al's (2007) study were found to be confident in reporting end of life symptoms, but reporting pain did not always result in the decision to administer appropriate medication, as there could be reluctance by qualified nursing staff to administer opioid analgesia due to fear and a belief that morphine would hasten the death of residents (Kapp, 2003, Ersek et al., 1999). The nurses in Kapp's (2003) study were concerned with the potential of being sued by family members if a death occurred after medication administration. Indeed this led to a preference of sending residents to hospital to be treated so staff could not be blamed for a death whilst they were on duty. There was evidence that nursing home participants were more confident to administer morphine than colleagues working in an acute geriatric care setting were (Piers et al., 2012).

3.5.4.4.4 Dying trajectory

Palliative care was viewed as a contrast to the day-to-day care for the frail older population of nursing home residents (Beck et al., 2012a) whereby it was only instigated in the last few days of life, rather than being integral to care provision. Using a palliative care approach was identified as a means of supporting staff and

relatives to come to terms with dying as a natural process (Beck et al., 2012a). This is important because the diminishing physical state of a resident is perceived as contributing to their suffering at the end of life and a lingering death is identified as causing the most distress for staff (Froggatt, 2001, Goodridge et al., 2005, Hanson et al., 2002, Kapp, 2003, Waldrop and Nyquist, 2011). Diagnosing dying is seen as an inexact science and a lack of confidence can prevent staff from saying they believe that a resident is dying (Hockley et al., 2005). Using a palliative care approach and an integrated care pathway for the dying can improve end of life care and lead to increased confidence in recognising dying (Hockley et al. 2005).

3.5.4.5 Communication

Good communication is a fundamental aspect of palliative care in nursing homes (Reitenger et al., 2014), especially involving the residents, relatives and nursing home staff and could contribute to how end of life care is experienced by staff (Brazil et al., 2006, Dreyer et al., 2010, Enes and de Vries, 2004, Ersek et al., 1999, Forbes, 2001, Gjerberg et al., 2010, Mitchell et al., 2011, Katz et al., 2001, Trotta, 2010, Zheng and Temkin-Greener, 2010). The lack of involvement in decision making, and not being heard has been recognised as problematic in nursing homes especially for care assistants (Hanson et al., 2002). This has been found to have a detrimental effect on how the staff viewed care (Ersek et al., 1999, Piers et al., 2012).

A direct correlation was made between good communication and positive care outcomes at the end of life in Zheng and Temkin-Greener's (2010) extensive care assistant study. This was found to reduce the distress they experienced. Lack of confidence, however, contributed to a third of care assistants feeling that they were unable to communicate with relatives and residents about end of life care (Whittaker

et al., 2007). Edwards et al.'s (2013) participants recognised the value of the healthcare assistants as the staff members who often knew more about the resident, and they were valued for their contribution to care planning discussions. Despite this, care assistants have been identified as the group of staff least likely to be involved in care planning discussions, even though they would like the opportunity to contribute more to discussions to influence care, reducing resident suffering (Burack and Chichin, 2001, Ersek et al., 1999, Trotta, 2010, Zheng and Temkin-Greener, 2010). Beck et al. (2012a) found that the older person's dying trajectory and lack of support for them as healthcare assistants contributed to this lack of involvement with relatives.

Beck et al.'s (2012a) study found that talking about death was too stressful for healthcare assistants and they steered away from any conversations about death and dying especially with residents and relatives. Residents were also reported as being reluctant to talk about death and dying by Schaffer et al. (2007). Forbes (2001) however found the opposite as residents accepted the inevitability of death once they were admitted to the care home. Staff in Porock and Parker-Oliver's (2007) study, suggested that when residents were able to discuss death it indicated that they were ready to die and wanted to say their goodbyes, and that this readiness to have discussions occurred when they were closer to death.

Inadequate communication skills between staff, other healthcare professionals and relatives could have a detrimental effect on care and cause frustration (Brazil et al., 2006, De Bellis and Parker, 1998, Enes and de Vries, 2004, Ersek et al., 1999, Katz et al., 2001, Trotta, 2010) which could contribute to the experience of moral distress.

Communication issues were identified as being most problematic with GPs, with 63% of staff in De Bellis's (1998) survey of directors of nursing stating they had difficulties with GPs. Poor communication by medical staff resulted in a deference to a relative's decisions and wishes, rather than following what staff believed to be appropriate care causing distress for staff (Brazil et al., 2006, Dreyer et al., 2011).

3.5.4.6 Emotional work

Emotional work as a factor in this review relates to the experiences of care staff and how end of life care has both a positive and negative impact on their emotions.

The complexities of end of life care already discussed also impact on the emotional feelings of healthcare assistants when a resident dies (Beck et al., 2012a). In studies where staff were asked about their experiences of end of life care, they frequently identified that there was an emotional attachment to residents, which management rarely appreciated (Burack and Chichin, 2001, Ersek et al., 1999, Goodridge et al., 2005, Lopez, 2007, Miskella and Avis, 1998, Osterlind et al., 2011, Trotta, 2010, Waldrop and Nyquist, 2011, Whittaker et al., 2007). This emotional attachment enabled carers in some organisations to provide the emotional care which was recognised as important to residents (Goodridge et al., 2005). Knowing the resident enabled staff to carry out care that was conducive to the resident even when they were unable to articulate their needs any longer (Burack et al., 2001, Hanson et al., 2002). Provision of end of life care for residents was rewarding, and made staff feel proud of their work but was also emotionally draining (Burack and Chichin, 2001, Dwyer et al., 2009, Komaromy et al., 2000).

Relationships with relatives were the most influential in contributing to the staff experience of end of life care in nursing homes (Beck et al., 2012a, Goodridge et al., 2005, Trotta, 2012, Schafer et al., 2007). Indeed, Dreyer et al. (2010) suggests that end of life care in nursing homes is caring more for the relative than the resident.

Staff assumed the role of surrogate family when residents did not have relatives, and when the resident was at the end of life the emotions of caring were intensified (Osterlind et al., 2011, Waldrop and Nyquist, 2011). Consequently, on the death of the resident the loss experienced could be similar to that of a relative for staff (Waldrop and Nyquist, 2011). Staff were bereft, and needed time to mourn (Beck et al., 2012a) but there was a lack of bereavement support offered to staff in this care setting (De Bellis and Parker, 1998). Katz et al. (2001) study found that staff limited their communication to reduce the risk of them suffering anxiety or distress when a resident was dying, and any emotional response was reliant on the emotional tone set by the manager. It was taboo to discuss dying in Porock et al.'s (2007) study, where staff were able to identify when a resident was close to death, but were not allowed to acknowledge this with the resident or relatives.

Care of the dying was seen as part of the job for the staff in these studies, resulting in poor recognition of their emotional needs and a general lack of support by the managers (Osterlind et al., 2011, Mitchell et al., 2011). It was identified that management needed to recognise the level of emotional attachment, and assist carers to acknowledge their feelings and provide additional support, such as bereavement care or to implement reflective practice (Burack et al., 2001, Mitchell et al., 2011, Reitingner and Heimerl, 2014). Funk et al. (2013) however found that some

staff found the carrying on with work and not having to address their emotions worked as a coping mechanism after a resident died. Higher levels of emotional exhaustion were found to contribute to higher levels of moral distress in Piers et al. (2012) study. Schaffer et al. (2007) also recognised that managing the burden of care given when a resident was dying, contributed to the emotional state of nursing home staff.

3.6 FURTHER IDENTIFIED ASPECTS OF CARE

Aspects of end of life care which could not be aligned to the contributory factors to moral distress were also found in the review. Spiritual needs had been difficult to discuss and meet (Schaffer et al., 2007 Whittaker et al., 2007) or not discussed (Forbes, 2001). The social and psychosocial aspects of dying were identified as missing in end of life care resulting in some residents feeling lonely (Lopez, 2007) or being isolated (Froggatt, 2001). These factors are important for end of life care in this environment and when they are associated with staff being unable to achieve a resident's wishes, could contribute to moral distress.

3.7 LIMITATIONS

The limited literature on moral distress in nursing homes meant that the search needed to be expanded. An inclusive approach was adopted using literature which was less methodologically sound than others and may contribute to a lack of rigour for this review, but this was important to expand the review beyond the limited literature of three papers. Utilising the contributory factors to moral distress as a sorting mechanism for associated literature was complex and subjective.

3.8 CONCLUSION

The aim of this review was to identify nursing home staff experiences of caring for residents at the end of life, with specific reference to moral distress. The literature review confirms the presence of moral distress in its different forms, for staff providing end of life care in nursing homes. Only one Belgian study specifically explored end of life care and moral distress in nursing homes and concluded that it did exist (Piers et al., 2012), however as a quantitative study it did not explore the staff experience. De Veer et al.'s (2013) study was also quantitative and identified the characteristics of moral distress but not how staff experience it. Edwards et al. (2013) did investigate the staff experience of moral distress, finding that conflict related to care decisions, including those related to end of life, contributed to the staff experience of initial moral distress, but this was not the main purpose of their investigation.

The review has identified that there is a gap in the knowledge literature on UK nursing home staff's experience of moral distress when caring for residents at the end of life, which is worthy of further exploration.

CHAPTER 4 METHODS AND METHODOLOGY

The aim of this study is to understand how nursing home staff experience moral distress when they care for residents coming to the end of life, which will address the gap in knowledge identified in chapter three. The research question to be answered is: *'How do nursing home staff experience moral distress when providing end of life care to residents?'* and the objectives of the study are:

- To explore how staff experience end of life care in nursing homes
- To identify and understand the factors influencing the experience of moral distress in the participant group.

Interpretivism has been adopted as the epistemological stance to address the research question and interpretive description has been chosen as the qualitative research methodology. This chapter will discuss the rationale for the methodological choice for the study as well as for the methods chosen. Recruitment strategies; data collection; use of the critical incident technique; and thematic analysis will be explored and how they link with the chosen methodology with an explanation of how the processes and procedures were carried out. Ethical considerations, which were identified prior to the study commencing, are also explored in more detail.

4.1 EPISTEMOLOGY

The literature review has identified that there are external and internal factors that contribute to the end of life care provision in nursing homes. Organisational values and the social world lived in by the staff can influence how care is given. This is particularly the case if the culture within nursing homes is one of 'obedience', and of following instructions unquestioningly which can be detrimental to care (Werhane et

al., 2011), as well as personal values influencing how decisions are made (Cottone, 2001, Lehr and Sumarah, 2004), which can affect the care that is provided. Recognition that the social world impacts on care in this way led the researcher to adopt interpretivism as the epistemological stance for this study (Snape and Spencer, 2003). Interpretivism not only acknowledges the impact the social world has on people's lived experiences, but also that the researcher's views and values can affect the interpretation of the social world under investigation (Denzin and Lincoln, 2000). Interpretive description addresses the researcher's views and values as it accepts that they exist.

4.2 METHODOLOGY

In keeping with the interpretive epistemological stance, a qualitative research approach has been chosen for this study as this can enable the human experiences under investigation to be explored more fully and answer the research question (Snape and Spencer, 2003). Qualitative research requires planning and a framework which supports the methodological choices that are made within it (Carter and Little, 2007). The framework identified by Carter and Little (2007) relates the epistemology, methodology and methods for this study (Figure 2).

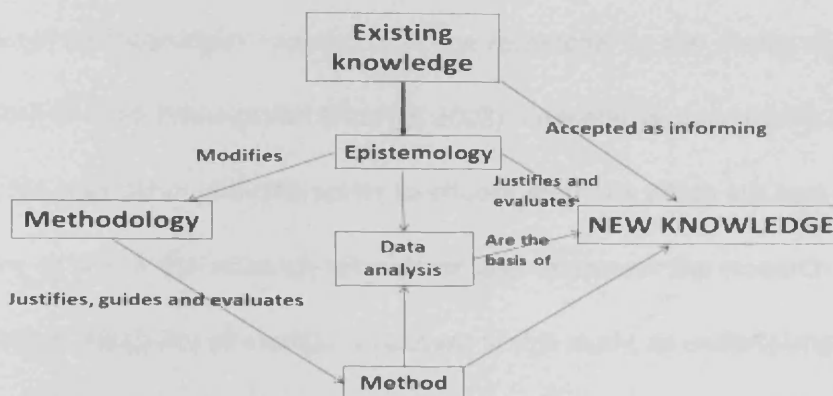


Figure 2 The relationship between epistemology, methodology, and method (adapted from Carter and Little 2007 p1317)

4.2.1 INTERPRETIVE DESCRIPTION

Research questions asked by nurses often aim to address an improvement in practice by finding a practical solution (Thorne, 2008). Interpretive description has been selected as the methodology for this study because it has been developed for use by nurses to permit the search for solutions that can improve outcomes for patients and staff by addressing practice issues (Thorne, 2011, Morse, 2010). Interpretive description moves away from the need for a researcher to locate themselves with one of the traditional qualitative social science methodologies; ethnography, grounded theory and phenomenology, which Thorne (2008) suggests can constrain the nurse researcher in finding practical solutions in a timely manner. Interpretive description accepts that the knowledge from the clinical expert undertaking the research and previous knowledge on the subject will inform the findings alongside the data (Thorne, 2008). Some traditional methodologies develop new theory from the data, or from observation where utilising previous knowledge would be detrimental to the rigour of the research (Thorne, 2008).

The need to adhere to specific methods of research design and methods of analysis in traditional methodologies can also limit the researcher in the choice of methods they choose in their investigation (Thorne, 2008). Interpretive description, however, provides the researcher with the ability to choose methods which are best suited to the setting in which the research takes place and to answer the research question (Morse, 2010). Flexibility of method is relevant in this study, as undertaking research in nursing homes can be problematic due to limited access and time constraints (Luff et al., 2011). Health research can be a low priority for patients and practitioners, therefore requiring methods which will engage them, and are suitable for the environment is important (Morse, 2010). Interpretive description has been used successfully within nursing homes to investigate moral distress (Edwards et al., 2013).

Despite its use as an emerging methodology there are limited examples of studies that have used it, and those that do tend not to give a detailed overview of the methodology or of its limitations in practice which can be problematic (Hunt, 2009).

An interpretive descriptive study requires 'theoretical scaffolding' (Thorne, 2008) after a practice orientated goal or question has been identified, and this requires a literature review and reflection of the researcher's 'theoretical baggage' (Thorne, 2008). This scaffolding provides the framework for the research, enhancing the rigour of the study and informing the format and methods chosen to answer the research question.

Identification of a practice orientated goal

Generation of new knowledge of nursing home staff experience of end of life care in order to inform future initiatives for staff support.

A literature review

The literature review was carried out prior to the study commencing (chapter three).

Reflection on theoretical baggage

As the end of life facilitator, and a nurse educator I regularly reflect on the education sessions I provide in nursing homes to improve engagement and to have a better understanding of the challenges that staff face. Reflection has enabled sessions to be better tailored to the nursing home environment to address some of the difficulties staff experience related to end of life care. Resuscitation scenarios, sedation and treatment decisions and the difficulties staff face with some of the relatives of residents have particularly required more in depth reflection. These reflections have contributed to the 'theoretical baggage' I bring to the study, in the form of assumptions. I assume relationships within families are complex and contribute to care decision making being taken out of the hands of staff, which cause difficulties for them. I assume that best practice is to care for residents in the nursing home rather than send them to hospital and that nurses have the confidence to make the right decision. Further reflection occurred during the data collection and analysis stages of the study and are reported in section 4.3.5.

4.3 METHODS

This study adopts an interpretive descriptive methodology to answer the research question (Thorne, 2008). Time constraints and difficulty of access to nursing home staff (Luff et al., 2011, Dwyer et al., 2010) have contributed to the methods chosen. This section will describe these methods and give an account of the analysis process.

4.3.1 POPULATION

Accessing nursing homes for research can be problematic as Luff et al. (2011) identified. I work with the 17 nursing homes in my borough, and following ethical approval (Appendix 3) these homes were selected to be the population from which a sample of staff could be taken. The culture of an organisation can affect care provision (Suhonen et al., 2014), therefore nursing homes from large national companies and small independent ones within the study area were divided into two separate groups. All nursing homes were allocated letters of the alphabet, and an electronic randomisation tool was used to select the order the nursing homes would be approached. Nursing homes were approached in the order generated by the randomisation tool to avoid research bias by selecting homes I felt more familiar with (Barrett and Coleman, 2006). Initially six homes (National F, J, D, Independent A, M, I) were approached to take part in the study as the intended number of recruits was between 15 and 20 with an aim to collect 50 critical incidents. If this had not been achieved in the first six homes the next three on the list would have been approached, until the number of incidents had been achieved. Interviewing staff did not require further ethical approval in any of the organisations approached to take part.

4.3.2 SAMPLE

Qualitative studies usually have small numbers of participants due to the amount of data that are collected (Ritchie et al., 2003). The sample from within the nursing homes included all staff who were over the age of 18, spoke English, and had experience of providing end of life care to residents. This offered as much diversity of participant as possible to answer the research question (Ritchie et al., 2003).

4.3.3 RECRUITMENT

Accessing the intended sample of staff in nursing homes required approaching the home manager of the selected homes as this was the easiest route to recruiting the population required (National Institute of Health Research, 2014). A letter of introduction, (Appendix 4) and an information leaflet on the research project (Appendix 5) were sent to each of the managers to share with staff. Initial recruitment was slow, so to increase numbers four managers agreed for me to meet with staff to inform them of the study objectives and to answer any questions. Staff were asked to contact me after the meeting if they wanted to participate so they did not feel pressurised to agree during the meeting. This increased the number of participants and a total of 16 was achieved; the recruitment process can be seen in Figure 3.

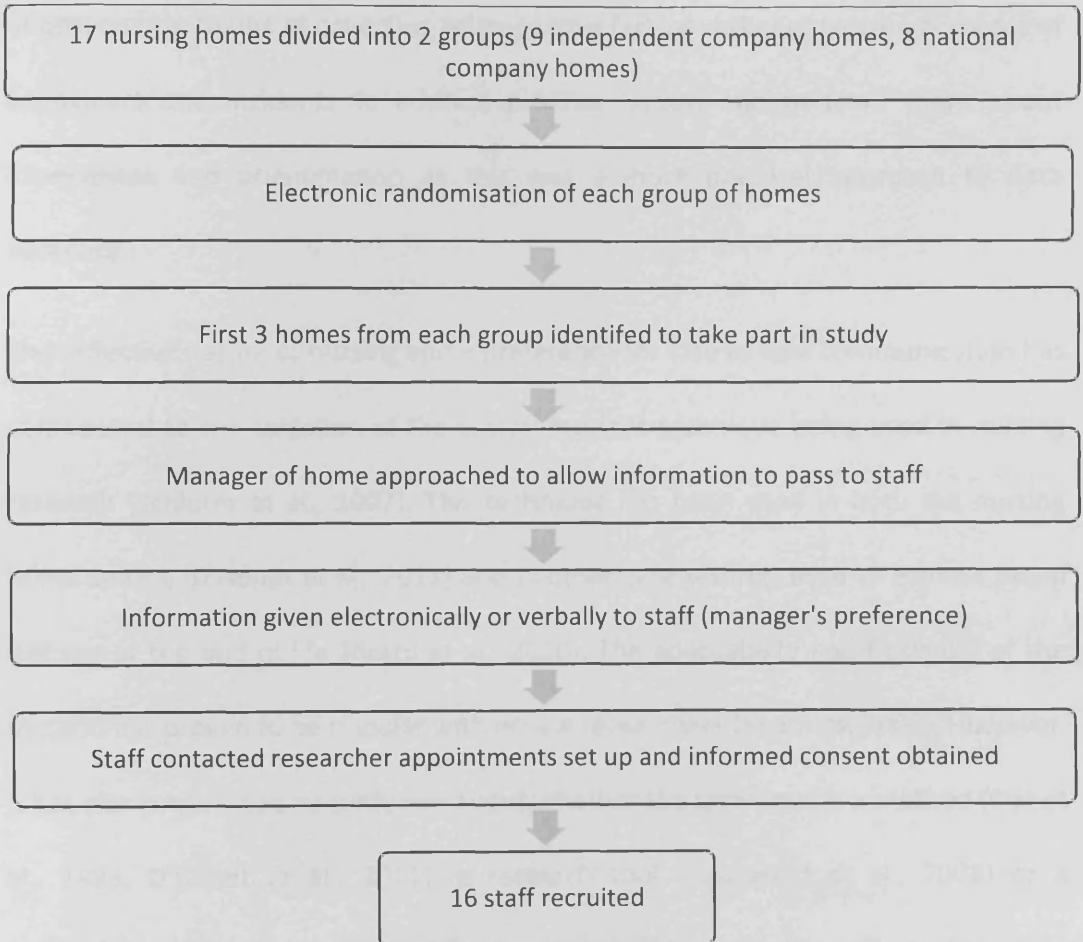


Figure 3 Process of recruitment

4.3.4 DATA COLLECTION

In identifying an appropriate method for data collection it was important to consider the limitations and constraints of this study, namely the time available to staff (Dwyer et al., 2010). Accessing participants within work time was permitted by the home managers. To ensure the time was utilised efficiently and effectively, critical incident technique was used as the method of data collection (Kemppainen, 2000).

4.3.4.1 Critical Incident Technique

The critical incident technique was originally devised as an observational technique to collect data to address specific work related practical and procedural problems experienced by aircraft pilots in an attempt to improve standards (Flanagan, 1954). Flanagan (1954) and Norman et al. (1992) developed the technique from purely one

of observation to one of collecting retrospective factual verbal or written accounts of behaviours and incidents to address practice issues, and to learn more about experiences and phenomenon as this was a more practical approach to data collection.

The reflective nature of nursing and a preference for face to face communication has contributed to the selection of the critical incident technique being used in nursing research (Schluter et al., 2007). This technique has been used in both the nursing home setting (D'Hondt et al., 2011) and in other care settings used to explore moral distress at the end of life (Brazil et al., 2010). The adaptability and flexibility of the method has proven to be popular with novice researchers (Keatings, 2002). However, it has also contributed to confusion about whether the technique is a method (Cox et al., 1993, D'Hondt et al., 2011), a research tool (FitzGerald et al., 2008) or a methodology (Bradbury-Jones and Tranter, 2008). This study utilises the technique as a method of data collection, as it can steer participant stories which relate to the research question in a short space of time.

A frame of reference is required prior to collecting information to establish which incidents are relevant (Flanagan, 1954) and what constitutes as a critical incident within a study (Bradbury-Jones and Tranter, 2008). In this study, participant critical incidents were those which related to all the over 65 year old residents who had died and whether they were positive or challenging experiences, expected or unexpected deaths which held resonance for the staff. In studies utilising critical incident technique Flanagan (1954) suggests that the number of incidents collected depends on the information being provided by the participants and whether the incidents are

providing new information not previously seen or mentioned. Schluter (2007) also found that the flexibility about how many critical incidents are required can mean that data can be collected until no new ideas are found, reaching data saturation. Twelker (2003) recommends that no less than 50 incidents be collected within a study using critical incident technique. In practice the precise number of required incidents can only be known after preliminary analysis takes place to ascertain the quality of the data. Fifty incidents was the minimum number of incidents adopted to achieve in this study. Sixteen participants consented to participate and were interviewed and after preliminary analysis of the data, 63 'incidents' were identified with no new ideas being raised by participants in the last two interviews which equates to data saturation (Schluter 2007) see Appendix 6.

4.3.4.2 Semi-structured interviews

Sixteen people volunteered and information on the storage of digital recordings on an encrypted computer and anonymization of all transcripts and nursing homes was given to each participant before they provided consent to be interviewed (Appendix 7).

A semi-structured interview guide was utilised to guide the interviewer through the interview (Appendix 8). Many of the participants' first language was not English and the flexibility of questioning using the guide meant that questions could be re-phrased in language that the participant was more familiar with (Birks et al., 2007). The guide was also useful in reducing the risk of the researcher providing an influencing opinion and advice whilst questioning during the interview (Jack, 2008, Thorne, 2008).

The interviews were held in the work environment which the participant was familiar with, helping them to feel at ease. Discussion of day to day events at the start of the interviews built rapport with participants which encouraged them to share their stories (Luff et al., 2011, McCosker et al., 2001, Birks et al., 2007). The interviews were digitally recorded enabling the researcher to pay full attention to the participant by actively listening, rather than writing notes. Listening to stories and experiences, probing for more information are skills that I am familiar with as an experienced nurse, and these were utilised to obtain relevant data for this study (Carter and Henderson, 2005).

The terminology used to explore critical incidents in the interviews was developed to reduce the amount of potential confusion, due to a lack of knowledge of 'moral distress' as it is an unfamiliar term in the UK. General terms such as 'difficulties', 'challenges', and 'upset', were used alongside the language utilised by the participant in the interviews to reduce any misunderstanding. The researcher was also wary of the potential for over talking and using her existing knowledge of the phenomena under investigation, which could have caused the participant to withdraw and reduce the amount they said (Thorne, 2008). Field notes at the end of each interview were made and constituted part of the reflective data following interpretive descriptive design (Thorne, 2008, see Appendix 9). Thorne (2008) identifies the importance of using researcher notes on the reflections made after interviews as these can be used to inform the analysis process and questions being asked in subsequent interviews.

4.3.5 DATA ANALYSIS

Braun and Clarke's (2006) process of thematic analysis (Table 7) was chosen to manage and analyse the data obtained in this study. Analysis can be a complex

process requiring a strategy and plan to ensure that all data are equally explored and managed (Schilling, 2006, Thorne, 2008). Ensuring in depth analysis takes place in interpretive descriptive studies can be challenging as there is a danger that results will not be interpreted fully enough and remain descriptive (Hunt, 2009). The use of thematic analysis facilitates the identification of themes and patterns in qualitative data, providing a higher level of interpretation as is required in an interpretive descriptive study (Thorne, 2008). Throughout each stage of analysis, the process is steered by the researcher who decides what is relevant, and how it will be structured and conceptualized for dissemination (Thorne et al., 2004). The use of notes, and reflections on thought processes during the analytical process can be invaluable (Thorne et al., 2004) and they have been utilised to inform decisions made during the process. Analysis for this study followed Braun and Clarke’s (2006) five step process, which are summarised in Table 7. Step five is reported in the findings (chapter five) and step 6 formulates the discussion chapter (chapter six).

Table 7 Application of Braun and Clarke's (2006) five stage analytical process for thematic analysis

| Process steps | Action |
|------------------------------|--|
| 1. Familiarisation with data | <ul style="list-style-type: none"> • Reflective notes were recorded after each interview • Digital recordings listened to after downloading onto an encrypted computer • Transcription • Transcripts checked against digital recording for accuracy |
| 2. Generating initial codes | <ul style="list-style-type: none"> • Data relevant to end of life care was highlighted and copied into tables • Incidents were then categorised/divided into 'incident', 'like', 'other' • These were then re-read and initial thoughts from interview field notes and listening to the recordings were noted • Moral distress issues identified in the literature review used as an expanded coding template to code data • Initial codes identified from a compilation of these sources |
| 3. Searching for themes | <ul style="list-style-type: none"> • Data coded as broadly as possible using the initial codes • Codes under the 'incident', 'like', 'other' sections combined due to level of duplication • Data within each code were re-read to identify potential themes |
| 4. Reviewing themes | <ul style="list-style-type: none"> • Themes reviewed by constantly comparing codes within each theme • Data were reviewed to identify patterns |

| Process steps | Action |
|-------------------------------|---|
| | <ul style="list-style-type: none"> • Further themes identified from patterns |
| 5. Defining and naming themes | <ul style="list-style-type: none"> • Themes reviewed and codes grouped into sub-themes and linked to the overarching themes • The scope and content of each theme briefly described • Two overarching themes identified that 'hold' the themes and subthemes |
| 6. Writing the report | <ul style="list-style-type: none"> • Using the themes to report the findings from the data in a cohesive and methodical way |

4.3.5.1 Familiarisation with the data

Reflective data of first impressions and broad ideas following interviews were used to start the process of familiarisation and interpretation of the data, followed by listening to the recordings and making further notes (Thorne, 2008). Familiarisation with the data could be further improved if interviews were transcribed by the researcher (Thorne et al., 2004, Thorne, 2008). A denaturalized approach to transcription, where grammar is corrected and stutters, pauses or repetitive speech are removed, was selected for this study as transcribing verbatim can cause distraction from the actual content of the data (Maclean et al., 2004, Halcomb and Davidson, 2006, Oliver et al., 2005). All transcripts were checked for accuracy against the original recordings and further notes and impressions noted.

4.3.5.2 Generating initial codes

Generating initial codes required utilising as much data as possible to improve the credibility of this interpretive design study (Thorne, 2008). Flanagan's (1954) critical incident method only used incidents in which the participant had been actually involved to inform the results. In this study limiting the data to the 63 end of life incidents that directly involved the participants would have omitted valuable insights, opinions or anecdotes. As such, the decision was to categorise the incidents into three broad categories: 'incidents', 'like' and 'other', following Norman et al. (1992) and Webster and Mertova (2007) (Figure 4).

| | |
|----------|--|
| Incident | <ul style="list-style-type: none"> •events that relate specifically to a resident the participant had cared for at the end of life (63 identified) |
| Like | <ul style="list-style-type: none"> •had similar incident characteristics but the story did not meet the criteria of a critical event e.g. someone else's story, or a resident who was dying but recovered, or a death elsewhere |
| Other | <ul style="list-style-type: none"> •all data collected on the generalisations or observations about end of life care that participants had made |

Figure 4 Incident categories (developed from Webster and Mertova, 2007)

'Incidents' and 'other' were identified within the transcripts by highlighting in different colours. Participants did return to a story (the incident) throughout the interview, (see Appendix 10). These incidents were then pasted into a table where all 'other' incidents were amalgamated, prior to the incidents being aligned to initial coding ideas (see Appendix 11). The utilisation of all incidents is in keeping with Thorne (2008) who suggests that it is difficult to claim that data saturation has been reached as the next participant could possibly have a new idea.

Initial ideas of potential codes were formulated from the reflective notes and interviews, and researcher knowledge (Appendix 12). Using a coding template (Crabtree and Miller, 1999), initial coding was developed on the factors contributing to moral distress identified in chapter two: conflict, organisational constraints, resources, complexity of patient issues, communication and emotional work, and an after death code (Appendix 13). At this stage of coding very little interview content was eliminated to ensure the context of what had been said was not lost (Braun and Clarke, 2006).

Data were saved in Word documents and initially codes and comments were made alongside the data. Following this, all data were uploaded to NVIVO 10 to facilitate

effective data management and for ease of application of codes to as much data as possible (Leech and Onwuegbuzie, 2011).

4.3.5.3 Searching for themes

The initial data coding was very broad with a lot of codes being used, ensuring that all coded data could be compared (Seale, 2010, Braun and Clarke, 2006). However, it was noted that there was duplication within the categories of 'incidents' and 'other' with no incidents falling into the 'like' category. Therefore the data were amalgamated and critical incidents were considered to be all end of life stories related to residents the participants had known. Re-reading, reflection on the data within coded sections and using constant comparison within the codes ensured consistency of code application and for patterns within the data to be observed (Seale, 2010). Engagement with the interview data in this way enabled the researcher to formulate potential themes within the data (Bradley et al., 2007, Pope et al., 2000, Schluter et al., 2007) broadly linked to the factors contributing to moral distress.

4.3.5.4 Reviewing themes

In practice, attempting to code the literature to the contributory factors was found to be limiting as the temptation was to see data only in the context of the moral distress contributory factors identified in the literature review (Appendix 13). Reviewing the data for themes, which were not specifically linked to the contributory factors to moral distress, was carried out. Looking for and developing understanding of the meaning within incidents, and not just describing what the incident was (Norman et al., 1992) allowed a higher level of interpretation to be achieved (Hunt, 2009). This more inductive approach allowed for broader themes (Braun and Clarke,

2006) of positive and challenging aspects of end of life care to be identified, some of which did not relate to the contributory factors of moral distress. These were: communication, external relationships, internal relationships, powerlessness, the dying process, achieving resident's wishes, giving good care and recognition (Appendix 14).

NVIVO 10 facilitated the organisation of the themes and for the data to be mapped to the broad themes (Thorne et al., 2004, Pope et al., 2000, Ritchie et al., 2003). This permitted the researcher to see coherence within the identified broad themes (Braun and Clarke, 2006). Further analysis was undertaken to include comparison of the incidents across each of the participants to find concurring and contradictory data to inform the themes. The demographic data of age, ethnicity, qualifications and length of time in nursing homes was utilised within themes to see if there were further patterns in the data aligned with the intention of increasing the level of interpretation (Ritchie et al., 2003).

4.3.6 CREDIBILITY AND RIGOUR

Caelli et al. (2003) suggest there are four areas which need to be addressed in a generic qualitative research study to improve credibility, a) the researcher's position is fully explained within the research, b) the methodology is congruent with the methods, c) strategies that demonstrate rigour within the study are clear, and d) the lens through which the data is analysed is evident. In this study the position of the researcher has been described in section 4.2.1, and her 'theoretical baggage', as required in an interpretive descriptive study (Thorne 2008), has been articulated. The chosen methods of critical incident technique for data collection, using semi-structured interviews and thematic analysis are congruent with the interpretive

descriptive methodology (see section 4.2). Rigour is demonstrated by the provision of a clear audit trail of where codes and sub codes developed, in order to ensure that the findings were plausible within this interpretive descriptive study (Thorne, 2008). Finally, the lens through which the data have been analysed was that of moral distress using definitions from Varcoe et al. (2012) and Peter (2013), as articulated in section 2.7.1.

4.3.7 ETHICAL PROCESSES

The undertaking of research with human participants is governed by procedures and processes that ensure that they are protected from harm (Barrett and Coleman, 2006). Prior to approaching any potential participants ethical approval was sought and this study has been reviewed and approved by Lancaster University Ethics Committee (Appendix 3).

The key ethical issues that were addressed in this study were: (1) consent, (2) duty of care to residents, (3) staff safety, (4) confidentiality and (5) power dynamic due to the researcher's role.

4.3.7.1 Consent

Informed consent is required for all participants of research (Silverman, 2006). The information sheet (Appendix 5) and consent form was read with each participant prior to obtaining written consent and commencing any interviews (Appendix 7).

4.3.7.2 Duty of care to residents

As a registered nurse bound by the Code of Professional Conduct, the researcher had a duty of care to the residents in the nursing homes where the study took place (Nursing and Midwifery Council, 2015). Identification of any unsafe or dangerous practices during the participant interviews would have required the researcher to

invoke the protocol for unsafe practice (Appendix 15). This was explained on the consent form (Appendix 7) and explained at the beginning of each interview.

4.3.7.3 Staff safety

The emotional nature of caring for residents at the end of life has been established (Ersek et al., 1999) and talking about death and dying can be considered to be a sensitive research topic which could have resulted in challenges being faced by the participant and the researcher during the interviews (McGarry, 2010, McCosker et al., 2001). Participants were able to stop and withdraw from the study at any time during the interview, and up to two weeks afterwards. Although no staff showed any distress, a plan was drawn up whereby if staff had become distressed during the interview, it would have been suspended and reassurance would have been given. Onward referral to an appropriate agency would have been made if this had happened.

4.3.7.4 Confidentiality and anonymity

Confidentiality in this study relates to residents, participants, and nursing homes. Participants were assured that the information they gave during the interviews would only be utilised once identifying features had been removed. Consent forms were the only piece of data with the participant's name on and confidentiality was assured by identifiable data being stored in a locked cabinet in the researcher's house in accordance to the Data Protection Act (Great Britain, 1998). If participants had chosen to be interviewed in the nursing home, they needed to be aware that the manager and other staff might know they were partaking in the study. Nursing homes were only identified as national or independent and only those who took part were aware of who they were, as this had not been shared with others.

The personal anonymity of residents identified within interviews was maintained by removing their names and any identifiable information from transcripts. Digitally recorded interviews were deleted once they were downloaded onto a password-protected computer, in line with the Data Protection Act (Great Britain, 1998). Transcripts were numbered and not attributed to the interviewee by name and all documents were encrypted and stored on a password protected computer (Great Britain, 1998).

4.3.7.5 Power dynamics and the researcher's role

As the end of life facilitator for care homes, the researcher was known to some of the participants. Being a 'nurse specialist' could potentially have resulted in an unwanted power dynamic in the interviews (Bourdeau, 2000). In this study, which involved asking sensitive questions, a high level of trust was required (McGarry, 2010, McCosker et al., 2001). The benefits of knowing the participants was seen positively in the context of a study using critical incidents, as staff may have been less willing to speak to a stranger. The fine line between trust to obtain good in depth data and professional distance is difficult but required for ethical rigour (Guillemin and Heggen, 2009). A researcher's influence on participants is not uncommon in qualitative research. This can be reduced by personal presentation, full explanations and reflexivity, because putting the interviewee at ease helps to dissipate the risk (Jack, 2008). Acknowledgement of this before commencing the project reduced the risk once interviews commenced (Eide and Kahn, 2008).

Acknowledging the tension between benefitting from the level of trust afforded to the researcher and coercing staff to take part because of the researcher's professional role was important (Karnieli-Miller et al., 2009). This was managed by

communicating with staff and jointly reviewing the consent form, in order to stress that participants did not have to take part and they were able to stop the interview at any time. No participant withdrew or terminated the interview and all seemed pleased to be involved.

Listening to staff and not offering advice or giving personal opinions during the interview, enabled the participant to tell their story without the researcher taking over. Clarity was sought where needed in a facilitative way (Jack, 2008) using probing questions appropriately in what was hopefully a non-threatening manner (Fielding and Thomas, 2008).

4.4. CONCLUSION

Prior knowledge of nursing homes and end of life care was the first building block for this piece of research, providing the basis for a study using an interpretive descriptive methodology. Interpretivism as the epistemological stance for the study recognised that individuals can be influenced by the environment, culture, and society in which they work and live. Studies that use this methodology face the challenge of breaking new ground because little has been written about it (Hunt, 2009). The logical steps and processes were flexible and fitted with the chosen methods. Using the critical incident technique enabled the collection of appropriate stories that related to the topic under investigation, where time was limited for participants. The in depth level of the data interpretation enabled the identification of themes expanding the understanding of the nursing home staff experience of end of life care.

CHAPTER 5 FINDINGS

5.1 INTRODUCTION

This chapter reports step five of Braun and Clarke's (2006) analytical process, where 'good dying' values and their contribution to the practice of end of life care are identified and presented. The elements of practice which were found to influence end of life care were advocating, caring, communicating and relating. These elements enabled staff to provide residents with what they considered to be a 'good death', which they felt was 'doing the right thing'. The inability to 'do the right thing' made staff feel powerless to do what they considered to be right for the resident which could result in poor care outcomes and a 'bad death'. The correlation between the staff's 'good dying values', the practice elements and how they influence 'doing the right thing' and 'powerlessness' are presented. The powerlessness experienced characterises the staff experience of moral distress, which was predominantly due to the incongruent values of others (relatives, GPs or colleagues), and this is reported in this chapter.

5.2 DEFINING AND NAMING THEMES

In this study, the researcher identified that challenging and positive aspects of end of life care were influencing factors on the experiences of care provision, rather than being individual themes in their own right. A pattern of values related to 'good dying' were identified, which were used to inform how the practice of end of life care was carried out, and is the element of focus in an interpretive design study (Figure 5).

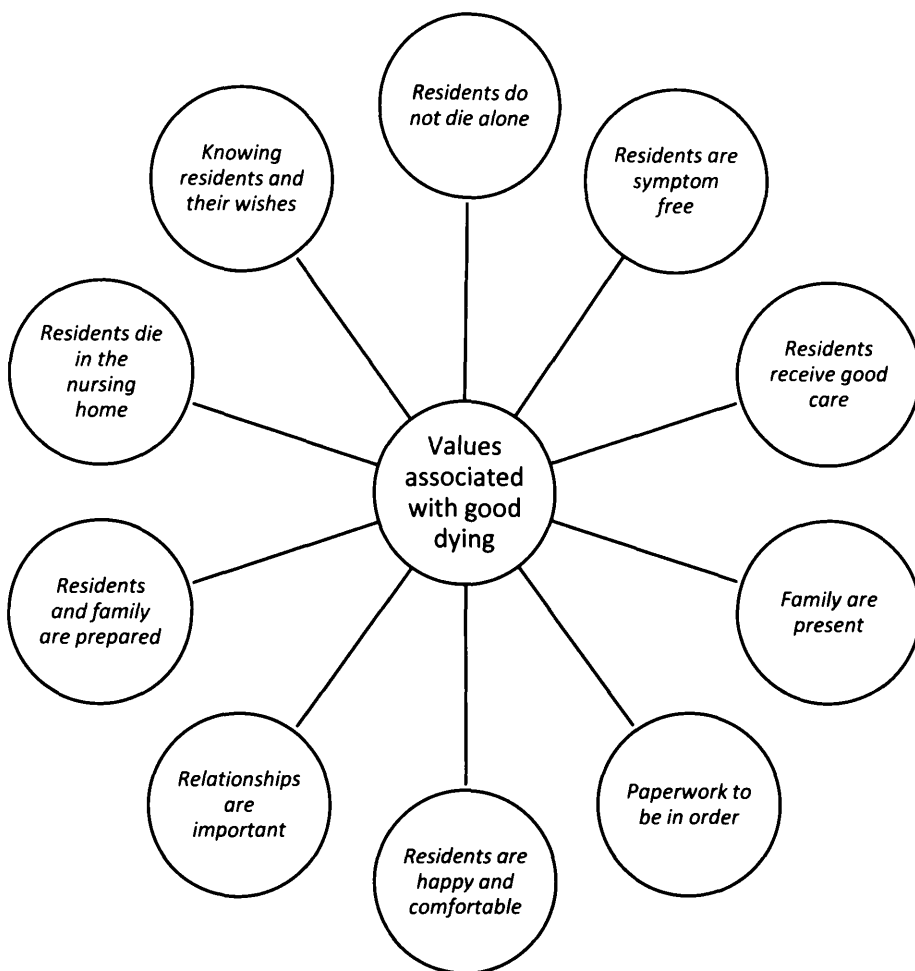


Figure 5 Good dying values

Staff attributes influence the practice of care of residents at the end of life (Froggatt and Payne, 2006, Beck et al., 2012b, Bedlin et al., 2012) and in order to explore if the factors that contribute to the staff experience of moral distress are demographically linked data on experience, age, health related qualifications, ethnicity, and length of time working in nursing homes (Appendix 16) were collected and compared across the identified themes and elements.

Reviewing themes and conceptualising what themes meant in relation to the research question enabled further amalgamation of data under four main themes (Appendix 17). Further interpretation and in depth thinking (Thorne, 2008) resulted in condensing and reclassification of the identified themes (Appendix 18 and 19) into

the four final practice elements (Appendix 20) which were aligned to factors associated with end of life care in this study (Table 8).

Table 8 Final elements

| Factors associated with end of life care | Practice elements |
|--|---|
| Achieving residents and relatives end of life wishes and choices | Advocating contributes to the experience of end of life care, positively when a resident’s death is considered to be as they would wish, and negatively if staff are unable to advocate on behalf of a resident to achieve their wishes. |
| Fear of consequences | |
| Good care for the dying | Caring for the dying can distress staff in nursing homes due to the dying trajectory being unpredictable in nature as well as giving them a sense of satisfaction that the care they have provided is the best a resident could have received. |
| The lingering death | |
| Managing symptoms | |
| Care after death | |
| Communicating with residents and their relatives | Communicating well with all concerned in the end of life care of a resident can contribute to a ‘good death’, conversely when communication is poor it can contribute negatively resulting in a ‘bad death’, therefore contributing to staff distress. |
| Communicating with internal and external colleagues | |
| Inside the nursing home Residents Colleagues | Relating to residents and all those who are involved in the end of life care in nursing homes contribute to the positive or negative staff experience of end of life care, with poor relationships contributing to distress. |
| Outside of the nursing home Relatives | |
| GPs | |
| Hospital/hospice | |

Advocating on behalf of residents and their relatives, enables staff to fulfil end of life wishes as well as ensuring everyone is kept informed of the situation. Staff could also be fearful of the consequences of advocating for their resident due to fear of losing their job, or having a complaint made against them if they make a ‘wrong’ decision. **Caring** for residents includes the management of symptoms, coping with gradual deterioration, good care provision and care after death. **Communicating** internally and externally is pertinent to all the practice elements and is fundamental for the staff to achieve the ‘good dying’ that staff value. **Relating** with residents, relatives, colleagues and other health professionals involved in the end of life care of residents

also contributes to the staff experience. These practice elements and the ‘good dying’ values lead to two overarching themes which contribute to end of life care in nursing homes: ‘**doing the right thing**’ and ‘**powerlessness**’. The correlation between the practice elements: ‘good dying’ values, ‘doing the right thing’ and ‘powerlessness’ are presented in Table 9.

Table 9 The elements contributing to the experience of end of life care in nursing homes

| Values associated with good dying | Doing the right thing | Powerlessness | Practice elements |
|---|--|---|---------------------------------------|
| <i>Know residents and their wishes</i> <i>Paperwork to be in order</i> <i>Residents are happy and comfortable</i> | Anticipate dying, advance care plan and communicate with residents and relatives so they feel supported. | Difficulties in recognising that a person is at the end of life and have processes that support staff and relatives to provide appropriate care, or to get decisions made in advance i.e. do not resuscitate paperwork. | Advocating Caring Communicating |
| | Respect the resident’s wishes. | Difficulties influencing the surrogate decision maker when the resident is cognitively impaired. | Advocating Relating |
| | Work in partnership with other organisations through liaison and information sharing. | Difficult to influence other organisations who provide care to provide the standard of care to their residents that they believe is right. | Communicating Relating |
| <i>Residents do not die alone</i> <i>Family are present</i> | Work together as a team and acknowledge the difficulties of caring for the dying and being with the dying person at the end. | Controlling the knowledge or resources that internal and external colleagues have, to carry out end of life care. | Caring Relating |
| | Anticipate dying, advance care plan and communicate with residents and relatives so they feel supported. | Difficulties in recognising that a person is at the end of life and have processes that support staff and relatives to provide appropriate care, or to get decisions made in advance i.e. do not resuscitate paperwork. | Caring Relating |
| <i>Residents are symptom free</i> | Diagnose and anticipate dying so that everyone is aware of prognosis and to manage symptoms. | For residents or relatives to accept that a person is coming to the end of life and to stop people dying in pain. | Advocating Caring Relating |
| | Acknowledge frailty as a normal part of the ageing process. | Prevention of the gradual decline of many residents. | Caring |
| <i>Residents receive</i> | Diagnose and anticipate | For residents or relatives to | Advocating |

| Values associated with good dying | Doing the right thing | Powerlessness | Practice elements |
|--|---|---|----------------------------------|
| <i>good care</i> <i>Residents die in the nursing home</i> | dying so that everyone is aware of prognosis and to manage symptoms. | accept that a person is coming to the end of life and to stop people dying in pain. | Caring Relating |
| | Anticipate dying, advance care plan and communicate with residents and relatives so they feel supported. | Difficulties in recognising that a person is at the end of life and have processes that support staff and relatives to provide appropriate care, or to get decisions made in advance i.e. do not resuscitate paperwork. | Advocating Communicating |
| | Work in partnership with other organisations through liaison and information sharing. | Difficult to influence other organisations who provide care to provide the standard of care to their residents that they believe is right. | Communicating Relating |
| <i>Relationships are important</i> <i>Residents and family are prepared</i> | Be aware of the emotional aspects of caring for residents at the end of life for both relatives and staff and seek appropriate support. | Provision or access support when there are difficulties associated with death. | Relating |
| | Diagnose and anticipate dying so that everyone is aware of prognosis and to manage symptoms. | For residents or relatives to accept that a person is coming to the end of life and to stop people dying in pain. | Advocating Caring Relating |
| | Anticipate dying, advance care plan and communicate with residents and relatives so they feel supported. | Difficulties in recognising that a person is at the end of life and have processes that support staff and relatives to provide appropriate care, or to get decisions made in advance i.e. do not resuscitate paperwork. | Advocating Communicating |

The identified practice elements, presented alphabetically, provide the structure of this chapter with *values* being linked to the facilitation of ‘good dying’ and the ‘powerlessness’ staff experienced when the values of ‘others’ were incongruent with their own, and how the roles of staff, their culture and religion influence their experience of moral distress.

5.3 ADVOCATING

Advocating was found to be a practice element of end of life care which could enable staff to 'do the right thing' by achieving the end of life wishes of residents. *Knowing a resident and their wishes* was found to be a 'good dying' value held by almost all of the participants. Nursing home managers, nurses and one healthcare assistant described how they were able to advocate to 'do the right thing'. *Knowing the resident and their wishes* did not always mean that residents achieved their wishes, and when staff were unable to advocate on behalf of the residents or their relatives the staff felt powerless to change or influence the care provided, which contributed to their experience of moral distress.

5.3.1 ACHIEVING RESIDENTS AND RELATIVES END OF LIFE WISHES AND CHOICES

A resident's end of life wishes could include where they would prefer to die, or what care they would not want at the end of life. These wishes were often recorded in an advance care plan in the participating nursing homes. Participants also reported accommodating residents' last minute wishes, which were not recorded in advance but contributed to 'doing the right thing'.

'She kept on about wanting to eat tomatoes. She couldn't, so we were wetting her lips, we pureed up some tinned tomatoes then strained them so we could use on the mouth swabs. We rubbed the tomato drink round so she could get the taste of tomatoes. Little things like that, the family were so pleased because they said she had been asking all night for tomatoes'. (MAN1)

Staff were aware that having discussions about end of life care could assist them to know what the resident's wishes were but this did not always mean that discussions

took place. It was difficult to facilitate some residents or their relatives to share their end of life wishes if they were unable, or did not wish to do so.

'He didn't want to talk about it, about death, so it was really very hard to deal with because he didn't want to. One of them said that 'maybe I can still get a cure'. The family would bring some herbs to rub in so they were just mixing the traditional medicine, with the western medicine, so because of their beliefs it was very difficult to discuss it'. (RGN1)

This clash of values, and the *knowledge that it was the resident's wish* not to discuss end of life care meant that staff were powerless to do what they believed to be right to facilitate 'good dying'. In this case, staff identified that the resident was dying but he held an unrealistic hope of a cure which prevented appropriate end of life care from taking place. Consequently the relatives considered that the man had died 'unexpectedly', and blamed the nursing home for what they considered to be his 'premature' death. The result was incongruence with the *value of preparing relatives* which caused the participants moral distress as they were unable 'to do the right thing', even though they had preserved the *value of knowing the resident's wishes* by not denying him his hope of a cure.

The *value of preparing relatives* required participants to initiate difficult conversations. In cases where they felt they had *prepared relatives* for the resident's impending death but relatives who declined to engage with this conversation caused frustration and increased staff distress. Relatives were reported as carrying on with their normal visiting routines when staff felt they should *stay with their relative*,

especially after information about a resident's deteriorating condition had been provided and staff felt powerless to more explicitly encourage the relative to stay.

'Her son kept saying: 'She smiled at me when I was up there', and you think no, she didn't. That can be really hard, even when you are actually saying, 'She is dying it's fine if you want to hope for the best, but to be honest she's not really going to last for more than another day or two', and he'd go, 'Well, maybe see you next Wednesday'. (MAN1)

Participants reported that engaging residents in discussions about end of life care enabled them to 'do the right thing' by *achieving the resident's wishes*, and by ensuring they *received good care* that made them *'happy and comfortable'*. Residents with advanced dementia or cognitive impairment were not able to disclose their wishes for end of life care. Relatives often made decisions on their behalf which could result in staff feeling powerless to advocate in order to achieve care that they believed the resident would have wanted. Relatives were seen to make care choices which were more invasive than palliative in nature which staff did not agree with and found challenging to enact.

'When individual or family members want to prolong the life of their loved ones the challenge has been the understanding of what end of life is and how imminent it is and the resident's families understanding of it'. (MAN2)

Participants in this study *knew their residents well* and felt that they were respecting the choice of residents with dementia, who were declining to eat and drink, by not forcing them to do so. They believed that the decision was a conscious one and a normal part of the dying process. Relatives, however, could make staff feel

uncomfortable about this, as they would complain that their relative was not being fed.

'Her family were really criticizing and were complaining, the mum, the woman she wasn't eating. The family said; 'She's not being looked after the staff were not getting her to drink'. It took them months to come to terms with the fact that she does not want to eat and we cannot force her'. (HCA3)

Advocating on behalf of a resident who had an advance decision to refuse artificial nutrition proved problematic for one nurse when the relative's wishes were at odds with the resident, particularly when the family persuaded the resident to have a feeding tube inserted.

'We had one resident here who did not want to go to hospital, she didn't want to be fed or anything, when it came to the end of life we should let her go. But when she started not eating we were relying on that thing [advance decision to refuse treatment], and then the family step in 'we can't leave her like this something has to be done'. This woman had in writing that she didn't want to be PEG [percutaneous endoscopic gastronomy tube] or tube fed. The family forced and we had to put NG [nasogastric] tube in'. (RGN4)

The resident in this case had the capacity to change her mind about being tube fed but the nurse felt she had been forced into a position to accept care she didn't want. The nurse felt that she had been unable to influence the resident's new decision, which was against her previous (and true) wishes, and to 'do the right thing' for the resident.

Advance care planning was acknowledged as a way to ‘do the right thing’ to *meet the wishes of residents* and could contribute to a ‘good death’, although this was not always the outcome, (Box 1 case report). This case demonstrates the complexities of advance care planning, as knowing the wishes of the resident did not always result in what the staff considered to be a ‘good death’.

Box 1 Case report 1

A resident was admitted to hospital following a very severe stroke. The manager knew that his end of life wishes were to die in his own bed in the nursing home. The manager was in constant contact with the ward to take him back to the nursing home, as the wife had told her there was nothing more they could do. The manager was powerless to influence the discharge and the man experienced what the wife considered to be a bad death in hospital even though up until that point all the planning, and communicating would have facilitated a ‘good death’.

Reliance on those outside of the nursing home contributed to the moral distress of this participant. Although the participant *knew that the resident wanted to die* in the nursing home she had been powerless to get him returned home.

The ability to advocate on behalf of a resident was identified as requiring skill, determination and courage (Box 2 case report 2). Here a manager had to stand up to family members to achieve a resident’s wishes. The complex family dynamics in this scenario were such that it was only the ability of the participant to advocate, that facilitated ‘good dying’ to be achieved for the resident.

Box 2 Case report 2

A woman was admitted to the nursing home for end of life care as she had a large family who did not get on with each other: she wanted to see both sides of her family as she knew she was dying. One side of the family were very aggressive and were involved in fights in the car park of the nursing home and frightened staff. The participant knew the resident wished to remain in the nursing home to die, even though her family kept arriving and packing her belongings to take her home. To ensure both sides were not in the home at the same time a visiting rota for each side of the family was formulated. A conversation with the resident identified which side of the family she wished to be present at her death. All her wishes were achieved. The staff were also able to get her estranged son to visit her before she died. However, the relatives who were not chosen to be present at the death made a very large unsubstantiated complaint, with threats that they would go to the local paper. The advance planning, knowing the resident and the manager's ability to advocate on her behalf meant that nothing came of the complaint and the participant felt that they had been able to 'do the right thing' in the end. (MAN1)

The healthcare assistant participants in this nursing home gave other examples where the manager had stepped in to advocate on behalf of residents and their relatives, either to prevent hospital admission or return residents to the home from hospital.

GPs were reported as also able to advocate on behalf of residents and, in one case, were able to step in and make the end of life decision on behalf of a cognitively impaired resident when a family were disagreeing about the level of intervention the resident should receive. The participant had worked closely with this GP for several years and there was a perception of shared values about 'good dying'.

5.3.2 FEAR OF CONSEQUENCES

In seeking to *achieve the wishes of residents*, there was also an element of fear of consequences. For the nurse participants there was fear about when there were legal and procedural requirements that needed to be adhered to. The *record of a 'do not attempt resuscitation' order* was identified by nurse participants as the main factor in preventing a hospital admission. Procedurally, if this order was not in place nursing staff were scared of a resident dying in the nursing home, as they had a duty to intervene and attempt cardiopulmonary resuscitation. To prevent this from

happening, participants reported that they had sent actively dying residents to hospital even though they knew this was against the wishes of the resident, their relatives and colleagues. The 'good dying' values came second to the need to ensure procedural correctness, resulting in moral distress.

'I knew he would die and we didn't want to send him but if we didn't send him then there would be a problem on our side'. (RGN2)

All participants were fearful of how their intentions to provide, what they felt was, 'good care' and 'the right thing' to do might be misinterpreted especially by relatives who could get staff into 'trouble'.

'We do things out of the goodness of our heart, and it would just turn out to be the wrong thing or could be taken the wrong way, we just have to be careful really, and that can be quite distressing as well'. (HCA3)

Participants did what they believed 'to be right' in accordance with their values but they were powerless to act against the procedures, and the power of others as their good intentions could be misconstrued. The fear of getting into trouble could mean disciplinary action or loss of employment; nurses in particular were fearful of losing their nurse registration, which was their livelihood. Good relationships and communication could make staff less fearful but nursing home end of life processes still needed to be followed.

5.4 CARING

Care and caring were reported in all the participants' experience of end of life care which contributed to 'caring' being identified as a practice element. The ability to care in a way which facilitated 'good dying' was identified as fundamental to all the

participants. They reported that residents were cared for better in the nursing homes than elsewhere. Staff believed that *residents should die in the nursing home* where they could be kept *happy and comfortable* and *free from symptoms*, contrary to what they believed would happen if they were admitted to hospital.

'End of life care in the nursing home is more peaceful and better. We got good care and good nursing homes they make you feel comfortable and decent, respect and everything. Not like at hospital you know, its lack of complete care. So when you go to hospital you are not expecting to die in hospital as you expect to get better. But to come to a home is always at the back of your mind 'this is the end of my life I won't go out again'. We do give complete care and I think we have decent deaths in nursing homes. (RGN 4)

Participants realised that the *good care* they provided would not prevent death from occurring, which made many of them feel sad. However, they accepted dying as an inevitable part of life and this was seen as an important factor in facilitating a 'good death'.

'It is always sad looking after somebody at the end of their lives. And I think it is just for me the positive, if I know that I have looked after the person to the best I could, just to make the life at the end of life really calming, and to give them the support not only for that person who was dying but also for the families'. (HCA8)

The unpredictable nature of dying in the frail nursing home residents also compounded the complex nature of care, as sometimes *good care* was seen as the reason why some residents rallied and did not die when they had been predicted to

do so. Staff discussed that the *good care* they gave contributed to the extension of their residents' lives.

'He was in the hospice previously before then came here to die given three or four weeks but stayed here for six months, he was with us for six months'.

(MAN2)

Recognising when a resident was at the end of life was difficult, as demonstrated above. Another resident was reported as having been admitted with a prognosis of two weeks but lived for two years (RGN1). When dying was recognised, staff were able to keep residents *'happy and comfortable'* and *stay with them so they did not die alone* which was seen as the *'right thing to do'*.

'You know, it's like you try and be there, and stay there with them, because, I don't know it's just I don't feel it's right for them to be on their own'. (HCA6)

'I think it is better in the nursing homes than it is in the hospitals, I do believe you're left for quite a while on your own and you die alone in hospital'. (HCA2)

'We sat with him a lot towards the end'. (HCA10)

When dying was recognised, *staying with a resident* could be planned so that there were enough staff on duty to ensure that the resident was not left alone. If residents had no relatives to stay with them, the staff adopted this role. Only one participant (HCA3) expressed that it was not always possible to remain with a dying resident due to the staffing limitations. Residents who died alone due to staffing issues, or death being unpredicted caused sadness for staff rather than moral distress. For residents with family for whom death had been recognised but the family chose not to be

present was incongruent with the staff value of *family being present*, which could cause moral distress as staff did not think 'the right thing' was being done. Two of the healthcare assistants from one home discussed finding this particularly upsetting and non-attendance was seen as an affront to the resident, of whom they were both very fond. They found it difficult to understand the reasons for the family's absence, as his life drew to a close.

'Because when he did actually pass, a couple of us were quite well, 'Where's his family they should be here?' But you don't know the circumstances of their relationship'. (HCA9)

'Yes it sort of made me feel 'Oh that's really nasty you know I couldn't do that to my dad', but then you just don't know do you, so I did feel a little bit you know. I mean I think his son managed to get over a couple of days before you know, but then I could not understand why he didn't come back again. They had been told that he was going to, you know die, so it's a bit awkward to understand why they didn't come back, they didn't come back until he died to clear out his stuff'. (HCA10)

5.4.1 MANAGING SYMPTOMS

Caring for residents included ensuring they were comfortable, *without any pain or distressing symptoms*, which staff felt was the right way to die. Staff with five or more years of experience identified that there was more hospice involvement for *symptom management* in end of life care in nursing homes than they had previously encountered.

'You know it's not like now where there is more when the patient is end of life, and then you got all the things in place like pain killers, too much secretions you got the hyoscine and all that. But it wasn't like that then where I've worked before'. (RGN2)

The local hospice was seen to directly influence the standard of end of life care due to increased support related to *symptom management* and recognition of dying. However, lack of good communication between nurses and healthcare assistants could still result in poor symptom management especially pain control. This was reported as a lack of analgesia administration by nurses who did not always act on information from healthcare assistants. This group of staff were reliant on nurses to administer analgesia and medication, and when nurses did not act on the information provided, it caused distress for healthcare assistants as they interpreted this to mean the nurse did not care for the resident. This could contribute to what was considered poor care due to being powerless 'to do the right thing', which resulted in moral distress.

'It's where you can see that the residents are agitated or in pain, you can see the facial expression. If they can't already tell you that there is something wrong then you can see there is something wrong. As a carer in a nursing home you don't have much power to do anything about it. Yes, you can report I think there is agitation, there is pain when we changed and checked. Whatever you can see the facial expressions so but when we informed the nurses and it's up to them to do something'. (HCA8)

'I know that because of my experience, I know there is a medication to give them to settle the breathing as well and again I received the answer from the nurse 'oh he's going to die anyway''. (HCA8)

If nurses did manage symptoms when they were informed, the healthcare assistants perceived *good care* had been given and a 'good death' had been achieved. Some aspects of end of life care were not predictable or treatable, especially if they occurred suddenly and took the staff by surprise. Two participants described incidents where a haemorrhage occurred at the time of death, but had not been an anticipated result of disease progression. The staff were unable to control the bleeding but felt they had been able to reduce additional stress for the resident by being with them as they died and providing care that enabled them to *die in the nursing home*. Reducing suffering was the aim of their care even if that meant deviating from the truth; reassuring the resident that everything would be all right in one case. In another, the participant felt 'the right thing' to do was to lie to the relative about the resident's death, as she believed this would reduce the suffering that the relative would experience.

'I remember somebody having an embolism and it was horrible she absolutely heaved her heart out, blood everywhere and when the family asked. 'Did my mum die peacefully?' I said 'Yes'. (HCA2)

Here there is overlap between the *value of good symptom management* and the practice theme of relating, but both are underpinned by the *value of the importance of relationships* and *keeping a resident free from pain*. Haemorrhage was the only complicated unexpected aspect of dying that was identified in this study. What was

more commonly reported by the participants was managing the complexities involved with a gradual decline leading to a lingering death.

5.4.2 THE LINGERING DEATH

Caring was challenged by some types of dying. The gradual decline of a resident could result in, what staff described as, a lingering death. This was found hard to come to terms with as they perceived the resident to be suffering for longer. Incidents where the gradually declining residents reduced their food and fluid intake were the ones that caused the most distress for participants. An example of one resident who made the decision to reduce, and eventually stop eating and drinking was discussed; whilst staff respected his decision, it caused them distress although was in keeping with the *value of achieving his wishes*.

‘Quite distressing really because as I say he was quite a large man when I came and to see he was so thin by the time he actually went there was nothing really of him anymore and he just slept most of the time near the end’. (HCA9)

Doing ‘the right thing’ and achieving the wishes of residents with dementia when they chose not to eat and drink was more difficult, as relatives could make staff feel that they were not providing *good care*. Staff would continue to offer food and fluids as part of basic care provision but would not force residents to eat and drink, when they believed the refusal was the resident’s choice.

‘We had a woman recently and she wasn’t eating for months and the only thing we could do was push fluids, you can’t force as that would be abuse. It is

distressing because you just want them to drink but you can't force them, you know that if they don't drink that could be it'. (HCA3)

Participants acknowledged the distress that relatives experienced when residents oral intake reduced as this could be associated with the resident coming to the end of life, although it could be a slow process. The dying trajectory in these cases was complicated as some residents could spontaneously start to eat again and carry on living. Communicating to relatives that the reduction of eating and drinking was a normal part of the dying process was reported as helping relatives to understand what was happening, and prepared them for the inevitable, but as previously noted this was not always understood and there was a fear of consequences.

5.4.3 CARE AFTER DEATH

Participants acknowledged the normality of death for their residents, however after death care was identified as an aspect of care that almost all of them had found difficult. Staff had varying ideas about what happened to a person after death, many of which related to their belief of the existence of life after death. This study found that staff in nursing homes experienced fear and anxiety in dealing with a dead body for the first time. This contributed to them avoiding seeing other residents who had died, as they wanted to remember them as they were. After the first time of administering last offices to a deceased resident, the task itself became less stressful and if the resident was well known to the staff member, it was seen as the completion of care.

The experience of sadness at a resident's death could sometimes be underestimated by senior colleagues and very little specific bereavement support was reported in any of the participating nursing homes.

'The nurse was called in to confirm, and then I got really upset and she said 'come on now pull yourself together' type of thing and I was like I'm not meaning to do this it's like it's just a reaction'. You don't know how you're going to react at the time so anyway I pulled myself together'. (HCA9)

5.5 COMMUNICATING

Communication was the practice theme that underpinned all of the identified areas of practice in this study and could contribute to reducing or increasing the risk of moral distress. Communicating with residents and their relatives enabled staff to provide *good care* according to resident's wishes. Communication was also fundamental to the building of relationships internally and externally to the nursing home.

5.5.1 COMMUNICATING WITH RELATIVES AND RESIDENTS

Discussing end of life care in advance has already been identified as a contributory factor to facilitating a 'good death' in this study. In some of the nursing homes, the future care needs of residents were discussed with them and their relatives in advance of deteriorating health, as well as between colleagues internally and externally.

'Now I'm doing the Preferred priorities¹ advance care planning and it's really good that you get to know what they want'. (RGN3)

This participant was not British born or trained and had experienced many child deaths in her own country, which had contributed to difficulties in communicating about end of life care. She acknowledged the difficulties and recognised the importance of education and training in enabling her to have these conversations.

'Before the training on end of life it was so hard for me to discuss about death because of the bad experience that I have, although it's old people you can't expect to live forever, but it's hard for me to ask the family 'What is your plan? What are your wishes? It was so hard'. (RGN3)

Communicating well with relatives could also distress the staff. Discussing the insertion of a feeding tube with a resident of the same cultural and ethnic background held resonance for one participant.

'There was some limited English. I sat her down and we spoke in Chinese and I could totally understand what she was saying, you know she wanted to be able to feed him to give him something. That was the dilemma. That was my dilemma. Do I respect the Chinese values and cultures and or this business about; 'let's give end of life care in a dignified way?' (MAN2)

5.5.2 COMMUNICATING WITH INTERNAL AND EXTERNAL COLLEAGUES

Internal and external communication could contribute to the staff experience of end of life care in a positive or negative way. All the participating nursing homes had

¹ Preferred priorities for care is a document for recording the wishes of people who are able to write their own advance care plan (Lancashire and Cumbria Cancer Network 2004 revised 2007)

allocated GPs. This was seen by participants who had worked without an allocated GP as good, as it provided the opportunity for regular communication. This had improved relationships and advance care planning, when compared with the nursing homes participants had previously worked in without an allocated GP.

‘Sometimes, well here it’s a good environment because you work with the doctor and the doctor is you know, you can communicate with your doctor and you can communicate with the pharmacist’. (RGN2)

Written communication about end of life wishes, or advance care plans, enabled staff to contribute to the decision making process with external healthcare professionals. Several participants identified this as an improvement in communication of the resident’s wishes, which could enable them to advocate on the resident’s behalf.

Good communication from the hospital during admission and on discharge was seen to be lacking, resulting in staff believing that residents who had died in hospital had not experienced a ‘good death’. Inadequate written information on discharge caused distress about having to make difficult decisions which could have negative consequences (as discussed earlier).

‘He wasn’t seen by our GP and even though he was end of life, coming from the hospital there wasn’t any resus status². So the man, I knew he would die and we didn’t want to send him but if we didn’t send him then there would be a problem on our side’. (RGN2)

² Resus status in this quote means the absence of a do not attempt cardiopulmonary resuscitation order without which residents in nursing homes are not able to die without intervention.

A similar situation occurred again in the same nursing home when a colleague had advised the staff on duty that she had a 'duty of care' to admit a resident to hospital, as there was nothing in writing about resuscitation status or health status. The rest of the staff were morally distressed by this as hospital admission for this particularly well known resident was not considered to be the 'right thing to do'. The admission resulted in the resident dying in the hospital, which caused anger and frustration amongst the staff as they had been powerless to prevent the resident being admitted.

Hospital communication when residents were inpatients also caused distress for nursing home staff and their relatives, as residents often died without being discharged back to the home, even when their condition indicated that they were at the end of life.

'We had two last year that went into hospital who had strokes. They were here, they just suddenly collapsed with the signs of a stroke and quite rightly got sent in the hospital. Then as they deteriorated, they were just kept in the hospital. With one of them it was, 'Oh maybe on Thursday maybe tomorrow'. Then it went on and on until the relative phoned and said 'they died yesterday'. There appeared to be no logic or reasonable reason, just that the hospital never got round to co-ordinating themselves to get the person home'.
(MAN1)

This went against the staff *value of residents dying in the nursing home*, which was felt to be the right place for them, and meeting the resident or relative's wishes. Staff experienced moral distress because they were powerless to influence the hospital

staff, even though it had been communicated to staff there that the nursing home could accommodate and care for the dying resident.

5.6 RELATING

The final practice theme to be discussed in this chapter is relating, in terms of relationships within (internal) and outside (external) the nursing home. *Relationships within the nursing homes were found to be important* influencers on end of life care. The strongly held value that *relationships are important*, captured relationships staff had with residents, relatives, and colleagues within the home, as well as those who came from other agencies. Maintaining these relationships was important. Participants identified that their nursing homes were similar to ‘an extended family’, providing care for their loved ones.

‘I think in a nursing home like we are all like one big family, that’s how I feel any way. They are an extended part of my family they could be my Nan, my aunt’. (HCA6)

‘I don’t know about other nursing homes, the carers here are always looking out for them do you know what I mean they always check on them every hour or every half hour and they always do mouth care making them comfortable. I think they are quite giving at this home, I know homes, certain homes shown on the news are not so much but at this home it’s quite giving we do love our residents’. (HCA7)

5.6.1 INSIDE THE NURSING HOME

5.6.1.1 Residents

Participants often reported a positive attachment to residents; especially to those that they knew well. The connections could be social, emotional, or cultural in

nature, which in turn could influence the relationship with residents during, and at the end of their lives. Socially, staff in this study knew which biscuits they liked with tea, which music they liked to dance to and what made them laugh. Staff had sometimes taken on the social role of surrogate relative during the active phase of dying in the absence of relatives, *being with them until the end*.

'Yes, I know that most of our residents are fortunate to have their family with them through all the hard time, but there are other residents who can only rely on carers and nurses'. (HCA3)

Participants formed emotional attachments with residents who stayed for long periods of time. Witnessing their gradual decline made staff feel sad, but not morally distressed, unless there were any conflicting values about care such as residents dying in hospital.

'It does pull on the old heart strings especially where I've been here for nearly two years and you see them. One resident we had used to trot about and she used to dance and then you find that when they go to hospital and then they come back they go [die]'. (HCA7)

The emotional attachment to residents was seen as normal for all but two of the study participants who stated that they did not feel emotional at work.

'You have different attitudes towards things with care staff, but if a member of staff breaks down I will comfort them, even if I don't feel that what they are upset about I wouldn't be, but I accept them for being them for a certain amount of time and then it's back to work type of thing with me'. (HCA1)

'I can't say that I get upset over it'. [Death]. (HCA2)

These two participants were clear that not feeling sad when a person died did not prevent them from caring for residents as it was just who they were, how they worked and they were unconcerned by this lack of emotional attachment. Relationships with residents were the least likely to provide challenging aspects of end of life care. Although when these resident made choices which ran counter to the values of the staff, such as deciding not to eat and drink to hasten death, staff experienced distress as they were unable to influence the resident's decision.

On a cultural level, awareness of the resident's cultural needs and values related to the end of life strengthened the internal relationship for staff and residents. This was clearly demonstrated by one of the managers who shared the ethnic background, culture, and language with one of the residents and their relative, and although it was a challenging experience, it revealed to her the importance of being culturally aware when discussing end of life care to facilitate a 'good death'.

'I felt strongly, because of the culture, you need to give them information. That was very difficult, very very difficult. There was lots and lots of tears. I was in tears with her lots. But once that was laid out she did make the decision in the end not to do anything. But I think it had to be for me I had to give her those options so that she could go away and think about it'. (MAN2)

Doing 'the right thing' to enable *good care* provision in this situation was due to the participant's relationship with the wife, good communication skills, cultural awareness, and knowledge of the wider social world in which the resident was living. Speaking the same language and having this understanding contributed to the

relationship that she was able to develop with the wife, which she felt benefitted the resident. This was a distressing situation for the participant, but not morally distressing as the participant was questioning her cultural values at the same time as wanting the man to have a 'good death', which she believed he should have.

5.6.1.2 Colleagues

Good working relationships with colleagues improved the care outcomes for residents due to effective team working.

'We work as a team so if there's an issue we just discuss it and find a way to look after our resident, you know, um, if they are a weaker person, there is always a stronger one who can deal with what is going on. We work hand in hand. If I need help on some of them, I will just make room for that, call them in to sort the problem for me, so far we work like that so it tends to work well. We are not overcome with obstacles which are stopping us to give them the best care'. (RGN4)

Support from colleagues was important in helping to deal with the number of deaths they had experienced in the nursing homes. The support was described as informal in nature and accessible if needed, but participants felt that dealing with death was seen as a normal part of the job which they got on with. Support and education by a colleague whilst caring for dying residents, and seeing what good care looks like had enhanced the experience of end of life care for one healthcare assistant.

'In this country I was lucky to work alongside a really, really good nurse who taught me a lot of things'. (HCA8)

Conversely, the inability to convey information about a resident's needs between colleagues in an empathic supportive way resonated with healthcare assistants who felt that 'they were only carers' and were not required to know all the information related to a resident. In one home, this made healthcare assistants feel that the nurses did not value the work they did and the contributions they could make to decisions about care when they felt they knew the residents best.

5.6.2 OUTSIDE THE NURSING HOME

Good working relationships with relatives and multidisciplinary colleagues, GPs, hospital and hospice staff, were found to help facilitate 'good dying' by enabling residents to achieve their wishes through sharing information about these. Relatives were seen as being the main influencers of care but they were not considered to be an integral part of the 'team' caring for the resident, which is why they are discussed in the context of being external to the nursing home.

5.6.2.1 Relatives

Good relationships with relatives in this study were reported by the staff as being those where relatives conformed to the participant's value of a 'good relative'. This notion comprised of a relative who visited regularly, carried out care for the resident, and recognised that there were other residents in the home also requiring care. *'Good' relatives also stayed with their loved one* when they were dying. Staff went out of their way to accommodate and support these relatives, and their portrayal of relationships with them was different to those relationships with relatives who did not.

'We have to be sharing the floor with the family. So I went to the kitchen I said 'now we have a family here who really want to be here'. So we were catering

for their food some of them sleep on the couch, some would sit but they were just there. Eventually I said to myself; 'If I can organise this thing they will be very pleased and it will be very good'. Eventually the woman passed away after three weeks, they were there for three weeks'. (RGN1)

However, relationships with relatives who were present all the time when a resident was dying were also difficult. One example of this was the large and anxious family of a resident admitted for end of life care. They had high expectation of staff to constantly check on the dying resident, which was difficult to manage due to the needs of other residents. The relationship became more strained as the resident was seen as being exhausted by them and wanting to sleep. One of the healthcare assistants was able to persuade all but one of the relatives to go home, so the resident could get the rest he was requesting. The healthcare assistant's confidence and relationship with the resident enabled her to have this conversation and advocate on his behalf by informing the relatives about his needs, achieving her values of *good care* and *patient choice*.

Personal values and expectations of 'family' also contributed to the challenges staff experienced when relatives behaved in a way the staff considered to be inappropriate for a relative, such as fighting in the car park or threatening to discharge a resident so that relatives could look after them (Box 2). This was a distressing case for the staff, but not morally distressing, as the resident was in receipt of *good care* and *her wishes* were achieved.

5.6.2.2 GPs

The nursing homes in this study were aligned to specific GP practices which were seen to facilitate *good working relationships* between the nursing home staff and GPs. Improved relationships resulted in earlier referrals to the local hospice and improved communication which *anticipated symptoms*, or *initiated planning* for end of life care. *Good relationships* with GPs were seen to support *residents to die in the nursing home* and prevented inappropriate hospital admissions.

In contrast, staff at one nursing home had a strained relationship with their allocated GP who was seen as being concerned about the financial implications of prescribing end of life drugs which might not be utilised. Whilst two nurses had built up a good relationship with him and were able to get end of life medication prescribed when they were on duty, at other times this did not occur which meant that not all residents received medication in a timely manner.

Relationships with GPs faltered when a medical opinion was required out of hours (evenings, nights and weekends). The GPs who provided out of hours care were seen as lacking knowledge and understanding of the residents and consequently hospital admissions were more likely when a resident's condition deteriorated during out of hours. Nurse participants reported that support from GP colleagues was required to prevent care interventions they considered to be inappropriate being carried out. The nurses were able to recognise when a resident was dying and would contact the GP for confirmation. If the GPs did not agree this could result in unnecessary admission to hospital or death occurring very quickly after GP assessment. This led to what participants felt was not a 'good death', as residents did not die in the nursing home therefore contributing to staff moral distress.

'There was this gentleman, and the doctor came and saw him and said 'oh he has got to go to hospital' and the nurse said; 'Well basically he is dying and what is the point of sending him to hospital, because he probably won't even get there and he will be dead'. But the doctor insisted that he went. The nurse tried to prolong him going as much as possible but then he did die on the way to hospital'. (HCA6)

Nurses in this study appeared to lack confidence to discuss the GP decision and would be fearful of not doing as the GP had requested.

5.6.2.3 Hospital staff

The relationships with hospital staff were generally described in a negative way. Staff felt that the care provided for their residents in hospital was not as good as the care they gave. If residents were admitted to hospital, it was considered likely that they would either not come back or would die shortly after return to the home, due to the inadequate care in hospital.

Relationships between the hospital and nursing home staff did not appear to be grounded in mutual respect; one participant felt that the hospital staff thought nursing home staff were 'stupid', and knew nothing. The lack of verbal and written communication between the two groups resulted in inadequate discharges or people dying in hospital, which caused nursing home staff distress, particularly when they had tried hard to achieve the place of death wishes of residents or their relatives and had seemingly failed.

'When we sent him back the next day the hospital accident and emergency department called up asking; 'Why did you send this man to hospital?' I said

'well he's unwell and there was nothing we can do for him he was not taking anything orally so we couldn't give him any medication.' They said 'but he is for end of life care.' I said 'well we weren't aware of that because you didn't send anything with him to say that he is palliative care.' He was not supposed to go back to hospital should anything happen to him so how would we know if they hadn't sent any paperwork.' (RGN2)

This situation caused moral distress to the nurse as it was against her 'good dying' values to send the resident to hospital, but she was powerless to ignore the requirement for appropriate information regarding the condition of the resident. In this case the staff needed *written confirmation* that the resident was at the end of life, and the care he required was palliative but the nurse participants were unable to make this decision independently.

5.6.2.4 Hospice staff

The relationship with hospice staff was described in a more positive way. Staff felt supported by the nurses from the hospice either in person or by them providing support over the telephone. This support mainly addressed *symptom management* at the end of life, which was an important aspect of a 'good death', but examples of hospice staff supporting relatives of dying residents were also shared in this study. When residents were admitted to the nursing homes from the hospice, participants felt that the hospice was acknowledging their ability to provide good end of life care.

5.7 ADDITIONAL FINDINGS

5.7.1 PARTICIPANT ROLES AND EXPERIENCE

The participants in this study were found to have had different experiences of end of life care delivery depending on their role in the nursing home. The challenges faced

by healthcare assistants were mainly related to not being involved in care decisions when they were the main provider of hands on care for residents. Nurses found their relationships with relatives and other healthcare professionals to be the most challenging, as they often disagreed with what they perceived to be incorrect decisions made about care for residents. Managers were affected by the failings of external organisations such as hospitals, and their inability to act in what the manager believed was the best interests of the resident. Managers were also challenged by relatives and GPs with incongruent values, but they were more confident and able to advocate on the resident's behalf.

Participants, who had worked for five or more years in this environment, recognised the changing population of nursing homes with residents being more frail and dependent than those who had been admitted to the home in previous years. There was also increasing numbers of deaths in the nursing homes due to residents being discharged from hospital and hospices for end of life care. The increase in numbers of deaths and greater focus on end of life care had not made the experience of caring for the dying less challenging for staff, even though they accepted dying as normal, the number of deaths were difficult for some staff to deal with.

Age, ethnicity or qualifications did not influence the experience of end of life care provision in this study. The data on length of time working in nursing home care highlighted that challenging incidents still held resonance for staff, as some examples remained vivid for participants many years after they had occurred.

5.7.2 PARTICIPANT CULTURE

This study's participants were culturally diverse but only three participants mentioned their culture as a value on which their care for residents was based. Knowledge of the culture and communicating in the same language had had a direct effect on the care outcome. However, some participants experienced communication difficulties due to the experience of death in their own country. One participant's work was guided by a moral code of conduct 'to do good' in this life as this directly affected how her whole family would be judged by others.

5.7.3 PARTICIPANT RELIGION

Religion was identified as the value on which one participant based her care, although there was evidence of spiritual awareness from other participants, such as awareness of a resident's Christian faith or personal values about life after death. Data on participant's religions were not collected, but staff reporting different beliefs about life after death, such as the idea that nursing homes were haunted with two participants thinking that residents had control over the timing of their death, especially if they were waiting for the arrival of a relative or event.

5.8 CONCLUSION

This study has found that values associated with 'good dying' influenced participants in caring for residents at the end of life. These values enabled them to facilitate nursing home residents to have a 'good death' by doing what the staff believed to be 'the right thing'. The value of '*knowing the residents and their wishes*' contributed to delineating the care that staff gave to a dying resident. This care would sometimes not concur with the staff's other 'good dying' values or their own personal values, but accommodating the resident's wishes was the most important aspect of the care.

Where there were incongruent values between the staff and residents, emotional distress rather than moral distress was experienced because the staff were doing 'the right thing' by achieving the resident's wishes.

When staff were unable to enact care in a way that met their values because of the incongruent values of others (relatives, GPs, colleagues or those external to the nursing home) this related to: poor recognition and acceptance of dying, the decisions made on behalf of residents, care provision and symptom control, poor communication, or relationships contributed to staff feeling powerless to provide the care they knew they could to facilitate a 'good death'. The feelings of powerlessness is the characteristic of their moral distress.

The dying trajectory of nursing home residents was identified as contributing to staff sometimes being unable to do 'the right thing', because diagnosing dying is not an exact science and can be complex in the frail older population. 'Doing the right thing' and powerlessness could occur concurrently during the dying trajectory, with values influencing care right up to the end of a resident's life. When a decision, which was incongruent with values resulted in a hospital admission, staff considered this to be a 'bad death'. However, up until the point of death even when there were incongruent values during the care, a 'good death' was still possible in the nursing home with family around them as shown in Box 2. This study has found that emotional and moral distress are experienced when providing end of life care in nursing homes both of which can influence the staff's values in future care associated with 'good' and 'bad dying'.

Moral distress was found to exist in the nursing home staff in this study related to caring for residents at the end of life.

CHAPTER 6 DISCUSSION

6.1 INTRODUCTION

This chapter is the report discussed as step six of Braun and Clarke’s (2006) analysis process, contextualising the findings discussed in chapter five and develops the themes into a ‘model of experience of moral distress in nursing homes’ (Figure 6).

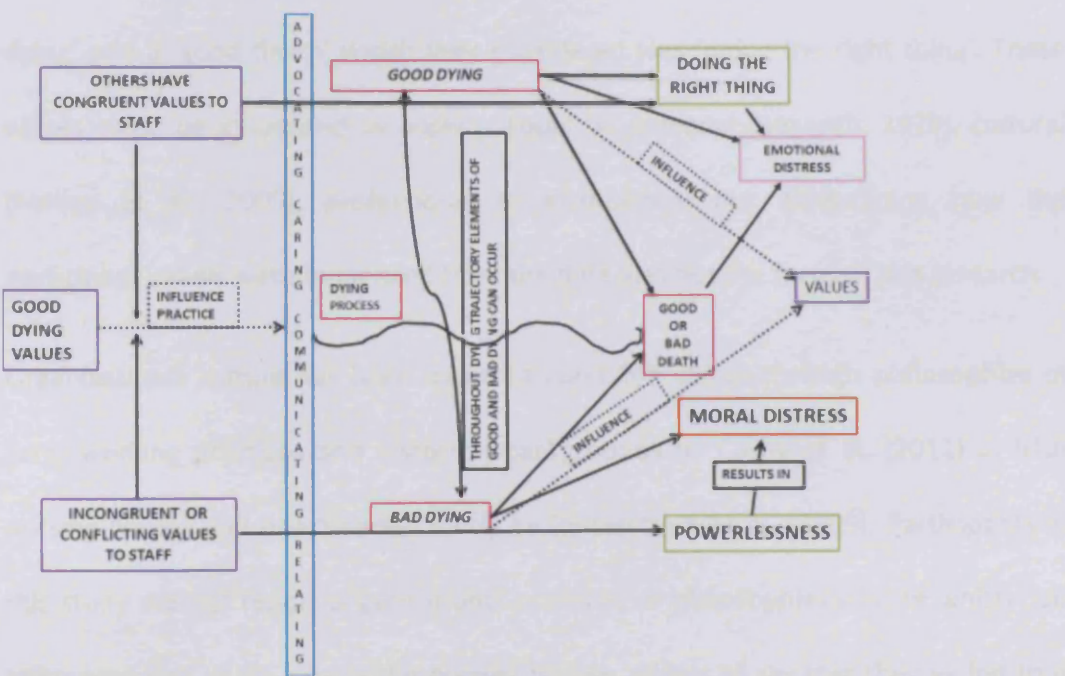


Figure 6 Model of the experience of moral distress in nursing homes

This model is critically discussed using literature from the background chapter, literature review and new literature, linked to the notion of ‘good dying’ values identified in chapter five. How these values influence the practice elements of advocating, caring, communicating and relating in end of life care will also be discussed. The staff experience of the dying process for residents in nursing homes and how this contributes to their emotional distress and their moral distress is explored prior to discussing the identification of moral distress in nursing homes and

its consequences. A new definition of moral distress is proposed, and the strengths and reflections on the research process are presented.

6.2 PARTICIPANT VALUES

The nursing home staff were found to hold values associated with 'good dying', which influenced their practice of end of life care, enabling them to facilitate 'good dying' and a 'good death' which they considered was 'doing the right thing'. These values could be influenced by society, could be personal (Rokeach, 1973), cultural (Malloy et al., 2009), professional or institutional but determining how the participant values were influenced from the data was not the focus of this research.

Organisational culture has been found to condition values through philosophies of care, working practices and historical backgrounds by Casey et al. (2011) in Irish nursing homes and in a Swedish study by Rytterstrom et al. (2009). Participants in this study did not report organisational practices or philosophies of care which had influenced end of life care in the nursing homes, except to say that they all felt that they provided very good end of life care for their residents.

Cultural differences and influence on end of life values were not explored in this study, neither was it evident that they contributed to the staff's 'good dying' values, however this has been found to be the case elsewhere in Europe (Gysels et al., 2012). Cultural diversity of staff was found to have a positive impact on care provision in Zheng and Temkin-Greener's study (2010) and although the cultural background of the staff in my study was diverse, only three participants identified their cultural background as influencing the way they provided care for their dying residents.

Tong (2008) suggests that values could also be influenced by gender, as women tend to focus on the needs of others rather than themselves. There was only one male participant in this study which is reflective of the workforce in the nursing home environment and of previous research studies (Porock and Parker-Oliver, 2007, Osterlind et al., 2011). Reitingger and Heirmerl (2014) discuss that there is an imbalance of gender in nursing home management structures with fewer women in the top positions which was reflected in the homes in this study. They argue that this could influence the ethical decision making process due to the potential difference in the values held by men and women (Reitingger and Heirmerl, 2014). Vallis and Boyd (2002) suggest that being female contributes to the nursing home ethic of care rather than cure, which was born out in this study. Most of the participants did not value acute interventions for their residents who were dying, concurring with Epstein and Hamric's (2009) discussion on futile care contributing to moral distress. It was not evident from the findings whether there was a difference between the gender of relatives and the decisions they made regarding interventional or palliative care.

6.2.1 GOOD DYING VALUES

'Good dying' values influenced care so that a 'good death' could be achieved. Hart et al (1998) argue that the ideology of a 'good death' can constrain the choice that people have as there is more desire for people to conform to the ideal of a 'good death'. When this does not occur then the death is considered to be suboptimal. McNamara and Rosenwax (2007) also suggest that when a person is considered to be in denial about death, palliative care practitioners see it is an obstacle to be removed, rather than accepting it as personal choice.

The staff in this study acknowledged the right to personal choice as *achieving resident's wishes* was the 'good dying' value that could override all others, even when this meant staff perceived that the death was or could be suboptimal. When the resident's values were incongruent with staff values, emotional rather than moral distress was experienced. Respecting residents choices and culture and maintaining their dignity were seen as important in contributing to a 'good death' (Leichtentritt and Rettig, 2001, Dwyer et al., 2009). Respecting residents choices in this study aligns with Schwartz et al.'s (2012) value of 'universalism-tolerance' which recognises that people are different and that the values of older people about 'good dying' may not concur with those of the healthcare professional (Gott et al., 2008b, Vig et al., 2002, Goldsteen et al., 2006).

Watson's (2012) work on human caring integrates morals, values, knowledge, skills and the ability to understand people (Gallagher, 2010, Horton et al., 2007). Human caring is not only a value (Schwartz et al., 2012) but also the moral obligation of nursing which maintains dignity (Watson, 2012). The 'good dying' values enabled the participants to do what they considered to be 'the right thing', with staff reporting that knowing the residents and treating them like family members, (Casey et al., 2011, Hanson et al., 2002, McCarthy and Deady, 2008, Fagermoen, 1997, Tronto, 2010) along with good end of life care planning, could facilitate what staff believed to be a 'good death' (Naden and Eriksson, 2004). Utilising the palliative care approach (Radbruch et al., 2006), including advance care planning could improve care, and reduce hospital admissions at the end of life concurring with Seymour and Horne's (2011) palliative care research. Staff, however, felt powerless when those involved with residents did not hold the same values, as this could result in what staff

believed to be 'bad dying' or a 'bad death', especially if this occurred in a hospital. The participants identified futile care and inappropriate hospital admission as the main contributory factors, which contributed to 'bad dying' or a 'bad death'.

6.3 PRACTICE ELEMENTS OF END OF LIFE CARE

The 'good dying' values discussed in chapter five inextricably link with the practice elements of care to facilitate 'doing the right thing'. The day to day practice of end of life care in nursing homes enables residents to have their choices respected. This is achieved by **advocating** on the residents behalf, by **caring** which includes the assessment and control of symptoms and recognising when a resident is at the end of life. **Communicating** well with residents, their relatives and others who are involved in end of life care within the nursing home and establishing good relationships conducive for the best care outcomes for the resident by **relating**. These practice elements with the 'dying values' can result in emotional and moral distress when the values of others are different to those of the staff.

6.3.1 ADVOCATING

Advocating on behalf of residents when their wishes were known, enabled staff to provide good end of life care. When residents were unable to express their wishes, or when staff were unable to advocate and carry out wishes, caused them to experience conflict. Evidence suggests that lack of advance care planning (Dreyer et al., 2010), families wanting more treatment (Edwards et al., 2013), or family and staff holding conflicting views of what was best for the resident, either with colleagues or other family members (Ersek and Wilson, 2003, Gjerberg et al., 2010, Mitchell et al., 2011) can all contribute to an increase in disagreements about care provision. Examples of family conflict were found in this study, and staff were powerless to

prevent this, and were sometimes unable to deal with it to ensure the wishes of residents were carried out. This most commonly occurred with residents with cognitive impairment or dementia.

Palliative care and end of life care planning for people with dementia in care homes has not been well supported (Seymour et al., 2011) and can be complex due to the living, dying trajectory. The Dementia Strategy (Department of Health, 2009) and the Mental Capacity Act (Chapman and Makin, 2011) in the UK, both state that people with dementia should be involved with care decisions. Participants in this study identified that the increased levels of cognitive impairment experienced by new residents to nursing homes makes this level of involvement difficult. This resulted in staff feeling powerless to instigate end of life care planning with the resident. Ashton et al.'s (2014) study recommends that staff undertake end of life care planning discussions with relatives when it is not possible with residents, but in this study participants found that some relatives were not receptive to the idea and staff felt unable to persuade them otherwise, despite believing that having the conversation was 'the right thing' to do.

Staff in nursing homes acknowledged their limitations when dealing with conflict with relatives (Lopez, 2007). In this study the managers and nurse participants were able to address some familial conflict but powerless to resolve others. This could result in residents receiving, perceived, suboptimal care, especially when there were incongruent values on treatment options as found by de Veer et al. (2013). Healthcare assistants felt unable to address any conflict with relatives as they perceived that they are 'only carers' with no influence or power.

Dionne-Odom and Bakitas (2012) discuss in detail the complex nature of making decisions on behalf of someone else, as did Winter and Parks (2012), who found that older people and their proxies would not always make the same decision, as reported in this study (section 5.2.1). The powerlessness that staff experienced when there were incongruent values had also been experienced by relatives in Horntvedt et al.'s (2014) study, but this was not explored, acknowledged or alluded to in this study, but could have been present.

The disparity, particularly concerning interventional rather than palliative care, could be associated with relatives not seeing dying as normal (Munn, 2006). Indeed, research has indicated when others made decisions, (Nicholas et al., 2014), futile care interventions were increased (Pavlish et al., 2011).

6.3.2 CARING

This study's findings on end of life care share similarities with previous research which identified that diagnosing dying and recognising palliative care needs in the older population can be problematic (Pugh, 2009, Addicott and Ashton, 2009, Lorenz et al., 2007, Hockley et al., 2005). Nicholson et al. (2012), Waldrop and Kusmaul (2011) and Beck et al. (2012a) all recognised that caring for frail older adults was complex due to the unpredictable dying trajectory, as older people can be close to death and then recover. Diagnosing dying is not an exact science (Hanson et al., 2002) and predicting mortality in other healthcare settings has also resulted in staff believing that patients or residents can be in receipt of care they consider to be futile (Elpern et al., 2005, Piers et al., 2012).

Futile care has been recognised as an ethical dilemma in the nursing home environment especially for the gradually declining resident (Gjerberg et al., 2010, Schaffer, 2007). It has been found to contribute to the moral distress experienced by nurses (Piers et al., 2012). The participants in this study saw hospital care for older people at the end of life as futile and, if admission was required, they assumed that residents would either die there or return to the home in a poorer state than when they left. Research carried out supports their assumptions as 33% of residents died on admission and over 50% did not survive longer than six weeks following admission to hospital in Ahearn et al.'s UK study (2010). Participants expressed that there was a lack of professional respect from hospital colleagues which is supported in research by McCloskey (2011). Hospital admission could lead to staff feeling distressed as this was often felt not to be the 'right decision' for the resident, especially when the resident had dementia and was unable to make their own choices.

Caring for the deceased was found to be as important as caring for the living (Osterlind et al., 2011) but was found to be emotionally distressing by healthcare assistants in this and previous studies in nursing homes (Burack and Chichin, 2001, Ersek et al., 1999, Funk et al., 2013). It was especially distressing when it was someone with whom they had a special relationship. Participants were aware that this was the completion of care for a resident but some managers did not recognise the emotional aspect of caring for the deceased and it was considered to be a normal part of the job (Beck et al., 2012a). The lack of support for participants in this study was not found to be to the same extent as previous research carried out in nursing homes, where the emotional side of caring for the dying had resulted in staff

experiencing high levels of distress (Funk et al., 2013, Katz et al., 2001, Miskella and Avis, 1998, Österlind et al., 2008, Waldrop and Nyquist, 2011).

6.3.3 COMMUNICATING

Poor communication with external healthcare providers increased the risk of people receiving futile care (Palda et al., 2005) and this was most common with out of hours GPs in this study. This was also the case in nursing homes with more than one GP practice, as relationships and communication were not as good which could affect end of life care provision (Hockley et al., 2005). Inadequate communication from medical staff has been identified as contributing to poorer care outcomes due to lack of skills (Enes and de Vries, 2004) or a reluctance to talk about dying (Zuzelo, 2007). Fosse et al. (2014) identified that relatives wanted more communication and information provided by medical staff, which was done more frequently by the homes with GP attachment in this study. Communicating between colleagues, especially from healthcare assistants to nurses, was found to be problematic when nurses did not appear to listen to or act on information that they provided. Brazil et al. (2006) found that poor communication and lack of competence influenced working relationships which increased the conflict between colleagues, resulting in decisions which could contribute to moral distress.

Communicating with some relatives was found to be difficult especially when they were in denial that death was happening, or when staff found communicating about death and dying difficult. Hertzberg et al. (2003) found that staff communicated less with relatives who appeared to be content than those who were seen to be more challenging. Relatives of nursing home residents have acknowledged the difficult transition they experience when their loved one moves into a nursing home, and a

lack of communication from staff contributes to the struggle they face (Ryan and McKenna, 2015). As more residents are admitted in a very frail state, with a lack of cognitive function, communicating with relatives is very important, as a lack of communication at the end of a resident's life can contribute to relatives feeling dissatisfied with the nursing home staff (Munn et al., 2008).

6.3.4 RELATING

Relationships with relatives were found to be the main contributory factor to achieving a 'good death' for the resident. This was especially true of relationships with those who held similar family and congruent care values as the staff including, visiting regularly, providing physical care for the resident and being present during the dying phase. Relatives were found to be both a resource and a hindrance in Hertzberg et al.'s (2003) study, where staff described relatives as being 'demanding' especially when they were very busy or short staffed. Relatives in this study who conformed to the ideal of a 'good relative' were spoken of in a positive way and staff would go out of their way to make the relatives feel at home. When relatives did not meet with these values it caused staff to be judgemental about the relative and to feel distressed on behalf of the resident when relatives chose not to be in attendance when a resident died, causing staff to feel very angry and frustrated, which was also found by Lopez (2007). This did not always cause conflict between staff and relatives but it was not considered to be 'doing the right thing'. Despite this, a 'good death' could still occur as the staff would take on the family role and be in attendance instead. Munn (2006) found that the closeness of relationships in nursing homes contributed to staff being able to achieve the end of life wishes of their resident.

Healthcare assistants in this study spent more time with residents providing hands on care and were more likely to experience moral distress than the nurses due to their relationships with residents, something supported by the literature (Ersek et al., 1999, Trotta, 2010, Zheng and Temkin-Greener, 2010). The moral distress healthcare assistants experienced occurred when they were not listened to or consulted about the care for a resident, which resulted in care outcomes they felt were not right for the resident (Russell, 2012). Undervaluing a healthcare assistant's contribution to decision making was also identified in Zheng and Temkin-Greener's (2010) study. Not all healthcare assistants in this study, however, felt undervalued. Those who had good relationships with supportive managers and colleagues were more involved, which was also the case for the participants in Beck et al.'s (2012a) study. Good leadership in an organisation was found to change the way staff experience end of life care, which could have reduced the incidence of moral distress in this study which de Veer et al. (2013) also found.

In this study staff were able to openly discuss the good relationships and emotional attachments they had with their residents, which contributed to them knowing the residents well, but caused distress when they died. Good relationships with residents and a desire to achieve a resident's wishes meant that when incongruent values between residents and staff existed emotional, rather than moral distress, was the result. When a staff's values were in conflict with relatives, colleagues or other healthcare professionals they experienced feelings of frustration, anxiety, guilt or distress which concurs with Rokeach's (1973) and Beagan and Ell's (2007) work on values and could result in moral distress.

6.4 IDENTIFYING MORAL DISTRESS

Beagan and Ells (2007) use the terms 'moral distress' and 'ethical distress' interchangeably in their study on values, as do the Canadian Nurses Association (2003). They explain that it is both 'ethical distress' and 'moral distress' which can result when one is prevented from 'doing the right thing'. Moral distress was an unfamiliar term for the staff in this study as were associated terms, such as 'ethics' or 'moral judgements'. Therefore, this language was not utilised during the interviews by the researcher. The language the participants used to describe their experiences used words such as: 'challenged', 'difficult' and words describing negative feelings such as: 'upset', 'powerless' 'frustration' and 'fear'. This language aligns to 'initial' distress which Jameton (1993) suggests occurs prior to staff being hindered in their ability to do what they believe to be right. Situations which go unresolved and are repeated can cause stronger reactions on each occasion, and can lead to burnout (Epstein and Hamric, 2009). The participants in this study did not report experiencing an increase in the strength of feelings they encountered in the stories they shared, (a crescendo effect, Epstein and Hamric, 2009) although hospital admissions were reoccurring events which frustrated some staff and a build-up of these feelings could cause moral residue (Epstein and Hamric, 2009). Thomas and McCullough (2015 p 102) acknowledge the crescendo effect, and propose a 'philosophical taxonomy of ethically significant moral distress' where situations can cause greater intensity of moral distress by challenging, threatening or violating individual or professional 'moral integrity'. The feelings of frustration and anger that were reported by staff indicated that they were experiencing moral distress, and the intensity was greatest when futile care was instigated.

6.5 EMOTIONAL DISTRESS

Emotional distress was also reported by the participants, by using words such as 'upset', 'sadness' and 'crying', which was often linked to the death of a resident, even when the death was considered to be a 'good death' making staff feel sad, but rewarded when they knew they were fulfilling the residents wishes. Funk et al. (2013) found that staff coped in different ways with the emotions they felt when a resident died, depending on how attached they were. Beagan and Ell's (2007) study on nurse's values found that some nurses chose to remain unattached to patients due to wanting to remain emotionally in control, especially when they were unable to achieve care fitting with their personal values. Participants who were attached to their residents in this study did not report a reduced attachment when their 'good dying' values were not achieved. Nurses in Rodriquez's (2011) study, however, identified it was the managers who discourage staff from being emotionally attached to the residents as it was deemed by some to be counterproductive. The study participants reported that providing end of life care in nursing homes was not only emotional and challenging but could also be rewarding, which concurs with previous research (Burack and Chichin, 2001, Dwyer et al., 2009, Funk et al., 2013).

6.6 MORAL DISTRESS IN NURSING HOMES

Moral distress was found to be as a result of the powerlessness the participants felt when they were unable to 'do the right thing' because of the incongruent 'good dying' values of others. The reports of challenging situations on end of life care in this research were in keeping with ethical issues found in previous studies. Lillemoen and Pedersen (2013) identified that resources, communication, relationships and decision-making were some of the everyday ethical issues that care home staff

encounter. Futile care, poor symptom management and patient suffering, which were all identified as contributing to moral distress in chapter two, were all found in this study to contribute to the staff experience of end of life care.

The participants reported that out of hours GP's lacked knowledge about clinical care, especially recognising dying, palliative care and of the residents which could result in a resident's admission to hospital. This extends the causes of moral distress beyond organisational constraints, which means Jameton's (1984) definition on moral distress is too limiting to apply to this study's findings, as the experience of moral distress in these participants was not only relevant to organisational factors. His revised definition on initial distress, however, can be better applied to this study as staff did feel frustrated when there was a personal conflict of values (Jameton, 1993). Varcoe et al.'s (2012a) definition, was the lens through which this study was viewed, which is broader in context but there was no evidence that staff felt that they had been seriously compromised when caring for residents in the nursing homes. Peter's (2013 p 298) assertion that moral distress is 'a challenge that arises when one has an ethical or moral judgement about care that differs from that of others in charge' is more in keeping with this study and this links directly to the notion of 'good dying values' (Figure 5) which where the incongruence exists staff feel powerless to influence practice.

Moral distress was experienced differently in the different staff groups which reflects their different roles and responsibilities for care in the nursing home. Managers are more confident to advocate on the behalf of residents to fulfil their end of life wishes and are fully appraised of the procedural requirements when residents are dying,

although they rarely provide hands on care (Froggatt and Payne, 2006). Their moral distress was caused by conflict, due to moral and ethical dilemmas, or between families, or other healthcare professionals. For them, incongruent values were those associated with decisions to give futile and inappropriate care when a resident was coming to the end of life, a finding which concurs with other studies on nursing homes and moral distress (Piers et al., 2012, Edwards et al., 2012, de Veer et al., 2013).

Nurses were found to make decisions which conformed to the ideas of 'others' (relatives, GPs or colleagues). This conformity can be linked with Kohlberg's conventional stage of moral development as found by Dierckx de Casterlè et al's (1998) meta-analysis of nurses responses to ethical dilemmas in practice. Arguably the nurse participants were in the conventional stage of Kohlberg's model, (Kohlberg, 1976) due to the processes and procedures which made them fearful of making the wrong decision, even when the result ended up with care which was incongruent with their values. This could cause moral distress, as it prevented them 'doing the right thing' for residents. Nurse managers, however, can be considered 'expert nurses' whose moral development has moved into Kohlberg's 'post conventional' stage (Kohlberg, 1976). They were more confident in their decision making capability and made decisions in a resident's best interest and consequently reported less moral distress. Relatives, however, were the foremost decision makers identified in this study and this caused the staff moral distress when the relative's decisions made them feel powerless to 'do the right thing' when a resident was dying. Healthcare assistants did not report being involved in the decision making

process regarding the care choices for residents and are considered to be in the pre-conventional stage of carrying out the instructions of others (Kohlberg, 1976).

Participants were found to experience powerlessness when they were unable to practice end of life care in accordance with their 'good dying values', contributing to their experience of moral distress (Figure 6). Powerlessness, as a characteristic of moral distress, has been recognised (Wilkinson, 1987, Russell, 2012, de Veer et al., 2013, Varcoe et al., 2012a). Huffman and Rittenmeyer's (2012) systematic review on moral distress identified powerlessness as one of the experiences causing moral distress in the studies they reviewed. Nursing assistants in Beck et al.'s (2012a) study recognised that managers and nurses were sometimes powerless to influence change to care. Although these changes focused on resources, something that was not found in this study, the notion of senior colleagues being powerless was visible. Erlen and Frost (2001) investigated nurses perceptions of powerlessness associated with ethical decision making and found that nurses perceived that 'others' were in a greater position of power to make decisions than they were. This could be due to the historical hierarchical positioning of nurses in healthcare settings found by Malloy et al. (2009), which identified that staff experience frustration when decisions are made by physicians who they deem more powerful. Huffman and Rittenmeyer (2012) also found that unequal power in professional relationships can contribute to moral distress linked to hierarchical decision making which could cause conflict (Goethals et al., 2010). Relatives were identified as the most powerful decision makers in this study, as well as them being more likely to act on the advice of doctors, rather than those of the nurses who actually knew the resident.

Relationships with relatives in this study were frequently described as having a negative influence on end of life care provision, either due to the instigation of futile care or the experience of conflict, which concurs with Tan and Manca (2013), and Forbes (2001). The study by Winter and Parks (2012) into relative proxy decision-making found it was dependant on the health status of their loved one. Those with a poorer health status were found to receive more life prolonging treatments at the behest of relatives, which was also identified by the decisions relatives made in this study. Admission to hospital could be instigated from the pressure from relatives (Dreyer et al., 2010) or because of personal values related to death and dying (Oberle and Hughes, 2001), which could then contribute to staff experiencing moral distress.

Moral distress has been described as 'relational trauma' because there is a link between the individual's experience of moral distress and the organisational practice in which they work (Musto et al., 2015). This is evident where nurses act in a way which increases their moral distress because the organisational practices are not questioned, or challenged e.g. sending a resident to hospital because paperwork is unavailable. The violation of a person's values can be interpersonal and institutional in nature, both of which can prevent a person doing what they believe to be right. Moral distress around end of life care was individually experienced in the context of a wider system of care, but in these nursing homes, not organisationally shaped in the way described by Jameton (1984). Organisational end of life practices were found to contribute to moral distress but the lack of financial resources identified in other studies (Austin, 2012) was not found to contribute to the moral distress of the participants of this study. They acknowledged how hard they worked, but a lack of staff resource was not found to contribute to the moral distress of these participants.

Nursing homes, as independent organisations in the UK, rely heavily on GPs, who are arguably the cornerstone of the 'institution' of nursing home care. The relationship between nursing homes and GPs has been found to negatively affect end of life care in residents (Seymour et al., 2011). However, participants in this study experienced good working relationships and communication with the GPs allocated to their nursing homes. These good working relationships were not found to be well supported in the literature but have contributed to a reduction of residents dying in hospital and for better end of life care provision in the study's nursing homes, enabling staff to 'do the right thing', reducing their levels of moral distress.

6.7 CONSEQUENCES OF MORAL DISTRESS

The consequences of moral distress can be costly to staff and to the health economy when there is lack of understanding and support for staff working in this environment. This is due to inappropriate admissions to hospital causing moral distress, but in a time of resource cutbacks and political drive for savings, they are also costly (Purdy, 2010). Reducing futile care can reduce moral distress and save money (Purdy, 2010) in the current healthcare climate. The complexity of the residents' healthcare needs at the end of life in this study was similar to other nursing home research (Bedlin et al., 2012) and the themes identified resonate with previous studies carried out in this environment (Gjerberg et al., 2010, Hall et al., 2011, Munn et al., 2008).

The fear of consequences was visible in the nursing home staff when residents died without a 'do not resuscitate order' in place, or when staff made decisions which relatives might complain about, or by disagreeing with the GP. McGilton et al. (2014) discusses the inflexibility and over regulation of nursing homes, which can instil fear

and prohibit professional growth. This could contribute to an increase in the levels of moral distress staff experienced because of making decisions that were incongruent with their own 'good dying' values. The deputy managers and nurses were aware of the processes and procedures required to facilitate a 'good death', but often had to make decisions independently without support, which Russell (2012) identified as another contributory factor to moral distress. Nurses were afraid to make decisions in case it was deemed to be the wrong one, and instead deferred to relative and GP decisions even when they were not in agreement with the decision made (Varcoe et al., 2012). This contradicts the study by Bedlin et al. (2012) who suggested that nurses are the lynchpin for coordinating care decisions and Vallis and Boyd's (2010) study, which found that nurses are the gatekeepers of care in nursing homes. Managers, in this study, as senior nurses, were more confident to advocate on behalf of residents and their relatives to achieve their 'good dying' values, which links in with Vallis and Boyd's (2002) suggested ethical principle of 'defence of best interest' and they did not experience as much fear related to the decisions they made.

A lack of bereavement support for staff following a death in the nursing home was identified, concurring with previous research in nursing homes (De Bellis and Parker, 1998, Mitchell et al., 2011), the consequences of which are not reported. In some cases in this study, death was identified as just a part of the day to day work of staff in nursing homes as was the case in Funk et al.'s (2013) study. When staff are unsupported and the number of deaths where 'good dying' values are not achieved, feelings can accumulate resulting in 'moral residue' after each occasion (Epstein and Hamric, 2009). This can result in the crescendo effect (Epstein and Hamric, 2009) which can build up causing stress, sickness, burnout or job leave (Corley and Minick,

2002). Acknowledging the emotional burden and risk of 'moral residue' can help develop reflective sessions tailored around bereavement issues which may be beneficial in supporting staff reducing the risk of the consequences of moral distress as suggested by Funk et al. (2013), and Reitingner and Heimerl (2014).

6.8 REDEFINING MORAL DISTRESS

Conceptual ideas do not remain static, they are built upon and added to through research and new knowledge making them more fluid (Rodgers, 1989). The evolution of the concept of moral distress is no exception to this, which may explain why its lack of clarity has been criticised (Hanna, 2004, Johnstone and Hutchinson, 2013). Johnstone and Hutchinson (2013) argue that for moral distress to exist nurses must first be able to critically reflect on why they believe something to be right before they are able to be distressed for not being able to do it. Staff in this study were able to articulate what they believed was the 'right thing to do' when a resident was coming to the end of life, and this linked with their 'good dying' values. They did not report or reflect on the ethical or moral nature of the critical incidents they shared, or contextualised their values as being ethical or moral in nature. As the values focused on benefitting others they can be considered to be moral values (Schwartz et al., 2012). This justifies that the distress they experienced was more than emotional in nature (Johnstone and Hutchinson, 2013) and therefore they were experiencing moral distress.

This study found that staff experienced moral distress when they felt powerless to 'to do the right thing' to facilitate 'good dying' when caring for residents at the end of life. The identification of 'good dying values' that underpin the practice elements of advocating, caring, communicating and the challenging nature of the dying

trajectory are reflected in a proposed new definition of moral distress for nursing homes.

‘Moral distress in nursing home staff is characterised by the powerlessness that staff experience when there is dissonance between their ‘good dying’ values, and those of relatives, GPs and colleagues. This can contribute to staff being unable to influence end of life decisions made on behalf of their residents, during the complex living and dying trajectory their residents experience’.

This definition will be used with the model of the experience of moral distress (Figure 6) to base supportive sessions for nursing home staff who care for residents at the end of life in the UK, and to share with those who have an interest in nursing home care provision.

6.9 REFLECTIONS ON THE RESEARCH PROCESS

The use of interpretivism as the epistemological stance informed the choice of methods in this study to answer the research question as end of life care in nursing homes does not occur in a vacuum, and the care that is provided is influenced by social, organisational and individual values and systems. Interpretive description fits with interpretivism as it is a flexible qualitative research approach which can explore the practice under investigation. The relationship between the epistemological stance and the research methods have been fully explained in chapter four. Utilising the contributory factors for moral distress in the literature review enabled a more in depth exploration of how conceptually moral distress could link to the findings of the identified studies, which then informed this study’s methods, findings and discussion.

The flexibility of interpretive description as a research methodology facilitated the use of appropriate methods to collect data in the nursing home environment. The method of recruitment and selection of participants for this study was easier than expected, in part due to the managers being known to the author, although not all participants were. The critical incident technique used as the method to collect data was a strength in this study, as it allowed the focus to be on the specific stories related to the research question which was important given the limited time available. The transparency of the analytical process is demonstrated with a clear audit trail from original thoughts (Appendices 9, 10, 11, 14, 15, 16, 17 and Figure 5) to the conceptualisation of the model of the experience of moral distress in nursing homes (Figure 6), which is important for the credibility of an interpretive descriptive study.

Credibility can also be improved within a qualitative study by demonstrating consistency and appropriateness of themes related to the research aims (Lewis and Ritchie, 2003). Discussion of the themes with academic supervisors assisted in this process, as well as note taking to track the thought processes behind the themes and conclusions drawn (Thorne, 2008). Critical reflection on the research process also improved the credibility of the study (Appendix 21) as the researcher was able to return to the notes and comments made throughout, to follow the trains of thought, as well as identifying the strengths and limitations (Taylor, 2000, Silverman, 2011).

6.10 CONCLUSION

This chapter has explored the staff experience of moral distress when providing end of life care in nursing homes in the UK. The nature of moral distress is linked to values of 'good dying' and the desire 'to do the right thing'. The evidence is clear that staff want to do the best for their residents and, for them, that means keeping residents in the nursing home where they can be looked after by staff who know them. The incongruent values of 'others' could make the staff feel powerless to influence the decisions that are made for residents, contributing to the moral distress they experience. Moral distress is an evolving concept and the proposed new definition of moral distress formulated from this study's findings is more embracing of this work environment at the current time.

CHAPTER 7 CONCLUSION.

7.1 INTRODUCTION

The subject of this thesis is important as the number of frail, dependent and vulnerable older people dying in nursing homes suffering from complex health needs is increasing. These residents require a confident skilled workforce to care for them throughout the unpredictable dying trajectory. Recognising that end of life care contributes to moral distress in this environment can contribute to better provision of appropriate support to deal with the challenges that staff face.

This thesis posed the question '*How do nursing home staff experience moral distress when providing end of life care to residents?*' An interpretive descriptive methodology guided the chosen methods of critical incident technique for data collection, and thematic analysis to fully interpret the data, with the purpose of providing new knowledge to answer this question. This chapter discusses the empirical findings and their theoretical implications. Recommendations for future research and practice will be made and the study limitations will be discussed before concluding.

7.2 EMPIRICAL FINDINGS

The staff in this study held 'good dying' values which influenced their practice of advocating, caring, communicating and relating within the scope of their role as manager, nurse or healthcare assistant. I found that nursing home staff experience moral distress when these 'good dying' values are incongruent with the values of 'others' who make decisions about the care of the residents at the end of life. These decisions made by relatives, GPs, colleagues, or staff from outside the nursing home

are often interventional rather than palliative in nature. They are considered to be futile and to cause more suffering for the resident which results in distress for staff. These decisions make the staff feel powerless to change the care outcomes for residents contributing to what staff consider to be 'bad dying' or a 'bad death'. The powerlessness they experience was found to be the nature of their moral distress as it meant they were unable to 'do the right thing'; something which is seen to contribute to a 'good death'. In contrast, incongruent values with residents did not lead to moral distress. Meeting these values were seen as meeting the 'good dying' value of *knowing the resident and their wishes* and was considered to be 'doing the right thing', although it could result in emotional distress.

The fear that nurses experience when caring for residents at the end of life was also found to contribute to their experience of moral distress. Fear of the consequences of making a mistake or a wrong decision overrode the participant's need to maintain the 'good dying' values, even when they knew the result would cause more distress to the resident or family. The managers, as more experienced nurses, were not fearful of the decisions they made and were more able to advocate on a resident's behalf. Whereas the nurses were more likely to conform to the wishes of others than cause conflict, which they believed would get them into trouble.

7.3 THEORETICAL IMPLICATIONS

My work contributes to the literature on the experience of moral distress when caring for the dying in nursing homes in the UK. This has not previously been explored. The findings from the research builds on work into moral distress undertaken in other countries and care settings (e.g. Corley et al., 2001, Elpern et al., 2005, Brazil et al., 2010). The nature of the moral distress in this study is different to

that identified in previous work, which found organisational resources to be the main contributory factor to moral distress. This work found that when incongruent values on dying exist between staff and 'others' staff can experience powerlessness which is the nature of their moral distress. Powerlessness in this study associates with the inability to influence the decisions that are made by 'others' who are identified as holding more 'power' to make them (Erlen and Frost, 2001). Relatives of residents are identified as the most powerful decision makers who influence care outcomes, which are incongruent with the staff's 'good dying' values, although out of hours GPs are also discussed. This new knowledge challenges the original definition of moral distress which has been used to underpin much of the research on the concept as it identifies the factors contributing to moral distress beyond the organisational.

End of life care has been found to contribute to moral distress in other care settings but it is difficult to compare the findings as much of the research from other settings are acute in nature. In contrast, long term care can have different challenges especially around the type of relationships that staff experience, and the sometimes unpredictable and prolonged dying trajectories of residents. Research has shown that there are different contributory factors to moral distress in long term geriatric and acute geriatric care settings (Piers et al., 2012), which is pertinent to this study due to more people living in care homes than there are beds in the National Health Service (Office for National Statistics, 2014). The relationships are built over longer periods of time in the non-clinical environment of the nursing home. Death is seen as a natural occurrence and not a failure, although as this research has shown, it is still difficult to cope with and to predict when it may occur.

The findings from this research concur with the literature. First that that knowledge and training for nursing home staff on palliative care can contribute to improving end of life care for older people in nursing homes (e.g. Burack and Chichin, 2001, Edwards et al., 2013). Second that good leadership and teamwork can provide support for staff when residents die (Forbes, 2001). Providing information on the results of this study to organisations who provide end of life care, or support for older people could provide better knowledge of the processes and procedures that can help to reduce moral distress from occurring. Discussing the findings with staff can highlight that not everyone will have the same dying values as them. A 'good death' for one person may not be the same for another. This will improve their understanding of why the decisions that are made may not be in accordance with what they think is right. Information for relatives about the complex disease trajectory and the need for planning in advance to inform decision making, could also assist staff to communicate with relatives at the end of life improving the openness of the subject.

The new knowledge gained can illuminate the powerlessness to influence care decisions which impact on care outcomes related to 'good dying'. This is not only important for staff working in nursing homes but also for those who commission hospital admission avoidance schemes locally. Providing information on the position that staff find themselves, where they feel powerless to prevent the hospital admission of a dying resident, may help to build better understanding between organisations who provide care.

7.4 LIMITATIONS

Interpretive description has been used in research studies in nursing homes but little attention has been given to describing the methodology or its application in practice.

This has resulted in this research relying on the primary author's work (Thorne, 2008).

The adoption of the critical incident technique for data collection may also have constrained the foci of the data collected, as probing questions about values, culture, religious beliefs, morals and ethical situations were not asked. These may have enriched the data and better informed the findings. The use of the critical incident technique allowed the focus of the interviews to be on exploring specific end of life experiences and how staff felt about these. It may have limited the collection of other information related to the general experience of working in a nursing home, which may have further contributed to the discussion on moral distress.

Staff were interviewed during their working day to minimise inconvenience, but this added time pressures with some interviews feeling rushed, and some critical incidents seeming less in depth than others. My awareness of having taken staff away from residents also contributed to the rushed nature of some of the interviews. Interviewing staff outside of the nursing home environment may have yielded more in depth data, but recruitment may have been limited due to staff having to give up personal time to talk to a researcher.

There was only one male participant. Although this is reflective of the care workforce in nursing homes, it may skew the data as a gender difference of values has been identified in research into values (Tong, 2008). Moral distress was experienced differently by the managers, nurses and healthcare assistants, who were the predominant participant group. This group had the least influence on informing care decisions, and therefore they reported more of the contributory factors to moral

distress. Recruiting a balance of staff groups may have been beneficial but the sample is indicative of the workforce in care homes.

7.5 RECOMMENDATIONS FOR PRACTICE AND FUTURE RESEARCH

Staffing resources in nursing homes are limited; keeping experienced staff in their posts should be a top priority to maintain high standards of end of life care. Research into moral distress and ‘good dying’ values could contribute to supporting those involved in end of life care in this environment better. The following are recommendations for further research in this area:

1. Moral distress is a new concept in the UK and further studies exploring the extent of moral distress in nursing homes could be utilised to inform service development and identify the issues that contribute most to moral distress in UK staff in this environment. A quantitative study using the adapted moral distress scale would allow measurement of the extent of moral distress in this setting. This information could inform work on mitigating moral distress, such as the development and testing of an intervention.
2. There are complex ethical decisions to be made in nursing homes and a more in depth evaluation of moral dilemmas and ethical issues from the perspectives of all staff, relatives, residents and GPs could also contribute further to the understanding of which issues contribute to moral distress. Exploration of these ethical issues could inform educational interventions which could benefit organisations by providing tangible data on what contributes to moral distress and possible support mechanisms for staff and relatives.

3. Cognitive impairment contributes to the staff experience of moral distress.

Further research on interventions to improve advance care planning in earlier stages of dementia could be beneficial. A longitudinal study into the timing of advance care planning with this group of patients would inform when best to undertake the process for the benefit of the person.

4. Exploration of the cultural religious, spiritual and gender values of internal and external staff, relatives and residents related to end of life care in nursing homes could contribute to a better understanding of difference, and how this influences the decisions which are made in nursing homes. This could help to provide appropriate information and support for all involved.

Changes to practice will involve working with the values and ethics of nursing home staff. This could be undertaken using end of life scenarios to facilitate better understanding of personal values and why 'others' values may differ, and the implications of these on care decisions. Presenting the findings of this research to home owners and managers may also highlight the staff experience of caring for dying residents as part of the normal routine, and the implications of this in terms of moral and emotional distress. Recognising the experience of managers, senior nurses and carers and provide support and strategies for them to support junior colleagues in practice. End of life introductory programmes could be facilitated in the borough so that new staff could attend, providing them with resources and contacts if they require further support or education.

7.6 CONCLUSIONS

Moral distress is a complex and evolving concept which has been found to arise from the situations nursing home staff find themselves in when caring for a resident at the

end of life. This study identifies that staff experience moral distress when dying residents are not able to receive the care that staff think they should, in order to facilitate what staff believe to be a 'good death'. Valuing a 'good death' is subjective and may not be the same for everyone, which emphasises the importance of communicating with residents about their wishes. It is equally important to acknowledge that the values of staff, residents, relatives, and other health professionals can all influence care provision at the end of life, and understanding the different values held by individuals could reduce moral distress. The 'good dying' values of staff influence the way that they provide end of life care in practice. Their ability to comprehensively fulfil the practice of end of life care depends on their role within the home and how confident they are to challenge the decisions of 'others'. Healthcare assistants feel powerless to influence decisions as they are not included in care decisions. Nurses feel powerless to challenge relatives or GPs, and managers feel powerless to influence the hospital to discharge residents in a timely manner.

Values inform the decisions that are made, influencing the experience of moral distress and care outcomes through congruency or powerlessness. Moral distress increases when relatives make care decisions for residents who are cognitively impaired, who the staff know well, which is seen to be at odds with 'good dying' values. Nurses conform to the relative's decisions rather than discussing what could be in the best interest of the resident, which further contributes to moral distress. In addition, the fear held by nurses about losing their jobs or nurse registration could contribute to residents having care which was incongruent with staff values, as their fear of consequences is greater than the need to achieve a 'good death'. Good leadership and support from senior nurses leads to greater confidence in decision

making from nurses, and a sense of engagement in decision making from healthcare assistants.

Nursing home staff work hard and are committed to providing good care, providing adequate support for them to continue to carry out their roles is important and this study identifies that moral distress exists, and with the provision of better support it can hopefully be reduced.

REFERENCES

- Abel, J., Rich, A., Griffin, T., Purdy, S. 2009. End-of-life care in hospital: A descriptive study of all inpatient deaths in 1 year. *Palliative Medicine*. 23 616-622.
- Addicott, R., Ashton, R. 2009. *Delivering better care at end of life the next steps*. London: The Kings Fund.
- Afzal, N., Buhagiar, K., Flood, J., Cosgrave, M. 2010. Quality of end-of-life care for dementia patients during acute hospital admission: a retrospective study in Ireland. *General Hospital Psychiatry*. 32, 2: 141-146.
- Age UK. 2013. Later Life in the United Kingdom: Age UK.
http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true [Accessed 3.6.2013].
- Ahearn, D., Jackson, T., Mcilmoyle, J., Weatherburn, A. 2010. Improving end of life care for nursing home residents: an analysis of hospital mortality and readmission rates. *Postgraduate Medical Journal*. 86 131135.
- Alzheimer's Society. 2011. The later stages of dementia.
www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=101 [Accessed 17.7.2011].
- Ashton, S., Roe, B., Jack, B., Mc Clelland, B. 2014. The experiences of advance care planning amongst family caregivers of people with advanced dementia- A qualitative study. *Dementia*. 0, 0: 1-18.
- Austin, W., Lerner Meyer, G., Goldberg, L., Bergum, V., Johnson, M. S. 2005a. Moral distress in healthcare practice: the situation of nurses. *HEC Forum : An Interdisciplinary Journal on Hospitals' Ethical and Legal Issues*. 17, 1: 33-48.
- Austin, W., Rankel, M., Kagan, L., Bergum, V., Lerner Meyer, G. 2005b. To stay or to go, to speak or stay silent, to act or not to act: moral distress as experienced by psychologists. *Ethics & Behavior*. 15, 3: 197-212.
- Austin, W. J., Kagan, L., Rankel, M., Bergum, V. 2008. The balancing act: Psychiatrists' experience of moral distress. *Medicine, Healthcare, and Philosophy*. 11, 1: 89-97.
- Austin, W. 2012. Moral distress and the contemporary plight of health professionals. *HEC Forum : An Interdisciplinary Journal on Hospitals' Ethical and Legal Issues*.
- Barrett, G., Coleman, M. 2006. Ethical and political issues in the conduct of research. In: Bowling, A. and Ebrahim, S. (eds.) *Handbook of Health Research Methods: Investigation, Measurement and Analysis*. Maidenhead: Open University Press.

- Beagan, B., Ells, C. 2007. Values that matter, barriers that interfere: The struggle of Canadian nurses to enact their values. Canadian Journal of Nursing Research. 39, 4: 36-57.
- Beck, I., Tornquist, A., Brostrom, L., Edberg, A. 2012a. Having to focus on doing rather than being-Nursing assistants' experience of palliative care in municipal residential care settings. International Journal of Nursing Studies. 49 455-464.
- Beck, I., Tornquist, A., Edberg, A. 2012b. Nurse assistants' experience of an intervention focused on a palliative care approach for older people in residential care. International journal of Older People Nursing. 9, 2: 140-50.
- Bedlin, M., Droz-Mendelzweig, M., Chappuls, M. 2012. Caring for elders: the role of registered nurses in nursing homes. Nursing Inquiry. 20, 2: 111-120.
- Birks, M., Chapman, Y., Francis, K. 2007. Breaching the wall: Interviewing people from other cultures. Journal of Transcultural Nursing. 18 150-156.
- Bolmsjo, I., Sandman, L., Andersson, E. 2006. Everyday ethics in the care of elderly people. Nursing Ethics. 13, 3: 249-263.
- Bourdeau, B. 2000. Dual relationships in qualitative research. The Qualitative Report, 4. [Accessed 16.07.2012].
- Bradbury-Jones, C., Tranter, S. 2008. Inconsistent use of the critical incident technique in nursing research. Journal of Advanced Nursing. 64, 4: 399-407.
- Bradley, E., Curry, L., Devers, K. 2007. Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. Health Research and Educational Trust. 42, 4: 1758-1772.
- Braun, V., Clarke, C. 2006. Using thematic analysis in psychology. Qualitative Research in Psychology. 3, 2: 77-101.
- Brazil, K., Kassalainen, S., Ploeg, J., Marshall, D. 2010. Moral distress experienced by healthcare professionals who provide home-based palliative care. Social Science & Medicine. 71 1687-1691.
- Brazil, K., Kreuger, P., Bedard, M., Kelley, M., Mcainey, C., Justice, C., Taniguchi, A. 2006. Quality of care for residents dying in Ontario long-term care facilities: findings from a survey of directors of care. Journal of Palliative Care 22, 1: 18-25.
- British Geriatric Society. 2011. Quest for Quality: British Geriatric Society Joint Working Party Inquiry into the Quality of Healthcare Support for Older people in care homes: A call for leadership, Partnership and Quality. London: British Geriatric Society.

- Burack, O. Chichin, E. 2001. A support group for nursing assistants: Caring for Nursing home residents at the end of life. Geriatric Nursing. 22, 6: 299-307.
- Caelli, K. Ray, L. Mill, J. 2003. 'Clear as Mud': Toward Greater Clarity in Generic Qualitative Research. International Journal of Qualitative Research 2 (2) Article 1
- Canadian Nurses Association. 2003. Ethical distress in healthcare environments. Ethics in practice. Available: https://cna-aic.ca/~media/cna/page-content/pdf-en/ethics_pract_ethical_distress_oct_2003_e.pdf?la=en [Accessed 10.1.2015].
- Canadian Nurses Association 2008. Code of ethics for registered nurses. Centennial edition ed. Canada: Canadian Nurses Association.
- Care Quality Commission. 2014. Active locations for providers registered under the health and social care act, 13 February: Care Quality Commission. cqc.org.uk/data [Accessed 12.9.2014].
- Carter, M., Little, M. 2007. Justifying knowledge, justifying method, taking action: epistemologies, methodologies, and methods in qualitative research. Qualitative Health Research. 17 1316-1328.
- Carter, S., Henderson, L. 2005. Approaches to qualitative data collection in social science. In: Bowling, A. Ebrahim, S. (ed.) Handbook of Health Research Methods: Investigation, Measurement and Analysis. Maidenhead: Open University Press.
- Casey, D., Murphy, K., Aine Ni, L., Larkin, P., Payne, S., Froggatt, K., O'Shea, E. 2011. Dying well: factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland. Journal of Clinical Nursing. 20, 13/14: 1824-1833.
- Chapman, S. 2011. End-of-life care for people with dementia should be discussed early. British Journal of Neuroscience Nursing. 7, 1: 461.
- Chapman, S., Makin, A. 2011. The implications of the Mental Capacity Act 2005 for advance care planning and decision making. In: Thomas, K. Lobo, B. (eds.) Advance care planning in end of life care. Oxford: Oxford University Press.
- Clark, D. 2006. The development of palliative medicine in the UK and Ireland. In: Bruera, E. Higginson, I. Ripamonti, C. Gunten, C. (eds.) Textbook of Palliative Care. New York: Hodder Arnold.
- Corley, M. 2002. Nurse moral distress: A proposed theory and research agenda. Nursing Ethics. 9, 6: 636-650.

- Corley, M. C., Elswick, R. K., Gorman, M., Clor, T. 2001. Development and evaluation of a moral distress scale. *Journal of Advanced Nursing*. 33, 2: 250-6.
- Corley, M. C., Minick, P. 2002. Moral distress or moral comfort. *Bioethics Forum*. 18, 1-2: 7-14.
- Corley, M. C., Minick, P., Elswick, R. K., Jacobs, M. 2005. Nurse moral distress and ethical work environment. *Nursing Ethics*. 12, 4: 381-90.
- Cornwell, J. 2011. The care of frail older people with complex needs: time for a revolution. The Sir Roger Bannister Health Summit, 2011 Leeds Castle. The Kings Fund.
- Costello, J. 2006. Dying well: Nurses experiences of 'good and bad' deaths in hospital. *Journal of Advanced Nursing*. 54, 5: 594-601.
- Cottone, R. 2001. A social constructivism model of ethical decision making in counseling. *Journal of Counseling and Development*. 79 39-45.
- Cox, K., Bergen, A., Norman, I. 1993. Exploring consumer views of care provided by the Macmillan nurse using the critical incident technique. *Journal of Advanced Nursing*. 18 408-415.
- Crabtree, B., Miller, W. 1999. Using codes and code manuals: a template organizing style of interpretation. In: Crabtree, B. F. and Miller, W. (eds.) *Doing qualitative research*. California: Sage.
- D'Hondt, A., Kaasalainen, S., Prentice, D., Schindel, M. 2011. Bathing residents with dementia in long-term care: critical incidents described by personal support workers. *International Journal of Older People Nursing*. 7 253-263.
- De Bellis, A., Parker, D. 1998. Providing palliative care in Australian nursing homes issues and challenges. *Geriaction*. 16, 3: 17-23.
- de Veer, A., Francke, A., Struijs, A., Willems, D. 2013. Determinants of moral distress in daily nursing practice: A cross sectional correlational questionnaire survey. *International Journal of Nursing Studies*. 50, 1: 100-108.
- Deady, R., Mc Carthy, J. 2010. A study of the situations, features, and coping mechanisms experienced by Irish psychiatric nurses experiencing moral distress. *Perspectives in Psychiatric Care*. 46, 3: 209-20.
- Denzin, N., Lincoln, Y. 2000. Introduction: The discipline and practice of qualitative research. In: Denzin, N. & Lincoln, Y. (eds.) *Handbook of Qualitative Research*. London: Sage.

- Department of Health. 2001. National Service Frameworks for Older People. London: HMSO.
- Department of Health. 2008. The End of Life Care Strategy. London: HMSO.
- Department of Health. 2009. National Dementia Strategy. London: HMSO.
- Department of Health. 2011. Governance arrangements for research ethics committees. London: Department of Health.
- Dierckx De Casterlé, B., Roelens, A., Gastmans, C. 1998. An adjusted version of Kohlberg's moral theory: Discussion of its validity for research in nursing ethics. Journal of Advanced Nursing. 27 829-835.
- Dionne-Odom, J., Bakitas, M. 2012. Why surrogates don't make decisions the way we think they ought to. Insights from moral psychology. Journal of Hospice and Palliative Nursing. 14, 2: 99-106.
- Dreyer, A., Førde, R., Nortvedt, P. 2010. Life-prolonging treatment in nursing homes: how do physicians and nurses describe and justify their own practice? Journal of Medical Ethics. 36, 7: 396-400.
- Dreyer, A., Førde, R., Nortvedt, P. 2011. Ethical decision-making in nursing homes: Influence of organizational factors. Nursing Ethics. 18, 4: 514-525.
- Dwyer, L., Andershed, B., Nordenfelt, L., Ternestedt, B. 2009. Dignity as experienced by nursing home staff. International Journal of Older People Nursing. 4 185-193.
- Dwyer, L., Hansebo, G., Andershed, B., Ternestedt, B. 2010. Nursing home residents' views on dying and death: nursing home employee's perspective. International Journal of Older People Nursing. 6 251-260.
- Edwards, M., Mc Clement, E., Read, L. 2013. Nurses' response to initial moral distress in long-term care. Bioethical Inquiry. 10 325-336.
- Eide, P., Kahn, D. 2008. Ethical Issues in the qualitative researcher-participant relationship. Nursing Ethics. 15, 2: 199-207.
- Eizenberg, M. M., Desivilya, H. S., Hirschfeld, M. J. 2009. Moral distress questionnaire for clinical nurses: instrument development. Journal of Advanced Nursing. 65, 4: 885-92.
- Elpern, E. H., Covert, B., Kleinpell, R. 2005. Moral distress of staff nurses in a medical intensive care unit. American Journal of Critical Care : An Official Publication, American Association of Critical-Care Nurses. 14, 6: 523-30.

- Enes, P., De Vries, K. 2004. A survey of ethical issues experienced by nurses caring for terminally ill elderly people. *Nursing Ethics*. 11, 2: 150-164.
- Epstein, E. G., Hamric, A. B. 2009. Moral distress, moral residue, and the crescendo effect. *The Journal of Clinical Ethics*. 20, 4: 330-42.
- Epstein, E., Delgado, S. 2010. Understanding and addressing moral distress. *The Online Journal of Issues in Nursing*. 15, 3.
- Erlen, J. A., Frost, B. 1991. Nurses' perceptions of powerlessness in influencing ethical decisions. *Western Journal of Nursing Research*. 13, 3: 397-407.
- Ersek, M., Kraybill, B., Hansberry, J. 1999. Investigating the educational needs of licensed nursing staff and certified nursing assistants in nursing homes regarding end-of-life care. *American Journal of Hospice & Palliative Medicine*. 16, 4: 573-582.
- Ersek, M., Wilson, S. 2003. The challenges and opportunities in providing end of life care in nursing homes. *Journal of Palliative Medicine*. 6, 1: 45-57.
- European Association for Palliative Care. 2010. Definition of palliative care: European Association for Palliative Care.
<http://www.eapcnet.eu/Corporate/AbouttheEAPC/Definitionandaims.aspx>
[Accessed 6.4.2015].
- Fagermoen, M. S. 1997. Professional identity: values embedded in meaningful nursing practice. *Journal of Advanced Nursing*. 25, 3: 434-441.
- Fenton, M. 1988. Moral distress in clinical practice: implications for the nurse administrator. *Canadian Journal of Nursing Administration*. 1, 3: 8-11.
- Ferrell, B. R. 2006. Understanding the moral distress of nurses witnessing medically futile care. *Oncology Nursing Forum*. 33, 5: 922-30.
- Fielding, N., Thomas, H. 2008. Qualitative interviewing. In: Gilbert, N. (ed.) *Researching Social Life 3rd Edition*. London: Sage.
- Fitzgerald, K., Seale, S., Kerins, C., Mcelvaney, R. 2008. The critical incident technique: A useful tool for conducting qualitative research. *Journal of Dental Education*. 72, 3: 299-304.
- Flanagan, J. 1954. The critical incident technique. *Psychological Bulletin*. 51, 4: 327-358.
- Forbes, S. 2001. This is heaven's waiting room. *Journal of Gerontological Nursing*. 27, 11: 37-45.

- Forde, R., Aasland, O. G. 2008. Moral distress among Norwegian doctors. *Journal of Medical Ethics*. 34, 7: 521-5.
- Fosse, A., Schaufel, M., Ruths, S., 2014. End-of -life expectations and experiences among nursing home patients and their relatives- A synthesis of qualitative studies. *Patient Education and Counseling* (in press June).
- Fossum, M., Alexander, G. L., Goransson, K. E., Ehnfors, M., Ehrenberg, A. 2011. Registered nurses' thinking strategies on malnutrition and pressure ulcers in nursing homes: a scenario-based think-aloud study. *Journal of Clinical Nursing*. 20, 17-18: 2425-35.
- Francis, R. 2010. *Final report of the independent inquiry into care provided by Mid Staffordshire NHS Foundation Trust*: London.
- Franklin, L., Ternestedt, B., Nordenfelt, L. 2006. Views on dignity of elderly nursing home residents. *Nursing Ethics*. 13 130-146.
- Froggatt, K. 2001. Life and death in English nursing homes: Sequestration or transition. *Ageing and Society*. 21, 3: 319-332.
- Froggatt, K., Payne, S. 2006. A survey of end-of-life care in care homes: issues of definition and practice. *Health and Social Care in the Community*. 14, 4: 341-348.
- Froggatt, K., Wilson, D., Justice, C., Macadam, M., Leibovici, K., Kinch, J., Thomas, R., Choi, J. 2006. End of life care in long term care settings for older people a literature review. *International Journal of Older People Nursing*. 1, 1: 45-50.
- Funk, L., Waskiewich, S., Stajduhar, K. 2013. Meaning-making and managing difficult feelings: Providing front-line end-of-life care. *Omega: Journal of Death and Dying*. 68, 1: 23-43.
- Gallagher, A. 2010. Moral distress and moral courage in everyday nursing practice. *The Online Journal of Issues in Nursing*, 16. Available: <http://www.ncbi.nlm.nih.gov/pubmed/22088157> [Accessed 17.4.2013].
- Georges, J., Grypdonck, M. 2002. Moral problems experienced by nurses when caring for terminally ill people: a literature review. *Nursing Ethics*. 9, 2: 155-178.
- Gjerberg, E., Reidun, F., Perdersen, R., Bollig, G. 2010. Ethical challenges in the provision of end-of-life care in Norwegian nursing homes. *Social Science & Medicine*. 71 677-684.
- Goethals, S., Gastmans, C., De Casterlé, B. 2010. Nurses' ethical reasoning and behaviour: A literature review. *International Journal of Nursing Studies*. 47, 5: 635-650.

- Goldsteen, M., Houtepen, R., Proot, I., Abu-Saad, H. H., Spreeuwenberg, C., Widdershoven, G. A. 2006. What is a good death? Terminally ill patients dealing with normative expectations around death and dying. *Patient Education and Counseling*. 64 378-386.
- Gomes, B., Cohen, J., Deliens, L., Higginson, I. 2011. International trends in circumstances of death and dying amongst older people. In: Gott, M. and Ingleton, C. (eds.) *Living with Ageing and Dying Palliative and end of life care for older people*. Oxford: Oxford University Press.
- Gomes, B., Higginson, I. 2008. Where people die (1974-2030): past trends, future projections and implications for care. *Palliative Medicine*. 22 33-41.
- Goodridge, D., Bond, J., Cameron, C., Mckean, E. 2005. End-of-life care in a nursing home: a study of family, nurse and healthcare aide perspectives. *International Journal of Palliative Nursing*. 11, 5: 226-2332.
- Gott, M., Ingleton, C. (eds.) 2011. *Living with Ageing and Dying*. Oxford: Oxford University Press.
- Gott, M., Stosz, L., Alaszewski, A. 2008a. At odds with the End of Life Care Strategy. *Nursing Older People*. 20, 7: 24-26.
- Gott, M., Small, N., Barnes, S., Payne, S., Seamark, D. 2008b. Older people's views of a good death in heart failure: implications for palliative care provision. *Social Science & Medicine*. 47, 5: 565-79.
- Great Britain. 1998. *Data Protection Act*. London: Stationary Office.
- Guillemin, M., Heggen, K. 2009. Rapport and respect: negotiating ethical relations between researcher and participant. *Medical Healthcare and Philosophy*. 12 291-299.
- Gysels, M., Evans, N., Meñaca, A., Andrew, E., Toscani, F., Finetti, S., Pasman, H. R., Higginson, I., Harding, R., Pool, R. 2012. Culture and end of life care: A scoping exercise in seven european countries. *PLoS ONE*. 7, 4: 1-16.
- Halcomb, E., Davidson, P. 2006. Is verbatim transcription of interview data always necessary? *Applied Nursing Research*. 19 38-42.
- Hall, S. R., Kolliakou, A., Petkova, H., Froggatt, K., Higginson, I. 2011. *Interventions for improving palliative care for older people living in nursing homes (review)*. London: Wiley.

- Hamric, A. B. 2012. Empirical research on moral distress: issues, challenges, and opportunities. HEC Forum : An Interdisciplinary Journal on Hospitals' Ethical and Legal Issues.
- Hanna, D. R. 2004. Moral distress: The state of the science. Research and Theory for Nursing Practice. 18, 1: 73-93.
- Hanson, L., Henderson, M., Menon, M. 2002. As individual as death itself: A focus group study of terminal care in nursing homes. Journal of Palliative Medicine. 5, 1: 117-125.
- Hart, B., Sainsbury, P., Short, S. 1998. Whose dying? A sociological critique of the 'good death'. Mortality. 3, 1: 65-77.
- Hawker, S., Payne, S., Kerr, C., Hardey, M., Powell, J. 2002. Appraising the evidence: Reviewing disparate data systematically. Qualitative Health Research. 12 1284-1298.
- Hertzberg, A., Ekman, S., Axelsson, K., 2003. 'Relatives are a resource, but...'. Registered Nurses' views and experiences of relatives of residents in nursing homes. Journal of Clinical Nursing 12: 431-441.
- Hockley, J., Dewar, B., Watson, J. 2005. Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life'. Journal of Research in Nursing. 10 135-152.
- Holloway, M. 2009. Dying old in the 21st century: A neglected issue for social work. International Social Work. 52, 6: 713-725.
- Horntvedt, M., Romoren, M., Solvoll, B. 2014. Ethical problems related to intravenous fluids in nursing homes. Nursing Ethics. 21, 8: 890-901.
- Horton, K., Tschudin, V., Forget, A. 2007. The value of nursing: a literature review. Nursing Ethics. 14, 6: 716-740.
- House of Commons Health Select Committee. 2015. End of Life Care. London: The Stationary Office.
- House, R., Rizzo, J. 1972. Role conflict and ambiguity as critical variables in a model of organizational behavior. Organizational Behavior and Human Performance. 7 467-505.
- Houston, S., Casanova, M., Leveille, M., Schmidt, K., Barnes, S., Trungale, K., Fine, R. 2013. The intensity and frequency of moral distress among different healthcare disciplines. The Journal of Clinical Ethics. 24, 2: 98-112.

- Huffman, D. M., Rittenmeyer, L. 2012. How professional nurses working in hospital environments experience moral distress: a systematic review. *Critical Care Nursing Clinics of North America*. 24, 1: 91-100.
- Hughes, J., Jolley, D., Jordan, A., Sampson, E. 2007. Palliative care in Dementia: issues and evidence. *Advances in Psychiatric Treatment*. 13 251-260.
- Hunt, M. 2009. Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*. 19, 9: 1284-1292.
- Jack, S. 2008. Guidelines to support nurse-researchers reflect on role conflict in qualitative interviewing. *The Open Nursing Journal*. 2 58-62.
- Jameton, A. 1984. *Nursing Practice The Ethical Issues*, New Jersey: Prentice-Hall, Inc.
- Jameton, A. 1993. Dilemmas of moral distress: moral responsibility and nursing practice. *AWHONN's Clinical Issues in Perinatal and Women's Health Nursing*. 4, 4: 542-51.
- Johnstone, M., Hutchinson, A. 2013. 'Moral distress'- time to abandon a flawed nursing construct? *Nursing Ethics*, 001-10. [Accessed 3.1.2014].
- Kable, A. K., Pich, J., Maslin-Prothero, S. E. 2012. A structured approach to documenting a search strategy for publication: A 12 step guideline for authors. *Nurse Education Today*. 32, 8: 878-886.
- Kalvemark, S., Hoglund, A. T., Hansson, M. G., Westerholm, P., Arnetz, B. 2004. Living with conflicts-ethical dilemmas and moral distress in the healthcare system. *Social Science & Medicine*. 58, 6: 1075-84.
- Kapp, M. 2003. Legal anxieties and end of life care in nursing homes. *Issues in Law and Medicine*. 19, 2: 111-134.
- Karnieli-Miller, O., Strier, R., Pessach, L. 2009. Power relations in qualitative research. *Qualitative Health Research*. 19, 2: 279-289.
- Katz, J., Sidell, M., Komaromy, C. 2001. Dying in long-term care facilities: Support needs of other residents , relatives, and staff. *American Journal of Hospital Palliative Care*. 18, 5: 321-326.
- Keatings, D. 2002. Versatility and flexibility: Attributes of the critical incident technique in nursing research. *Nursing and Health Sciences*. 4 33-39.
- Kemppainen, J. 2000. The critical incident technique and nursing care quality research. *Journal of Advanced Nursing*. 32, 5: 1264-1271.

- Kohlberg, L., Hersh, R. 1977. Moral development a review of the theory. Theory Into Practice. XVI, 2: 53-59.
- Komaromy, C., Sidell, M., Katz, J. 2000. The quality of terminal care in residential and nursing homes. International Journal of Palliative Nursing. 6, 4: 192-200.
- Lacey, D. 2005. Tube feeding, antibiotics, and hospitalization of nursing home residents with end-stage dementia: perceptions of key medical decision-makers. American Journal of Alzheimer's Disease and Other Dementias. 20, 4: 211-219.
- Lancashire and Cumbria Cancer Network 2004. Preferred Priorities for Care.
- Larkin, P., Hegarty, M. 2011. Workforce development: an international perspective on who will provide care. In: Gott, M. and Ingleton, C. (eds.) Living with Ageing and Dying Palliative and End of Life Care for Older People. Oxford: Oxford University Press.
- Leadership Alliance for the Care of Dying People. 2014. One Chance to Get it Right. London: Leadership Alliance for the Care of Dying People.
- Leech, N. L., Onwuegbuzie, A. J. 2011. Beyond constant comparison qualitative data analysis: Using NVivo. School Psychology Quarterly. 26, 1: 70-84.
- Lehr, R., Sumarah, J. 2004. Professional judgement in ethical decision making: Dialogue and relationship. Canadian Journal of Counselling/Revue canadienne de counseling. 38, 1: 14-24.
- Leichtentritt, R., Rettig, K. 2001. Values underlying end-of-life decisions: A qualitative approach. Health and Social Work. 26, 3: 150-159.
- Lerkiatbundit, S., Borry, P. 2009. Moral distress Part 1: Critical review on definition, magnitude, antecedents and consequences. The Journal of Pharmacy Practice. 1, 1: 3-11.
- Lewis, J., Ritchie, J. 2003. Generalising from qualitative research. In: Ritchie, J. and Lewis, J. (eds.) Qualitative Research Practice: A guide for Social Science Students and Researchers. London: Sage.
- Lievesley, N., Crosby, G., Bowman, C. 2011. The changing role of care homes. London: BUPA.
- Lillemoen, L., Pedersen, R. 2013. Ethical challenges and how to develop ethics support in primary healthcare. Nursing Ethics. 20, 1: 96-108.

- Lithgow, S., Jackson, G., Browne, D. 2012. Estimating the prevalence of dementia: Cognitive screening in Glasgow nursing homes. *International Journal of Geriatric Psychiatry*. 27, 8: 785-791.
- Lloyd, L. 2004. Mortality and morality: ageing and ethics of care. *Ageing and Society*. 24 235-256.
- Lloyd, L., White, K., Sutton, E. 2011. Researching the end-of-life in old age: cultural, ethical and methodological issues. *Ageing & Society*. 31, 03: 386-407.
- Lopez, R. 2007. Suffering and dying nursing home residents. Nurses Perceptions of the role of family members. *Journal of Hospice and Palliative Nursing*. 9, 3: 141-149.
- Lorenz, K., Rosenfeld, K., Wenger, N. 2007. Quality Indicators for Palliative and End-of-Life Care in Vulnerable Elders. *Journal of the American Geriatrics Society*. 55 S318-S326.
- Luff, R., Ferreira, Z., Meyer, J. 2011. *Care Homes*. London: National Institute for Health Research. School for Social Care Research.
- Lützén, K., Cronqvist, A., Magnusson, A., Andersson, L. 2003. Moral Stress: synthesis of a concept. *Nursing Ethics*. 10, 3: 312-322.
- Lutzén, K., Kvist, B. E. 2012. Moral Distress: A Comparative Analysis of Theoretical Understandings and Inter-Related Concepts. *HEC Forum : an interdisciplinary journal on hospitals' ethical and legal issues*.
- Maclean, L., Meyer, M., Estable, A. 2004. Improving accuracy of transcripts in qualitative research. *Qualitative Health Research*. 14 113-123.
- Malloy, D. Hadjistavropoulos. T. McCarthy, E., Evans, R., Zakus, D., Park, I., Lee, Y., Williams, J. 2009. Culture and organizational climate: Nurses' insights into their relationships with physicians. *Nursing Ethics*. 16, 6: 719-733.
- Martin, L., Schoeni, R., Andreski, P., Jagger, C. 2011. Trends and inequalities in late-life health and functioning in England. *Journal of Epidemiology Community Health*. 66 874- 880.
- Maslach, C., Schaufeli, W., Leiter, M. 2001. Job burnout. *Annual Review of Psychology*. 52 397-422.
- Matthews, F., Arthur, A., Barnes, L., Bond, J., Jagger, C., Robinson, L., Brayne, C. 2013. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the Cognitive Function and Ageing Study I and II. *The Lancet*. 382 1405-1412.

- Mc Carthy, J. 2010. Moral instability: the upsides for nursing practice. *Nursing Philosophy*. 11, 2: 127-135.
- Mc Carthy, J., Deady, R. 2008. Moral distress reconsidered. *Nursing Ethics*. 15, 2: 254-62.
- Mc Closkey, R. 2011. A Qualitative Study on the Transfer of Residents Between a Nursing Home and an Emergency Department. *Journal of the American Geriatrics Society*. 59, 4: 717-724.
- Mc Cosker, H., Barnard, A., Gerber, R. 2001. Undertaking sensitive research: Issues and strategies for meeting the safety needs of all participants. *Forum: Qualitative Social Research*. 2, 1: article 22.
- Mc Garry, J. 2010. Exploring the effect of conducting sensitive research. *Nurse Researcher*. 18, 1: 8-14.
- Mc Gilton, K., Boscart, V., Brown, M., Bowers, B. 2014. Making tradeoffs between the reasons to leave and reasons to stay employed in long-term care homes: Perspectives of licensed nursing staff. *International Journal of Nursing Studies*. 51 917-926.
- McNamara, B., Rosenwax, L. 2007. The mismanagement of dying. *Health Sociology Review*. 16, 5: 373-383.
- Miskella, C., Avis, M. 1998. Care of the dying person in the nursing home: exploring the care assistants' contribution. *European Journal of Oncology Nursing*. 2, 2: 80-86.
- Mitchell, G., Nicholson, C., McDonald, K., Bucetti, A. 2011. Enhancing palliative care in rural Australia: the residential aged care setting. *Australian Journal of Primary Health*. 17, 1: 95-101.
- Mobley, M., Rady, M., Verheijde, J., Patel, B., Larson, J. 2007. The relationship between moral distress and perception of futile care in the critical care unit. *Intensive and Critical Care Nursing*. 23 256-263.
- Moriarty, J., Rutter, D., Ross, P., Holmes, P. 2012. *End of life care for people with dementia living in care homes*. London: Social Care Institute for Excellence.
- Morse, J. 2010. How different is health research from qualitative research? Do we have a subdiscipline? *Qualitative Health Research*. 20 1459-1468.
- Munn, J. 2006. *Defining a good death for residents in long term care*. Doctor of Philosophy University of North Carolina.

- Munn, J., Dobbs, D., Meier, A., Williams, C., Biola, H., Zimmerman, S. 2008. The end-of-life experience in long-term care: Five themes identified from focus groups with residents, family members, and staff. *The Gerontologist*. 48, 4: 485-494.
- Musto, L., Rodney, P., Vanderheide, R. 2015. Toward interventions to address moral distress: Navigating structure and agency. *Nursing Ethics*. 22, 1: 91-102.
- Naden, D., Eriksson, K. 2004. Understanding the importance of values and moral attitude in nursing care in preserving human dignity. *Nursing Science Quarterly*. 17, 86-91.
- Nathaniel, A. 2006. Moral reckoning in Nursing. *Western Journal of Nursing Research*. 28 419-438.
- National End of Life Care Intelligence Network. 2012. *What do we know now that we didn't know a year ago? New intelligence on end of life care in England*. National end of life care programme: London.
- National Institute of Clinical Excellence. 2011. End of Life Care for Adults Quality Standard.
<http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp>
[Accessed 29.12.2011].
- National Institute for Health Research 2014. Enabling research in care homes: Practical advice. <http://www.enrich.dendron.nihr.ac.uk/research-community/practical-advice.html#.VAL73sU7vLk> [Accessed 25.8.2014].
- Nicholas, L., Bynum, J., Iwashyna, T., Weir, D., Langa, K. 2014. Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Affairs*. 33, 4: 667-674.
- Nicholson, C., Meyer, J., Flatley, M., Holman, C., Lowton, K. 2012. Living on the margin: Understanding the experience of living and dying with frailty in old age. *Social Science & Medicine*. 75 1426-1432.
- Nolan, M. T., Mock, V. 2004. A conceptual framework for end-of-life care: A reconsideration of factors influencing the integrity of the human person. *Journal of Professional Nursing*. 20, 6: 351-360.
- Norman, I., Redfern, S., Tomalin, D., Oliver, S. 1992. Developing Flanagan's critical incident technique to elicit indicators of high and low quality nursing care from patients and their nurses. *Journal of Advanced Nursing*. 17, 5: 590-600.
- Nursing and Midwifery Council 2015. *The Code: Professional standards of practice and behaviour for nurses and midwives*. London: Nursing and Midwifery Council.

- O' Conner, S. 2008. End of life care definitions and triggers to assessment: A summary and discussion of the literature. Available: [http://www.endoflifecare.nhs.uk/assets/downloads/EOLC Literature Review Oct2008.pdf](http://www.endoflifecare.nhs.uk/assets/downloads/EOLC_Literature_Review_Oct2008.pdf) [Accessed 18.6.2013].
- Oberle, K., Hughes, D. 2001. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *Journal of Advanced Nursing*. 33, 6: 707-715.
- Office for National Statistics. 2012. Cancer registration statistics England 2012. http://www.ons.dcp171778_367563.pdf [Accessed 15.4.2015].
- Office for National Statistics. 2014 Life expectancy at birth and at age 65 by local areas in the United Kingdom.: Office of National Statistics,. http://www.ons.gov.uk/ons/dcp171778_385458.pdf [Accessed 5.4.2015].
- Office for National Statistics. 2011. *Statistical Bulletin; Older People Day 2011*. London: HMSO.
- Ohnishi, K., Ohgushi, Y., Nakano, M., Fujii, H., Tanaka, H., Kitaoka, K., Nakahara, J., Narita, Y. 2010. Moral distress experienced by psychiatric nurses in Japan. *Nursing Ethics*. 17, 6: 726-40.
- Oliver, D., Serovich, J., Mason, T. 2005. Constraints and opportunities with interview transcription: Towards reflection in qualitative research. *Social Forces*. 84, 2: 1273-1289.
- Orellana, K. 2014. *Care home managers: a scoping review of the evidence*. London: School for Social Care Research Scoping Review. National Institute of Health Research.
- Österlind, J., Hansebo, G., Andersson, J., Ternestedt, B., Hellstrom, I. 2011. A discourse of silence: Professional carers reasoning about death and dying in nursing homes. *Ageing and Society*. 31 529-544.
- Palda, V., Bowman, K., Mclean, R., Chapman, M. 2005. 'Futile' care: Do we provide it? Why? A semi-structured, Canada-wide survey of intensive care unit doctors and nurses. *Journal of Critical Care*. 20 207-213.
- Pauly, B. M., Varcoe, C., Storch, J. 2012. Framing the Issues: Moral Distress in Healthcare. *HEC Forum : An Interdisciplinary Journal on Hospitals' Ethical and Legal Issues*.
- Pavlish, C., Brown-Saltzman, K., Hersh, M., Shirk, M., Rounkle, A. 2011. Nursing Priorities, Actions, and Regrets for Ethical Situations in Clinical Practice. *Journal of Nursing Scholarship*. 43, 4: 385-395.

- Payne, S., Seymour, J., Ingleton, C. (eds.) 2004. Palliative Care Nursing Principles and Evidence for Practice, Maidenhead: Open University Press.
- Pendry, P. S. 2007. Moral distress: recognizing it to retain nurses. Nursing Economics. 25, 4: 217-21.
- Peter, E. 2013. Advancing the concept of moral distress. Bioethical Inquiry. 10 293-295.
- Piaget, J. 1932. The Moral Judgement of the Child, New York: Free Press.
- Piers, R. D., Van Den Eynde, M., Steeman, E., Vlerick, P., Benoit, D. D., Van Den Noortgate, N. J. 2012. End-of-life care of the geriatric patient and nurses' moral distress. Journal of the American Medical Directors Association. 13, 1: 80 e7-13.
- Pope, C., Ziebland, S., Mays, N. 2000. Qualitative research in healthcare. Analysing qualitative data. BMJ. 320 114-116.
- Porock, D., Parker-Oliver, D. 2007. Recognizing dying by staff in long-term care. Journal of Hospice and Palliative Nursing. 9, 5: 270-278.
- Pugh, E. 2009. Delivering better care at end of life. London: The Kings Fund.
- Purdy, S. 2010. Avoiding hospital admissions what does the research evidence suggest? London: Kings Fund.
- Radbruch, L., Payne, S., And the Board of Directors of the European Association for Palliative Care 2009. White Paper on standards and norms for hospice and palliative care standards and norms for hospice and palliative care in Europe: part 1. European Journal of Palliative Care. 16, 6: 278-289.
- Range, L. M., Rotherham, A. L. 2010. Moral distress among nursing and non-nursing students. Nursing Ethics. 17, 2: 225-32.
- Raudonis, B., Kyba, F., Kinsey, T. 2002. Long-term care nurses knowledge of end-of-life care. Geriatric Nursing. 23, 6: 296-299.
- Reitinger, E., Heimerl, K. 2014. Ethics and gender issues in palliative care in nursing homes: An Austrian participatory research project. International Journal of Older People Nursing. 9 131-139.
- Rice, K., Coleman, E., Fish, R., Levy, C., Kutner, J. 2004. Factors influencing models of end-of-life care in nursing home: Results of a survey of nursing home administrators. Journal of Palliative Medicine. 7, 5: 668-675.

- Ritchie, J., Spencer, L., O'Conner, W. 2003. Carrying out qualitative analysis. In: Ritchie, J. and Lewis, J. (eds.) Qualitative Research Practice A guide for social science students and researchers. London: Sage.
- Rodgers, B. 1989. Concepts, analysis and the development of nursing knowledge: The evolutionary cycle. Journal of Advanced Nursing. 14 330-335.
- Rodney, P. 2013. Seeing ourselves as moral agents in relation to our organizational and sociopolitical contexts. Commentary on 'A reflection on moral distress in nursing together with a current application of the concept' by Andrew Jameton. Bioethical Inquiry. 10 313-315.
- Rodriguez, J. 2011. 'Its a dignity thing': Nursing home care workers use of emotions. Sociological Forum. 26, 2: 265-286.
- Rokeach, M. 1973. The nature of human values, New York: The Free Press.
- Rowe, J. 2013. Understanding the context of moral dilemmas in healthcare organizations: Perspectives for employee training and continuing education. Home Healthcare Management and Practice. 25, 4: 141-146.
- Royal College of Nursing. 2010. Care homes under pressure- an England report. London: Royal College of Nursing.
- Royal College of Nursing. 2012. Persistent challenges to providing quality care. An RCN report on the views and experience of frontline nursing staff in care homes in England. London: Royal College of Nursing.
- Russell, A. C. 2012. Moral distress in neuroscience nursing: An evolutionary concept analysis. American Association of Neuroscience Nurses. 44, 1: 15-24.
- Ruth, K., Verne, J. 2010. Deaths in older adults in England. London: National End of Life Care Intelligence Network.
- Ryan, A., McKenna, H. 2015. 'It's the little things that count'. Families' experience of roles, relationships and quality of care in rural nursing homes. Journal of Older People Nursing. 10 38-47.
- Rytterstrom, P., Cedersund, E., Arman, M. 2009. Care and care giving culture as experienced by nurses working in different care environments: A phenomenological- hermeneutic study. International Journal of Nursing Studies. 46 689-698.
- Schaffer, M. 2007. Ethical problems in end of life decisions for elderly Norwegians Nursing Ethics. 14, 2: 242-257.

- Schilling, J. 2006. On the pragmatics of qualitative assessment. *European Journal of Psychological Assessment*. 23, 1: 28-37.
- Schluter, J., Seaton, P., Chaboyer, W. 2007. Critical incident technique: a user's guide for nurse researcher. *Journal of Advanced Nursing*. 61, 1: 107-114.
- Schwartz, S. 1994. Are there universal aspects in the structure and contents of human values. *Journal of Social Issues*. 50, 4: 19-45.
- Schwartz, S., Cieciuch, J., Vecchione, M., Davidov, E., Fischer, R., Beierlein, C., Ramos, A., Verkasalo, M., Lonnqvist, J., Demirutku, K., Dirilen-Gumus, O., Konty, M. 2012. Refining the theory of basic individual values. *Journal of Personality and Social Psychology*. 103, 4: 663-688.
- Schwartz, S. 2005. Basic Human Values: An overview. Available: <http://segr-did2.fmag.unict.it/Allegati/convegno%207-8-10-05/schwartzpaper.pdf> [Accessed 23.10.2014].
- Schwartz, S. 2007. Universalism and the inclusiveness of our moral universe. *Journal of Cross-Cultural Psychology*. 38, 6: 711-728.
- Seale, C. 2010. Using computers to analyse qualitative data. In: Silverman, D. (ed.) *Doing Qualitative Research* London: Sage.
- Selye, H. 1973. The Evolution of the Stress Concept: The originator of the concept traces its development from the discovery in 1936 of the alarm reaction to modern therapeutic applications of syntoxic and catatonic hormones. *American Scientist*. 61, 6: 692-699.
- Seymour, J. 2012. Looking back, looking forward: the evolution of palliative and end-of-life care in England. *Mortality*. 17, 1: 1-17.
- Seymour, J. 2007. Quality of life to the end: Commentary. *Communication and Medicine*. 4, 1: 117-118.
- Seymour, J., Gott, M. 2011. The challenge of health technology for ageing and dying. In: Gott, M. and Ingleton, C. (eds.) *Living with Ageing and Dying palliative and end of life care for older people*. Oxford Oxford University Press.
- Seymour, J., Horne, G. 2011. Advance Care Planning for the end of life: an overview. In: Thomas, K. and Lobo, B. (eds.) *Advance Care Planning in End of Life Care*. Oxford: Oxford University Press.
- Seymour, J., Kumar, A., Froggatt, K. 2011. Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. *Palliative Medicine*. 25, 2: 125-138.

- Shanley, C., Whitmore, E., Conforti, D., Masso, J., Jayasinghe, S., Griffiths, R. 2011. Decisions about transferring nursing home residents to hospital: highlighting the roles of advance care planning and support from local hospital and community health services. *Journal of Clinical Nursing*. 20, 19/20: 2897-2906.
- Silverman, D. 2006. *Interpreting qualitative data 3rd edition*. London: Sage.
- Silverman, D. 2011. *Doing qualitative research*. London: Sage.
- Skilbeck, J., Payne, S. 2005. End of Life care: a discursive analysis of specialist palliative care nursing. *Journal of Advanced Nursing*. 51, 4: 325-334.
- Skills for Care. 2013. The size and structure of the adult social care sector and workforce in England, 2013: Skills for Care. <http://www.skillsforcare.org.uk/Document-library/NMDS-SC,-workforce-intelligence-and-innovation/Research/Size-and-structure-2013-vweb2.pdfw>. [Accessed 6.4.2015].
- Snape, D., Spencer, L. 2003. The foundations of qualitative research. In: Ritchie, J. and Lewis, J. (eds.) *Qualitative Research Practice: A guide for Social Science Students and Researchers*. London: Sage.
- Spilsbury, K., Hewitt, C., Stirk, L., Bowman, C. 2011. The relationship between nurse staffing and quality of care in nursing homes. *International Journal of Nursing Studies*. 48 732-750.
- Stillman, D., Strumpf, N., Capezuti, E., Tuch, H. 2005. Staff perceptions concerning barriers and facilitators to end of life care in the nursing home. *Geriatric Nursing*. 26, 4: 259-264.
- Suhonen, R., Stolt, M., Gustafsson, M., Katajisto, J., Charalambous, A. 2014. The associations among the ethical climate, the professional practice environment and individualised care in care settings for older people. *Journal of Advanced Nursing*. 70, 6: 1356-1368.
- Tan, A., Manca, D. 2013. Finding common ground to achieve a 'good death': family physicians working with substitute decision-makers of dying patients. A qualitative grounded theory study. *BMC Family Practice*, 14. Available: <http://www.biomedcentral.com/147-2296/14/14> [Accessed 22.11.2014].
- Taylor, B. 2000. *Reflective practice. A guide for nurses and midwives*. Buckingham: Open University Press.
- Thomas, T., McCullough, L. 2015. A philosophical taxonomy of ethically significant moral distress. *Journal of Medicine and Philosophy*. 40 102-120.
- Thorne, S. 2008. *Interpretive description*. California: Left coast press, Inc.

- Thorne, S. 2011. Toward methodological emancipation in applied health research. Qualitative Health Research. 21 443-453.
- Thorne, S., Kirkham, S., O'Flynn-Magee, K. 2004. The analytic challenge in interpretive description. International Journal of Qualitative Methods. 3, 1: 1-21.
- Tilden, V., Thompson, S., Gajewski, B., Bott, M. 2012. End-of-Life care in Nursing Homes: The high cost of staff turnover. Nursing Economics. 3, 3: 163-166.
- Tong, R. 2008. Feminist thought. Philadelphia: Westview press.
- Tronto, J. C. 2010. Creating Caring Institutions: Politics, Plurality, and Purpose. Ethics and Social Welfare. 4, 2: 158-171.
- Trotta, R. 2010. Cultivating knowing and relationships: A grounded theory of quality of death in the nursing home. Doctor of Philosophy Dissertaton, University of Pennsylvania.
- Twelker, P. 2003 The Critical Incident Technique: A Manual for its Planning and Implementation
<http://ix.hncu.net:8083/mc/1604046/%E7%AC%AC%E4%BA%8C%E7%AB%A0%E9%80%9A%E7%94%A8%E7%9A%84%E5%B7%A5%E4%BD%9C%E5%88%86%E6%9E%90%E6%96%B9%E6%B3%95-3/%E7%AC%AC%E4%BA%8C%E7%AB%A0%E9%80%9A%E7%94%A8%E7%9A%84%E5%B7%A5%E4%BD%9C%E5%88%86%E6%9E%90%E6%96%B9%E6%B3%95-5/The%20Critical%20Incident%20Technique.htm> accessed 6.12.2015
- Ulrich, C., Taylor, C., Soeken, K., O'Donnell, P., Farrer, A., Danis, M., Grady, C. 2010. Everyday ethics: Ethical issues and stress in nursing practice. Journal of Advanced Nursing. 66, 11: 2510-2519.
- Vallis, J., Boyd, K. 2002. Ethics and end-of-life decision making. In Hockley, J. and Clark, D. (eds.) Palliative care for older people in care homes. Buckingham: Open University Press.
- Varcoe, C., Pauly, B., Webster, G., Storch, J. 2012a. Moral Distress: Tensions as Springboards for Action. HEC Forum : An interdisciplinary journal on hospitals' ethical and legal issues.
- Varcoe, C., Pauly, B., Storch, J., Newton, L., Makaroff, K. 2012b. Nurses' perceptions of and responses to morally distressing situations. Nursing Ethics. 19, 4: 488-500.
- Vig, E., Davenport, N., Pearlman, R. 2002. Good deaths, bad deaths, and preferences for the end of life: A qualitative study of geriatric outpatients. Journal of the American Geriatrics Society. 50, 9: 1541-1548.

- Waldrop, D., Kusmaul, N. 2011. The living-dying interval in nursing home based end of life care: Family caregivers experiences. *Journal of Gerontological Social Work*. 54 768-787.
- Waldrop, D., Nyquist, K. 2011. The transition from routine care to end-of-life care in a nursing Home: Exploring staff perspectives. *Journal of the American Medical Directors Association*. 12, 2: 114-120.
- Watson, J. 2012. *Human Caring Science. A theory of nursing*. Sudbury: Jones and Bartlett Learning.
- Webster, L., Mertova, P. 2007. *Using narrative inquiry as a research method*. Abingdon: Routledge.
- Werhane, P., Hartman, L., Moberg, D., Englehardt, E., Pritchard, M., Parmar, B. 2011. Social constructivism, mental models and problems of obedience. *Journal of Business Ethics*. 100, 103-118: 103.
- Whittaker, E., Kernohan, W., Hasson, F., Howard, V., McLaughlin, D. 2007. Palliative care in nursing homes: exploring care assistants' knowledge. *International Journal of Older People Nursing*. 2 36-44.
- Wiegand, D., Funk, M. 2012. Consequences of clinical situations that cause critical care nurses to experience moral distress. *Nursing Ethics*. 19, 4: 479-487.
- Wilkinson, J. M. 1987. Moral distress in nursing practice: experience and effect. *Nursing Forum*. 23, 1: 16-29.
- Winter, L., Parks, S. 2012. The reluctance to burden others as a value in end-of-life decision making: A source of inaccuracy in substituted judgment. *Journal of Health Psychology*. 17, 2: 179-188.
- World Health Organisation 2011. *World Health Organisation: Palliative care for older people: Better practices*. In: Hall, S., Petkova, H., Tsouros, A., Costantini, M. and Higginson, I. (eds.). Copenhagen: WHO Regional Office for Europe.
- Zheng, N. T., Temkin-Greener, H. 2010. End-of-life care in nursing homes: The importance of CNA staff communication. *Journal of the American Medical Directors Association*. 11, 7: 494-499.
- Zuzelo, P. R. 2007. Exploring the moral distress of registered nurses. *Nursing Ethics*. 14, 3: 344-59.

Appendix 1 Summary table of the studies included in the literature review

Abbreviations: USA = United States of America, EOL = End of life, NH = Nursing Homes, MD = moral distress, CNA = certified nursing assistants, CA = care assistant, NA = nursing assistant, SW = social workers, LTC = long term care, OOH = out of hours, RGN = registered general nurse, GP = general practitioner, OT = occupational therapist, RC = residential care, QOD = quality of death

| Source paper | Aim | Conflict | Organisational culture | Resources | Complexity of patient issues | Communication | Emotional Work |
|--|---|----------|------------------------|-----------|------------------------------|---------------|----------------|
| Beck, et al 2012 Sweden Score 32 Qualitative focus group study | To illuminate nurse assistant experiences of EOL care in NH 25 NA in six focus groups Setting NH | | X | | | X | X |
| Brazil, et al 2006 Canada Score 31 Quantitative study Postal questionnaire | To investigate the quality of dying for the residents of Ontario long term care facilities Setting: LTC facilities 426/554 directors All LTC facilities in Ontario | | X | X | | X | |
| Burack, et al 2001 USA Score 17 Qualitative Focus groups and short questionnaire | To investigate the experiences of nursing assistants related to NH residents at the EOL and whether a support intervention was successful Setting NH 35 NA A large urban NH (1300 beds on two sites) | | X | X | X | X | X |
| Casey, et al 2011 Ireland Score 31 Qualitative Semi-structured interview | To investigate the perspectives of staff in long stay settings in Ireland on EOL care Setting long stay setting Six randomly selected homes from 327. 33 staff - 20 RGN, two GP, one OT asst., one physio asst., nine HCA | | X | X | | | |
| De Bellis, et al 1998 Australia Score 25 Survey with open and closed questions | An investigation of palliative care and the barriers to providing palliative care in aged care facilities Setting long term care facilities 147/335 directors of nursing | X | | X | X | X | X |
| de Veer, et al 2013 Netherlands Score 30 Quantitative cross sectional correlational study | To identify job characteristics associated with moral distress Setting NH (69 nurses), home care (120) homes for the elderly (79), and acute hospitals (97) | | X | X | X | X | |
| Dreyer, et al 2010 | How do Drs and nurses address patient autonomy | X | | X | X | X | |

| Source paper | Aim | Conflict | Organisational culture | Resources | Complexity of patient issues | Communication | Emotional Work |
|--|---|----------|------------------------|-----------|------------------------------|---------------|----------------|
| Norway Score 30 Qualitative descriptive method | at the EOL in NH and justify their own practices at EOL Setting NH <i>Who had taken part in a previous study regarding relative's views on EOL care? 10 nurses, nine Drs</i> | | | | | | |
| Dreyer, et al 2011 Norway Score 28 Qualitative In depth interviews | An exploration of how doctors and nurses experience of collaboration in NH affects EOL care Setting NH <i>Nine Drs, 10 nurses</i> | | | X | X | X | |
| Dwyer, et al 2009 Sweden Score 32 Qualitative descriptive study | To explore NH staff experience of dignity at EOL for older people in NH what it means for the staff and the older person Setting NH <i>Four managers, Five RNs, 12 HCAs</i> | X | | X | | | X |
| Edwards, et al 2013 Canada Score 26 Interpretive Descriptive Qualitative Approach | To explore long term care nurses experience of initial moral distress Setting LTC facilities 15 nurses | X | X | X | X | X | |
| Enes, et al 2004 UK Score 24 Mixed methods | To investigate the ethical issues (especially disclosure) of caring for elderly terminally ill people in care homes Setting care home <i>13 care homes, 53 nurses</i> | X | | X | X | X | X |
| Ersek, et al 1999 USA Score 32 Survey Focus groups Telephone interviews | To look at what may be the educational needs of the staff in NH related to EOL care Setting NH <i>88 licensed staff</i> <i>136 CNA (certified NA) completed surveys, 10 licensed, 25 CNA focus groups, five administrators (telephone interviews), five NH (survey), two NH focus groups</i> | X | X | X | X | X | X |
| Forbes 2001 USA Score 35 | To look at EOL care in one NH in America from all concerned, relatives, staff and residents whose health was in decline | X | X | X | X | X | |

| Source paper | Aim | Conflict | Organisational culture | Resources | Complexity of patient issues | Communication | Emotional Work |
|--|--|----------|------------------------|-----------|------------------------------|---------------|----------------|
| Qualitative methods Participant observation in depth and semi-structured formal and informal interviews, focus groups | Setting NH 170 bedded NH 13 English speaking residents considered to be in declining health and three family members (45 encounters) 30 staff | | | | | | |
| Froggatt 2001 UK Score 23 Qualitative case study Participant observation | Life and death in English NH Sequestration or transition Setting NH Fieldwork in four NH 411 hours, 43 interviews home owners, RN HCA and ancillary staff | | X | X | X | X | |
| Funk, et al 2013 Canada Score 26 Qualitative semi-structured interviews Interpretive analysis | To find how front line staff manage emotions when providing EOL care Setting NH 11 HCA | X | | X | X | | X |
| Gjerberg, et al 2010 Norway Score 28 Mixed methods through an anonymous survey open and closed questions | To look at the ethical challenges in NH related to EOL care Setting NH 364/469 NH who had responded to a national survey. 664 respondents (heads of wards, managers, RNs, auxiliary's or expert staff) | X | | X | X | X | |
| Goodridge, et al 2005 Canada Score 31 Qualitative Exploratory descriptive 26 semi-structured interviews | To explore the experience of staff and relatives of EOL care in NH specifically looking at the last 72 hours of life Setting NH 15 deaths in total analysed, 14 RN, four HCA and four family members (triad or 2/3 members who cared for resident in last 72 hours). | | | X | X | X | X |
| Hanson, et al 2002 USA Score 32 Qualitative 11 focus groups | To define a good death in a nursing home and to identify what barriers exist in preventing a good death Setting NH 77 participants from NH Two NH facilities | | | X | X | X | |

| Source paper | Aim | Conflict | Organisational culture | Resources | Complexity of patient issues | Communication | Emotional Work |
|--|---|----------|------------------------|-----------|------------------------------|---------------|----------------|
| Hockley, et al 2005 UK Score 31 Qualitative Participant observation Document analysis Field notes Document analysis | To evaluate the implementation of an integrated care pathway in NH Setting NH 16 key champions | | X | X | X | X | |
| Kapp 2003 USA Qualitative Score 19 Qualitative Interviews and telephone interviews | A critical examination of the evidence regarding NH legal anxieties when caring for residents at the EOL Setting NH (in title but not stated) A substantial number of staff from medical directors to NA Unknown | X | | X | X | | |
| Katz, et al 2001 UK Score 24 Qualitative Formal and informal interviews | Exploration of the support required by staff, residents and relatives of the dying in long term care Setting LTC 12 case study homes from a selection of 1,000 randomly selected homes, 100 home managers Over 300 informants in total 30 relatives | | X | X | | X | X |
| Komoromy, et al 2000 UK Score 22 Mixed methods Postal survey of 1000 Participant observation case studies | An investigation to look at the quality of palliative care in care homes Setting care homes 412 postal surveys (41% response rate) | | X | X | | | X |
| Lacey 2005 USA Score 27 Quantitative survey | A study of the decisions taken by key decision makers in nursing homes regarding medical interventions in end stage dementia Setting NH 138 NH social service staff | X | | | X | | |

| Source paper | Aim | Conflict | Organisational culture | Resources | Complexity of patient issues | Communication | Emotional Work |
|--|---|----------|------------------------|-----------|------------------------------|---------------|----------------|
| Lopez 2007 USA Score 33 Qualitative in depth interviews Descriptive | To investigate the relationship of relatives and staff on EOL decisions in NH and how this relates to suffering Setting NH Nine nurses Three NH in Massachusetts NH one urban two suburban | X | | X | X | | X |
| Miskella, et al 1998 UK Score 31 Qualitative semi-structured interviews | To investigate how care assistants viewed their role when caring for dying residents in nursing homes Setting NH Four nursing homes in Nottingham with registered palliative care beds | | X | X | | | X |
| Mitchell, et al 2011 Australia Score 21 Mixed methods A records audit (not included in this review) Focus groups two had in depth interviews due to not attending group | To investigate the quality of palliative care and the needs of staff within NH in rural Australia Setting NH 723 residents notes audited 27 relatives, 28 healthcare providers from the NH 16 NH | X | | X | X | X | X |
| Munn J (dissertation) 2006 USA Score 36 Focus groups using semi-structured interviews | To investigate and define a good death in NH To investigate stakeholders perceptions of EOL care in long term care facilities (started off looking at a good death but other themes emerged during study so study was expended wider to embrace this information) Setting NH 13 LTC facilities inc. five NH and eight RC or LTC without nursing 65 people - 11 residents, 19 family members, 20 paraprofessional staff and 15 licensed staff | | X | X | X | | X |
| Quantitative studies for different tools for measuring QOD by surrogate decision makers Two tools one for those with cognitive impairment | Measuring the quality of dying in long term care 117 RC/AL 31 NH 439 family 332 staff from a stratified random sample | | | | | | |
| 'A Good death for residents of long term care: family members speak' Telephone interviews | Setting NH 199 NH across 4 USA states 437 relatives of deceased residents from care homes | | | | | | |

| Source paper | Aim | Conflict | Organisational culture | Resources | Complexity of patient issues | Communication | Emotional Work |
|--|---|----------|------------------------|-----------|------------------------------|---------------|----------------|
| Osterlind, et al 2011 Sweden Score 32 Qualitative Five focus groups | To identify how staff in NH see death and dying, by exploring the discourse (not visible experiences) Setting NH 4 NH in Sweden 28 staff | | | X | | | X |
| Piers, et al 2012 Belgium Score 34 Quantitative survey study | To identify factors that cause moral distress when caring for geriatric patients Setting 22 NH and three acute geriatric wards 222 nurses (57% response rate) | X | X | X | X | X | X |
| Porock, et al 2007 USA Score 24 Qualitative study In depth interviews | To identify cues that staff used to recognize that a resident was dying Setting NH Five RN four LPN five CNA | | X | | X | X | X |
| Raudonis, et al 2002 USA Score 22 Quantitative study Questionnaire | To assess the knowledge of nurses working in NH on end of life care Setting NH 164 licensed nurses from 24 NH | | | X | | | |
| Reitinger, et al 2014 Austria Score 30 Qualitative study Focus groups creating narrative | To highlight the insights regarding ethical and gender issues based on NH staff experiences Setting NH 11 nurses, four HCA, five drs, three occupational therapists, six managers, six other allied professionals | | X | | X | X | X |
| Rice, et al 2004 USA Score 33 Mixed methods Interviews with open and closed scaled questions | To identify the factors which influence the model of end of life care chosen by the administrators of care homes Setting Care home 30 administrators Purposeful sample of 30 NH in Denver | | | X | | X | |
| Schaffer, et al 2007 USA Score 33 Qualitative Semi-structured interviews | Explored the ethical problems encountered at the end of life for elderly Norwegians Setting NH hospital, home care organisations and hospice education 25 health professionals six elderly people five | X | | X | X | X | X |

| Source paper | Aim | Conflict | Organisational culture | Resources | Complexity of patient issues | Communication | Emotional Work |
|---|---|----------|------------------------|-----------|------------------------------|---------------|----------------|
| | <i>family members 11 from NH seven from hospitals three home care organisations three hospice one education</i> | | | | | | |
| Seymour, et al 2011 UK Score 36 Mixed methods Survey Case study homes - interviews | Investigating whether NH have the required support in place to provide EOL care Setting NH 180 homes sent questionnaires Two NH one rural one urban 82 NH (questionnaire) eight NH staff, 10 external staff associated with NH | X | | X | X | | |
| Stillman, et al 2005 USA Score 22 Quantitative Survey | To determine if a palliative care education intervention affects the knowledge and attitudes of the staff Setting NH Six homes on two occasions one year apart 296 for first time (243 intervention, 53 non-intervention) 243 for second time (195 intervention, 48 non-intervention) | | | X | X | X | |
| Trotta (dissertation) 2010 USA Score 36 Qualitative Grounded theory | To investigate 'what is the quality of death in a NH' Setting geriatric care 21 indexed residents 59 secondary participants (20 CNA eight nurses eight drs five SW nine other staff Nine family members or friends | | | X | X | X | X |
| Waldrop, et al 2011 USA Score 32 Qualitative structured interviews | To investigate staff experience of the transition from care to EOL care in a NH Setting NH 35/130 staff 21 nurses, nine CNA, five SW A 122 bedded NH in an American state (this was a sub study) | | X | | X | | X |
| Whittaker, et al 2007 UK Score 24 Mixed method questionnaire | To explore level of palliative care knowledge in CA in NH Setting NH 508 CA from 48 NH | | | X | X | X | |

| Source paper | Aim | Conflict | Organisational culture | Resources | Complexity of patient issues | Communication | Emotional Work |
|--|---|----------|------------------------|-----------|------------------------------|---------------|----------------|
| Zheng, et al 2010 USA Score 33 Quantitative study Analysis of previous surveys | To investigate whether good communication skills of CNA's contributes to better EOL care by assessing and treating symptoms at the EOL Setting NH <i>107 directors of nursing</i> <i>2636 CNA</i> | | | X | | X | |

Assessment Form 1:

Reject/Accept

Author(s): Date of Publication:

Abbreviated Title:

Reviewer:

Aims and objectives of the study

The aim of this study is to understand how nursing home staff experience moral distress when caring for residents coming towards the end of life.

Review question

‘How do nursing home staff experience moral distress when caring for residents at the end of life?’

Relevance to review questions

☐ directly relevant

☐ partially relevant

☐ adds to general discussion but not specific enough

Nursing homes/care homes with nursing

☐ focus or major part of study

☐ minor part of study

☐ mentioned in discussion/results

End of life care

☐ focus or major part of study

☐ minor part of study

☐ mentioned in discussion/results

Moral conflict/moral distress

☐ focus or major part of study

☐ minor part of study

☐ mentioned in discussion/results

Source of data

☐ managers/administrators

☐ nurses

☐ care assistants/nursing aids

☐ family

Study type: - (ring)

[1] empirical study—peer reviewed

[2] theoretical paper—peer reviewed

[3] research paper—non-peer reviewed

[4] theoretical paper—non-peer reviewed

[5] professional document

[6] case study

[7] other

Comment:

Assessment Form 2

Author(s):

Date of Publication:

Abbreviated Title:

Assessor:

Date Assessed:

Study Design

Location of Study:

Sample—Description:

☐ quantitative

☐ qualitative sample—size:

[] combination

Aim:

Research Questions/Hypothesis (If any):

Method and Analysis:

Intervention (If applicable):

Results:

Conclusions, Comments, and Issues Raised:

Modelled on appraisal form from Hawker et al 2002

Author and title: _____

Date: _____

| | Good 4 points | Fair 3 points | Poor 2 points | Very poor 1 point | Comment |
|--------------------------------------|---------------|---------------|---------------|-------------------|---------|
| 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. and POWELL, J. 2002. Appraising the Evidence: Reviewing Disparate Data Systematically. *Qualitative Health Research*, 12, 1284-1298.

LANCASTER
UNIVERSITY



Applicant: Amanda Young
Supervisors: Dr Katherine Froggatt, Dr Sarah Brearley
Department: DHR

21 November 2012

Dear Amanda, Katherine and Sarah

Re: The nature of moral conflict experienced by nursing home staff when caring for residents towards the end of life

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Professor T McMillan (Chair, UREC); Professor Paul Bates (Chair, FHMREC)

Research Support Office
Research and Enterprise Services

Lancaster University
Bowland Main
Lancaster LA1 4YT
United Kingdom

Tel: +44 (0) 1524 592002
Fax: +44 (0) 1524 593229
Web: <http://www.lancs.ac.uk>

Hainault Health Centre

Manford Way

Chigwell

IG7 4 DF

Date 13.05.2013

Dear

My name is Amanda Young and I am undertaking some research with the staff in nursing homes in Havering. Your home has been randomly selected to be offered to take part in the research and I would like to personally take this opportunity to ask if you and your staff would like to be involved in this.

Participation is voluntary, and all information I receive is confidential, anonymised and only shared with my academic supervisor. This applies to all staff whether they are a healthcare assistant, registered nurse or a home manager.

I have attached the participation leaflet with further information on the study. If you agree that the staff in your home can participate please contact me on the number below and I can arrange for individual letters for all your staff. If you have any questions or comments please do not hesitate to contact me to discuss these.

I look forward to hearing from you.

Yours sincerely

Amanda Young

07507269943

Participant information sheet

The nature of moral conflict experienced by nursing home staff when caring for residents towards the end of life.

My name is Amanda Young and I am conducting this research as a student on the PhD in Palliative care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

I am interested in understanding your experience of caring for residents who have been at the end of life and have died. I am interested in examining situations when you felt death was a positive experience and in situations which you have felt that you were unable to carry out what you believed was the right course of action for the resident, either because of your personal beliefs and experience or because of other circumstances beyond your control.

Understanding your perspective will help develop initiatives that will provide support for healthcare providers responsible for the care of residents at the end of life in difficult care giving situations.

Aims and objectives of the study

The aim of this study is to understand the nature of moral conflict experienced by nursing home staff who care for residents coming towards the end of life, how the causes of these conflicts contribute to their moral distress and how these issues can be addressed in the current healthcare climate to improve the level and type of support the staff receive.

Research Question:

What factors contribute to the moral conflict of nursing home staff when caring for residents at the end of life?

The objectives:

1. To explore what the staff identify as the causes of moral conflict and if a difference exists between their position, age, experience, health related qualifications and ethnicity.
2. To establish if there is a link between moral conflict and moral distress in this group of participants.
3. To identify if these conflicts affect the care that residents receive when they are coming towards the end of life.
4. To identify and understand the issues that cause moral conflict and moral distress from the staff perspective to inform a more appropriate approach to staff support that can address the identified issues in the current health economy.

Why have I been approached?

You have been approached because the study requires information from people who care for residents in nursing homes.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to undertake an interview with me, at a time and location convenient to you, which would be about your experiences of caring for residents who are coming toward the end of their life or who have died. The interview would last about 45 minutes and be digitally recorded. The information collected would then be used as the data for the study.

Will my data/information be confidential?

The information you provide is confidential. It will not be possible to tell which nursing home you come from.

Your participation in the study will not be discussed with any other staff in the nursing home. The content of your interview will not be discussed with any other staff member.

The data collected for this study will be stored securely and only the researcher conducting this study will have access to it and aspects of it will be discussed with the academic supervisor:

- Audio recordings will be destroyed and/or deleted after the project has been submitted and examined.
- Hard copies of transcripts will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself is password protected. These will be kept until I have been awarded the PhD.
- At the end of the study, hard copies of transcripts will be kept securely in a locked cabinet for five years. At the end of this period, they will be destroyed by the researcher.
- During the analysis stage of the project an external peer will look at the anonymised transcripts to ensure that themes identified from the study are appropriate.
- The typed version of your interview will be made anonymous by removing any identifying information including your name and which nursing home you work in. Anonymised direct quotations from your interview may be used in the reports or publications from the study, and your name will not be attached to them.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, or there is mention of unsafe practice according to the NMC standards, I will have to break confidentiality and follow the protocol in Appendix 12.

What will happen to the results?

The results will be summarised and reported in a dissertation/thesis and may be submitted for publication in an academic or professional journal. The results will also be shared at related conferences and teaching events.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

a.young@lancaster.ac.uk 01708 465094.

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Sarah Brearley sarah.brearley@lancaster.ac.uk Tel: 01524 592574

Faculty of Health and Medicine

Lancaster University

Lancaster

LA1 4YD

If you wish to speak to someone outside of the Palliative care Doctorate Programme, you may also contact:

Professor Paul Bates Tel: 01524 593718

Associate Dean for Research Email: p.bates@lancaster.ac.uk

Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster

LA1 4YD

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance - CRUSE bereavement service helpline number for personal bereavement issues (0844 477 9400). Other resources will be provided at interview if required, depending on the organisation you work for and the area in which you live (can add organisation helpline number as appropriate once randomization has taken place).

Appendix 6 Number of incidents per participant

| Participant | Number of critical incidents |
|-------------|------------------------------|
| 1 | 5 |
| 2 | 8 |
| 3 | 3 |
| 4 | 2 |
| 5 | 5 |
| 6 | 2 |
| 7 | 5 |
| 8 | 6 |
| 9 | 5 |
| 10 | 4 |
| 11 | 2 |
| 12 | 5 |
| 13 | 2 |
| 14 | 3 |
| 15 | 3 |
| 16 | 3 |
| TOTAL | 63 |

Appendix 7 Consent form

Consent Form

Study title: The nature of moral conflict experienced by nursing home staff who have cared for residents at the end of life.

I am asking if you would like to take part in a research project which hopes to identify the causes of conflict related to moral problems that nursing home staff have when caring for residents at the end of life, using examples that you have experienced in practice.

Before you consent to participating in the study I ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent please speak to me, Amanda Young. Please initial each statement after reading.

| | |
|---|--|
| 1. I confirm that I have read the information sheet and fully understand what is expected of me within this study. | |
| 2. I confirm that I have had the opportunity to ask any questions and to have them answered. | |
| 3. I understand and give permission for my interview to be audio recorded, downloaded onto a password protected computer and then made into an anonymised written account (transcript). | |
| 4. I understand that audio recordings will be kept until the research project has been examined. | |
| 5. I understand that I am not obliged to take part in this study and can withdraw my participation before, during, or up to 2 weeks after my interview. | |
| 6. I understand that the information from my interview will be pooled with other participants' responses, anonymised reviewed by an external person for research purposes, and may be published in a nursing journal. | |
| 7. I consent to information and quotations from my interview being used in reports, conferences and training events. | |
| 8. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to residents in which case the researcher will have a duty of care to report concerns to her academic supervisor prior to any further action being taken. | |
| 9. I consent to Lancaster University keeping written transcriptions of the interview for 5 years after the study has finished. | |
| 10. I consent to take part in the above study. | |

Name of Participant _____ Signature _____
Date _____

Name of Researcher _____ Signature _____
Date _____

The nature of moral distress experienced by nursing home staff when caring for residents towards the end of life.

Interview guide based on Brazil et al. (2010)

I am interested in understanding the challenges experienced by healthcare providers caring for residents coming towards the end of life in nursing homes. I am particularly interested in examining situations in which healthcare providers have felt that they were unable to pursue what they believed was the right course of action, or fulfil their own expectations of care commitments or obligations to a resident who was coming towards the end of their life.

Understanding your perspective will help develop initiatives that will assist healthcare providers responsible for the care of those at the end of life in difficult care giving situations and as a consequence, will assure that patients will receive the best possible care.

Introductory question:

How long have you worked in the care home environment?

Have you cared for someone at the end of life in the last 6 months? Can you tell me about your experience?

In caring for these residents what have you found to be positive about the experience of caring for them as they came towards the end of life?

Have there been any challenges you have experienced related to how you feel things should have been done while providing end of life care to individuals within the nursing home?

Critical incident exercise:

Think about a particular example, when you cared for a resident at the end of life, which made you feel that there was some conflict with your personal beliefs and values.

1. What happened?
2. When and where did it occur?
3. How did it make you feel?
4. Was anyone else involved in this example?
5. What did you feel could have been done differently in the situation you described?
6. Have you any other examples of end of life care of residents which have made you feel like this example?
7. (if the answer is yes explore the same questions as above)

Wrap up:

What did you learn about these experiences that you shared with me about caring for residents at the end of life?

How has this learning helped you manage similar incidents afterwards? Would you do anything differently in the future?

If a colleague was facing a similar incident in their practice, what advice would you give them?

Is there anything else you would like to share in relation to caring for residents at the end of their lives?

DATA COLLECTION FORM

(To be completed at time of interview)

Participant ID: _____

Sex: **M** **F**

Age: _____ **years**

Occupation: _____

Healthcare qualifications: _____

Length of time in role: _____

Ethnicity: _____

Interview 5

- R:** How long have you worked in the home care environment
- P:** A year and a half
- R:** And has that always been in a Nursing Home
- P:** Yes
- R:** You have not worked in a residential care home or anything else It's all been in the same home
- P:** Yes
- R:** Have you looked after residents that have come to the end of life in that time
- P:** Yes
- R:** Can you tell me about how you found that experience if you have any specific examples that would be great
- P:** I think it is really distressing anything can happen at any time and it make you feel uneasy always checking thinking anything could happen. I think once you come to term with someone going then it gets easier when you first find out someone is poorly and haven't got long to go it gets to you more but as time goes on you sort of come to terms with it
- R:** So initially when you know or someone tells you that they are end of life or do you know how far in advance would you know do you think
- P:** If someone ends up going to hospital and then they come back as palliative and they will be going soon yes that's when you think oh my god or you think or sometimes you can see the person's health deteriorating and you just get an idea.
- R:** And that's what you find distressing it's knowing that they are actually going to die
- P:** Yes you get attached to someone and you think I don't like it
- R:** Is there anything specifically you don't like about looking after someone when they are dying or is it the fact that they are dying that you don't like if that makes sense
- P:** It makes sense I'm just trying to think could you repeat it again
- R:** Of you think about someone that you've been looking after, and then you find out they are dying is it the actual fact that they are dying that distresses you or is it the looking after them while they are dying
- P:** It's a bit of both really

- R: Its a bit of both , When you are looking after them when they are dying what do you find difficult about that
- P: You just want to make them happy and comfortable and obviously being just a carer you can't do everything the only thing you can do is care for them
- R: never just say only a carer its very important
- P: there is only so much we can do. Yes it is quite sad that we can't do more than that
- R: What more would you want to do
- P: If it was my own family member who was in a home I would be caring for them and spending more time with them keep staying by their side and talking to them.
- Whereas here because you have other responsibilities you can only spend a certain amount of time and then come back to them, If it was possible I would like to stay by with someone the whole time so they are not alone and they know that someone is there for them
- R: Do you find it difficult that some people do not have someone with them all the time
- P: Yes its really upsetting
- R: Can you think of a specific example of somebody that has happened to recently
- P: Well recently a few people have gone and they have had their family with them 24/7. I know that when I first started working here there was a woman who had nobody no family members nothing so she only had whoever was here the carers and the nurses she was my first resident that I actually cared for and I got attached to her it was really sad thinking oh my god she's got no one.
- R: And because she had no one did that make it worse
- P: Yes I know that most of our residents are fortunate to have their family with them through all the hard time but there are other residents who can only rely on carers and nurses.
- R: When you looked after that lady was there anything else that was difficult she didn't have any family and it was the first person you looked after that had died that was difficult in its self was there anything else that you didn't like about you said it was difficult she had no relatives, and she was dying and it was your first death.
- When you were actually carrying out care for her was any of that difficult did you find any of the systems any of the nurses anything else that happened in the building outside things happening that you thought if I was looking after this lady at home if she was my relative this would happen but I can't do that because of this.
- P: When this specific person when she passed away I wasn't around at the time I only came in a few days later, the day after and heard, I think most of the time when

someone goes I relate it to as if someone was in my own family and what I would have done, some residents never get the chance to say how they want their funeral or they want things everyone has their own way they want things a lot of people want people to wear pink on their funeral so its just it would help knowing how they wanted things you can only really go by the traditional normal way of doing things but you don't know how they wanted things the is quite upsetting.

R: So you think you are doing some things that the person might not have wanted

P: Yes you really don't know

R: Has there been any residents that have died that you did know what they wanted

P: Yes a woman recently passed and she knew she was going and she said she wanted her funeral to be a happy occasion with people having fun – I didn't actually go to her funeral a few of the carers went and they said that's how it was everyone was just having fun just laughing. If you get the chance to say how you want things and that's how it happens then you are lucky there's a lot of people who don't really.

R: You said it's sometimes difficult when peoples don't have someone with them is there any other things that you can think of with a Nursing Home that make looking after someone who is dying difficult.

P: Everyone has different needs there could be someone refusing to eat and drink we had a woman recently and she wasn't eating for months and the only thing we could do was push fluids you can't force as that would be abuse it is distressing because you just want them to drink but can't force them you know that if they don't drink that could be it. There are some residents that are un-cooperative they understand that you are doing it for their own benefit I think that's where dementia comes in your minds not doesn't know what's going on

R: The lady you were talking about that wasn't eating and drinking did she have dementia

P: Yes

R: So that was difficult when you were looking after her

P: Yes

R: Did they say she was coming to the end of her life

P: Yes

R: So she wasn't eating or drinking how did that make you feel on the days you cared for her that she wasn't eating and drinking

P: It used to irritate me not her it was just the fact that I can't do nothing there is only so much I could do I would sit there, you can't force her to eat it would drive me

crazy that I can't do more it is hard knowing that your caring for a person it's your job to care for them but you can't.

R: Have you had many cases of people not eating and drinking

P: Yes a lot of them in the last months they stop eating you know when someone stops eating it's a bad sign and you think oh god not another one

R: Do you find each one of those quite upsetting when you're caring for that person and they are not eating and drinking

P: Yes especially if you are really attached to them me I just get attached to anyone so easily even though sometimes they drive you crazy sometimes at the end of the day when they go you miss them

R: If we go back to the lady who was not eating and drinking was there anything else difficult about that situation from any other people involved in her care that was difficult.

P: Her family were really criticizing and were complaining the mum the woman she wasn't eating she not being looked after we're not getting her to drink, it was really It took them months to come to terms with the fact that she doesn't want to eat and we can't force her.

I remember in the beginning it was really hard we used to get your not doing this you're not giving my mum drinks it was all there recorded it was not like we were just leaving her every time we were walking past we offered a sip but she doesn't want it but if she didn't want it there was nothing we could do.

It did make me feel uncomfortable walking around the lounge and them looking at you I would think I'm not doing nothing wrong why are they looking at me like that.

R: So the relatives sometimes make it difficult

P: Yes

R: How does that make you feel

P: It just makes you feel what am I doing wrong

R: Any body else involved in that persons care any doctors or other nurses

P: It was just the family that was making it difficult – there was another woman who went and the only problem with her family was the son he didn't want to come to terms with his mum going he was denying it 'no she's not going to go' and trying to force her to eat, obviously we can't, we have to just sit back and see him doing it and you can't the only thing you can do is comfort him and try to get her to eat.

But as Health Care Assistants and Nurses you must be professional and you can't get too close you have to keep your distance sometimes and take a step back

R: And is that hard

P: Yes because it's sad watching it all happen and it's not in your hands I think working in a Nursing Home you have so much responsibility even things that are not your responsibility you just think if I could fix it if I could sort it out but there is not much we can do, sometimes we do things out of the goodness of our hearts and it would just turn out to be the wrong thing or could be taken the wrong way be just have to be careful really and that can be quite distressing as well.

R: What being careful about what you're doing

P: You could do things perfectly but it's not just the residents it's the family that's involved as well because they might think we are saying Mum/dad are not drinking but we can't force them to drink because that would be abuse we can get in trouble for that but the family will be seeing it as neglect if she is not given a drink I think it can be misunderstandings from different ends

R: It can be a bit of a dilemma really

P: Yes as to what to do

R: Is there any other examples of patients in particular that you think were more difficult or any examples of residents that you looked after and you think that you did really well that was a positive experience.

P: There was another woman recently who had about 7 daughters they were her in turns 24/7 all the time by her side everyone just loved the resident she was such a bubbly person everyone got so attached to her. They really loved the staff here we did our best to make her comfortable and happy she knew she was going and the family knew she was going we just did our best there was no point in being depressed about it just tried to keep her smiling and happy. They used to come in and the mum was just going they used smile people were keeping a positive attitude even if you were feeling upset you can't show it as it would just make the whole situation worse.

R: Is it hard to be that smiley

P: Sometimes the night before she went I finished at 9.00pm I just had a feeling I'm not going to see her any more I knew that when I came in the next day she wouldn't be here. Her daughter was sitting next to her so I came in just before I left to say goodbye, even though she was asleep I was talking to her like I would be seeing her tomorrow even though I knew I wouldn't even her daughter was saying I don't think she is going to make it. I said I'll see her one day if she doesn't she just said yeah. I feel it is important for everyone family and the professionals nurses Managers the carers to keep strong and keep a positive attitude. I think it helps

- R:** Is there anything else you would like to add regarding looking after people who are dying from a health care assistants perspectives
- P:** Like what
- R:** Any other comments about looking after dying people in a nursing home
- P:** All I can say is that you just get used to it my first few deaths I came across here I used to just go home mum dad someone passed away and was so upset and now but now it just a normal feeling . Before I come in here in the whole of my life I had only heard about 2 or 3 deaths and after years of just one person here it's just such a common thing you just get used to it and I think you just come to terms with it you learn more about it and how to deal with things. I think its important for some people to say I just don't want to do it don't want to do it I don't want to wash a person that's passed away but I think it helps if they are given a chance to do it then you get your head round these things It's not as bad as you think it is going to be.
- R:** Thank you very much I really appreciate it

Appendix 11 table of separated incidents and first stage of coding

Incidents separated in the first instance.

| Incident No. Line no. | Critical Incident extracts from text | Initial coding ideas |
|--------------------------|--|---|
| OTHER 13-16 | I think it is really distressing anything can happen at any time and it make you feel uneasy always checking thinking anything could happen. I think once you come to term with someone going then it gets easier when you first find out someone is poorly and haven't got long to go it gets to you more but as time goes on you sort of come to terms with it | Emotional work Watching deterioration is difficult but has to be expected. |
| 19-21 | If someone ends up going to hospital and then they come back as palliative and they will be going soon yes that's when you think oh my god or you think or sometimes you can see the person's health deteriorating and you just get an idea. | Recognised as dying |
| 23 | Yes you get attached to someone and you think I don't like it | Emotional work, attached to resident. |
| 27-30 | R: Of you think about someone that you've been looking after, and then you find out they are dying is it the actual fact that they are dying that distresses you or is it the looking after them while they are dying P: It's a bit of both really | Make them feel happy and comfortable |
| 33-34 | You just want to make them happy and comfortable and obviously being just a carer you can't do everything the only thing you can do is care for them | Emotional work |
| 36 | there is only so much we can do. Yes it is quite sad that we can't do more than that | Do not want them to die alone |
| 38-42 | If it was my own family member who was in a home I would be caring for them and | Other work can get in the way sometimes |

| | | |
|---------|--|--|
| 46 | spending more time with them keep staying by their side and talking to them. Whereas here because you have other responsibilities you can only spend a certain amount of time and then come back to them, If it was possible I would like to stay by with someone the whole time so they are not alone and they know that someone is there for them | Families should stay |
| 52-53 | Well recently a few people have gone and they have had their family with them 24/7 | Families should stay but staff can stand in |
| 71 | Yes I know that most of our residents are fortunate to have their family with them through all the hard time but there are other residents who can only rely on carers and nurses. | |
| 84-86 | Yes you really don't know | Dementia residents more difficult to cope with |
| 100-101 | There are some residents that are un-cooperative they understand that you are doing it for their own benefit I think that's where dementia comes in your minds not doesn't know what's going on | Eating and drinking difficult |
| 104-106 | Yes a lot of them in the last months they stop eating you know when someone stops eating it's a bad sign and you think oh god not another one | Loss |
| 121 | Yes especially if you are really attached to them me I just get attached to anyone so easily even though sometimes they drive you crazy sometimes at the end of the day when they go you miss them | Lack of knowledge |
| 128-129 | It just makes you feel what am I doing wrong | Undervalued, sad, appropriate emotions |
| 131-136 | But as Health Care Assistants and Nurses you must be professional and you can't get too close you have to keep your distance sometimes and take a step back | Caring is challenging |

| | | |
|----------------|---|---|
| <p>138-144</p> | <p>Yes because it's sad watching it all happen and it's not in your hands I think working in a Nursing Home you have so much responsibility even things that are not your responsibility you just think if I could fix it if I could sort it out but there is not much we can do, sometimes we do things out of the goodness of our hearts and it would just turn out to be the wrong thing or could be taken the wrong way be just have to be careful really and that can be quite distressing as well.</p> <p>You could do things perfectly but it's not just the residents it's the family that's involved as well because they might think we are saying Mum/dad are not drinking but we can't force them to drink because that would be abuse we can get in trouble for that but the family will be seeing it as neglect if she is not given a drink I think it can be misunderstandings from different ends</p> <p>All I can say is that you just get used to it my first few deaths I came across here I used to just go home mum dad someone passed away and was so upset and now but now it just a normal feeling . Before I come in here in the whole of my life I had only heard about 2 or 3 deaths and after years of just one person here it's just such a common thing you just get used to it and I think you just come to terms with it you learn more about it and how to deal with things. I think its important for some people to say I just don't want to do it don't want to do it I don't want to wash a person that's passed away but I think it helps if they are given a chance to do it then you get your head round these things It's not as bad as you think it is going to be.</p> | <p>Emotional work</p> <p>Family conflict</p> <p>Eating and drinking, recognising as normal</p> <p>Get used to it</p> <p>Number of deaths</p> <p>Care after death</p> <p>Relatives can get you into trouble (fear)</p> |
| <p>169-177</p> | | |

| | | |
|---|---|---|
| <p>INCIDENT 1 46-50</p> | <p>I know that when I first started working here there was a woman who had nobody no family members nothing so she only had whoever was here the carers and the nurses she was my first resident that I actually cared for and I got attached to her it was really sad thinking oh my god she's got no one.</p> <p>When this specific person when she passed away I wasn't around at the time I only came in a few days later, the day after and heard, I think most of the time when someone goes I relate it to as if someone was in my own family and what I would have done, some residents never get the chance to say how they want their funeral or they want things everyone has their own way they want things a lot of people want people to wear pink on their funeral so its just it would help knowing how they wanted things you can only really go by the traditional normal way of doing things but you don't know how they wanted things the is quite upsetting.</p> | <p>emotional work (sad)</p> <p>(not asking ACP)</p> |
| <p>INCIDENT 2 73-77</p> | <p>Yes a woman recently passed and she knew she was going and she said she wanted her funeral to be a happy occasion with people having fun – I didn't actually go to her funeral a few of the carers went and they said that's how it was everyone was just having fun just laughing. If you get the chance to say how you want things and that's how it happens then you are lucky there's a lot of people who don't really.</p> | <p>positive experience</p> <p>accepted she was dying wishes</p> |

INCIDENT 3
81-84

Everyone has different needs there could be someone refusing to eat and drink we had a woman recently and she wasn't eating for months and the only thing we could do was push fluids you can't force as that would be abuse it is distressing because you just want them to drink but can't force them you know that if they don't drink that could be it.

The lady you were talking about that wasn't eating and drinking did she have dementia

P: Yes

R: So that was difficult when you were looking after her

P: Yes

R: Did they say she was coming to the end of her life

P: Yes

R: So she wasn't eating or drinking how did that make you feel on the days you cared for her that she wasn't eating and drinking

P: It used to irritate me not her it was just the fact that I can't do nothing there is only so much I could do I would sit there, you can't force her to eat it would drive me crazy that I can't do more it is hard knowing that your caring for a person it's your job to care for them but you can't.

Her family were really criticizing and were complaining the mum the woman she wasn't eating she not being looked after we're not getting her to drink, it was really it took them months to come to terms with the fact that she doesn't want to eat and we can't force her.

I remember in the beginning it was really hard we used to get your not doing this you're not giving my mum drinks it was all there recorded it was not like we were just leaving her every time we were walking past we offered a sip but she doesn't want it but if she didn't want it there was nothing we could do.

It did make me feel uncomfortable walking around the lounge and them looking at you I would think I'm not doing nothing wrong why are they looking at me like that.

109-117

Complex patients (relatives and choice not to eat complaints from relatives)

emotional (felt uncomfortable)

communication (complaining)

dementia end of life difficult resident cannot express choice

INCIDENT 4
123-127

there was another woman who went and the only problem with her family was the son he didn't want to come to terms with his mum going he was denying it 'no she's not going to go' and trying to force her to eat , obviously we can't, we have to just sit back and see him doing it and you can't the only thing you can do is comfort him and try to get her to eat.

futile care (forcing her to eat)
complex (son)
emotional (only thing we could do)

INCIDENT 5
148-164

There was another woman recently who had about 7 daughters they were her in turns 24/7 all the time by her side everyone just loved the resident she was such a bubbly person everyone got so attached to her . They was really loved the staff here we did our best to make her comfortable and happy she knew she was going and the family knew she was going we just did our best there was no point in being depressed about it just tried to keep her smiling and happy. They used to come in and the mum was just going they used smile people were keeping a positive attitude even if you were feeling upset you can't show it as it would just make the whole situation worse.

emotional (hard to be smiley)
communication (say goodbye) emotional, attached to resident

colleague competence (positive from manager and carers)

R: Is it hard to be that smiley

P: Sometimes the night before she went I finished at 9.00pm I just had a feeling I'm not going to see her any more I knew that when I came in the next day she wouldn't be here. Her daughter was sitting next to her so I came in just before I left to say goodbye, even though she was asleep I was talking to her like I would be seeing her tomorrow even though I knew I wouldn't even her daughter was saying I don't think she is going to make it. I said I'll see her one day if she doesn't she just said yeah. I feel it is important for everyone family and the professionals nurses Managers the carers to keep strong and keep a positive attitude. I think it helps

recognising dying, relationships important with relatives to support them. Remain professional

Appendix 12 Step 2 of analysis initial codes

| Initial codes/ideas | | |
|---------------------------------------|--|--------------------------------------|
| After death | Family conflict | Number of deaths |
| Appropriate emotions | Fear | Nurses |
| Attachment | Finance | Organisational conflict |
| Best job | Food and nutrition | Organisational culture |
| Care decisions | Frustration | Organisational culture and resources |
| Care including clinical conversations | Funding affects choices | Pain and suffering |
| Care as a result of dying | Funerals | Pain and suffering caused by others |
| Caring is challenging | Funerals - plans after death | Personal beliefs |
| Changes in deaths in NH | Futile care | Personal experiences |
| Colleague conflict and competence | Gets easier | Planning |
| Colleague | Good care | Positive experiences of dying |
| Comfort measures | Good death | Resident condition |
| Communication | Helpless | Resident wants to die |
| Complexity of patient issues | Hospice care | Rooms and belongings |
| Conflict | Hospital care | Sadness |
| Consequences | Human factors | Spiritual belief |
| Culture | Inappropriate care | Spirituality |
| Cultural difference | In control of dying | Support |
| Decision making | Internal | Unable to explain emotions |
| Dementia | Knowledge | Undervalued |
| Dichotomy | Knowing resident | Unexpected death |
| Doctors | Lack of understanding from others | Unfazed |
| Dying alone | Last offices | Uninformed |
| Dying is unpleasant | Lingering | Unpleasant |
| Education | Loss | Untreated pain |
| Emotional work | Love | Upset appropriate emotions |
| Equipment | Medication | Weight loss |
| Ethos of care | Memories | When |
| Expectations | No emotion part of the job | Where |
| Expected death | Not an exact science | Workload |
| External | Not just older people die in nursing homes | Values |
| Family | Not included | |

Appendix 13 Step 2 of analysis codes aligned to moral distress literature

| CODE | INCIDENT | | LIKE | OTHER |
|----------------------------|-------------------|--------------------|------|------------------------------|
| AFTER DEATH | Support | Organisational | | Care as result of death |
| | | Informal | | Fear |
| | | Personal | | Funerals - plans after death |
| | Sudden | Expected | | Last offices |
| | | Unexpected | | Loss |
| | Fear | | | Memories |
| CONFLICT | | | | Number of deaths |
| | | | | Support |
| | Influence on care | Positive | | Care |
| | | Negative | | Helpless |
| | | | | Communication |
| | | | | Doctors |
| ORGANISATIONAL CONSTRAINTS | | | | Nurses |
| | | | | Cultural difference |
| | | | | Knowledge |
| | | | | Organisational conflicts |
| | External | Hospital | | Cultural issues |
| | | Hospice | | External |
| | | Medication | | Finances |
| | Internal | Planning | | Internal |
| | | Resident condition | | After death |
| | | Medication | | Care decisions |
| RESOURCES | | Human | | Equipment |
| | | Financial | | Ethos |
| | | Education | | Support |
| | | Good Care | | Training |
| | | Knowing resident | | Not just older people |
| | | Good care | | Workload |
| | | Colleagues | | |
| | | Education | | Education |
| | | | | Colleagues |
| | | | | |

| CODE | INCIDENT | | LIKE | OTHER |
|------------------------------|-----------------------|--------------------|------|-------------------------|
| COMPLEXITY OF PATIENT ISSUES | | Working hard | | Workload |
| | | Hospice | | GP |
| | Dementia | Decision making | | Changes in deaths in NH |
| | Food and nutrition | | | Dementia |
| | Family | Communication | | |
| | | Expectations | | |
| | | Conflict in family | | |
| | Medication | Knowledge | | |
| | | Processes | | |
| | Symptom management | Good examples | | Caused by others |
| FUTILE CARE | | Poor examples | | Comfort measures |
| | Patient comfort | Good examples | | Lingering |
| | | Poor examples | | Untreated pain |
| | Spiritual | Good examples | | Weight loss |
| | | Poor examples | | |
| COMMUNICATION | Inappropriate care | | | |
| | Not included/left out | | | ACP |
| | Lack of communication | | | Colleague |
| | Good communication | | | Consequence |
| | Helplessness | | | Family |
| | Reflection | | | Support |
| EMOTIONAL WORK | | | | Uninformed |
| | Sadness | | | Appropriate emotions |
| | Fear | | | Attachment |
| | Love | | | Challenging |
| | | | | Dichotomy |
| | | | | Fear |
| | | | | Frustration |

| CODE | INCIDENT | LIKE | OTHER |
|--|----------|------|-----------------------------------|
| | | | Gets easier |
| | | | Powerless |
| | | | Loss |
| | | | No emotion - part of the job |
| | | | Personal experiences |
| | | | Unable to explain |
| PERSONAL BELIEFS Values associated with dying | | | Best job |
| | | | Caring is challenging |
| | | | Dying alone |
| | | | Hospital care |
| | | | In control of dying |
| | | | Lack of understanding from others |
| | | | Spiritual beliefs |
| | | | Dying is unpleasant |
| | | | Values |
| | | | Good death |
| | | | Symptom free |
| | | | Respectful |
| | | | Dignified |
| | | | Calm and relaxing |
| | | | Having things in place |
| | | | In the home |
| | | | Not forcing food and fluids |
| | | | Peaceful |
| | | | Happy |

| CODE | INCIDENT | LIKE | OTHER | | |
|------|----------|------|-------|-------------|------------------|
| | | | | | Achieving wishes |
| | | | | Memories | |
| | | | | Unfazed | |
| | | | | Family | |
| | | | | Undervalued | |

Appendix 14 Step 4 of analysis challenges and positive aspects of end of life care

| Themes | Level 1 sub themes | Level 2 sub themes | Level 3 sub themes |
|--|---------------------------|-------------------------------|--------------------|
| Challenges | Communication | Communication organisational | |
| | | Communication professional | |
| | | Communication relative | |
| | | Family | culture |
| | External relationships | GPs | |
| | | Hospitals | |
| | | Staff fear of consequences | |
| | Internal relationships | Colleague | |
| | | Resident | Choices |
| | | | Dementia |
| Positive aspects associated with care of the dying NH resident | Powerless | | |
| | | After death | |
| | The dying process | Dying is not an exact science | |
| | | Eating and drinking | |
| | | Poor symptom management | |
| | | Symptoms | |
| | Achieving resident wishes | | |
| | Communication | | |
| | Giving good care | | |
| | Recognition | | |
| | External relationships | GPs | |
| | | Hospice | |
| | | Family | |
| | Internal relationships | Colleagues | |
| | | support | |

Appendix 15 Protocol for the reporting of unsafe practice

The aim of this document is to rationalise a procedure for dealing effectively and sensitively with unsafe practice uncovered in care homes during the research process.

What constitutes unsafe practice?

- Activities relating to a care home that could have a negative impact on the well-being of care home residents, their family, friends or staff.
- Issues of a serious nature, more specifically issues of abuse, unethical practice and serious misconduct.

What action should be taken when unsafe practice is observed and identified?

Emphasis will be placed on factual information. Great care will be taken to avoid becoming emotionally involved in a given situation.

What action should be taken when unsafe practice is observed?

Where possible, the issue will be discussed with my supervisors. Together a judgement will be made about whether an issue constitutes bad practice and whether further action is necessary.

Informal complaints procedure

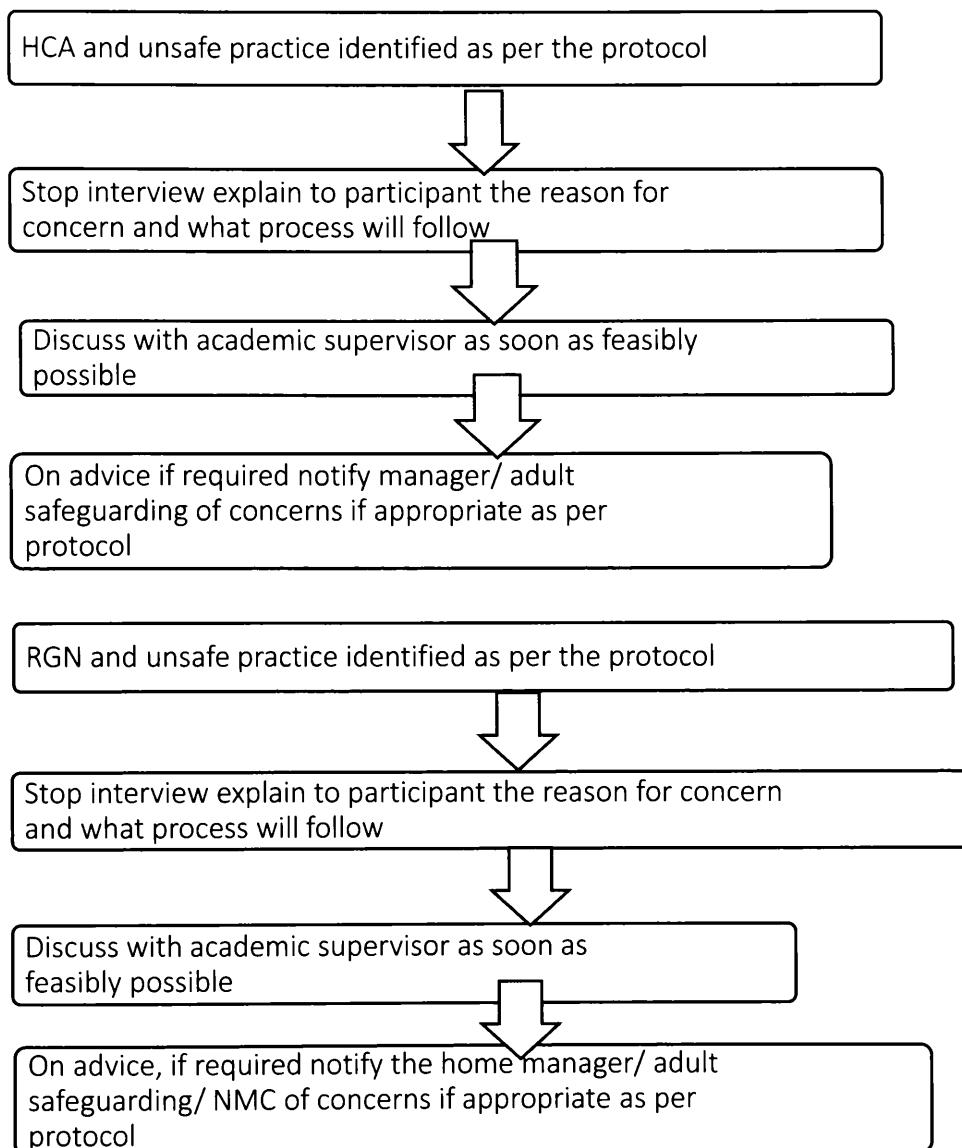
If after careful consideration it is established that unsafe practice has taken place, an informal complaint to the care home manager will be made. The complaint will be issued in either of the following ways:

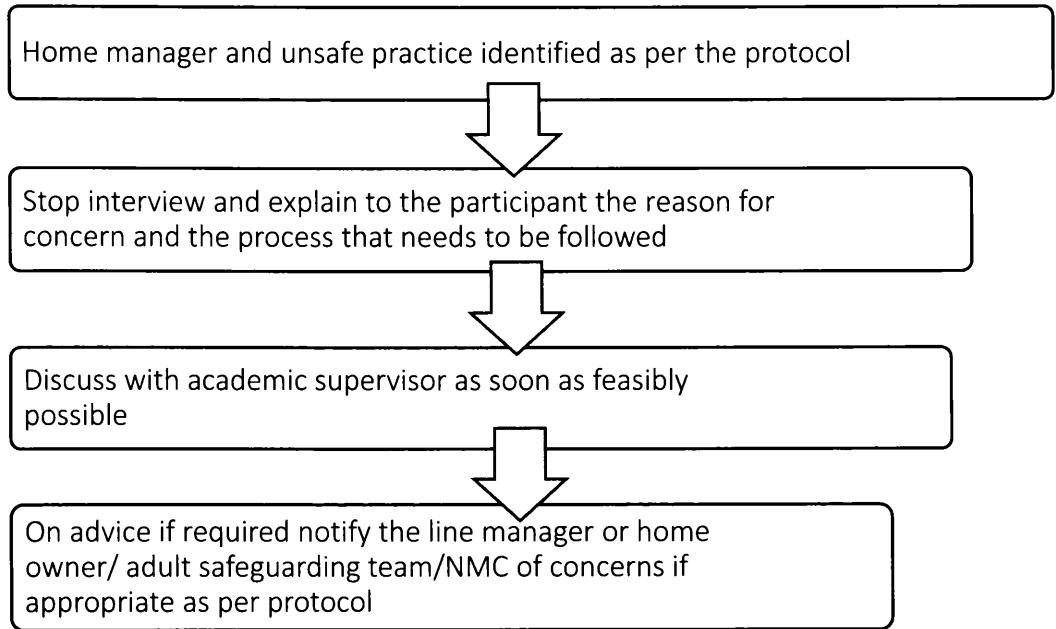
1. A letter to the care home manager (a copy will be retained).
2. Delivered verbally by the researcher, either in person or over the phone to the care home manager. In this case the care home manager will be asked to acknowledge the complaint in writing, providing information concerning who is investigating the matter.
3. Feedback from the care home manager will be requested, regarding how the issue has been resolved. However, delay of feedback will not detract from making a formal complaint if necessary.

Formal complaints procedure

- If the research team are dissatisfied with the way that concerns have been dealt with, a formal complaint will be lodged. The Care Quality Commission (CQC) handles formal complaints concerning national minimum standard issues. Complaints concerning abuse (e.g. theft, negligence, physical or emotional abuse) are dealt with by the local council social services protection of vulnerable adults' co-ordinator. In such cases, the CQC will be contacted initially to obtain contact details of the appointed co-ordinator within social services.
- A record of telephone conversations will be kept concerning formal complaints, and information provided to the researcher verbally will also be requested in writing.

Source: adapted with permission from a protocol developed by C Goodman for the study: *APPROACH: Analysis and Perspectives of integrated working in Primary care organisations And Care Homes*. c.goodman@herts.ac.uk





Appendix 16 Demographic details of participants

| No. | Age/ sex | Role | Length of time in current role or NH | Qualifications | Ethnicity |
|-----|-------------|-------------------|--|--------------------------------|---------------------|
| 1 | 50(M) | Deputy manager | 1 yr | BSc Nursing | Black Caribbean |
| 2 | 48(F) | Manager | 5 yrs | RGN | White British |
| 3 | 50(F) | Senior HCA | 28 yrs | NVQ 2, 3 Team leadership 2 | English |
| 4 | 64(F) | HCA | 22 yrs | None | English |
| 5 | 19(F) | HCA | 1 ½ yrs | Health and social care level 3 | British Bangladeshi |
| 6 | 32(F) | HCA | 3 ½ yrs | NVQ level 5 | Philippine |
| 7 | 60(F) | HCA | 16 yrs | NVQ 2 | Philippine British |
| 8 | 49(F) | RGN | 8 yrs | RGN (Diploma) | Caribbean |
| 9 | 35(F) | Deputy manager | 15 yrs | BSc Nursing | Philippine |
| 10 | 47(F) | HCA | 30 yrs | NVQ 3 | White British |
| 11 | 24(F) | HCA | 2 yrs | None | White British |
| 12 | 30(F) | HCA | 9 yrs | None | Czech |
| 13 | 49(F) | HCA | 2 yrs | NVQ 2/undertaking NVQ 3 | British |
| 14 | 63(F) | RN | 7 yrs | Dip Nursing | African |
| 15 | 58 (F) | Manager | 4 months | MSc Health and Social Care | Chinese |
| 16 | 50(F) | HCA | 4 yrs | NVQ 2 doing NVQ 3 | English |

| Factors minimising distress (positive aspects of EOL care) | | Factors contributing to distress (negative aspects of EOL care) | |
|--|--|---|---|
| Dying process (?care) | Nursing home staff know the residents they look after and know what they like and don't like. This enables staff to facilitate good symptom control as they are aware of what is normal for the resident | Dying process (?care) | Death is not an exact science and can be protracted or sudden |
| | Good quality care can be given in the nursing home | | Lack of communication can contribute to residents dying with uncontrolled symptoms |
| | Residents can die a comfortable, happy and peaceful death (according to staff values) | | Complex symptoms (e.g. bleeding) |
| | Staff can say goodbye | | Reduced fluid and nutritional intake |
| | Staff can support family | | Staff find relatives difficult to support when they want care that the staff do not think is the right thing for the resident |
| Communicating | With residents: advance care planning | Communicating | Lack of advance care planning because resident or relative are in denial that death will occur |
| | With relatives: involvement in care planning, keeping them up to date, engage them in conversations about advance care planning/decisions | | When family members are in conflict and disagree about a plan of care |
| | With relatives: staff can protect them from the truth about harrowing deaths | | Lack of information sharing about what is happening with residents, especially non engagement of HCA's in EOL decisions for residents |
| | With colleagues internally: to facilitate team working and information sharing | | RGN's not listening to HCA's about symptoms they are witnessing and failing to act on the information provided resulting in poor symptom control |
| | With external colleagues: to facilitate co-ordinated care and achieve residents EOL wishes. Facilitates the conversations to anticipate deaths. Facilitates documentation of resuscitation status. | | Lack of information transferred with residents discharged from hospital can result in re-admission which staff do not believe is in the best interest of the resident |
| | With residents and relatives: enables staff to be aware of cultural needs around EOL care | | Lack of documentary evidence of plan of care or resuscitation status can result in 999 calls or hospital admission which the staff do not think is the right thing for the resident |
| | | | Not being open and honest about EOL care can have an impact on residents left behind and cause upset for staff |

| Factors minimising distress (positive aspects of EOL care) | | Factors contributing to distress (negative aspects of EOL care) | |
|--|--|---|---|
| Advocating | Can enable residents to die in the nursing home and their EOL wishes to be met if staff are allowed to put the residents wishes forward at the end of life | Advocating | Staff fear consequences of death (loss of nurse registration, complaints from relatives), if they do not send residents to hospital so practice out of fear rather than advocating on behalf of residents |
| | Improves communication with residents and relatives by opening up discussions about personal wishes | | If advocating on behalf of a resident goes against their personal beliefs and values i.e. choice of not eating and drinking can cause stress |
| | | | When there is family conflict it can be challenging to advocate on behalf of the resident |
| | | | Healthcare systems and finances can add complexity to the care of residents |
| | | | Meeting residents needs and wishes sometimes conflicts with the needs and wants of families |
| Relating | To residents/relatives/colleagues can facilitate residents wishes being met | Relating | Poor relationships with family can reduce the amount of support that the family gets |
| | Can improve open communication | | It is difficult to relate to family members and residents in denial that death is occurring |
| | Co-ordinates care between organisations | | Poor relationships between residents and their families can affect the relationship that staff have with the resident |
| | Can enable support to be provided to relatives, by accommodating their needs when a loved one is dying | | Poor relationships with hospitals results in a lack of mutual respect for the care residents receive there |
| | To residents enables staff to become surrogate family members when no family are available | | Poor relationships internally can affect communication |
| | To the local hospice enables staff to get support when it is needed | | Poor relationships with GPs can affect communication and can result in decisions which staff do not agree with being carried out |
| | Support within a nursing home between staff can reduce emotional upset when there are a lot of resident deaths | | Having good relationships with residents in NH can be very emotional as so many of them die |

Appendix 18 Step 5 of analysis main themes and sub themes

| Main themes | Sub themes | Sub themes |
|----------------------------|---|--------------------------------------|
| Advocating (care planning) | Achieving the residents EOL wishes | |
| | Residents choices about their care | |
| | Staff fear of consequences | |
| | Cognitive difficulties | |
| Communicating | Communicating within the nursing home | |
| | Communicating with internal and external colleagues | |
| | Communicating with residents and their relatives | Cultural understanding |
| | Giving good care even though death will occur | |
| The Dying process (caring) | Dying is not an exact science | |
| | The lingering death when not eating and drinking | |
| | Managing symptoms | |
| | Symptoms | |
| | Care after death | |
| | Outside of the nursing home | Relatives GPs Hospital/hospice |
| | | |
| Relating | Inside the nursing home | Colleague Resident |
| | Supportive relationships | Inside the nursing home |
| | | Outside the nursing home |
| | | |
| | | |

Appendix 19 Step 5 main themes defined

| Main themes | Sub themes | Sub themes |
|---|--|-------------------------------|
| Caring can cause distress to staff in nursing homes due to its lingering, unpredictable nature to as well as give them a sense of satisfaction that the care they have provided is the best a resident could have received. | Giving good care even though death will occur | |
| | Dying is not an exact science | |
| | The lingering death when not eating and drinking | |
| | Managing symptoms | |
| | Care after death | |
| Advocating contributes to the experience of end of life care, positively when a resident's death is considered to be as they would wish, and negatively if staff are unable to advocate on behalf of a resident. | Achieving residents and relatives EOL wishes and choices | |
| | Cognitive impairment | |
| | Staff fear of consequences if they advocate | |
| | Outside of the nursing home | Relatives GPs |
| Relating to all those who are involved in the end of life care of residents in nursing homes contribute to the positive or negative experience of dying for this group of staff, with poor relationships contributing to distress. | Inside the nursing home | Hospital/hospice Colleague |
| | | Resident |
| | | Cultural understanding |
| | Supportive relationships | Inside the nursing home |
| | Communicating with internal and external colleagues | |
| Communicating well with all concerned in the end of life care of a resident contributes to a good experience of death, conversely when communication is poor it can contribute negatively to the experience of death therefore contributing to staff distress. | Communicating with residents and their relatives | |

| Practice themes | Specific areas identified |
|---|--|
| Caring for the dying can distress staff in nursing homes due to the dying trajectory being unpredictable in nature as well as give them a sense of satisfaction that the care they have provided is the best a resident could have received. | Giving good care even though death will occur |
| | Caring for those who may or may not be dying |
| | The lingering death |
| | Managing symptoms |
| | Care after death |
| Advocating contributes to the experience of end of life care, positively when a resident's deaths is considered to be as they would wish, and negatively if residents do not achieve their wishes, contributing to staff distress. | Achieving residents and relatives EOL wishes and choices |
| | Advocating |
| | Fear of consequences |
| Relating to residents and all those who are involved in the end of life care of residents in nursing homes contribute to the positive or negative experience of dying for this group of staff, with poor relationships contributing to distress. | Inside the nursing home <ul style="list-style-type: none">• Residents• Colleagues |
| | Outside of the nursing home <ul style="list-style-type: none">• Relatives• GPs• Hospital/hospice |
| | Communicating with residents and their relatives |
| Communicating well with all concerned in the end of life care of a resident contributes to a good experience of death, conversely when communication is poor it can contribute negatively to the experience of death therefore contributing to staff distress. | Communicating with internal and external colleagues |

