

**Advance care planning and living with dying:
the views of hospice patients**

Sarah JF Russell

Submitted to the
University of Hertfordshire
In partial fulfilment of the requirements of the degree
Doctorate in Health Research
May 2016

Acknowledgements

This dissertation was made possible by the generosity of time and thoughts of the hospice participants who took part in the research interviews.

I am most grateful to my supervisors Professor Hilary Thomas and Dr Angela Dickinson from the Centre for Research in Primary and Community Care at the University of Hertfordshire. They patiently supported and encouraged me. Thank you also to my friends and colleagues in the hospices, hospitals, community, care homes, social, health, palliative and education teams that I have worked with. They consistently motivated me to make a difference to those we care for. I am also grateful for the many unnamed others who continually provoked my thinking in publications, education sessions, conferences, discussions and through social media.

Finally, thank you to my husband and daughter for their constant interest, support and encouragement.

Abstract

Advance care planning for adults is a process of consideration, discussion and decisions about care at the end of life. There is evidence that advance care planning improves outcomes such as the achievement of preferred place of death and the quality of dying. However, the uptake of advance care planning is variable. There are calls for more research to understand what influences people to carry it out to plan services and improve the quality of life of patients and their families.

This dissertation reports on a qualitative, video interview study of 15 adult hospice patients. The study was interpretative influenced by the narrative approach with data driven thematic analysis and a video aide memoir. Coding was carried out using the Computer Assisted Qualitative Data Software programme Transana. The rigour and credibility of the study was viewed through the lens of trustworthiness which included the development of a Continuous Conversation Framework. The aim of the study was to investigate what would influence hospice patients to discuss their advance care planning to develop future education programmes based upon the perspectives of people at the end of their life:

1. What influences hospice patients in their advance care planning?
2. What communication skills do hospice patients find helpful when clinicians discuss advance care planning?

Three findings are reported. These suggest that the influences on advance care planning activity and conversations is the less reported relationship of the personal context of a person's life (as well as services, diagnosis and prognosis considerations). First, the findings highlight the relevance of how people with an incurable illness live with and talk about their dying within the individual context of their daily lives. Secondly, differences are illustrated between how people prepare (for themselves) and plan (for others) in their dying. Thirdly, clinician communication behaviours such as empathy (through mutual connection and visible behaviours), tailored conversations (through accessible and selective honesty) and the design and use of space empower people to carry out conversations which support them as they live with, prepare and plan for dying. The three findings contribute to the perspective which supports the complexity of advance care planning that should focus on the context of person's life as well as the paperwork, prognosis or diagnosis. A contribution to person-centred care is suggested through a model of *relational advance care planning*.

Contents

Acknowledgements.....	2
Abstract.....	3
Glossary of terms	9
Chapter 1: Introduction	10
Study background	10
Introduction to advance care planning.....	12
Rationale for the research question	15
Organisation of the thesis.....	15
Chapter 2: Literature Review	17
Introduction	17
Overview of the literature searching strategies	17
When and how the literature was searched.....	17
Data bases used to search the literature.....	18
Search timeframe and terms used.....	18
Figure 1: literature key search terms.....	19
Searching the literature	19
The benefits of advance care planning.....	20
How successful is advance care planning?	21
Terms, documents, legal and organisation frameworks	22
Hidden and vulnerable populations.....	24
Diagnosis inequity.....	25
Demographic factors.....	26
Person-centred care.....	28
Living with dying	30
Timing of advance care planning conversations.....	30
Living with uncertainty.....	33
Planning and preparing for dying.....	34
The cost of dying.....	36
Home as the preferred place of death.....	38
Decisions made in advance and surrogate decision makers	39
Autonomy	44
The good death	46
Assisted dying	49

The communication skills literature	51
Barriers and blocks to communication	51
Benefits of communication.....	52
Communication and advance care planning.....	53
Communication and advance care planning education	56
Literature review summary.....	59
Chapter 3: Methodology.....	61
Introduction	61
The research questions.....	61
Epistemological and methodological approach.....	61
Qualitative approach rationale	62
Narrative influence	64
Reflexivity: the defended subject and examples.....	66
Figure 2: example of continuous conversation framework.....	70
Trustworthiness	71
Credibility.....	73
Transferability.....	74
Dependability.....	74
Confirmability.....	75
Figure 3: audit and decision trail for transcription, coding and analysis.....	76
The interviews.....	76
Video interviews	80
Examples of data density and video aide memoir.....	82
Transana™ Computer Assisted Qualitative Data Analysis Software.....	84
Ethical approval.....	85
Ethical considerations.....	86
Being an ethical palliative care researcher	87
Sampling.....	89
The research site.....	90
Recruitment	91
Figure 4: recruitment, consent and interview process.....	92
Consent	93
Figure 5: participant consent variances.....	93
Conducting the video interviews	94
Figure 6: questions asked in all the interviews.....	94
Transana™ and video interviews	95

Follow up.....	95
Participants’ experience of taking part in the interviews.....	96
Figure 7: participants’ views on being video interviewed	96
Thematic analysis.....	97
Figure 8: phases of thematic analysis	98
Participants’ previous advance care planning activity.....	99
The participants	100
Chapter 4 Results: Living with Dying.....	104
Introduction	104
Living with dying	105
Unfamiliarity with the term advance care planning	105
Living with the knowledge of their inevitable death	107
A constant companion	107
The personal context	109
Living with the uncertainty of time of death	112
Emotional resilience.....	117
Living with dying summary	123
Chapter 5 Results: Preparing and Planning for Dying.....	124
Introduction	124
Preparing for dying	124
An individual approach	125
Personal mental preparation	127
Friendships.....	130
Family responsibilities.....	134
Planning for dying	137
Dying at home.....	137
Future needs of children.....	141
Planning for suicide.....	144
Preparing and planning for dying summary	156
Chapter 6 Results: Communication with clinicians.....	157
Introduction	157
Empathy	157
Defining empathy and its benefits.....	157
Mutual connection.....	159
Visible empathy.....	169
Tailored conversations.....	180

Honesty	180
The design and use of the environment	187
Communication with clinicians' summary	194
Chapter 7: Discussion.....	195
Introduction	195
Summary of study's findings.....	195
Contribution to the evidence base	197
Living with, preparing and planning for dying	198
Person-centred conversations	206
Implications for communication education programmes	218
A model of relational advance care planning	219
Figure 10: relational advance care planning.....	221
Implications for policy, education and practice.....	222
Strengths and limitations of carrying out the research	224
Future research recommendations	225
Final thoughts	226
References	227
Appendices.....	307
Appendix 1: examples of international terms for advance care planning.....	307
Appendix 2: seminal cases in advance care planning history	308
Appendix 3: summary of literature search strategy based upon PRISMA (2009)	309
Appendix 4: dying and illness trajectories concepts.....	310
Appendix 5: dying awareness	311
Appendix 6: publication list.....	312
Appendix 7a: summary of participants' contribution to the study themes:	317
living with dying	317
Appendix 7b: summary of participants' contribution to the study themes:	318
preparing and planning for dying.....	318
Appendix 7c: summary of participants' contribution to the study themes:.....	319
clinicians' communication.....	319
Appendix 7d: examples of data driven thematic analysis process	320
Appendix 8: University of Hertfordshire ethics approval	324
Appendix 9: research site ethics approval	328
Appendix 10: research site research policy	330
Appendix 11: examples of being an ethical palliative care researcher	338
Appendix 12: sample invitation to participate in research flyer	341

Appendix 13: participant information sheet.....	343
Appendix 14: staff information sheet	347
Appendix 15: consent form one: video and audio.....	350
Appendix 16: consent form two: audio only.....	351
Appendix 17: interview schedule guide/reminder	352
Appendix 18: sample thank you letter.....	353

Glossary of terms

Advance care planning: Overarching term for thinking and planning about your future death.

Advance care plan: A written summary of your wishes and decisions about end of life care. In England and Wales this may include an advance statement, advance decision to refuse treatment, lasting power of attorney or similar.

Advance decision to refuse treatment (ADRT): In England and Wales this is a formal way to document what treatments you do not want in the future if you cannot say so at the time. Other international terms used include living wills, advance health directive, advance directives or similar.

Advance statement: A written or verbal statement of your wishes and preferences for care at the end of life.

Best interests: A process for clinicians to follow to assess, ascertain and decide what is in the best interests for care for a person if they cannot say so themselves. Advance care planning tools such as advance statements, advance decisions to refuse treatment and lasting power of attorneys may be used to help gain as much information as possible about a person wishes.

DNACPR: Do not attempt cardio-pulmonary resuscitation.

End of life care: An approach to care for when somebody may be in the last years, year, months, weeks or days of life.

Hospice care: An approach to care (as in palliative care) which includes helping people who have an incurable illness live well until they die (and into bereavement for those that matter to them) through person-centred care. Includes inpatient and outpatient care, outreach, symptom control, conversations, education and research.

Lasting power of attorney (LPA): A term used in England and Wales for a legally appointed surrogate decision maker. Can distinguish between health and financial decisions. Other international terms include enduring, durable, health, continuing or similar.

Palliative care: A multi-professional approach to care for those who have an incurable illness (as in hospice care) with a focus on physical, emotional, psychological, spiritual and social support. Takes part in any setting and for those with cancer or non-cancer diagnoses.

Patient-centred care: An approach to care which situates the patient as an individual through their bio-medical experience of ill health and disease.

Person-centred care: An approach to care which situates the person within the context of their own social relationships, networks and experiences.

Supportive care: An umbrella term sometimes used for hospice, palliative and terminal care.

Terminal care: Often refers to the last weeks or days of life.

Chapter 1: Introduction

Study background

This study is about adult advance care planning. It is motivated by a desire to understand more about advance care planning to improve care through nursing research, policy, practice and education. This is compatible with the observation that professional doctorates are relevant not only to the knowledge economy but also with the potential to transform practice (Rolfe and Davies 2009). Nurse educators are in the business of transforming the view of the *“detached ivory-tower academic into meaningful, productive and mutually beneficial connections and collaborations with clinical colleagues and service areas”*. (Darbyshire, 2011:724). Transforming health and nursing palliative care practice through achievable and credible research and adding to the knowledge economy and practice was the motivation for the research topic and design.

During 20 years’ experience of teaching communication and advance care planning skills to health and social care professionals (clinicians); I have seen patients, their families and their experience of incurable illness made into a complex jigsaw of assessment, care, interventions and achievement of generic end of life goals. However, there seemed to be a mismatch between clinicians’ and peoples’ conversations and experiences. As an educator, I noticed that clinicians found it challenging to identify and discuss the advance care planning needs of patients and their families. This appeared to cause clinicians personal and professional distress as they tried to achieve a good death for their patients through a repertoire of communication skills and documents. Clinicians told stories of how patients did not want to have the conversations or care choices offered to them. I felt the need to examine more closely the influences on conversations such as advance care planning. My professional experience was that there was copious literature about what people wanted or did not want at the end of their life and fixed measurements of outcomes (for example. how many people died in their preferred place of death, had advance statements or advance decisions to refuse treatment, surrogate decision makers and Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decisions etc.). However, the relationship of the context of people’s lives with the

consideration of their future deaths appeared to be less reported. I was curious about the context of advance care planning conversations and the relational influences on why people did or did not talk, prepare or plan for their future dying.

In the last decade, there has been an emergence in national end of life care policy of an agenda of choice and individual autonomy through advance care planning activity such as advance statements, advance decisions to refuse treatment and appointment of surrogate decision makers. I became uncomfortable with the challenge of clinicians' trying to fit people into a tick box of predetermined end of life choices and decisions (local and regional policy often advocating that everyone should have an advance care plan) and that successful advance care planning was predominately measured on the presence of the plan and achievement of preferred place of death (often at home). Good care seemed to be less about understanding the complexity, the relationships or managing the uncertainty of peoples' lives and more concerned with patients as the sites or recipients of palliative care activity through a managed death (Kellehear 2007).

In my experience, communication and advance care planning education programmes had a predominate focus on facilitating decisions rather than developing a therapeutic partnership between the person and clinician as people lived with their dying. Talking about dying appeared to be an automatic precursor to decisions and documentation rather than a space for contemplation influenced by the relationships and context of peoples' lives. Advance care planning was becoming a reductionist, tick box; pre-set outcome approach to care – the primary target being the management of a good death through the achievement of a stated preferred place of death. It became important to me to understand both the sayable and unsayable aspects of human experience of illness (Schick Makaroff 2013) and the personal context for people of their advance care planning experiences and planning.

Introduction to advance care planning

Advance care planning for adults with a life shortening illness is an overarching term concerned with voluntary conversations about future dying and the documentation of wishes and decisions about future care including the right to refuse in advance treatments and the appointment of proxy or surrogate decision makers in anticipation of a future loss of capacity (National End of Life Care Programme 2010a). Internationally there are several different terms and definitions of advance care planning (appendix 1). In England and Wales, the legal terms are advance statements, advance decision to refuse treatment and lasting power of attorney (Lyne 2010). Whilst acknowledging the plethora of advance care planning, palliative care and end of life terms and definitions (Russell 2014); as a concept it represents the possibility of a person (with an illness that cannot be cured) and those who are important to them thinking and planning for the end of life. Advance care planning focuses on the goal of a good death event, with elements of individual needs, anticipated withdrawal or withholding of interventions, symptom control, dying in the expressed preferred place of death as well as not being admitted to hospital (Russell 2014).

Advance care planning as a concept is seen in a number of international end of life documents (for example. DH 2008; NICE 2011; The Leadership Alliance for the Care of Dying 2014; The Independent Review of the Liverpool Care 2013; National Palliative and End of Life Care Partnership 2015; NHS Scotland 2008; NHS Wales Health Board 2013; Department of Health 2010; Queensland 2015). Advance care planning has been present in the health and legal literature since the latter half of the 20th century (Seymour and Horne 2011). In 1967, Luis Kutner, a human rights lawyer representing the Euthanasia Society of America described a document called 'a living will' (or advance directive). Made in advance it described the extent to which an individual might want treatment to be used when they were no longer able to make a health care decision themselves (Kutner 1969).

Following the seminal 1989– 1991 United States of America (USA) *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment* (SUPPORT), there was an increase in advance care planning activity (Seymour and Horne 2011). The SUPPORT study

objective was to improve decision making in order to address the growing national concern in the USA over the loss of control that patients had near the end of life and to reduce the frequency of a mechanical, painful, and prolonged process of dying (Hamel et al. 1999). The SUPPORT study prompted further discussion about advance care planning and challenged health care providers to design more flexible approaches to end of life care (Collins et al. 2006). This was especially pertinent as one of the outcomes of the SUPPORT study was to highlight that improving clinicians' communication skills on their own did not improve care (Brinkman-Stoppelenburg et al. 2014).

The rationale for the SUPPORT study was illustrated by a number of international seminal cases highlighting the need for clarity of legislative and clinical frameworks when there was a need to plan for clinical decision-making because of possible future incapacity (appendix 2). Central to the demand to clarify frameworks was consideration of the decision making process (advance decisions or similar) for the circumstances of when an individual was unable to express or consent themselves for interventions, the right to refuse treatments in advance for one self, as well as decisions to withdraw or with-hold treatments based upon precedent autonomy of previously expressed wishes or preferences rather than clinicians making in the moment decisions based on their perceptions of value or quality of life.

There was a parallel process for surrogate decisions makers. Attorneys (or an individual legally empowered to act on another's behalf (i.e. surrogate decision maker) have been within the international legal frameworks for some time. In Virginia, USA, 'durable power of attorneys' for property had been in force since 1954 (Sabatino 2010). In England and Wales, general powers of attorney represented by 'enduring power of attorney' were replaced by the more specific 'lasting power of attorney' in 2005 (Lyne 2010) which included both property and affairs or health and welfare authority. The surrogate decision makers enabled further detail and authority; for example, 'best interest' decisions at the end of life when the individual was unable to communicate their wishes or decisions about care or interventions and decisions needed to be made on their behalf.

Advance care planning not only developed within legal frameworks but also within national end of life clinical strategies seen in examples such as the United Kingdom End of Life Strategy (DH 2008), in Australia the Queensland state wide strategy for end of life care (Queensland 2015), Canadian Strategy on Palliative and End of Life Care (Health Canada 2007) and in Singapore the National Strategy for Palliative Care (On et al. 2011). However, national end of life care strategies and legal frameworks varied widely in terms of definitions, clinical focus, legal requirements and choice aspects (Sabatino 2010; Van Beek et al. 2013; Seymour and Horne 2011; Russell 2014). For example, a comparison of palliative care across seven European countries reported significant differences in the presence of legislation and regulations for advance care planning (Van Beek et al. 2013).

The focus of much advance care planning clinical and research activity has been on advance decision and surrogate decision maker variations (Brinkman-Stoppelenburg et al. 2014; Lovell and Yates 2014). However, there is robust evidence that this activity on its own does not improve end of life care (Prendergast 2001) with for example. questions about the stability of choices as well as assumptions of the validity of precedent autonomy (Seymour and Horne 2011). Indeed, there are persistent arguments that advance care planning should move towards seeing its social, health, behavioral and contextual process, with conversations about preparing for death, reviewing immediate goals, hopes for the future and strengthening relationships (Lovell and Yates 2014; Brinkman-Stoppelenburg et al. 2014; Sabatino 2010; Fins et al. 2005; Seymour and Horne 2011; Borgstrom 2015).

There is support for the view that advance care planning should be more than just documents and decisions. Sabatini (2010) argues the importance of a move away from a legal transactional model of advance care planning (for example. decisions and documents) toward a relational communications model. Fins et al (2005) questions the adherence to narrow notions of self-determination arguing that judgements are contextually informed. Furthermore, Rietjens et al (2016), comment that advance care planning should be seen as a complex intervention because it includes reflection and communication as well as the completion of documents. Borgstrom (2015) also points out that advance care planning tools

have become tasks to do as opposed to triggers for conversations which overshadow relational aspects such as care as an on-going process and relationships forged through connections to others. Furthermore, there are observations that the complexity of individuals and sociocultural factors and the legal health system is underestimated in advance care planning (Lovell and Yates 2014). There is also debate if place of death is the most important aspect of end of life care (NIHR Dissemination Centre 2015) as well as a need to understand more about the benefits of advance care planning and other approaches to listening to and incorporating patients' preferences (PeolcPSP 2015).

Rationale for the research question

There is a call within the research and clinical community to re-conceptualize advance care planning away from solely the legal documentation, decisions made in advance and surrogate decision makers to an iterative (Lovell and Yates 2014) and social (Singer et al. 1998) process with a wider more nuanced notion of self-determination (Fins et al 2005). Other social, clinical or professional contextual factors are recognized (Lovell and Yates 2014). This includes a move towards a communications model within a broader concept of patient-centered care and the quality of communication among the individual, family, and health care providers (Sabatino 2010; Brinkman-Stoppelenburg et al. 2014). The shift to conceptualize advance care planning as an activity within a philosophy of person-centered care, concerned with the complexity of the context of and relationships within an individual's life rather than the achievement of an advance care plan solely concerned with precedent autonomy, decisions and surrogate decision makers as well as legal frameworks is the fundamental motivation for this study. It reflects the importance of understanding more of the personal context of advance care planning and viewing advance care planning as a complex intervention influenced by social and personal considerations as well as others such as prognosis and diagnosis.

Organisation of the thesis

Advance care planning is introduced through an overview of its history, diversity of terms and definitions. The case for viewing advance care planning as more than the completion of

documents and appointment of surrogate decision makers is raised. In Chapter One, advance care planning is introduced. In Chapter Two, the literature review explores the evidence to the benefits and barriers of advance care planning, picking up on areas of interest that illustrate the relational influences on advance care planning. The evidence for types of communication behaviour and education is discussed. Chapter Three explains why a qualitative approach to the study was appropriate and describes the methods used for carrying out the interviews, transcription, coding and analysing the data. Ethical and reflexivity issues are explored and illustrated using examples from the study. The participants and research site are described. Chapters Four, Five and Six present the findings: *Living with dying, Preparing and planning for dying and Clinicians' communication*. These build the evidence to suggest how the relational aspects of a person's life influence their advance care planning. Chapter Seven discusses the study's findings in the context of the related literature and suggests a model of '*relational advance care planning*' as a contribution to person-centred care. The argument for how the findings add to the current advance care planning knowledge base and recommendations for future policy, education and practice is presented. Strengths and limitations of the study are considered and recommendations for future research are made.

Chapter 2: Literature Review

Introduction

This chapter outlines how the literature was searched, appraises the advance care planning and communication skills evidence and summarises areas of interest. The literature review illustrates the complexity of the context of advance care planning and conversations, providing the rationale for the study's research questions of what influences people to carry out advance care planning and the communication skills that hospice patients find helpful in such discussions.

Overview of the literature searching strategies

A continuous literature review of published and unpublished documents (Hart 1998) and resources was undertaken; before (to inform the research proposal), during (to keep up to date with current evidence) and after the research interviews to inform the analysis and findings (Robson 1993; Silverman 2010; Holloway and Wheeler 1996; Holloway and Freshwater 2007). Searching the literature in this way enabled the identification, evaluation and interpretation of the work of researchers, scholars and practitioners in the chosen field (Fink 1998), including what had already been written, emerging issues, knowledge gaps, avoiding duplication, keeping up to date with new methods of inquiry, how old methods had been redeployed and situating the findings in the existing literature (Holloway and Wheeler 1996).

When and how the literature was searched

The search was carried out throughout the study aiming to be "*dialogic rather than mere replication*" (Silverman 2010:321) and not a laundry list of studies (Rudestam and Rae 1992). This enabled a focus on studies that were relevant for defining the research (Silverman 2013). The literature became more directed as the analysis developed (Silverman 2010). Attention was paid to build upon existing literature (Denscombe 2007) by identifying particular

concepts of interest for the thesis for example. to stimulate questions, concepts and relationships (Silverman 2010; Strauss and Corbin 1990).

Data bases used to search the literature

Multiple computerised data bases were used as they are an effective way to retrieve the literature, albeit no one database is complete (Fink 1998; Gysels and Higginson 2007). Literature written in English was searched using for example. Pub Med, Google Scholar, Cumulative Index to Nursing and Allied Health Literature, Web of Science, Department of Health, Research Gate and the Cochrane Library. Hand searching and article electronic alerts of publisher sites such as Wiley and Blackwell, Sage Publications and BMC Palliative Care was also carried out including grey literature to capture references missed by electronic searches or literature just published (Gysels and Higginson 2007). In addition, authors or journal editors were contacted directly to check information or to inquire about planned publications.

Search timeframe and terms used

Literature regarding adult advance care planning, communication, palliative, terminal, hospice and end of life care was searched from 1960 to 2016 (figure 1). This time span recognised the evolvment of the hospice and palliative care movement and the development of the concepts of death awareness and denial from the 1960s (Glaser and Strauss 1965; Becker 1973), the emergence of the term advance care planning in the latter part of the 20th century (Teno et al. 1994; Seymour and Horne 2011) and key legislative moments which incorporated the individual right to make decisions about their end of life. For example, in England and Wales the Mental Capacity Act (Lyne 2010), in New Zealand the Code of Health and Disability Consumers Rights (Hardie Boys 1996), in Australia the Consent to Medical Treatment and Palliative Care Act (Parliament of South Australia 1995) and in the USA the 1990 Patient Self Determination Act (One Hundred and First Congress 1990). Whilst much of the published advance care planning evidence base comes from the USA (Lobo 2011; Brinkman-Stoppelenburg et al. 2014) the literature search included international studies as well as those from the United Kingdom.

Figure 1: literature key search terms

Figure 1: literature key search terms
To represent advance care planning
<ol style="list-style-type: none"> 1. Advance AND Care* or Planning* or Plan* 2. Advanced AND Care* or Planning* or Plan* 3. Future AND Care* or Planning* or Plan* 4. Ahead AND Care* or Planning* or Plan* or Thinking* 5. Anticipatory AND Care* or Planning* or Plan* 6. Advance AND Statement* or Statements* 7. Advanced AND Statement* or Statements* 8. Advanced AND Decision* or Refuse* or Treatment* or Directive* or Directives* 9. Advance AND Decision* or Refuse* or Treatment* or Directive* or Directives* 10. ADRT 11. 1,2,3,4,5,6,7,8,9,10 AND Cancer* or *Non Cancer* 12. 1,2,3,4,5,6,7,8,9,10 AND Respiratory* or Cardiac* or Heart Failure* or Neurological* or Dementia* or Kidney* or Renal* or Disease* 13. Living AND Will* or Wills* 14. Preferred AND Place* or Care* or Death* or PPC* or PPD* or Priorities* 15. GSF* or Gold Standard Framework* or Gold Standards Framework 16. Preferred Priorities AND For Care* or Of Care* 17. DNACPR AND Resuscitation* or Natural* or Death* 18. Attorney AND Power* or Lasting* or Enduring* or Durable* 19. Best AND Interest* or Interests*
To represent the experience of people who have an incurable illness.
<ol style="list-style-type: none"> 1. End AND of Life* or Care* or Registers* or Decisions* or Choices* or Wishes* or Preferences* 2. Palliative AND Care* 3. Terminal AND Care* 4. Supportive AND Care* 5. Hospice AND Care* 6. Last AND Days* 7. 1,2,3,4,5,6, AND Cancer* or Non Cancer* 8. 1,2,3,4,5,6 AND Respiratory* or Cardiac* or Heart Failure* or Neurological* or Dementia* or Kidney* or Disease*
To represent the experience of dying
<ol style="list-style-type: none"> 1. Dying AND Good* or Bad* or Living* 2. Death and Good* or Bad* 3. Assisted AND Dying* or Suicide* 4. Euthanasia AND Passive* or Active* or Suicide* 5. Right AND to die* 6. Death AND Anxiety* or Awareness* or Denial* or Denying* or Fear* or Preparedness* or Readiness* 7. Mortality AND Salience* or Awareness* 8. Terror AND Management*

Searching the literature

The literature, citations and references within individual publications were filleted (Silverman 2010) by skimming; for example. reading the abstract, first and last sentences and conclusions

before reading in full. The literature was stored and reviewed using the Mendeley reference manager programme. This helped in later retrieval of the literature in terms of for example. key words, content, research approach and organisation into topic or subject files. The search produced extensive results, so a summary strategy approach based upon PRISMA (Moher et al. 2009) helped to exclude less appropriate studies, prioritise more relevant articles and enabled a retrieval of references later on (appendix 3).

The benefits of advance care planning

There is a body of literature regarding the benefits of advance care planning activity stemming from a variety of international clinical audit, service evaluation and research literature (Russell 2014). This reflects the diverse and often competing needs of patients, health professionals, legislature and health systems (Lovell and Yates 2014). It is predominately based upon patient, family, clinician or organisational interventions and experiences in anticipation of an individual's future loss of capacity and the need to plan for that eventuality. Much of the literature is from research and practice in institutional settings such as hospitals, care homes and intensive care units (Brinkman-Stoppelenburgh et al 2014).

The literature regularly focuses on specific areas, particularly to do with where people want to die (preferred place of death), the anticipation of the loss of capacity (and appointment of surrogate decision makers) and the completion of documents identifying what treatments individuals do not want in the future (for example. advance decisions and DNACPR). There is evidence that advance care planning increases the achievement of the preferred place of death (often assumed to be at home) with less invasive or costly treatments (Detering et al. 2010; Houben et al. 2014; Wright et al. 2008). Much of the research is concerned with advance decisions (Institute of Medicine of the National Academies 2015), with benefits reported of for example. the enhancement of autonomy and decision making in anticipation of future loss of capacity (Conroy et al. 2009; Singer et al. 1998; Steinhauser et al. 2000; Vandervoort et al. 2014), relieving family anxiety by removing the burden of decision making (Detering et al. 2010), reducing futile interventions (Brinkman-Stoppelenburg et al. 2014) and reduction of inappropriate hospital admissions and associated economic costs (Klingler et al.

2015; Dixon, Matosevic, et al. 2015). Other studies report a reduction in aggressive medical treatments at the end of life (Wright et al. 2008) as well as satisfaction with primary physicians following advance care planning discussions (Tierney et al. 2001). Benefits noted include evidence of an increase in patient and surrogate shared decision making (Grimaldo et al. 2001; Westley and Briggs 2004; Brinkman-Stoppelenburg et al. 2014). Systematic reviews have reported that advance care planning may decrease the use of cardio pulmonary resuscitation, increase hospice and palliative care services, reduce family distress (Brinkman-Stoppelenburg et al. 2014) as well as increase the completion of advance directives and concordance between preferences for care and delivered care (Houben et al. 2014).

There is evidence that where discussions and decisions are made in advance, in line with patients values and when incapacity is planned for expressed goals such as achievement of preferred place of death and reduction of inappropriate hospital admissions occurs more frequently (Sabatino 2010; Teno et al. 2004). Studies report that advance care planning improves the quality of end of life care and patient and family satisfaction, reducing stress, anxiety, and depression in surviving relatives (Detering et al. 2010; Bischoff et al. 2013). The process in itself can be therapeutic (Thomas 2011; Seymour and Horne 2011) easing difficult situations at the end of life (Hildebrand 2012) and improves concordance between patients preferences and end of care received (Morrison et al. 2005; Detering et al. 2010).

How successful is advance care planning?

Advance care planning is repeatedly presented as a measure of success in end of life conversations, activity and interventions. However, the success of advance care planning is influenced by several contextual factors. These illustrate the value to examine its diversity and complexity. Some are presented here. Despite an abundance of literature since the 1990's (Seymour and Horne 2011), evidence for the success of advance care planning remains unclear in terms of what are the patients, families, clinicians or systems barriers, blocks, process or goals of advance care planning (Russell 2014). There is evidence that the uptake of advance care planning is low (Gillick 2010; Prendergast 2001) with few patients engaging in it (Institute of Medicine of the National Academies 2015). Furthermore, the contextual factors

of the uptake of advance care planning are poorly understood (Rhee et al. 2013) and there are a number of challenges within the literature of its effectiveness (Mullick et al. 2013; Pollock and Wilson 2015). Prendergast (2001) comments that the focus on advance directives in advance care planning has not reduced hospital admissions or improved care. Moreover, the SUPPORT study did not improve advance directives completion (Teno et al. 1994), with further comments that improving patient-physician communication on its own was not sufficient with a need to improve systems both within and across organisations (Lovell and Yates 2014; Teno et al. 1994; Teno et al. 2004).

Other studies report that clinicians and patients are uncertain of terms, definitions and documents (Rhee et al. 2013; Pollock and Wilson 2015; Institute of Medicine of the National Academies 2015). Questions have been raised about the value of documentation in itself (Sabatino 2010). Much of the research advocates a focus on on-going discussions rather than encouraging binding advance decisions (MacPherson et al. 2013). Brinkman-Stoppelenburg et al (2014) systematic review concluded that complex interventions may be more effective than written documents alone and that advance directives were not found to be clearly associated with symptom burden, quality of life/dying or satisfaction with care. The reasons why advance care planning activity is successful (or not) remains unclear or unproven and there continues to be persistent calls to recognise advance care planning as a complex intervention with a need for a broader evidence base to understand all its elements (Rietjens et al. 2016).

Terms, documents, legal and organisation frameworks

Examining the literature illustrates the multiple contexts within which advance care planning takes place including the plethora of international terms, documents and legal frameworks with varying legislative powers making it challenging to negotiate the literature and translate to practice (Russell 2014). Terms and documents range from advance care planning, advance statements, advance decision to refuse treatment and lasting power of attorney (England and Wales) to advance care directive (Ireland), statements of wishes and preferences (a values history), instructional advance directives (sometimes known as a living will) and durable

power of attorney for health care in the United States (Russell 2014). Ontario's framework in Canada describes advance care plans, goals of care designation, power of attorney/personal care and substitute decision makers (Wahl 2006). Moreover, there are numerous other related documents, with different uptake and authority such as Treatment Escalation Plans, Health Emergency Plans, Universal Form of Treatment Options and Physician Orders for Life Sustaining Treatments (Russell 2014), developed to communicate decisions such as DNACPR or decisions regarding future hospital admission.

International legislative frameworks vary enormously. In England and Wales, lasting power of attorneys and advance decisions to refuse treatment are included within the Mental Capacity Act (Lyne 2010). In the Republic of Ireland, advance care directives are not contained within a specific legal framework, but case law indicates that the courts will recognize them (Law Reform Commission 2009). In the United States there are significant differences across individual states in the breadth, depth and legislative origin of default surrogate consent laws (Sabatino 2010) as well as provincial variances in Canada (Wahl 2006). Furthermore, statute law relating to guardianship, surrogate decision makers and advance directives differs state by state in Australia (Parker and Cartwright 2004). In New Zealand, advance care planning operates within several legal frameworks (Ministry of Health 2011). There are also calls to recognise the difference between secular and religious frameworks at the end of life (Babgi 2009; Al-Jahdali et al. 2009) and to consider different cultural approaches to end of life care (Steinberg 2011; Wright et al. 2008) for both the patient and the clinicians (Kwak and Haley 2005; Mitchell and Mitchell 2009).

Recent literature (Boddy et al. 2013; Lovell and Yates 2014; Institute of Medicine of the National Academies 2015) identifies patient, practitioner and system centred barriers to advance care planning such as legal frameworks (Gates et al. 1996; Kelner et al. 1993; Seymour et al. 2010), organisational processes (Kjervik and Badzek 1998; Hagen et al. 2015; Seymour et al. 2010; Boddy et al. 2013) and documents (Gates et al. 1996; Boddy et al. 2013). Boddy et al (2013) review of Australian practitioners' perspectives reported barriers such as a lack of a central registry, conflicting state legislation and questions about roles,

responsibilities and cognitive capacity. Ahluwalia et al. (2015) comment on the lack of coordination and variation between providers as does Institute of Medicine of the National Academies (2015) who report widespread lack of coordination and collaboration between states, legislation and documents. Similar concerns are echoed by Robinson et al. (2013) and Rhee et al. (2013) who comment on clinicians' uncertainty of advance care planning documents and transferability across settings. Hagen et al (2015) identified barriers such as lack of support from organisational leaders to implement advance care planning. Seymour et al. (2010) study of community nurses reported similar findings including that advance care planning documents represented bureaucracy, a tick box approach and national legislation and policy rather than the existing every-day practice of nurses.

Other barriers include a lack of knowledge of advance care planning terms, process and documents for both patients and clinicians (Boddy et al. 2013; Pollock and Wilson 2015) including confusion over documentation as well as confusion and misunderstanding of the extent and intent of advance directives (Institute of Medicine of the National Academies 2015). Patients' preferences and wishes have also been shown to change over time (Over et al. 2007; Hawkins et al. 2005) making it challenging to keep track of such preferences between multiple providers (Institute of Medicine of the National Academies 2015). The plethora of terms, documents, legal and organisational process illustrates the challenge for patients, families and clinicians as they seek to discuss, understand and carry out advance care planning.

Hidden and vulnerable populations

There are questions about populations such as the homeless, who are hidden, vulnerable and disadvantaged in accessing palliative care and advance care planning (Webb 2015; MacWilliams et al. 2014). For example, Song et al.(2010) in a study of homeless people reported an increase in advance directives only when supported by an advance care planning session and counsellor. Moreover, there is evidence that clinicians do not understand the particular end of life needs of homeless populations (Song et al. 2010; National End of Life Care Programme 2010b). Similar findings are reported for those with intellectual disabilities

(Tuffrey-Wijne et al. 2008; Tuffrey-Wijne et al. 2007) and there is also evidence of barriers to advance care planning to groups such as the prison population (Torjesen 2008; Sanders et al. 2014; Maschi et al. 2014) with concerns over consent in a correctional institution (Thomas and Watson 1998), human rights (Maschi et al. 2014) and tensions between philosophies of care and custody (Turner et al. 2011). These examples illustrate the need to take into consideration the contextual issues in advance care planning of for example. relationships with services, process and legal frameworks for specific groups.

Diagnosis inequity

There is robust evidence of a paucity of research and unmet end of life care needs for those with a non-cancer diagnosis (Lovell and Yates 2014; Dixon et al. 2015; Kendall et al. 2015; Gadoud et al. 2014; Yohannes 2007; Skilbeck and Payne 2005; Boland and Johnson 2013; Gomez-Batiste et al. 2014). This is seen for example in; people with dementia (Treloar et al. 2009; Sampson et al. 2011; Harris 2007; Dixon et al. 2015), cardio vascular disease (Selecky et al. 2005; Pattenden et al. 2013; Murray et al. 2002; Stuart 2007; Whellan et al. 2014; Beard et al. 2014; Thai and Cujec 2010; Selman et al. 2007) and end stage renal disease (Davison and Simpson 2006; Davison et al. 2006; Holley 2012; Arulkumaran et al. 2012). This is troubling as early palliative care interventions (including advance care planning) have shown benefits across all disease groups (De Vleminck et al. 2014; Beernaert et al. 2015).

There are a variety of disease specific considerations (such as timing and type of conversations or decisions) reported in the literature (Russell 2015d). Examples from COPD (Curtis et al. 2004; Patel et al. 2012; Janssen et al. 2012), heart failure (Caldwell et al. 2007; Barclay et al. 2011; Whellan et al. 2014), renal patients (Murtagh et al. 2011; Holley 2012; Kolarik et al. 2002), dementia, (van der Steen et al. 2014; Dening et al. 2013; Sampson et al. 2011; Torke 2014; Exley et al. 2009) serve to illustrate that one size does not fit all in advance care planning (Russell 2015c). This is of potential importance as people who do not die of cancer are a major percentage of the population. For example, 75% of deaths in high income countries are caused by chronic conditions rather than a cancer diagnosis (Gomez-Batiste et al. 2014) with diagnosis such as COPD, heart failure, kidney disease and dementia being

significant causes of morbidity and mortality (Pauwels 2001; Boland and Johnson 2013; Yohannes 2007; Lewis and Scullion 2012; Hupcey et al. 2015; Holley 2012; Howlett et al. 2010; Denning et al. 2013; Davies et al. 2014; Nakanishi et al. 2015; van der Steen et al. 2014; Shah et al. 2013). There is constant debate about the relevance of different types of illness experience and disease trajectories described in the oncology, palliative care and non-cancer literature (Murray et al. 2010; Murray et al. 2005; Murtagh et al. 2011; Schell et al. 2013;) with the challenge of increasing integration of supportive and palliative care from the point of diagnosis and confusion about whether services work independently or collaboratively with each other (Lynn and Adamson 2003; Murray et al. 2005; Hawley 2014).

Demographic factors

There are reports of the influence of demographic factors on advance care planning. The relevance of age has been reported (Bravo et al. 2012; Institute of Medicine of the National Academies 2015) albeit with inconsistent findings (Gomes and Higginson 2006). Age is of interest because of the estimates that by 2030, 4 in 10 deaths will be from those aged at least 85 years (Hanratty et al. 2014). Some studies report the uptake of advance directives being positively correlated to older age (Black and Reynolds 2008; Dow et al. 2010; Institute of Medicine of the National Academies 2015) with others reporting the influence of previous experience of illness (Fried et al. 2009), health status or disability (Lovell and Yates 2014; Meeussen et al. 2011) on advance care planning activity. Some of the literature has examined age as a specific factor. For example, Gomes et al. (2011) report that in England in 2008, two-thirds of deaths occurred at age 75 and over; with people dying in this age group are more likely to die in hospital (Lock and Higginson 2005; Evans et al. 2014). It is unclear whether this is the result of the context of clinical and social circumstances associated with older age (such as living alone) or of different preferences amongst older people (Gomes et al 2011).

There are a variety of other related factors to take into consideration for the older population such as the likelihood of multiple co-morbidities, unpredictable dying trajectory, age stereotyping, generational differences in communication styles, physician discrimination, family dynamics to protective behaviours, cognitive impairment and capacity issues (Cheng

et al. 2008; Adelman et al. 2000; Samsi and Manthorpe 2011; Clarke and Seymour 2010; Froggatt et al. 2009; Evans et al. 2012). Whilst there is evidence that older age can be associated with a greater uptake of advance care planning (Lovell and Yates 2014; Black and Reynolds 2008), there is also evidence of a decreasing preference to die at home (as age increases) and an increased preference to die in a hospice (except for the group aged 55-64) (Gomes et al. 2011). However, there is evidence that despite wanting conversations (Malcomson and Bisbee 2009) advance care planning is often not discussed or documented in older patients (Sharp et al. 2013). Age as a factor in advance care planning bears consideration from a clinical comorbidity perspective, social context, living with dying experience as well as stereotypes associated with age. Moreover, the language of advance directives documents may be controversial as terms such as living well or extreme disability are personal and contextual, leading to questions about the use of such terms in documents and the subjective assessment of quality of life from others (for example. clinicians) (Institute of Medicine of the National Academies 2015).

Other demographic factors have also been reported such as the relationship between palliative care and ethnicity, race and cultural aspects (Russell 2015b; Dixon et al. 2015; Lovell and Yates 2014; Reynolds et al. 2008). Hopp and Duffy (2000) report a lower uptake of surrogate decision makers and decisions made in advance in non-white or non-European ethnic groups and there is evidence that non-white nursing home residents were less likely to have do not attempt resuscitation orders (Reynolds et al. 2008).

The role of socio-economic factors remains unclear in advance care planning. Whilst there is robust evidence of a relationship between social-economic factors and health outcomes (Lewis et al. 2014; Lewis et al. 2013). Some studies show that low socio – economic status does not necessarily mean the absence of advance care planning activity (Shrank et al. 2005). However, there is evidence that people with cancer and lower socio-economic status are less likely to die at home and have more barriers to palliative care (Chen et al. 2015). Literacy and the level of education has also been identified as a barrier to advance care planning (Sudore et al. 2007; Hopp 2000). Waite et al. (2013) reported a direct relationship between general

literacy and the uptake of advance directives. Furthermore, Volandes et al. (2008) identified that health literacy was an important factor in the completion of advance directives. The role of gender as a barrier also remains unclear, despite some studies reporting that it has an effect on advance care planning (Bravo et al. 2012; Hopp 2000) as does marital status (Kahana et al 2004), lesbian, gay, bisexual and transgender context (Cartwright et al. 2012; Stein and Bonuck 2001) and social support networks at the end of life (Lewis et al. 2013).

Person-centred care

There are a number of additional areas illustrating the contextual nature of advance care planning. The overarching challenge is the nature of advance care planning itself. Is it solely concerned with planning for dying (for those with an identifiable short prognosis); within a medical gaze (Foucault 1973) paradigm of choice and control through anticipation of biomedical death, future incapacity, foreseeing of future decisions and subsequent documentation with appointment of surrogate decision makers? Or is it something wider, broader, less planned and related to how people contemplate and live within their social worlds with the knowledge of their future deaths with choice and control not only concerned with the where and when of death but also rooted in how people choose to live with and talk about their dying?

The on-going patient and person-centred narrative is seen within numerous policy, strategic and clinical documents (for example. Francis 2013; National Palliative and End of Life Care Partnership 2015; NICE 2011). How advance care planning is conceptualised within this paradigm is of interest. For example, by defining an individual predominately as a patient rather than a person they become situated within the context of bio-medical disruption to their bodies from ill health as opposed to a person within for example. their social networks and relationships. This is of interest when considering what is the anticipated outcome of advance care planning activity. For example, is it concerned with choice and control over medical decisions, place of death and practical care within a last year of life paradigm or with other contextual aspects such as family relationships or choosing how to live with the knowledge of one's future death?

Patient-centred care predominately situates the individual as a patient through their bio-medical experience of ill health and disease. Barry and Edgman-Levitan (2012) point out that this highlights the importance of clinicians and patients working together to produce the best outcomes possible. It also focuses on experience and perspectives on what good quality care is (see Powis et al. 2004) and shared decision making for example. 'Nothing about me without me' as expressed by Valerie Billingham at 'Through the Patient's Eyes' Salzburg Seminar Session 356 (Seminar 2011) .

Person-centred care is often illustrated through the concept of 'personhood' as described by Kitwood (1992) and is concerned with the status that is bestowed upon one human being by others, in the context of relationships and social being (Kitwood 1997). The term is often used to exemplify good health or social care practice (Nolan et al. 2004), despite there being many interpretations as to what it is (Entwistle and Watt 2013). However there are overarching themes of treating and respecting the patient as a person (Miles and Mezzich 2011) rather than solely a site of bio-medical and services activity. These themes situate the person within the context of their own social relationships, networks and experiences rather than their diagnosis, prognosis or service activity outcomes by concentrating on what matters most to patients (Heyland 2006) taking full account of patient's values, preferences, stories, cultural context, fears, worries and hopes and which thus recognises and responds to their emotional, spiritual and social necessities in addition to their physical needs (Miles and Mezzich 2011). This sees the patient as being in a social world (McCormack 2004). End of life care and advance care planning seen through the person-centred lens is concerned with situating the individual as a person (by focussing on the person in the patient – see Clarke et al 2003) within their social world and relationships and what is important to them within that rather than sites of services and biological disruption to their bodies.

The person-centred approach has relevance to advance care planning especially when considering that *"for most people dying begins months or years before death"* (Hicks 2012). Moreover, it could be argued that person-centred advance care planning takes into account other aspects such as social dying where dying takes part in the context of relationships with others (Howarth 2011), involving a series of status passages as they die (Glaser and Strauss

1965) as well as the possibility of being socially marginalised and isolated before biological death (Sudnow 1967; Kellehear 2007; Glaser and Strauss 1965). Furthermore, advance care planning activity takes part in multiple contexts; from the individual themselves to health and social care systems (Russell 2012).

Living with dying

Living with dying as a term is seen within the health and social literature illustrated by the large body of evidence regarding for example. how people live with the effects of biographical disruption on the body in chronic illness (Bury 1982; Reeve et al. 2010), how dying affects identity (Hubbard and Forbat 2012; Henriksen and Hansen 2009) and in incurable cancer (Hubbard and Forbat 2012). In the sociological literature there is an on-going discourse about how society constructs and manages the illness, death and dying experience and role (Seale 1991; Seale and Addington-Hall 1995; Walter 2003; Walter 2004; Charmaz 1980; Mellor and Shilling 1993; Firth-Cozens and Field 1991; Field and Copp 1999; Lawton 1998; Lawton 2002; Howarth 2011). In addition, whilst there is data about the experiences of people in the last year of their life (Higginson and Addington-Hall 1999; Addington-Hall and McCarthy 1995; Seale and Addington-Hall 1995; Seale 2000; Pinnock et al. 2011; Kendall et al. 2015; Ellis 2013a) there still remain concerns about the extent of knowledge of the experience of dying (Kayser-Jones 2002) or living with dying (McTiernan and O'Connell 2015). Although there is evidence that for example. illness narratives affect and shape experiences, thoughts, and fears in the last months of life (Kendall et al. 2015); there are also calls to understand more how daily life is integral to understanding the ways in which people are able to maintain a sense of continuity during the circumstances of impending death (Ellis 2013b) as well as understanding more of the actual dying experience (Pollock and Wilson 2015).

Timing of advance care planning conversations

Reported in the literature is persistent uncertainty over the correct timing of advance care planning conversations within a person's illness or dying trajectory (Holley 2005; Holley 2012; Kendall et al. 2015; Schell et al. 2013; Murray et al. 2005). Much of the literature conceptualises advance care planning activity within (an accurate prediction of) the last year

of life. For example, this is seen in the End of Life Strategy Six Steps framework (DH 2008) and its advocacy of advance care planning conversations within this time span. There is evidence of the importance of the timing and style of advance care planning conversations in an advancing disease trajectory (Murray et al 2016).

However, there are arguments that a prognosis-based focus to the timing of advance care planning conversations is challenging as well as arguably not achievable in practice (Pollock and Wilson 2015). Moreover, the literature reports that prognostic tools are inconclusive, making timing of referral to palliative care services or prognosis based advance care planning conversations difficult to judge. For example, Coventry et al. (2005) point out that whilst there are some disease specific indications for people with dementia, COPD and congestive heart failure, there remains no validated clinical prognostic model and there is a need to take into account social and psychological factors. Cardona-Morrell and Hillman (2015) review of the (mostly hospital) literature identified a plethora of different types of screening and clinical decision tools to identify the end of life. However, the evidence for the accuracy of prognostic tools remains unclear with calls for further validation research (Institute of Medicine of the National Academies 2015). Russell (2015a) highlights that there is also debate about what we are really defining, measuring or talking about including dying and the duration of the dying phase with complexity of diagnosing dying highlighted within recent reviews of the Liverpool Care Pathway (Kennedy et al. 2014) and reflected in the current care of the dying patient guidance (NICE 2015) in the UK.

The dying and illness trajectory concept (appendix 4) has been present in the literature for some time (see Glaser and Strauss 1965; Hallenbeck 2003; Lunney et al. 2003) and is reflected in numerous examples (for example. Barclay et al. 2014; Murray et al. 2010; Lunney et al. 2003; Lunney and Lynn 2010; Covinsky et al. 2003). The literature has broadened out from distinct illness functional trajectories (Lunney et al. 2003; Lunney and Lynn 2010) to other aspects such as patient and carer social, psychological, and spiritual wellbeing (Murray et al 2010.), quality of life and physical trajectories (Tang and McCorkle 2002; Tang et al. 2014) and contrasting narratives between people with cancer and those with other incurable

illnesses (Kendall et al. 2015). Furthermore, Murray et al. (2005) discussion of illness trajectories of; a short period of evident decline (for example. cancer), long term limitations with intermittent serious episodes (for example. organ failure diseases such as respiratory and cardiac disease) and prolonged dwindling (for example. dementia) provided a further lens to view illness and dying. It is argued that trajectories provide a conceptual map of a broad timeframe, patterns of probable needs and health and social care interactions towards death (Murray et al. 2005). Moreover there is evidence that trajectories enable practical planning towards a good death (Murray and McLoughlin 2012) reflected in (Masso et al. 2015) phases of illness used within the UK palliative care funding review initiative (NHS England 2015).

The dying and illness trajectories offer a great deal to the evidence base, especially in terms of identifying referral points to palliative care services (Kennedy et al. 2014; Bruera and Hui 2010; Murray et al.2005; Tang et al. 2014) and conceptualising both carer and patient physical, spiritual, emotional and social trajectories. However, there are challenges in the literature that basing a conversation model around prognostic accuracy of a dying trajectory is at best risky and at worst ineffective as it *“presupposes a high degree of prognostic accuracy in identifying patients entering the last year of life which is not achievable in practice”* (Pollock and Wilson 2015:77). Moreover, it positions advance care planning only within a dying rather than a life cycle or disease management paradigm (Institute of Medicine of the National Academies 2015). There is evidence that one of the reasons clinicians do not initiate advance care planning discussions is because of fear of prognostic inaccuracy (Boyd et al. 2010; Robinson et al. 2013; Lovell and Yates 2014; Gott et al. 2009; Seymour et al. 2010). The challenge therefore is whether a policy focus on identifying the certainty of the last year of life as the predominant trigger for advance care planning conversations actually meets the advance care planning needs of those daily living with an incurable illness over a prolonged period of time.

This challenge is seen in the wider literature. For example, the Leadership Alliance for the Care of Dying (2014) emphasized the importance of early discussion and planning for death substantially in advance of the point at which an individual is recognized to have reached the

end of life (Pollock and Wilson 2015). Other commentators remark along similar lines advocating that the advance care planning process starts at any age and state of health (Institute of Medicine of the National Academies 2015). Advance care planning as a public health rather than dying conversation is seen elsewhere. For example, Vogel (2011) reports the Canadian end of life framework advocates advance care planning conversations before the diagnosis of a chronic or terminal illness. In New Zealand, the Ministry of Health (2011) point out that such discussions can occur at any time. Moreover, in America, a life-cycle model of advance care planning is proposed which is milestone specific (for example. obtaining driver license, marriage or buying a house), situation specific (for example. high risk occupations such as military service), part of primary care (for example. regular conversations when well), at the initial diagnosis of chronic disease (for example. at the beginning of illness), as health worsens (for example. at turning points in the disease) and in the final year of expected life with activity such as advance decisions and appointment of surrogate decision makers being seen as part of approaching death advance care planning activity (Institute of Medicine of the National Academies 2015:S52-54). The public health, disease management or prognosis approach to advance care planning conversations is of interest in terms of visualizing preparing and planning for dying away from a death prognosis towards conceptualizing death as an inevitable part of life with life milestones (Grimes 2015) as the trigger for conversations rather than prognostication.

Living with uncertainty

A related area is the literature regarding living with the uncertainty of when death will occur. Uncertainty has been described as being concerned with an individual's perception of outcomes or meaning of a situation, present orientated, dynamic with fluctuations in types of knowing and responses as well as individual adapting strategies (Penrod 2007). Glaser and Strauss (1965) reported upon critical junctures within a dying trajectory with passages of dying illustrating the complexity of the expectations of death (the uncertainty of timing of death). Uncertainty in general illness (see Mishler 1981) and in incurable illness (for example. Shaha et al. 2008; Karlsson et al. 2014; Kendall et al. 2015) can take many forms. For example, (Mathie et al. 2012) care home study reported how residents with limited life expectancy might live in the past or the present, think about or actively engage with planning for the

future. Goodman et al. (2015) describes treatment, relational and service uncertainty in the care of people with dementia.

Other studies have highlighted how clinical uncertainty at the end of life can be distressing for both patients and families (Bristowe et al. 2015). Shaha et al (2008) in their study of people with breast, prostate and colorectal cancer reported uncertainty because of limited or lack of information, concerning the course and treatment choices related to the disease, and related to everyday life and coping with the disease. Moreover, Karlsson et al (2014) study of people with cancer describes a struggle of living with an uncertain future despite efforts to live in the present. The literature therefore points to the position where living with uncertainty is integral to living with dying.

Planning and preparing for dying

One of the other challenges in the advance care planning literature is distinguishing the difference between preparing and planning for dying as well as understanding other terms such as death readiness, acceptance or attitude. Prepare, as a verb, noun or adjective is defined as getting ready and willing for something (Dooner 2011). Plan, as a verb, noun or objective is concerned with the detailed arrangements or making a plan for something (Dooner 2011). They are related concepts. In end of life care, preparing for dying is frequently conceptualised within a paradigm of both patient and family death preparedness and readiness related to the importance of being prepared to plan for a good death as well as subsequent psychological well-being for relatives in bereavement (Lowey 2008). This has suggestions of both the patient and family being ready and willing for death (preparing). Planning for dying is often conceptually defined within practical considerations about the dying process (i.e. the detailed arrangements or plan seen in advance care planning). Inherent in the concept of planning is the assumption that an individual is prepared to plan.

Seale et al. (1997) early work reported that open awareness of dying enabled death planning and increased choice over place of death. There is end of life and advance care planning

literature regarding the benefits of being ready, preparing and planning for dying dominated by an emphasis on the value of open awareness of dying, death acceptance and linked to the on-going debate about the role and function of death denial, awareness, anxiety and taboo in society. Indeed, when reviewing the relevant literature, preparing and planning, as terms are often undefined, used interchangeably, in the same sentence or with the same meaning. There is a recurrent theme of preparing and planning facilitating a good death through for example. naming surrogate decision maker, information about one's physical condition, putting financial affairs in order and having care and future treatment preferences in writing (Steinhauser et al. 2001). Other evidence includes; open discussions with subsequent choice and control (Seale et al. 1997; Lloyd-Williams et al. 2007), physical symptom control (Kahana et al. 2011), relationships (Kahana et al. 2004), finding meaning (Breitbart 2003; Lokker et al. 2012), peace (Mack et al. 2010), simultaneously maintaining hope and preparing for the worst (Back et al. 2007; Back et al. 2005) and an acceptance of death (McLeod-Sordjan 2014).

The literature also reports variable stages of readiness for advance care planning (for example. Fried et al. 2009) as well as comments that the over emphasis in research on the completion of advance directives has underestimated the impact of processes and behavioural changes in advance care planning (Sudore et al. 2013). Furthermore, there are suggestions that the advance care planning process should include contemplation, discussions and documentation (Sudore et al. 2008). This perspective of the wider considerations outside solely acceptance of dying and decision-making is reflected elsewhere. For example, Green and Levi (2012) discussing the use of technology in advance care planning comment that electronic resources not only provide information and documentation of decisions but also encourages deeper contemplation and dialogue with loved ones about what matters most to the person. Examples such as Sudore et al (2008 and 2013) and Green and Levi (2012) remind us that advance care planning activity is wider than decision making alone.

There is evidence that there are a variety of contextual factors that impact on patient and relatives' preparedness for and desire (or not) for conversations about dying (for example.

advance care planning). These include duration of caregiving or illness, previous caregiving or death experiences (Hebert et al. 2009; McLeod-Sordjan 2014). Moreover, there is a body of literature advocating some form of personal acceptance, readiness or preparation combined with death arrangements (advance care planning) to facilitate a good death. For example, readiness for death may affect the quality of the death experience (Moody et al. 2000). Whilst, individuals may be at different stages of readiness for advance care planning (Fried et al. 2009), there is evidence that previous experience with end of life care of others can influence greater readiness to participate in advance care planning (Amjad et al. 2014).

The cost of dying

An influence on advance care planning activity described in the literature are the costs of dying and the temptation to view it as a solution to a precarious health economy. Klinger et al (2016) recent systematic review comment on the ethical tension between the advance care planning goals of promoting patient autonomy and patient-centred care, and the economic goal of reducing costs of care (through for example. the articulation of preferred place of death and advance care planning). Dying imposes considerable costs on health systems (Gomes et al. 2011). In the United Kingdom, over half of deaths occur in hospital (Sleeman and Collis 2013). With much strategic and research attention on where and when people die (Deloitte Centre for Health Solutions 2014) and a growing commentary on economic cost considerations of good end of life care with the backdrop of a global ageing population and an anticipated rise in cancer and long term conditions deaths (Institute of Medicine of the National Academies 2014; Bardsley et al. 2010; Deloitte Centre for Health Solutions 2015), advance care planning as way to reduce costs is seen as a key part of health care policy for economic, clinical and ethical considerations (Wise 2014; Deloitte Centre for Health Solutions 2014; Institute of Medicine of the National Academies 2015; Bardsley et al. 2010).

There are a number of issues reported. Despite the limited information about end of life care costs (The Nuffield Trust 2014), successful advance care planning is often measured in terms of a reduction in hospital admissions and achievement of a preferred place of death (particularly at home). This defined outcome delivered by statutory services is perhaps far

more measurable than social process and relationships, which are also part of advance care planning including the less visible costs (and savings) of for example. the input of informal carers in end of life care. For example, there is robust evidence of the substantial cost of care provided by informal and family members (Gardiner et al. 2014; Gott et al. 2015) which is not always reported within economic evaluations which focus on statutory service provider costs (Gott et al. 2015).

Moreover, there are challenges of whether advance care planning interventions (if they are defined) increase or decrease costs in the last year of life. There is limited research on the full costs of advance care planning (Korfage et al. 2015) making it difficult to identify which intervention is making the saving. Dixon et al. (2015) points out that there are no published cost effectiveness savings, a predominant focus on out of hospital savings, in specific groups (for example. living in the community with dementia or nursing homes) as well as a need to factor in other aspects such as the cost of advance care planning interventions, facilitation and substitution of health, social or informal care. Klingler et al. (2015) also argue the necessity to consider all the formal and informal costs of advance care planning interventions. Borgstrom (2015) points out that the relational aspects of care of for example. time, empathy and supportive spaces is difficult to measure and financially incentivize within current systems of commissioning and contracting. The reported evidence is mixed if advance care planning diminishes economic costs by facilitating the reduction of end of life hospital admissions, length of stay, subsequent costs as well as being in line with patient preferences for a preferred place of death often at home (Dixon et al. 2015; Sleeman and Collis 2013; Gardiner et al. 2014; Gott et al. 2015; Gomes et al. 2012; Gomes et al. 2010; Deloitte Centre for Health Solutions 2014). Moreover, there still is a lack of conclusive evidence of which factors in advance care planning reduce for example. inappropriate hospital admissions (Seymour and Horne 2011).

The focus on the economic benefit of advance care planning is of concern as an increasing number of advance care planning initiatives are implemented without full knowledge of which part of the intervention or its relationship to other contextual factors made the

difference. Despite this, increased advance care planning discussions and documentation (Tan and Manca 2013), electronic patient registers (Deloitte Centre for Health Solutions 2014), improving the effectiveness of palliative care at home (Riolfi et al. 2014; Alonso-Babarro et al. 2013), psychological support (Reyniers et al. 2014) and education (Farrington 2014; Goodman 2014) have all been presented as advance care planning activity examples influencing the reduction of hospital admissions and economically effective (for example Pyper et al. 2013).

The paucity of evidence regarding costs is reflected in the wider palliative care literature (Smith et al. 2014; May et al. 2014). The challenge in the evidence base therefore is to not only to define the advance care planning intervention and demonstrate the cost effectiveness of the interventions including the individual quality of life benefits vs. hospital admission but also to cost all of the statutory and informal/family care interventions and the context of the less visible aspects including time, setting, supportive space, education and evaluation costs.

Home as the preferred place of death

The literature regarding home as the preferred place of death including the home space as a place for both family relationships and clinical interventions is mixed. Achieving the preferred place of death is often cited as a goal of palliative care (De Roo et al. 2014) and advance care planning (Pollock and Wilson 2015) and there is evidence within policy of an emphasis on facilitating and increasing home deaths (Hunt et al. 2014; NICE 2015; DH 2008). There is robust evidence that dying at home is the preferred place for a significant percentage of the population (Gomes et al. 2012; Higginson and Sen-Gupta 2000; Tang 2002; Bell et al. 2010). Furthermore, there is discussion about whether the choice to die at home is more likely with care provision such as access to end of life home-care programmes and rapid response teams (Gomes et al. 2013) and general practitioner involvement (Neergaard et al. 2009) or if other factors such as living alone influence achievement of dying at home (Holdsworth 2015).

However, home being the preferred place of death is contested (Collier 2013; Collier et al. 2015; Pollock 2015; Pollock and Wilson 2015) with evidence of the benefits unclear (Gomes

et al. 2015). Home has been described as both the best and the worst place to die (Parkes 1978). Shepperd et al. (2011) and Gott et al. (2004) point out the difficulty of people exercising the choice to die at home whilst simultaneously worrying about being a burden, seeing their families distressed or being involved in intimate aspects of care. Williams (2002) suggests that as health care delivery has moved out of hospitals into the home space the multiple meanings of home (as a dwelling as well as representing personal identity, security and privacy) is under researched. Morris et al. (2015) also comments on the complex set of social and emotional factors involved in providing care in the home. Collier (2013) in her eloquent thesis regarding home space at the end of life, challenges the policy rhetoric of the gold standard of home as the place to die because the notion of home is more than a physical entity (i.e. the meaning and familiarity of home can be transported to another physical space) and the implications of the burden of care emotionally and practically are under recognized or researched.

Some commentators point out that dying at home has become the only proxy marker of successful advance care planning and quality end of life care (Pollock and Wilson 2015), despite evidence that the desire for home death may decrease with age and illness severity (Gomes and Higginson 2006; Munday et al. 2009). Choice over preferred place of death is increasingly more debated (Borgstrom 2014; Borgstrom and Walter 2015; Gott et al. 2004; Pollock and Wilson 2015). Furthermore, there is evidence that other factors such as situational, interpersonal and organizational may underpin preferences about care and place rather than solely individual choice (Reyniers et al. 2014; Goodman et al. 2015). One particular challenge concerns combining the evidence that home is the preferred place of death for many, whilst also being contextual in terms of for example. relationships, concerns over being a burden, age and care provision. This must be viewed alongside the preferred place of death at home as the proxy marker of good advance care planning and measurable in terms of activity and outcomes.

Decisions made in advance and surrogate decision makers

Decisions made in advance and surrogate decision makers are a further illustration of the contextual nature of advance care planning. Hailed as a key part of advance care planning,

the uptake by patients is low (Wilkinson 2011; Prendergast 2001; Fagerlin and Schneider 2004) and there are challenges to their effectiveness (Gillick 2010; Perkins et al. 2007; Fagerlin et al. 2001; Fagerlin and Schneider 2004; Teno et al. 1997; Billings 2012). Decisions made in advance are found within a variety of international legislative frameworks with variable jurisdiction (Russell 2014). They are seen as preserving or enhancing an individual's precedent autonomy (Billings 2012; Seymour et al. 2010; Institute of Medicine of the National Academies 2015).

There are a number of reasons cited in the literature for the low uptake of advance care planning. These include clinicians failing to initiate conversations due to lack of confidence, resources or skill, knowledge or time, little or previous experience of advance directives, concerns over adverse consequences, taking away hope, challenges in completing or accessing documentation, needing more information for processes for completion and utilizing documents, lack of knowledge of federal and state laws, not knowing when in the disease or who should initiate conversations as well as belief that patients should initiate the conversation (Levi and Green 2010; De Vleminck et al. 2014; Gott et al. 2009; Seymour et al. 2010; Lovell and Yates 2014; Brinkman-Stoppelenburg et al. 2014; Horne et al. 2006; Munday et al. 2009; Silva et al. 2014).

A further challenge is that preferences and wishes for future care may not be stable (Evans et al. 2014; Auriemma et al. 2014; Ditto et al. 2003; Gready et al. 2000; Lockhart et al. 2001) making the validity of decisions made in advance difficult to judge. Studies have reported that up to one third of individuals will change their preferences over months to years before death influenced by changes in diagnosis, hospitalization, mood, health status, social circumstances and functional ability (Lobo 2011; Kohut et al. 1997). Moreover, there is considerable variability among studies looking at the stability of end of life choices, but also that it is the more seriously ill patients who most commonly have stable preferences for future treatments, despite advance care planning being advocated for when individuals are more well (Auriemma et al. 2014; Ditto et al. 2006).

Preferences for life sustaining treatment may be dependent upon the context within which they were made for example. whether individuals were healthy or ill (Ditto et al. 2006; Fried et al. 2007; Auriemma et al. 2014). This reinforces the need for regular re-evaluation of advance care planning wishes (Janssen et al. 2012) because advance directives and similar documents were proposed in order to allow patients to express what was assumed to be deeply held and presumably stable values regarding medical treatment (Emanuel and Emanuel 1998; Fried et al. 2007).

In addition to the questions about the stability of preferences over time there is an assumption that decisions made in advance consistently and accurately reflect individual's preferences. There is debate if this is true (Perkins et al. 2007; Winter et al. 2010; Lynch et al. 2008; Levi and Green 2010) with reports of a lack of concordance between patient's current and future preferences (Winter et al. 2010). There are questions of the ability to estimate accurately the impact of the disease on one self with concerns raised about the accuracy of "*future forecasting*" (Levi and Green 2010:5). Thorevska et al. (2005) comment that it is never possible to understand all future medical care possibilities. Studies have reported an over or underestimation of the impact of debility or disease on them by individuals (Levi et al. 2010; Loewenstein 2005; Ubel et al. 2005; Coppola et al. 1999).

Whilst avoiding unwanted treatments is reported as a common concern for patients, families and clinicians (Prendergast et al. 1998; Prendergast and Puntillo 2002), medical crises cannot be predicted in detail (Nauck et al. 2014). Studies have also reported misunderstanding and poor concordance between patients, providers or surrogate decision makers about future decisions such as DNACPR (DesHarnais et al. 2007). There is a scarcity of evidence on the benefit of the completion of advance directives on their own changing outcomes (Wilkinson 2011) because they are too narrowly constructed with little room for the full scope of individual's wishes (Teno et al. 1997; Brinkman-Stoppelenburg et al. 2014). Focussing advance directives on hypothetical discussions has also been shown to have limited bearing on decisions made later when faced by a concrete situation (Ditto et al. 2006). Moreover, treatment based directives are difficult to interpret and apply in the actual clinical setting

(Nauck et al. 2014; Kolarik et al. 2002) as they presuppose more control over the future than is possible (Bauer 2009; Nauck et al. 2014). The accuracy and role of surrogate decision makers (attorneys) has also been questioned. Surrogate decision makers are often family members (Black et al. 2009) and may take the formal title of for example. Lasting, Durable, Enduring or Health Care Power of Attorney depending upon their national legal frameworks. Their authority can take part in both the health and social care arena as well as property, affairs and finances. For example in England and Wales there are two types of Lasting Power of Attorney; Property and Affairs or Health and Welfare (Lyne 2010). There are a variety of international legislative frameworks under which they operate (Sabatino 2010; Ministry of Health 2011) with a range of powers and processes to formally activate this role, especially relevant when the individual cannot state their wishes or decisions themselves.

There is further evidence of confusion about how to carry out surrogate roles with calls for more research to understand the impact of being one. Much of the family member surrogate research literature has been directed to identifying accuracy in predicting choices (Shalowitz et al. 2006) underpinned by the principle that current decisions can be based upon previously expressed choices. Firstly these choices are durable and secondly because individuals are able to hypothesise about future situations and express future choices and preferences (Black et al. 2009).

Moreover, studies have reported that surrogates are inaccurate (Meeker 2004) despite having a self-perceived high confidence level in their accuracy (Hare et al. 1992). There are reports of family surrogates incorrectly predicting patients' end-of-life treatment preferences in up to one third of cases (Shalowitz et al. 2006), may favour refusal over withdrawal of treatments (Ditto et al. 2001) with cultural differences in end of life decision making (Calanzani et al. 2013). The literature also identifies concerns around whether surrogates are considering the views of the person from before, early, later on or at the end of illness (George and Harlow 2011).

In spite of the evidence that early end of life discussions improves surrogate accuracy (Sulmasy et al. 1998), there are reports of the possibility of a response shift (Sampson and Burns 2013) also being present in family surrogate decision making, where views change over time, especially as illness progresses. Individuals may also express different treatment preferences when they are healthy to that when they have deteriorated. (Ditto et al. 2003; Ditto et al. 2006). Woods (2007) refers to a gap between a philosophy of care and real world palliative care practice. This gap may be concerned with not only the variability of end of life choices but also is it possible for surrogates to implement individuals' wishes in practice as they face bewildering difficult decisions as to what they (as surrogates) would like vs. what is possible vs. respecting the wishes of the patient. There is evidence that surrogates may represent their own wishes for the patient rather than those expressed by the patient themselves (Vig et al. 2007; Fritsch et al. 2013).

There are also concerns with inconsistency and confusion over the role and framework for surrogate decision makers and lack of research on the impact on the surrogate (Meeker 2004) and a dearth of literature outside Western countries (Tang et al. 2005). The frameworks have been described as misunderstood, with difficult to use tools (Trarieux-Signol et al. 2014) with little training for clinicians in working with surrogates (Azoulay and Sprung 2004; Weissman and Block 2002). Surrogate decision maker laws are fragmented and inconsistent (O'Brien and Fiester 2014). Furthermore, legal and bureaucratic structures are orientated to individual decision makers (Meeker 2004) and these structures may in fact inhibit advance care planning (Brinkman-Stoppelenburg et al 2014) as some cultures may practice joint decision making activity (Ministry of Health 2011). Family surrogates may prefer to make shared group decisions, but there is great pressure on them to confront and somehow resolve the dissonance between a health care system reliant on individual decision makers with family surrogate preference for group decision making (Meeker 2004).

Studies have also reported conflict between family surrogates and health care professionals about what actually are the end of life decisions and how they are made (Abbott et al. 2001; Breen et al. 2001) as well as family surrogate and physician differences in predicting

accurately the patient's wishes (Meeker 2004). Clinicians find aspects challenging (Winzelberg et al. 2005) such as when surrogates' perspectives on the patients' views differ from that of the clinician (Vig et al. 2007; Tan and Manca 2013).

Surrogates may have varying degrees of preparation or comfort with the role (Vig et al. 2007), *“even though an individual person has the disease, whole families experience illness”* (Brown and Stetz 1999:195) and the burden of functioning as a decision maker is described as great (Meeker 2004). This is reported as stressful for surrogates (Christakis and Iwashyna 2003) with reports of surrogates having post-traumatic stress disorder symptoms (Azoulay 2005). Conflicts between family surrogates and clinicians are reported to affect family members (Kirchhoff et al. 2002) especially if the death is perceived to be a bad one with a lack of end of life preferences discussed or documented (Wright et al. 2008). Interventions that make a difference include finding common ground, time and multiple contacts especially in terms of not incurring the risk of family members developing future anxiety or stress (Tan and Manca 2013; Vig et al. 2007; Kirchhoff et al. 2002) as well as for example, early hospice care resulting in better health care outcomes for surrogates (Christakis and Iwashyna 2003).

The challenges for the surrogate role of accurately predicting, how to carry out the role and the impact of being a surrogate decision maker is a not to be underestimated context in the practice and evaluation of advance care planning. As family surrogates negotiate the struggle and uncertainty (Meeker 2004) of a family member living with dying, legal frameworks, significant conversations and the practical realities of dying; health and social care providers, commissioners, policy makers and researchers need to assess and respond to not the context of the patient and the surrogate decision maker but also their own confidence and competence in supporting individuals and their families at this time.

Autonomy

A significant contextual aspect when considering advance care planning is assumptions of a consensus of autonomy, self-determination and awareness of dying. Definitions of autonomy and self-determination has been described as muddled (Sandman 2005) and overemphasized

(Randall and Downie 2006), but they remain important because of assumptions within the palliative care philosophy of the value of individual autonomy, self-determination and open awareness of dying (Sandman 2005; Randall and Downie 2006; Lund et al. 2015).

Self-determination and autonomy with their principles of a causal connection between an individual's wants, decisions and actions (Sandman 2005) and the ability and freedom to make choices that shape our lives (Harris 1985) provides an arena for the playing out of dying awareness. Dying awareness (appendix 5) is the extent to which patients know about their impending death, and the significance of negotiating this awareness (Glaser and Strauss 1965, Lund et al 2015). The debate about the cultural consensus of these underlying ethical principles is significant because palliative care (and by implication advance care planning) relies upon "*contemporary western medical ethics.....the set of values and principles described by Beauchamp and Childress (2001) of autonomy, non-maleficence, beneficence and justice*" (Woods 2007:78). The relationship between wants, decisions, actions, ability and freedom to make choices (self-determination and autonomy) and being aware of dying is fundamental to advance care planning.

However, there are arguments that the idea of autonomy, self-determination, planning for incapacity and control over dying is not a universal value (Kwak and Haley 2005; Calanzani et al. 2013) nor shared in all parts of the world (Winston et al. 2004; Volker 2005). This is challenging to advance care planning as autonomy has been identified as a key component of palliative care (Wilson et al. 2014), despite there being little or no empirical evidence to support it (Drought and Koenig 2002). In addition, is the challenge of a normative cultural assumption that individuals do want to talk (and make choices and decisions) about end of life based upon an acceptance of "*our own mortality*" (Randall and Downie 2006:9)? This is despite different cultural views about the benefit, harm or practice of such conversations (Evans et al. 2012) and arguments that open disclosure and awareness of dying is Anglo centric (Firth 2001). This is problematic for advance care planning as self-determination and autonomy underpins the goals of future decision making through open disclosure and presumption of desire for choice and control.

Current autonomy models may not take in the wider aspects of decision making such as social context, individual narratives (Wilson et al. 2014) or family and shared decision making models (Winston et al. 2004; Kwak and Haley 2005). In addition, patients might not value autonomy in the same way, or define it differently to decision making self-determination (Winzelberg et al. 2005) or hold other values more important (Drought and Koenig 2002). Basing advance care planning upon generic autonomy principles does not fit consistently across all individuals or cultures. Studies in both the UK and USA have shown a wide cultural variation in the uptake of advance care planning and talking about end of life (Calanzani et al 2013). There are cultural, racial and ethnic differences between individual or family centred decision making (Kwak and Haley 2005) with some ethnic groups preferring to make family rather than individual based decisions (Searight and Gafford 2005). Truth telling, informed decision making and control over the dying process is not necessarily shared by those not from a white European background (Giger et al 2006) with reports of significant differences in end of life decision making between black and white groups (Hopp and Duffy 2000; Johnstone and Kanitsaki 2009; Kwak and Haley 2005). For example, Pacquiao (2001) argues that the concept of advance directives is consistent with the dominant value orientation in the American culture of self-reliance and individualism, which places a high premium on self-determination and control of one's own destiny. However, this value is not always consistent with the dominant cultural views of all sick or dying individuals (Pacquiao 2001).

The good death

A further consideration in the advance care planning literature is its relationship to the concept of a good death and the presumption that a good death is preceded by an open awareness of dying and discussion. Glaser and Strauss' dying trajectories combined with the dying awareness contexts (Field and Copp 1999; Glaser and Strauss 1965; Glaser and Strauss 1966; Glaser and Strauss 1974) are a fundamental part of the mainly Anglo centric (Firth 2001; DH 2008) construction of a good death based upon individual autonomy and open awareness and discussion of dying.

There are calls that this philosophy is flawed because it is based predominately upon hospice cancer experiences (Costello 2006) and is under researched (Kendall et al. 2007). It poses challenges for non-cancer groups (Russell and Russell 2007), imposes a particular set of beliefs and standards on end of life care (Randall and Downie 2010; Woods 2007), of a particular way to die which excludes denial as a valid way to face dying (Zimmermann 2007; Zimmermann 2012; Zimmermann and Rodin 2004). Moreover there are arguments that it is dominated by health professional definitions (Raisio et al. 2015) with underrepresentation from patients and carers (Bowling 2000) as well as being socially, historically and politically constructed (Walter 2003; Kellehear 2007; Borgstrom 2014).

Considering the effect of mortality on oneself has been present in the literature for some time represented in a myriad of examples (Glaser and Strauss 1966; Feifel 1959; Heidegger 1962; Kastenbaum 2000; Aries 1973; Kubler-Ross 1972; Becker 1973). These highlight not only being aware of and talking about death but also the meanings it may have for those who are dying, how we confront and manage our awareness of death as well as the rites and rituals of social, public and biomedical dying. In addition, the body of literature regarding Death Taboo (Kellehear 1984; Walter 1991), Death Attitudes (Neimeyer et al. 2003), Death Acceptance (Harding et al. 2005), Death Anxiety (Furer and Walker 2008), Mortality Salience and Terror Management Theory (Lehto and Stein 2009; Solomon et al. 1991; Pyszczynski et al. 1999; Shatil 2012) all flag up the variety of conceptual frameworks, scales and tools within which researchers, clinicians, society and individuals seek to understand the human experience of facing or preparing for the inevitability of death as well as the personal, social and psychological organization of the rites, rituals and routines of death and dying.

The definition of a good death is difficult to generalise despite consistently being described as a goal of palliative care (Clark 2002). There is no clear or shared understanding of what it is (Kehl 2006) and is difficult to quantify scientifically (Walters 2004). The conceptualisation has been frequently based around hospice cancer deaths with a prominence of self-awareness, individuality, symptom control and peacefulness (Russell and Russell 2007; Costello 2006). However, there is no agreement of all the interlinking components of a good

death despite copious reports that it contains elements including awareness of dying and acceptance of the inevitability of death, being in control, preparations, living ones' life till the end, pain and symptom management, clear decision making, completion, contributing to others and affirmation of the whole person (Hopkinson and Hallett 2002; Goldsteen et al. 2006; Kehl 2006; Steinhauser et al. 2000; Payne et al. 1996; Low and Payne 1996).

There are a number of commentators who present robust arguments that the dominance of a good death ideology (especially through hospice and Anglo centric conceptions of autonomy and open awareness of dying) has led to a social management of a particular way to die (Zimmermann 2007; Zimmermann 2012; Zimmermann and Rodin 2004; Randall and Downie 2006; Woods 2007; Borgstrom and Walter 2015). This is seen in policy and practice documents that consistently emphasise the key components of a good death being to recognise dying and impending death, timely honest conversations which manages uncertainty (National Palliative and End of Life Care Partnership 2015) as well as being treated as an individual, without pain, in familiar surroundings and in the company of close family or friends (DH 2008). Whilst the hospice movement has been credited as highlighting the importance of good quality dying (Seymour 2012) and transferring the philosophy of care into other settings such as hospitals and care homes (The Leadership Alliance for the Care of Dying 2014), it has also been criticised for presenting a good death or dying as unproblematic by omitting or ignoring the presence or absence of dying awareness (Borgstrom 2014).

There is a large body of work recognising the historical, social, political and cultural context on the definitions and operationalisation of a good death. Walter (2003) argues eloquently that a good death may depend upon the extent of secularization, individualism and how long a typical death may take within a society. He also challenges the taboo of talking about death suggesting that we may be more concerned with hiding rather than forbidding conversations and the influence of the media on the public discourse (Walter 1991). This is illustrated by examples such as redemption through dying of the celebrity Jade Goody (Walter 2010). Kellehear in a *Social History of Dying* points out that that dying has changed from a community to more private affair whilst also being “*more publically controlled and defended*” (Kellehear

2007:251). Furthermore, the sequestering of dying away from a shared experience has led to a state management of death with *“end of life care experience under formal medical supervision”* (Kellehear 2007:253). Borgstrom (2014) also argues that not only is the current end of life strategy in England and Wales underpinned by hospice led constructions of a good death but also there is also a gap between the policy discourse of individual choice in advance care planning and individual social interaction about death and dying.

The significant challenge to advance care planning is the assumption and assertion that open awareness of dying with related honest discussions leads to a good death through personal preparation and planning. This at best is controversial (if only because of different cultural assumptions of a good death, dying or shared/individual decision making processes) and at worst unrealistic because individual perceptions of a good death vary (including control of the process, timing and place) and individual choice may not be about for example. preferred place of death but more concerned with the related context of how people choose to face and talk about their dying. Moreover, the predominant principle of individual autonomy in advance care planning is contested as there is robust evidence that decisions are made within the context and relationships of people’s lives, experiences as well as societal and cultural norms (Borgstrom 2014; Kwak and Haley 2005; Kellehear 2007).

Assisted dying

The discourse concerning assisted dying is an example of the complexity of the debate regarding the conceptualisation of a good death as well as the contextual aspects of autonomy and choice. Carpentier and Van Brussel (2012) stress the political nature of the discourse of the good death. The topic of assisted dying and suicide *“generates debate on a variety of levels – ethical, moral, religious, spiritual, political, cultural, psychological, professional and legal”* (Pender and Hardwick 2011:4). Despite evidence of public support (Lobo 2011), assisted suicide or dying remains illegal in the UK. Autonomy and the right to choose when to die are central to the debate. Furthermore within that debate is assumptions, questions and meanings of unbearable suffering (Gather and Vollmann 2014), opinions about

the similarity and differences between palliative sedation and euthanasia (Morita et al. 2003), the blurring of the boundaries between prolonging life, killing or letting die (Randall and Downie 2010), concerns about safeguards, protecting vulnerable groups, implementation of a universal law (Battin et al. 2007) as well as clinicians' own attitudes and values towards suicide and death (Curry et al. 2002).

The debate is not always linked directly to advance care planning despite parallel public death literacy programmes such as Respecting Choices (United States), Ground Swell (Australia), Speak Up (Canada), Dying Matters (UK) and Silver Pages (Singapore) and assisted dying campaigns such as Dignity in Dying (UK), Right to Die (Canada) and the Voluntary Euthanasia Society (New Zealand) (Russell 2014). However, if advance care planning is concerned with the achievement of a good death from the individual's viewpoint there remain unanswered questions which must be considered (or at a minimum acknowledged) in advance care planning. For example, if individual choice is a high priority for end of life care how do we justify not permitting assisted dying (Randall and Downie 2010) and balance the sanctity of life doctrine (Woods 2007)? Within this, how is the accommodation of the possible change in choices as illustrated earlier in the examples of surrogate decision makers and decisions made in advance? As practitioners, how do we provide a therapeutic space to have conversations as advance care planning rather than assisted dying discussions and the associated personal, legal and ethical ramifications? (Russell 2014). Do we know enough about this area and can adequate palliative care obviate assisted suicide (Curry et al 2002)? Clinicians may agree with the intention of assisted dying but feel hesitant with the conclusion or encounter 'cry for help' situations rather than decisions to die (Gillett and Chamberlain 2013). What do we really mean by assisted dying and how honest are clinicians about them as how many 'means' are there to bring about death (Woods 2007)? Advance care planning advocates voluntary individual participation, choice and autonomy. There remain gaps in evidence regarding the relationship between advance care planning and assisted dying.

In this part of the literature review selected examples have illustrated evidence that advance care planning is relational to the personal, social, organisational, political and clinical context

within which it occurs. It is not solely about individual autonomous choices made in isolation about for example. preferred place of death, refusal of treatments in advance and appointment of surrogate decision makers. Instead it takes place within the arena of how society views a good death, how systems and processes operate within this and the relationships that people have with themselves and others as they live with the knowledge of their future death.

The communication skills literature

One of the motivations of the study was to inform the design of future education programmes. An examination of the communication literature illustrates another perspective on the development of such programmes.

Communication is advocated as a key part of patient and health care professional interaction (Russell and Russell 2007) benefiting both the patient and clinician (Maguire and Pitceathly 2002). Communication is seen as a core part of advance care planning (Institute of Medicine of the National Academies 2015) and is advocated as a fundamental clinical skill, with evidence of the benefits for patients of clinicians communication skills in a variety of settings (Lipkin 2010; Kurtz et al. 2005; Silverman et al. 2005; Moore et al. 2013; Fallowfield et al. 2002; Jenkins and Fallowfield 2002). Whilst there is multiplicity of definitions of communication (Bevan et al. 2011) and inconsistency as to what exactly constitutes a communication skill (Chant et al. 2002) there are regularly reported areas of facilitative behaviours, attitudes and traits of; empathy, genuineness, respect, unconditional positive regard and reflexivity (Bevan et al. 2011; Coulehan and Block 2006; Finlay and Gough 2003).

Barriers and blocks to communication

There is evidence that physician-patient communication can be suboptimal (Back et al. 2005). Barriers (reasons why good communication does not happen) can range from skills, competence, knowledge, confidence, and systems to organisational barriers (Bevan et al. 2011). Baile et al. (2000) suggests fear of being blamed, being untaught, eliciting a reaction, not knowing what to say, expressing own emotion, own death awareness and medical hierarchy all inhibit clinicians' communication about the end of life. Further barriers have

been suggested such as the fear of taking away hope and the work environment (Fallowfield et al. 2002b; Maguire and Pitceathly 2002; Maguire et al. 1996; Wilkinson et al. 2002; Knauft 2005). Blocking behaviour (verbal or nonverbal behaviours that inhibit conversations) include clinician rather than patient led agenda, poor eye contact, body language, avoidance, missing cues, premature or false reassurance, jumping to conclusions, explaining away distress as normal (normalisation), lack of empathetic response, collusion, lecturing, multiple questions, leading or closed questions, focussing on the physical, switching topic, person or timeframe, removing the emotion, ignoring psychological aspects, blaming, being defensive, judgemental, 'jollyng' along, poor information giving, withholding information, non-disclosure, jargon, language difficulties, cultural mismatches (Kurtz 2002.; Lambert et al. 1997; Bevan et al. 2011; Lipkin 2010; Hancock et al. 2007; Parker et al. 2001; Almack et al. 2012).

Barriers and blocks to communication are reported to lead to a failure to recognise or agree patients and concerns, under rate patient distress, increase psychological morbidity, a doctor centred approach to information gathering and giving, despite a patient-centred approach being preferred (Dowsett et al. 2000; Laidlaw et al. 2001; Baile et al. 1997; Maguire and Pitceathly 2002; Fallowfield et al. 1998). Furthermore, there is evidence that poor communication leads to missed opportunities to improve patient self-management (King and Hoppe 2013) with patient information needs underestimated (Fallowfield et al. 2002b). Poor communication can leave patients feeling anxious, uncertain and generally dissatisfied with their care (Commission Audit 1993). It is suggested that problematic communication contributes to health care professional increased stress, high malpractice claims, emotional burn out, low personal accomplishment, lack of job satisfaction and high psychological morbidity (Feinmann 2002; Ramirez et al. 1995; Ramirez et al. 1996).

Benefits of communication

Good communication is reported to engender meaningful and trusting relationships between healthcare professionals and their patients (Hoy 2004), with increased patient satisfaction, understanding, adherence, recall and health outcomes affects (King and Hoppe 2013).

Furthermore, effective communication facilitates accurate identification of patient problems resulting in better symptom, pain and treatment assessment and control, adherence to symptom control, influences the rate of patient recovery as well as physical, functional and psychological wellbeing and functioning (Razavi et al. 2003; Libert et al. 2007; Razavi et al. 2000; Fallowfield et al. 2002b). Maguire et al. (1996) suggest that communication skills improve patient's disclosure of psychological concerns resulting in better emotional health, resolution of symptoms and pain control. This has a likely beneficial effect on patient outcomes including patient satisfaction because of better information recall and ability to comply with instructions (Detmar et al. 2002; Weiner et al. 2013; Maguire and Pitceathly 2002; Hulsman et al. 1999; Hulsman et al. 2002).

Communication and advance care planning

Within the literature, the terms advance care planning and end of life conversations are often used interchangeably with a variety of overlapping topics including for example. shared decision making, transition from curative to palliative treatment, commencing or changing treatment, recurrence, survivorship, withholding and withdrawing treatment, preferred place of care or death, prognostication and life expectancy, future symptoms and management, communicating risk, assessing and managing depression and anxiety, maintaining hope, understanding fears and goals, breaking bad news, responding to emotions, denial and collusion, talking with family members, family conflicts, spirituality, assisted dying, awareness of dying and the process of dying (see Bernacki and Block 2014; Fallowfield et al. 2002b; Baile et al. 1997; Back et al. 2005; Walczak et al. 2014; Walczak et al. 2015; Lipkin 2010). Communication is not concerned only with explaining and supporting treatment decisions but also with accompanying the individual along their illness experience journey (Bevan et al. 2011).

There is evidence that skilled clinician communication is crucial to advance care planning (Janssen et al. 2011). The need for and value of early conversations about future care, how their condition might affect them in the future, treatment preferences and opportunities to record wishes and decisions for people with incurable illness is well reported in the literature

(Parry et al. 2014; DH 2008; Barnes et al. 2012; General Medical Council 2010). Lovell and Yates (2014) identify that end of life discussions are core business for palliative care health professionals and are an ideal setting to implement advance care planning. Moreover, studies suggest that decisions made in advance are ineffective without the accompanying communication skills and trust building processes (Bevan et al. 2011, Prendergast 2001).

There are also reports that conversations about the end of life do not increase patient distress or remove hope (Bernacki and Block 2014; Hancock et al. 2007; Clayton et al. 2005; Bélanger et al. 2014). Barnes et al. (2007) emphasize that health professionals should be skilled in judging the timing of such discussions, with the ability of health professionals in recognising barriers to discussing advance care planning seen as vital (Schickedanz et al. 2009). Studies have shown that patients value honesty, clarity and sensitivity in their doctors when they discuss end of life issues (Wenrich et al. 2001). This includes patient-centred communication through engaging with prognosis discussions, responding to emotion, informing about opinions and perspectives as well as framing uncertainty (Gramling et al. 2015). Moreover, the avoidance of honest and detailed discussion may lead to poorer patient satisfaction and increased psychological distress (Clayton et al. 2005; Hancock et al. 2007; Parker et al. 2007).

Some studies have shown that awareness of prognosis increase satisfaction with care as well as lower levels of depression (Chochinov et al. 2000; Schofield et al. 2003). Sudore et al. (2008) recommended that facilitating discussion between family and friends was a key element in advance care planning and there is evidence that advance care planning may be a series of discussions rather than just one event. Some of those discussions will be exploratory conversations rather than decision-making ones (for example. to decide and agree an advance decision to refuse treatment) (Seymour et al. 2004).

Empathy, honesty and personal approaches to information giving and conversations feature regularly in the literature. Systematic reviews have reported the value of truth telling (Hancock et al. 2007) and being able to balance hope, honesty and the knowledge of future

death (Clayton et al. 2008). Clinicians are valued who show empathy and honesty, encourage questions, and clarify and negotiate individual's information needs and level of understanding (Parker et al. 2007). Clayton et al. (2007) point out that a relationship with a confident expert is often preferred, and that short or long term relationships can both engender such relationships between clinicians and patient. Clinicians also benefit from open, clear advance care planning communication. Dias (2003) reports that it is both personally satisfying and professionally rewarding for health care professionals with studies reporting the impact of clinicians' competency self-awareness of and confidence in end of life conversations (Barnes et al. 2007, Russell and Russell 2007).

There is further literature regarding clinicians' barriers to end of life and advance care planning conversations, albeit with a caution that many of the studies have focussed on single patient groups (such as cancer) or only in terminal care (De Vleminck et al. 2014). There is a body of literature reporting; professional led conversations (Davison 2010; Pollock and Wilson 2015), lack of confidence (Almack et al. 2012; Parry et al. 2014) or training (Hancock et al. 2007), underestimating patients need for information whilst overestimating their understanding of prognosis and awareness (Hancock et al. 2007) and patients and clinicians awaiting the other to start conversations (Pollock and Wilson 2015, Almack et al. 2012). Other studies report lack of time to have conversations (Hancock et al. 2007), difficulty knowing when it is the right time for such conversations (Almack et al. 2012, Seymour et al. 2010), concerns over managing emotional responses (Clayton et al. 2007, Morita et al. 2004), uncertainty about prognostication, family dynamics (Hancock et al. 2007) and a desire for more evidenced based guidelines (Raijmakers et al. 2012). Moreover, there are arguments that patients' perceptions of clinicians' communication competence strongly influences end of life conversations (Pollock and Wilson 2015).

Other studies report competing needs, a desire to maintain hope, belief that patients are not ready or willing to have conversations as well as prognostic uncertainty, lack of confidence with different diagnosis dying trajectories and a reluctance to give bad news (Boddy et al. 2013; Walling et al. 2008; De Vleminck et al. 2014; Gott et al. 2009; Boyd et al. 2010; Froggatt

et al. 2009b; Institute of Medicine of the National Academies 2015). There is further evidence that clinicians are concerned about their communication skills (De Vleminck et al. 2014; Institute of Medicine of the National Academies 2015) and timing of conversations such as; when, where and from whom (Lovell and Yates 2014; Gott et al. 2009; Robinson et al. 2012; Rhee et al. 2012; Rhee et al. 2013). There are also comments on the 'bystander effect' where both patient and clinician are awaiting the other to initiate the conversation with the consequence that conversations occur too late (Pollock and Wilson 2015). Clinicians are reported to be uncomfortable with both carrying out conversations (Robinson et al. 2012, Seymour et al. 2010) as well as the advance care planning process in itself (Lovell and Yates 2014; Minto and Strickland 2011; Zhou et al. 2010; Froggatt et al. 2009a).

Communication and advance care planning education

Since the latter part of the 20th century, communication skills have been seen as a core element of medical practice and education (Kurtz 2002; Back et al. 2005) and by implication other health care professionals (Kurtz 2002; Heaven et al. 2006). Kurtz (2002) argues that a shift towards systematic communication skills training has been a response partly to the growth in the evidence base for communication skills and also the subsequent advocacy from patient, educator, research and health care providers.

There are a plethora of communication models, tools and training programmes representing the increased interest, activity, advocacy and evaluation of patient – clinician communication (Lipkin 2010; Simpson et al. 1991; Von Fragstein et al. 2008; Kurtz et al. 2005). However, Oczkowski et al (2016) recent systematic review and meta-analysis concluded that whilst structured communication tools can assist end of life decision making and conversations, there remains low quality evidence of which tool to use in what context. Many of communication and advance care planning models are translated or advocated into local, regional or national policy, guidance and education curricula (for example. DH 2008; NICE 2011; NICE 2015; The Leadership Alliance for the Care of Dying 2014; Government 2008; National Palliative and End of Life Care Partnership 2015). The overwhelming focus of communication training activity has been on the behaviour and skills of clinicians (Fellowes

et al. 2004) with an emphasis on learning a repertoire of communication tasks to foster the relationship, gather information, provide information, make decisions, respond to emotions and enable disease and treatment related behaviour (McCormack et al. 2011; McCormack et al. 2013). However, there are observations that training programmes are inconsistent, inadequate or unavailable in pre and post curricula leaving clinicians unprepared for difficult conversations (Levinson et al. 2010; Levinson and Pizzo 2011; Winterburn and Wilkinson 2011).

There is evidence of organisational or personal resistance to on-going education with examples of organisations not releasing staff for programmes (Pyper et al. 2013; Goodman 2014; Farrington 2014) as well as clinicians' personal barriers such as a lack of skill and understanding of the structures of conversational interaction, insufficient personal insight into communication difficulties, undervaluing the importance of communicating, language or cultural differences or seeing communication simply as problem solving (Hoy 2004; Kurtz 2002). Furthermore there is on-going debate about the content, delivery, format and evaluation of programmes (Epner and Baile 2014; Bagnasco et al. 2014; Marambe et al. 2012; Farrington 2014). Despite the need for better understanding of the efficacy of communication skills and what should be taught (King and Hoppe 2013), communication competencies and programmes have been incorporated into practice with many examples taken from cancer care (Lipkin 2010) with suggestions that training can lead to an improvement in clinicians' communication practice (Winterburn and Wilkinson 2011; Razavi et al. 2003; Razavi and Delvaux 1997; Wilkinson et al. 2002; Moore et al. 2013).

There remains a dilemma of what direction education should take. For example, Dwamena et al. (2012) review of patient-centred interventions (including communication) reported that new skills can be obtained by training clinicians to improve their ability to share control with patients about topics and decisions addressed in consultations. Moore et al. (2013) comment that various types of communication skills training improved clinicians' information gathering and supportive skills. However, Moore et al. (2013) were unable to determine if skills were

sustained over time, if consolidation sessions were necessary, what type of course worked best or the beneficial effect on health care professionals.

Whilst there remains a lack of consensus about the design of communication skills programmes, they continue to expand. The expansion of training is demonstrated by for example. development of formal curriculums in the United States, Canada, Australia and New Zealand (Rider et al. 2006; Charles et al. 2000; Clayton et al. 2012) as well as the implementation of the national Advanced Communication Skills Training programme in the UK (Winterburn and Wilkinson 2010) following the NHS Cancer Plan (DoH 2000).

The debate about the effectiveness of targeted advance care planning education programmes is represented in the variation in approach to training and outcomes (Ahluwalia et al. 2015). There are numerous advance care planning education programmes available, some of which report on the effectiveness of an end of life education programme (including advance care planning) on preferred place of death (Pyper et al. 2013; Goodman 2014; Farrington 2014). Others report similar findings (Baron et al. 2015; Badger et al. 2012; Cornally et al. 2015; Hockley et al. 2010) illustrating the desire for specific advance care planning education. However, there are challenges. For example, Workforce New Zealand (2015) who whilst successfully evaluating the satisfaction and effectiveness of an advance care planning education programme point out the low uptake of the target group of primary care practitioners.

Despite the evidence for programmes being mixed, communication skills and advance care planning training is considered a high priority in cancer and palliative care. The challenges of communication in advance care planning therefore remain two fold; what is the most appropriate education programme and how to overcome the clinical and organisational barriers to communication education and practice.

Literature review summary

Much of the literature focuses on advance care planning activity such as advance statements, advance decisions to refuse treatments and appointing a surrogate decision maker. There are dire warnings about the personal and economic cost of not carrying out advance care planning. Legislative frameworks, documentation and dissemination challenges is repeatedly reported. There is literature about why people do not participate in advance care planning and why clinicians find such conversations difficult. What communication skills and behaviours are valued and the subsequent education of clinicians is a regular topic of publications as is increasing awareness of dying through public campaigns and clinical and public health advance care planning interventions.

The value of open awareness of dying, personal vs. relational autonomy, choice and self-determination in end of life decision making plays a part in the literature, as does the context of diversity, inequalities of care, economic concerns and the reduction of hospital admissions influencing local, regional and national policy and strategy. Prognostication and dying trajectories is a factor with discussions about gauging the appropriate timing for conversations as well as referral to palliative care services. The public health vs. terminal care approach to advance care planning is present as is the plethora of multiple terminology and definitions used in advance care planning, end of life and palliative care with its associated challenges for service development, evaluation, research and user understanding.

There is an increasing focus on person or relational centred approaches with a discrete call to focus on the person rather than the paperwork in advance care planning. Perceiving people within their social networks and family dynamics is also present with increased insights into the relational aspects of dying and shared decision making and seeing planning for dying being also about social processes and relationships. Furthermore, education is advocated to increase clinicians' communication skills, competence and competence, but there remains an inconsistency in the models of education programmes.

All the current literature is of value. What is disappointing is the slow progress in transferring the evidence into sustained practice and the over focus on the documentation and decision-making aspects of advance care planning. Ironic as this might seem (as the term is 'advance care planning' after all), but not all end of life conversations are advance care planning ones and there is a danger of advance care planning hijacking all end of life discussions; thereby excluding the contemplative, consideration and reflective elements of conversations (with their own therapeutic value) as well as choice not solely being concerned with preferred place of death. Moreover, the reductionist approach of turning advance care planning activity into outcomes solely such as an advance care plan, advance statement, advance decision to refuse treatment are in the danger of what Thomas (2011) describes as a tick box approach to planning and over focussing on the plan rather than the context of a person's life. The research questions to this study adds to the evidence base by illuminating the need to understand more about the personal influences on advance care planning and perhaps more importantly focusing on the person and what matters to them as opposed to solely documents and decisions.

Chapter 3: Methodology

Introduction

This chapter provides the rationale for the approach taken to the design and carrying out of the study. First the influence of qualitative and narrative approaches including reflexivity based upon the defended subject concept is discussed. The trustworthiness of the study is explored. The Transana™ programme and use of a video interview method as a vehicle to capture density of data for coding and analysis through the video aide memoir is explained. Ethical considerations are explored through the concept of the ethical palliative care researcher including examples of challenges in practice. How the sampling, recruitment and research were carried out is described. The thematic analysis approach is explained and examples shown (appendix 7d) and the post interview participants' hospice records survey of previous advance care planning activity is presented. Finally, the participants are introduced.

The research questions

The purpose of the study was to investigate what would influence hospice patients to discuss their wishes and decisions for care at the end of their life (advance care planning). This was for future development of education programmes based upon the perspectives of people at the end of their life. The research questions were:

1. What influences hospice patients in their advance care planning?
2. What communication skills do hospice patients find helpful when clinicians discuss advance care planning?

Epistemological and methodological approach

The approach that informed this study was qualitative and interpretative as it explored the subjective experience of people at the end of their lives. The study drew upon qualitative and narrative approaches influenced by Mishler (1991), Holloway and Jefferson (2007) and Riessman (2008) and data driven thematic analysis approaches to coding and iterative analysis influenced by Clarke and Braun (2013). The trustworthiness of the study was based

upon Guba and Lincoln (1985). Ethical considerations for a potentially sensitive or vulnerable populations were also considered (de Raeve 1994; Raudonis 1992; Wilkie 1997) as well as location as a nurse researcher in my own work setting with reflexivity considerations. It is important for researchers to be aware of the framework or 'lens' (Moriarty 2011) through which they view each 'interlocking' (Crotty 1998) stages of their research. The lens for this study was concerned with understanding how hospice patients (participants) with an incurable diagnosis made sense of the context of their advance care planning with an interpretative approach in order to build explanations and theory.

Qualitative approach rationale

Methodological acrobatics (Sandelowski 2000), a vast array of diverse qualitative approaches and methods (Elliott and Timulak 2005; Neergaard et al. 2009; Thorne et al. 2004) and a range of epistemological positions (Thomas and Harden 2008) make a strategy for carrying out the research important (Denscombe 2007; Silverman 2013; Brannen 2005). Reviewing the methodology and topic literature identified that there was a question to be answered and consideration given to an appropriate methodology (Cleary et al. 2014; Walsh and Downe 2006) and a design congruent with the research question (Goodman et al. 2012; Cleary et al. 2014). The research design strategy contemplated a variety of methodological and data collection approaches (Robson 1993; Moriarty 2011; Silverman 2010). Single or mixed method approaches were considered (Creswell 2007) and a mix of quantitative methods or a mix of qualitative methods in the same study (Brannen 2005; Creswell and Clark 2010). Study design considerations also included the constraints of finite resources of both the researcher and researched in terms of time, capacity and resources (Payne 2007).

The qualitative single interview approach was used because the study was concerned with building explanations and theory from the thoughts and experiences of a small group of hospice patients with an incurable illness in the context of the influences on the potentially sensitive subject of their own advance care planning. An underpinning motivation of doing the study was the curiosity about the multiple individual contexts or truths influencing advance care planning. Moriarty (2011) highlights the importance of recognising multiple

truths commenting that where research questions are not based on assumptions about the existence of a single reality but aim to uncover a plurality of truths (Fraser 2004), then qualitative methods may be more appropriate in offering an explanation of causal relationships. The methodological lenses (van Manen 1990) of the study was to inquire through the eyes, words and experiences of the participants that which would influence them in their own advance care planning. It was driven by a curiosity for knowing more about the context of their worlds as they lived with the knowledge that they were dying in order to apply this knowledge to the future design, delivery and evaluation of person-centred education programmes.

A qualitative approach is well suited for the why, how and what questions about human behaviour, motives, views and barriers (Neergaard et al. 2009) rather than, as Silverman (2010) observes, the how many of questions (of quantitative or positivist science approaches). Attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them (Denzin and Lincoln 1994) and seeking to understand it as it is situated within its context (Cheek et al. 2004) was important to the study as the research questions were concerned with the context generated from a small group of participants themselves. In addition, qualitative research often relies more on linguistic rather than numerical data, and meaning based rather than statistical forms of data analysis (Polkinghorne 1983). An approach incorporating participants' face to face interviews provided opportunities to explore the multiple contexts and meanings of people's lives. Reicher (2000) highlights that qualitative research can be divided into how people understand their world (experiential) or how they use language to construct their world (discursive). In palliative care research, experiential approaches are better known than discursive ones (Payne 2007), despite the increase in language and end of life care metaphor research examples (Appleton and Flynn 2014; Harrington 2012; Demmen et al. 2015; Semino et al. 2015).

Nursing and palliative care research has an established history in qualitative approaches (Seymour 2012), providing evidence for practice (Bailey et al. 2002) and valuing the importance of listening to patient stories to inform clinical practice (Jack 2010). When Cicely

Saunders founded the modern hospice movement she based it upon four foundations of which research was one (Murtagh 2013). Whilst hospices remain variable in their uptake of research activity (Payne et al. 2013), peer reviewed published oncology and palliative care qualitative papers has noticeably increased since the 1990s (Borreani et al. 2004). Furthermore, Klinger et al (2016) report nearly two-fold number of publications on advance care planning in 2010–2015 compared to 2005–2010.

Narrative influence

The study's qualitative approach was influenced by narrative perspectives as "*narrative is a way for palliative care clinicians, patients and carers to communicate their practical and esoteric experience at the end of life*" (Bingley et al. 2008:653). Distinguishing between qualitative analysis applied to narratives and narrative analysis as a method is important (Thomas et al. 2009; Bingley et al. 2008). Qualitative data driven thematic analysis was applied to fifteen participant narratives. The approach was part of the lens influencing the collecting of the interview data because narrative research can be especially relevant in understanding the illness experience (Holloway and Jefferson 2007) and in advance directives (Grundstein-Amado 1992), offering an innovative and clinically informative way of accessing the personal worlds and perspectives of patients and carers in end-of-life scenarios (Thomas et al. 2009; Bingley et al. 2008).

The qualitative narrative approach sits within a post positivist and modernism paradigm (Riessman 2008). Advance care planning is a personal experience and a post-positivist approach, questioning the reality of an objective truth and emphasizing that knowledge is value-laden and reality is based upon multiple perspectives (Mitchell and Egudo 2003) was helpful for the research questions. Using an interpretative approach to understanding the participant's multiple context of reality, asking them to tell their stories, identifies that participants and researchers co-construct meaning and the researcher interprets and represents their interpretations. These constructions draw upon the belief that the social world cannot exist independently of human beings (Holloway and Jefferson 2008). How the

participants viewed and articulated the context of advance care planning in their world was important to answering the research questions.

The narrative research approach also helped guide the carrying out of the research interview by encouraging an open (Gysels et al. 2008) story telling approach from the participants (Riessman 2008). The underlying premise of narrative inquiry is the belief that individuals make sense of their world most effectively by telling stories (Bailey and Tilley 2002). For example, Frank (1994, 2013) describes a restitution narrative (the wish and possibility to get well), chaos narrative (might not get well) and quest narrative (accepting the challenge to learn from experience and wish to convey to others what they have learnt).

A motivation of the research approach was to have a curiosity to make more sense of the context of advance care planning experiences, discussions and decisions by encouraging a 'tell me your story' approach. This enabled a perspective on the participants' experiences and thoughts rather than a smaller focus on for example. advance care planning decisions. There is an ever increasing body of advance care planning research about what discussions people had, decisions made and if they were achieved (the outcome), but less about the process and the how and why those discussions and decisions occurred. The *"story as the object of study, focusing on how individuals or groups make sense of events and actions in their lives"* (Mitchell and Egudo 2003:3) helped to make a sense of the context and meaning of the participants' advance care planning.

The further rationale to incorporate this approach was to quietly reclaim a narrative competent therapeutic relationship between the clinician and patient where narrative skills enable one person to receive and understand the stories told by another (Charon 2006). To reject an increasing practice of communication rites, rituals and sound bite interactions and interventions where clinicians carried out the tasks of communication rather than connecting as people and engaging in a two-way interactive conversation of for example. what patients may know, think, feel and believe about how they lived with dying and discussed advance

care planning. It seemed important to contest what was increasingly being seen as the universal truth in advance care planning being predominately concerned with decision making such as preferred place of death and the refusal in advance of medical interventions. To explore more the meaning of participants' influences on their advance care planning conversations and choices seemed important; meaning being a legitimate end product of inquiry (Bailey and Tilley 2002).

Reflexivity: the defended subject and examples

Discussing death and dying is potentially challenging. An influence on the research design was Holloway and Jefferson's (2008) concept of the defended subject because: *"anxiety is inherent in the human condition, specifically, that threats to the self-create anxiety. Defenses against such anxiety are mobilized at a largely unconscious level...Defenses will affect meanings that are available in a particular context and how they are conveyed to the listener (who is also a defended subject)"* (Holloway and Jefferson 2008:299). The fundamental concept that both the participants and researcher is a defended subject means that in research interviews and accounts shared meanings cannot be achieved as transparency to self and others cannot be taken for granted (Holloway and Jefferson 2008) as people are motivated not to know certain aspects of themselves (Holloway and Jefferson 2007).

The premise that all facts are interpreted (Daly 1997) and discussions about the trustworthiness of a study (Horsburgh 2003) is not new in qualitative methodology; nor are other concepts such as bracketing; where suspending one's assumptions and previous understanding (Husserl 1970) or recognising that previous knowledge can co create new knowledge (Heidegger 1962) can add to the scientific rigour or validity of a study (Sorsa et al. 2015).

The defended subject concept provided a proactive lens through which the research process and the participants' private and public accounts could be viewed and my researcher interaction could be located. Advance care planning is concerned with contemplating one's

own mortality and the consequences of an individual becoming possibly frailer and incapacitated either physically or mentally. Although individuals may draw upon other peoples' dying experiences to formulate their thoughts or choices, you only die once – so it might not be possible to conceptualise for the future everything that one might want or choose about end of life care. Projecting a future end of life situation can be difficult for people to conceive until they are in the moment (Brohard 2012). Patients may not want to engage in discussions about their future care (Horne et al. 2009) and in some situations forced conversations may cause people harm as a result of the emotional labour of discussing a topic which some may prefer to avoid (Sanders et al. 2008). Michael et al. (2013) discussion of how cancer patients actualize, relinquish, and reject advance care planning reported that reactions can change over time and are informed by values, memories, personalities, health perceptions, appreciation of prognoses, and trust or doubts in their substitute decision makers. The concept of the defended subject and proactively using it as a reflexivity tool influenced the study recognizing its influence on myself as a researcher and the participants to reflect back on experiences, to project forward to possible future experiences and decisions not to reveal or discuss things.

Reflective practice as a way to recapture experiences, think about and evaluate them (Boud 1985; Schon 1983; Johns and Freshwater 2009) is a fundamental part of my practice as a clinician and educator. However, for the research process, it seemed important to extend this type of activity. Much writing up of any research tends to eliminate the self-analysis of the researcher (Smith 2013). Reflexivity as an *“immediate, dynamic and continuing self-awareness”* (Finlay and Gough 2003a:ix) was used within the study to help *“situate the research project”* (Finlay and Gough 2003:1), enhance transparency of the decisions made in the research process (Engward and Davis 2015) and consciously make more visible my individuality and effects on the research process (Gough 2003). The value of reflexivity's self-awareness and transparency is argued to be concerned with being able to see any influences that could affect data collection or analysis (Clancy 2013) as well as research design and presentation of findings (Gough 2003). Whilst acknowledging the myriad forms of reflexivity (Finlay 2003), variation in practice (Gough 2003) and that it may be difficult or probing (Clancy 2013), two strategies were put into place to facilitate reflexivity during the research process.

Firstly, influenced by Horsburgh's (2003: 308) definition of *"active acknowledgement by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation"*, iterative questioning within the interviews and awareness and questioning of own confidence and competence as nurse researcher aided an on-going observation of my skills, expertise and conduct especially within the interviews (Shenton 2004).

Regular formal and informal debriefing with topic and methods experts and interested parties was carried out (Shenton 2004). For example. Doctoral supervision as a systematic sounding board for research question, approach, methods, analysis, results and discussion challenged me to question; how robust am I? The video as a visual aide memoir provoked me to review my interaction within the interviews. Hospice, specialist palliative care peer group and generalist discussions provided a group for articulation of thesis argument and relevance of research question challenging my assumptions or argument and questioning if I made sense in practice as well as providing different clinical perspectives. Peer group scrutiny through publications, conference presentations and posters (appendix six) throughout the doctoral time line enabled an on-going challenging of assumptions, strength of emerging thesis argument, providing perspectives on how relevant the question and findings were to practice (Shenton 2004; Loh 2013; Kvale 2008). Social media conversations and blogs enabled discussions about advance care planning issues and research methodology, facilitating frequent debate about how do my arguments sound, is this applicable, providing perspectives, and challenges to my thinking. Audiences and multi-professional learners in the local, regional and national advance care planning and communication skills conferences and education programmes that I designed and taught enabled further thinking about relevance to practice as well as challenging assumptions. Throughout all of these methodological thinking processes there was backward and forward reflective questioning and reasoning.

Secondly, throughout the study, reflective field notes and memos were used to note emotions and thoughts throughout the research process for example. during data collection and analysis. Researcher reflexivity is ongoing (Sivell et al. 2015) and commentators note the value

of a reflective diary or log of decisions and inferences arguing it encourages methodological awareness (Riessman 2008), fosters reflexivity, critical self-awareness about how the research was done and the impact of critical decisions made along the way (Seale 2002). In other words, there was a commitment and structure to have a continuous conversation with myself.

The prime purpose of this activity was to provide a consistent way to locate myself as a researcher in the research process, enhance transparency of decisions and to remind myself of the potential to be a defended subject myself. The continuous conversation framework including the video aide memoir (Russell et al. 2016) and defended subject concept deliberately provoked me to consider how I interacted both professionally and personally with the research process. Examples of why this conversation was relevant to the research process included recognition at times that I was in danger of projecting onto participants my own views of advance care planning as well as the potential of allowing professional priorities influencing how I collected or analyzed data.

Reflexivity was illustrated by a structured approach to field notes based upon the defended subject concept. This was because during the course of the doctorate I experienced my own ill health, bereavement, major life and career decisions. All of these experiences were related to the research topic and as such I felt it was important to have a structure to continuously discuss with myself the impact of them on the research process. In addition to free text field notes and memos I developed a reflexivity structure based upon the defended subject approach in order to continuously reflect (figure 2).

Figure 2: example of continuous conversation framework		
My field notes reflections	Defended subject concerns	My Reflexivity Strategy
<u>Example One: Field notes post consent: Jacky (pseudonym)</u>		
<i>Just been to consent Jacky for research interview next week. Her children are the same age as (name of my daughter). As she was describing her concerns about choices for secondary school and that she might not be there when they have to make their choices. I could feel myself desperately wanting to say 'yes I know what you mean' and then to start giving advice...I MUST NOT DO THIS....this is her life and story not mine</i>	<i>I am over identifying with Jacky because I have been/am in similar situation. I am projecting onto her my concerns. This could influence how I carry out the interview</i>	<i>When I carry out the interview I will resist the urge to give advice and only follow up on children cues...I will be more aware to follow up all <u>her</u> threads</i>
<u>Field notes post interview: Jacky (pseudonym)</u>		
<i>I found that interview very emotional as could really really identify with Jacky but resisted temptation to give advice or say 'I know what you mean'. Actually Jacky spoke almost continuously without interruption which helped me</i>	<i>Still really identify with her and need to remember that in the coding and analysis</i>	<i>Be conscious when I code and analysis that I might see more than is there because of my over identification. Remember to say to myself SO WHAT and WHATS THE EVIDENCE for what I am coding</i>
<u>Example Two: Field notes pre consent: Liv (pseudonym)</u>		
<i>Wow she is really articulate and has the most amazing things to say, lots of brilliant sound bites that I could use in teaching, conferences and articles</i>	<i>There is potential that I might unconsciously encourage sound bites because I know that I could use them in teaching sessions.</i>	<i>When I interview her remember this is her story not mine...sit on your hands Sarah if you feel the temptation to facilitate a sound bite</i>
<u>Field notes post interview: Liv (pseudonym)</u>		
<i>Amazing interview, really articulate, lots to say, really made me think about other stuff such as environment</i>	<i>Ok, ok there were sound bites there, but I think (hope) when I listen back that there was no manipulation by me of her words, actually she is such a powerful woman in herself I doubt anyone would manipulate her</i>	<i>Honesty, honesty, honesty...be truly honest with yourself when you code and analysis</i>

Trustworthiness

Trustworthiness was used to establish the rigour and credibility of the study (Guba and Lincoln 1985). Demonstrating rigour in qualitative research is challenging for the novice researcher (Noble and Smith 2015) partly because of the lack of accepted consensus about the standards by which research should be judged (Rolfe 2006). However, demonstration of the methodological rigour of work is important (Payne 2007) to persuade audiences that findings are worth taking an account of (Robson 1993). Concern has been raised about the rigour and credibility of qualitative methods (Borreani et al. 2004) with questions about what criteria are most appropriate for evaluating qualitative research (Bailey et al. 2002).

Palliative care research also faces ethical and methodological challenges such as the predominance of small-scale and often poor quality studies, lack of a critical mass of experienced research groups and researchers and lack of user involvement (Payne et al. 2012). Concerns about the challenges of evidenced based medicine in palliative care research is reflected in discussions which comment on supporting clearly articulated research questions to drive the research process rather than a predominance on large scale studies (Aoun and Nikolaichuk 2014) as well as the value of qualitative themes to demonstrate a deeper and more useful understanding of the *“complex landscape of palliative care”* (Visser et al. 2015:198).

The use of established criteria such as Guba and Lincoln’s (1985) terms of credibility, transferability, dependability and confirmability is part of the much contested area of the reliability and validity of qualitative studies (Sandelowski 2000; Guba and Lincoln 1994). This paradigm warfare (Seale 2002) has led to the challenging of establishing fixed criteria to assess quality (Popay and Williams 1998; Crossley 2007) as well as the legitimisation crisis of rethinking terms such as validity, reliability and objectivity (Denzin and Lincoln 2011) and whether the same standards applied to quantitative research can be applied to qualitative research (Hammersley 2007; Rolfe 2006; Cleary et al. 2014; Noble and Smith 2015).

Whilst recognising the importance of this debate, this study sought through the lens of trustworthiness to have methodological awareness and anticipate the consequences of methodological decisions (Seale 2002), recognising that credibility is essential for all research (Silverman 2006). The methodological awareness in this study was concerned with the visibility of the description of methods, analytical and data collection techniques to be able to provide appropriate meaning (Walker 2008) and transparency of the rigour and process of motivations for the methodological actions.

Trustworthiness included recognising that qualitative and quantitative research approaches produce different types of knowledge (Crossley 2007), requiring different ways to demonstrate the trustworthiness of the findings (Morse et al. 2002; Hammersley 2007). Torrance comments that even though that standards and checklists in qualitative research *“cannot substitute for informed judgment”*, there is also a need to acknowledge and discuss *“the imperfections of qualitative research and enact the deliberative process of academic quality assurance”* (Torrance 2011:373).

Efforts were made to not be blind to the methodological consequences of research decisions (Seale 2002). For example, an awareness of the possible dynamics of interviewing within the home setting was considered; a methodological dilemma illustrated by Sivell et al. (2015) discussion regarding interviewing palliative care patients at home. Hammersley’s caution to consider guiding principles and lists of relevant considerations (Hammersley 2007) in assessing the quality of research studies was taken into account in the study through visibility of decisions, methods and reflexivity to minimize (Lietz et al. 2006) or at least be transparent of the effects of reactivity and bias.

Whilst, Lincoln and Guba’s (1985) concepts of credibility, dependability, transferability and conformability have arguably been widely accepted as established guidelines for trustworthiness (Loh 2013), they are also considered to be primitive (Guba 1985). They have been criticised for not recognise the on-going tensions between each stage of the research

process (Atkinson et al. 1999). Lincoln and Guba themselves point out that *“it is dubious whether ‘perfect’ criteria will ever emerge”* (Lincoln and Guba 1985:331), leading to the observation that the criteria serves as a guide (Loh 2013) and comments that criteria lists *“are not closed; they can be added to and subtracted from as the form and purposes of inquiries change”* (Sparkes 2002:11). The trustworthiness of the study was influenced by Lincoln and Guba (1985), Shenton (1994), Sparkes (2002) and Loh (2013) through the visible research practices of the study thereby leaving an auditable decision trail (Morse et al. 2002; Sandelowski 2000). The trustworthiness of the study also included incorporating considerations such as the COREQ guidelines for qualitative research (Tong et al. 2007) and the Critical Appraisal Skills Programme Qualitative Research Check List (CASP 2002). These served as a continuous reminder from planning through to the writing up of the thesis.

Credibility

Credibility *“persuades readers of the research that the data is reasonably likely to be accurate and appropriate”* (Denscombe 2007:297). To assess the appropriateness of the topic and methodology a pre and contemporaneous literature review (Shenton 2004) was carried out in qualitative, narrative, nursing, palliative care, illness and advance care planning research methodology and methods. This provided a constant examination to frame the findings and appropriateness of the methodological approach particularly in terms of how do they fit, what are the gaps, is there a question, validating existing knowledge and is there emerging new knowledge. Reflective notes and reflexivity including the defended subject concept was carried out throughout the study phases.

All the interviews were fully transcribed by myself using the Transana™ computer software packaging, which was then used to organise the interview data. Throughout the study a constant revisiting of the interview data using the video aide memoir approach and the Transana™ computer software package throughout transcription, coding and analysis process to review coding was carried out. Participants were invited to voluntarily take part in the study and discussed regularly that they could withdraw at any time. A person-centred approach to

research interviewing (for example, constant discussion about what matters most to you about how we carry out this research) combined with a narrative interview approach focused the interviews on what and how the participants wanted to tell their story.

Transferability

Transferability or showing that the findings have applicability in other contexts (Lincoln and Guba 1985) is comparable to the concept of 'external validity' seen in quantitative research (Ryan et al. 2007; Twycross and Shields 2005). The use of detailed description of people, their social world and experiences (Holloway and Freshwater 2007) is a key part of transferability enabling readers to draw conclusions about the transferability of findings from those detailed descriptions (Guba and Lincoln 1985).

Detailed description of the participants, research site, sampling, recruitment, interview process, coding and analysis process as well as the findings was operationalized to provide as thick a description as possible so that readers of the study could make up their own minds as to the transferability of it to other settings (Loh 2013, Shenton 2004). For example, appendices 7a to 7d illustrate this process. These descriptions and examples within the study strove to illustrate how I as a researcher responded to challenges that arose during the study. Examples such as ethical considerations or the adapting of the interview guide due to participants' unfamiliarity of the term of advance care planning are two such examples.

Dependability

Dependability is concerned with enabling evaluation of the accuracy of the analysis through the decision-making processes of the researcher (Holloway and Wheeler 2010, Lincoln and Guba 1985). Throughout the study visible detail of the decisions and process aimed to provide an inquiry audit (Lincoln and Guba 1985) for readers (for example, methods used, why and their effectiveness). The development of the use of the video aide memoir and the COREQ and CASP qualitative research guidance was helpful for this part of the study especially in

terms of using Transana™ to manage the interview data and provide illustrative examples of how the findings emerged.

Confirmability

Confirmability as the ability to demonstrate that the data represents the respondent's responses and not the researcher's bias or viewpoints (Cope 2014). It was utilised by employing a visible audit trail to provide clarity about methodological approach, the influences on data collection and the data driven thematic analysis process employed to code and analysis the interview data. This process included anonymising the interviews and then coding by a familiarising with the data, generating initial themes, searching for main themes, reviewing main themes, defining and naming the themes. The video aide memoir process was employed to continuously revisit interview data. The Transana™ CQDAS programme as a method to organise the interview data (for coding and analysis) and field notes and reflections was also used for confirmability in the study. Finally, to provide clarity, appendices 7a to 7d provide further detail of thematic analysis examples and the participants' contributions to the final themes including illustrative quotes used for each of the finding chapters. Figure 3 illustrates the audit and decision trail for transcription, coding and analysis.

Figure 3: audit and decision trail for transcription, coding and analysis	
<ol style="list-style-type: none"> 1. Interview Data transcribed fully using Transana software package 2. Transcriptions checked for accuracy against original video interview 3. Wording and transcription amendments made 4. Data driven coding using participants own words <i>Identified by interpreting meaning and frequency</i> <i>Constantly rechecked and revisited and checked against transcript</i> 5. Initial themes <i>Identified by interpreting meaning and frequency</i> <i>Constantly rechecked and revisited and checked against transcript</i> 6. Reviewed against transcripts and reallocated if necessary <i>Identified by interpreting meaning and frequency</i> <i>Constantly rechecked and revisited and checked against transcript</i> 7. Themes reviewed and reallocated if necessary <i>Identified by interpreting meaning and frequency</i> <i>Constantly rechecked and revisited and checked against transcript</i> 8. Analysis of preliminary themes <i>Identified by interpreting meaning and frequency</i> <i>Constantly rechecked and revisited and checked against transcript</i> 9. Themes reviewed and reallocated if necessary <i>Identified by interpreting meaning and frequency</i> <i>Constantly rechecked and revisited and checked against transcript</i> <i>Themes reviewed and rechecked during writing in order to reduce replication across chapters</i> 	Reflective diary and note taking Literature review of topic and methodology Peer and supervision debate and discussion
(Adapted from Twycross and Shields 2005)	

The interviews

One to one, face-to-face video interviews were used in this study. This method was chosen because the research question was concerned with exploring the participant’s thoughts and feelings about the individual context of their advance care planning. Conversation is a basic mode of human interaction (Kvale and Brinkman 2009) and the interview method as conversations with a purpose (Burgess 1984) aided the research question through being able to “*learn about their experiences, feelings and attitudes, and the world they live in*” (Kvale and Brinkman 2009:xvii).

The interview is a common method to collect data in qualitative research (DiCicco-Bloom and Crabtree 2006; Elliott and Timulak 2005; Holloway and Wheeler 1996; Moriarty 2011) ranging from structured; semi structured to unstructured with variations in between (Moriarty 2011). Interviews can be used to explore meaning and perceptions to gain a better understanding

and/or generate hypotheses (DiCicco-Bloom and Crabtree 2006) and can be knowledge-producing activity (Kvale 2009). The interviews were to generate knowledge and hypothesis rather than to test an established one (albeit the research questions were based upon informed clinical experience and review of the literature).

The epistemological stance for the study was drawn from Kvale and Brinkman's (2009) metaphors of the interviewer as miner or traveler with the latter being the position taken for the research. The miner metaphor of uncontaminated knowledge waiting to be unburied (Kvale and Brinkman 2009) did not feel appropriate because it seemed to me that there were multiple realities in the current research about the motivations and experience of advance care planning (such as future capacity, self-perceived burden, control, choice etc.). Advance care planning is not just about unearthing undiscovered, uncontaminated universal truths about the participants themselves. The traveler metaphor felt more true to the belief that there are multiple realities on the influences on advance care planning. Therefore, there is not one universal truth waiting to be uncovered, but multiple ones' dependent upon circumstances and context of each individual.

There are warnings about using the interview method including whether they really provide direct access to experience (Silverman 2010) and the importance of seeing interviews as a two way process through which a narrative is collectively assembled (Silverman 2010), being aware of the impact of research on participants and the challenge of respondents' giving different answers on different days to different researchers (Burnard et al. 2008). The popularity for using interviews as a data collection method is often related to the concept that talking is seen as natural (Doody and Noonan 2013). However, for this study, each interview was approached as: this was the data, in today's context, on this day.

A further influence on the study was drawn from the multiple discussions regarding the authenticity of the voice in interviews. Acknowledging the debate highlighted by Sandelowski (2000) that the qualitative research world is being taken in by the belief that interviews reveal

authentic experience and a direct expression of the true or private self, Miczo (2003) provides the argument of seeing the interview as a communicative event. Miczo (2003) argues that qualitative researchers should not fail to appreciate meta-communication factors in power issues in interviews. The emphasis on paying attention to the process and naturally occurring interaction of the interview is echoed elsewhere (Lomax and Casey 1998). An ongoing attention to the process of the research interview in itself through the use of the video as well as from recruitment through to interpretation, coding and analysis became a part of my reflexive research practice and influenced the use of the word and concept of participants as well as participant control of the research process. This was my commitment to see the people that I interviewed as co-participants in the process rather than passive recipients.

In addition was the balancing of the similarities and differences between a research and therapeutic interview reflected in a variety of accounts (Colbourne and Sque 2005; Holloway and Freshwater 2007; Kvale 2008). Colbourne and Sque's (2005) healthy debate on the culture of cancer and therapeutic nature of research interviews helped to normalize the mixed emotions that I was having whilst carrying out the interviews. It was reassuring to understand that others had also experienced the conflict of participants expecting a therapeutic component both within a research interview as well as outside of the actual interview recording. Furthermore, the narrative approach to research influenced the interviews. For example, I viewed the conduct of the interviews, coding and analysis within a conceptual framework that people tell stories of themselves and present/represent themselves as well as my interpretation and reinterpretation. In the same way that there are multiple definitions of a good death – so are the stories of how we face our own dying and advance care planning. Holloway and Wheeler (2010) identify that within the participant and interviewer interaction, interviews provide an opportunity for life events to be explored. Being attune to the dynamics within the research interview as well as coding and analysis contributes to the trustworthiness of the research.

As a clinician and a researcher, there were times within the interviews when it was difficult not to lean more to the clinical rather than the researcher role. Kvale (2006) points out the

delicate balance between cognitive knowledge seeking and the ethical aspects of emotional and human interaction. Bulpitt and Martin (2010) discussing this challenge, suggest that the research and therapeutic interview have distinct formats but agree with Kvale (2006) that both may lead to increased understanding; the therapeutic interview being concerned with personal change as opposed to intellectual understanding in a research interview. Bulpitt and Martin (2010) in their discussion of using reflexion to make research processes in studies transparent argue, *“The aim of a therapeutic interview is to bring about some form of ‘healing’ in its broadest sense or some resolution of psychological incongruence or dissonance for the benefit of the interviewee. The aim of a research interview is to bring about intellectual understanding for the immediate benefit of the interviewer, the interviewee (in a secondary sense) and ultimately the academic and professional communities”* (Bulpitt and Martin 2010:11). Reflection and reflexivity was an important strategy in the research vs. therapeutic interaction as well as recognizing that the buffer period (time after interview before I left) might include therapeutic interactions.

A further consideration during the study was the challenge of researching in my place of work. Dearnley (2005) provides useful reflections on the ethical implications of carrying out an investigation within her own organisation. Debate about defining where the researcher and nursing role ends is and the challenges of being an insider researcher are also frequently described (Smyth and Holian 1999). All of these considerations were experienced throughout the study, reinforcing the value of not only reflection and reflexivity but also my continuous commitment to trustworthiness and transparency of the research process.

There was another dilemma. For many years I have taught communication skills to clinicians that were comparable to the ones that might be used in a research interview. Targum (2011) discussion of this in the psychiatric field highlights many of the similarities in terms of building rapport and trust, facilitating open and honest communication, using both honest and closed questions etc.

The challenges therefore as nurse researcher was for example. to contain the instinct to validate or acknowledge the participants' emotions within their stories (strategies that I would use in clinical practice for therapeutic benefit) and instead stay within a facilitation of a research interview. Reviewing the first pilot interview clearly revealed that although I was using silences, pauses, reflection and prompts well, to facilitate the flow of the interview, I was also subconsciously directing the interview with very explicit validation of parts or emotions of the story. For example. *"that's interesting... I am particularly interested in...tell me more about...that sounds tough etc."* In the second and subsequent interviews there was a distinct difference in terms of holding back and less subconscious direction of the story telling for example. *" ummm...go on...tell me more...say more...can you explain"*.

Video interviews

Video interviews were used in order to aid the coding, analysis and interpretation of the interview by providing a density of data (Dufon 2002) visual aide memoir tool. Videos have the potential to access versions of conduct in everyday settings and explore how talk is inextricably embedded in the bodily conduct of participants (Swinglehurst 2011). Visual methods in social research take on a variety of mediums including researcher or respondent created data, audio and video recording, field notes, note taking, photo elicitation, visual prompts, participant generated photos and videos, memory books, visual metaphors, displays, picture and symbol boards, drawings, models and paintings (Pink 2003; Buckingham 2009; Bryman and Teevan 2004; Margolis and Pauwels 2011). Images are increasingly part of qualitative inquiry (Holloway and Wheeler 2010) with more digital methods for analyzing video (Loehr and Harper 2003). There are arguments that visual images should be taken seriously as video-making can enhance a research process by bringing credibility to the content of what is said (Chavez 2004).

Furthermore, there are arguments that video research has enabled the expansion of the repertoire of social researchers in the same way that audio tape recorder has done in the past providing *"a fine-grained multimodal record of an event detailing gaze, expression, body posture and gesture. It is a shared, malleable digital record in which all modes are recorded*

sequentially" (Jewitt 2012:2). DuFon (2002) in her discussion about issues of validity in video research emphasizes key opportunities in video research; including density of data, providing more contextual data such as who is speaking, postures, gestures, clothing and proxemics, which inform about speaker norms.

For the purpose of this research, the videoed one to one, face to face interview was the interview method used in order for a visual aide memoir for density of data (speaker norms) and a cyclical reflective process (Dufon 2002; Erickson 2011; Erickson 2007; Hopper and Quiñones 2012). The Flip Video™ device was used to record the interview in order to be able to pay attention to the flow of the conversation and to not be distracted by the recording of field notes during the actual interview. The video interview in the latter stages of transcription, coding and analysis became increasingly concerned with revealing nonverbal interactions and verbal interactions separately - to be able to see the trees rather than the forest (Erickson, 2007:). Repeated viewing of the interviews facilitated further layers of coding especially in terms of could I justify my interpretation of coding and themes? It enabled a record of the verbal and non-verbal language of the participant, which facilitated understanding of the context of different segments of the interview.

The density (DuFon 2002) of interview data enabled examination of the critical incident or aha moment as described by Hopper and Quinones (2012). This enhanced the credibility of the coding and analysis through the ability of repeated visual and aural reviewing of the interview for the coding and analysis and a decision trail of how the meaning of participants' stories were negotiated or presented by themselves during the interview and interpreted and re-presented by myself as the researcher. The analytical approach was not one of examination in detail of language as seen in for example. conversation analysis but more of how could repeatedly revisiting of the visual and oral record of the interview help with my interpretation and evidence for the thematic coding and analysis process. This developed in the study into a density of data video aide memoire process for the coding and themes process.

Examples of data density and video aide memoir

Firstly, when coding and examining pauses or silences during an interview, a visual reference could be checked to see the cause of the pause. For example. Sally's (pseudonym) motor neurone disease meant that she had a very dry mouth. Consequently, she frequently stopped to take sips of water. When she was discussing her worries about being a burden on her carer Jane, her pauses were because she was drinking to relieve her dry mouth. There was no visual evidence that her pauses were because she was distressed. Secondly, it facilitated a visual check within the interviews of the participants' norms of body language and if their individual non-verbal body language might indicate for example. when they were saying something that was meaningful to them. For example. Andrew always pointed with his finger when he was emphasising things that seemed important to him. I interpreted this as the way he used body language to emphasise a point. Mary's body language was consistent throughout all her interview in terms of quiet, not expressive (like Andrew). She frequently looked out of the window and took her time to say what she wanted to. I interpreted that as her non-verbal communication demonstrating her thinking rather than a reluctance to answer the question.

The visual aide memoir of the video strengthened the interpretative coding and analysis process by being able to visually check her usual body language. Finally, the video interview method enabled me as a researcher, particularly in the first interviews to check if I was attending to the flow of the interview. For example, did I interrupt the participants or was it just a natural overlapping conversation.

Using video interviews was approached with methodological, practical and ethical cautions, recognizing that video is not self-interpreting and open to multiple interpretations (Greenhalgh et al. 2016; Suchman 1995; Heath and Hindmarsh 2002). It was considered as one source of information for coding and analysis alongside field notes and the interview transcriptions. This approach was influenced by Erickson (2007) observations that although some researchers may view video data as a complete record, video data should be seen only as an information resource. Hopper and Quinones (2012) reinforce this pointing out that although there is a growing interest in collaborative approaches to qualitative inquiry using

video data, there is a need for more explicit accounts of critical and reflective approaches to and the epistemological grounding of video watching.

There is a need to be aware of the methodological approach taken for data collection and analysis (Derry et al. 2010) as well as recognizing that there will be similar technical and practical challenges whatever methodological approach that one takes (for example. equipment, lighting, storage and consent considerations). Lomax and Casey (1998) whilst highlighting the potential of video recording to research also emphasize that the visual record is about the enhancing of the process of research as much as the data collected. Visual images do not provide an unmediated, un co-constructed version of the truth (Buckingham 2009).

The technical competence and ethical issues with recording and storage of video data were influenced by Erickson (2007) recommendations. Considerations included embedding awareness and practical applications of the video or audio recording from the beginning of the research process. Riessman (2008) observes that publishers and academic journals are only beginning to catch up with the visual turn in social research (and the ethical issues of identification of individuals and institutions) but that investigators should not be paralyzed with uncertainty and instead work openly and collaboratively with participants. It is also suggested how important it is to be aware of the law and regulations regarding confidentiality and protection of individual's privacy because *"one of the most compelling aspects of video-based research is that the data are in a form that is easily communicable"* (Jacobs et al. 2007:288). In the same way Jacobs et al (2007) go on to make for example. recommendations for restricted and unrestricted videotapes (shown only under the specified circumstances or used and distributed in any way).

During the study my heightened awareness of the ethical issues of video recording interviews was illustrated by one potential participant who whilst wishing to take part gave me doubts as to whether he had fully understood how his words and images would be used (I was doubtful if he had fully read the information sheet and consent form). The potential

participant was very keen for me to interview him and had arranged for his family to be away from his hospice bed whilst I visited him. So I sat and listened to his story and did record the interview because he asked to see me turn it on. However, I deleted the recording from the Flip™ video device after the interview. I felt that this respected his wish to tell me his thoughts but also acted ethically in not using an interview which I had doubts about the participant's understanding of how his words and images would be used. He died 3 hours after my visit. His family mentioned to the ward staff that he had been pleased to see 'that nurse' and tell her his story. These confidentiality and access considerations formed part of the research ethics, consent and information process as well as my commitment to have a continuous conversation with myself (reflexivity).

Transana™ Computer Assisted Qualitative Data Analysis Software

The computer assisted qualitative data analysis software (CAQDAS) package (Transana™) was used in the study. Transana™ provided a way to store, organise and manage the interview data in order for it to be coded and analysed. Cautions with CAQDAS packages are that they are not an analysis tool in themselves and are only as good as the researcher using it (Lewins and Silver 2009). CAQDAS is software designed to assist the analysis of qualitative data and can be used to enable the coding and analysis of large amounts of qualitative (or quantitative) data (Duriau and Reger 2004; Lewins and Silver 2007). Generally concerned with the coding of text (Weitzman and Miles 1995; Lewins and Silver 2009) the term has expanded to include a variety of packages for qualitative data such as text, visual and multimedia forms of data (Lewins and Silver 2007). A variety of CAQDAS software was considered for example. ATLAS.ti5™, MAXqda2™, NVivo 7™ as systematically analysing the need of the project and the researcher to match the right software is crucial (Weitzman and Miles 1995) as well as considering the individual pros and cons of packages (Lewins and Silver 2007).

Transana™ was used because it is a qualitative analysis software package specifically designed for the analysis of video and audio data (Woods and Dempster 2011). It includes features to transcribe data, identify analytically interesting clips, assign keywords to clips, arrange and rearrange clips, create complex collections of interrelated clips, explore relationships

between applied keywords. The Transana™ Standard Version (single-user) version was privately purchased for this study as it is an affordable version for student and novice researchers to do transcription and qualitative analysis of simple video and audio data on a single computer. The standard version supports data sets that can be analysed with a single media file and a single transcript open at any given time. I found it to be accessible and flexible to use enabling me to organise and revisit the interview data.

Ethical approval

The University of Hertfordshire and the hospice research site granted approval for the carrying out of up to 20 research interviews. The University of Hertfordshire CRIPACC team supervised the research and thesis. Ethical approval was given by the University of Hertfordshire Ethics committee (University of Hertfordshire Ethics Reference Number: NMSCC/05/09/14/A) following minor amendments to the original application (appendix 8).

Approval was also given by the hospice research site (appendix 9). The hospice initially did not have a guidance or policy for the carrying out of research on site. It is not unusual for smaller hospices to not have a research policy in place, as research is not universally embedded in hospices (Murtagh 2013). Recommendations include the adoption of the Research Framework for Hospices taking hospices from being research aware to engaging in, generating or leading research activities (Payne et al. 2013). In my professional role at the hospice and in order to have research site approval, I took the hospice research site from being research aware to engaging in research activities. This included designing and implementing the research, clinical audit and service evaluation policy (appendix 10). For this study in order to strengthen probity, I excluded myself from the research approval process and requested approval from the hospice clinical governance committee (made up of senior clinicians and hospice trustees). Approval was given (Hospice Ethics Approval Number: 11/03). The policy was commended in subsequent Care Quality Commission inspection reports and the Hospice UK 2013 national conference (Russell et al. 2013).

Ethical considerations

Ethical considerations were considered at the beginning (Robson 1993) and throughout the research process (Holloway and Wheeler 1996). There is a large body of literature identifying ethical issues in palliative care research (Gysels and Higginson 2007; Murtagh et al. 2007) with little consensus of views (Higginson et al. 2013) including debate as to whether such research is ethically unique and uniquely challenging (Casarett et al. 2003). There is contradictory evidence about the emotional burden in participating (Gysels et al. 2008) and concerns about informed consent especially in vulnerable groups (Wiles et al. 2008) at the end of their lives. The MORECare research guidance group point out that the *“ethical decisions regarding the design and conduct of research determine the nature and quality of the research undertaken”* (Gysels et al. 2013:909). Other concerns include confidentiality as well as identifying and retaining the target population (Christakis 2006), handling missing data (Fielding et al. 2006) as well as should patients at the end of their lives be invited to participate in research (Gysels et al. 2008).

However, the literature also observes the importance of not forgetting the patient’s voice (Mak and Elwyn 2005) and that users views are considered central to policy (DH 2008). In addition there is evidence that some people facing death may wish to participate in research (Kendall et al. 2007) with evidence of benefit (Pessin et al. 2008; Gysels et al. 2008; Gysels et al. 2013). These benefits may include social interaction, a sense of contributing and the opportunity to discuss their illness (Pessin et al. 2008).

Many of the questions raised about doing any sort of sensitive qualitative research are compatible with that of palliative care research. Palliative care and qualitative research are comparable because both *“inevitably involves contact with human subjects in the field”* (Silverman 2010:152), as well as facing similar challenges (Gysels et al. 2008) such as suggestions they do not have value because do not start from a hypothesis or produce one definite result (Eardley et al. 1991). Moriaty (2011) points out the potential of causing distress, the demands made upon participants as well as the challenge of informed consent, anonymity and confidentiality in all qualitative research. Addington-Hall (2007) argues that the usual methods for protecting research participants (for example. risks, benefit and autonomous

informed decisions to participate) are the same in palliative care as in other types of sensitive research. Dickson-Swift et al. (2007) discussion about qualitative research challenges echo for palliative care for example. self-disclosure, listening to untold stories, feelings of vulnerability and leaving the research relationship. Other issues include the challenge of confidentiality, the power relationship between researcher and researched as well as balancing the role of clinician and researcher (Masso et al. 2004.; Moriarty 2011; Goodman et al. 2012).

Being an ethical palliative care researcher

Ethical issues were considered through the concept of being an ethical palliative care researcher. The frame of reference for being an ethical palliative care researcher revolved around the relationship of the researcher and researched, based upon the concept of the research being a collaborative process (Moen 2006) as well as the implicit and explicit contract between the researcher and researched (Josselson 2007). Bold (2012) argues that an ethical researcher will seek to balance the potential for harm against the benefits from the outcomes of the research for the participants and others.

My stance was concerned with this by designing and carrying out a study, which took into account as much as possible the possible consequences of a video interview on a sensitive subject with dying people. Indeed, my vulnerability concerns were more geared towards considerations of autonomous informed consent and the potential consequences of the use of participants' moving or still images in an increasingly active social media and technological age rather than that of the participants being a group of dying people. This echoes cautions about the ethical issues raised by the advent of technology (Schuck and Kearney 2006).

Being an ethical palliative care researcher also included balancing the detail of the formal ethics approval with the desire from some participants to have control over their interview. This was concerned with synergizing the values and detail inherent in the ethics approval with the attitude and commitment to see the participants as partners in the research process. Gysels et al. (2008) report similar considerations commenting on the importance of

recognising the context of how informed consent and interviews take place as well as that retrospective informed consent may be necessary.

Reflection and reflexivity strategies as already described were key to this process as well as on-going considerations of the implications of for example. the use of images, words and what informed consent meant in this context. Whilst carrying out the research there were distinct examples that stretched my thinking as an ethical palliative care researcher (appendix 11). These examples of informed consent, participant agenda, control, explicit contract and honesty illustrate some of the challenges and considerations in practice and are described to facilitate transparency of how I carried out the study as an ethical palliative care researcher.

The examples illustrate the real world ethical researcher challenges. Informed consent is a central concept in bio ethics and the practice of gaining it is an integral part of medical research (Helgesson et al. 2005). Elements of valid informed consent include capacity, disclosure, understanding, voluntariness and permission (Joffe et al. 2001). Whilst, there is no consensus about what comprises informed consent (Wiles et al. 2007), there is agreement that it involves the concept of autonomy and respect for the person and certainly the background to the legal framework to research ethics enshrined in Article 8 of the 1998 Human Rights Act (HM Government 1998b) and 1998 Data Protection Act (HM Government 1998a) identify this key concept. Josselson (2007: 538) argues that; *“ethical practice and codes rest on the principle of assuring the free consent of participants to participate, guarding the confidentiality of the material and protecting participants from any harm that may ensue from their participation”*.

Considering the importance of the explicit contract between participant and researcher is illustrated in appendix 11. In one example, the participant had made an explicit contract with the researcher as to what they had consented to. The issue was less about what they or I could or could not foresee or anticipate to consent to for the future (for example. anticipating that their family might want to see the video interview after their death), but more concerned

with honouring what they had explicitly consented to at the time of the consent and interview. In other words, not making assumptions or educated guesses after their death as to what, if asked at that time, they might have consented to before their death. This was motivated with protecting them from harm by their participation. This is compatible with the stance that involves: *“thinking through these matters and deciding how best to honour and protect those who participate in one’s studies while still maintaining standards for responsible scholarship”* (Josselson 2007: 538).

The illustrative cases also honour the participant by maintaining standards for responsible scholarship by following through on my decision regarding their understanding of how the words and images would be used. Josselson’s (2007) assertion about the importance of the explicit and implicit contract clarifies the role of the relationship between the researcher and participant and hence the importance of an ethical attitude to the detail of the consent (explicit contract) as well as the responsibility of the researcher/participant relationship (implicit contract). Josselson (2007) defines the explicit contract as being concerned with the role of relationships between researcher and participant for example. this is who I am, purpose of study, how I am doing the interview etc. The implicit contract is concerned with the development of the relationship between the researcher and participant for example. assumptions, expectations and contingencies of the relationship, trust and rapport.

Sampling

Purposeful sampling was used in the study. Qualitative sampling approaches are persistently criticised with concerns about generalisability or representativeness (Bold 2012; Denscombe 2007; Popay et al. 1998; Robson 1993) as well as the public discourse that qualitative and quantitative sampling approaches produce different types of knowledge (Denscombe 2007, Robson 1993). Furthermore, there are questions raised about sample size and how many interviews are need for theoretical saturation in qualitative research (Mason 2010, Guest et al 2006). Whilst acknowledging the debate (Mason 2010) concerning interview sample size and saturation, the approach taken in the study was drawn from Charmaz’s (2006) argument that the aims of the study drive the research design and sample size. A purposeful sampling

approach was taken to the study within the context that the sample was a small group of people with experiences and exemplars for the phenomena of interest (Yardley 2000) which the study could hone into (Denscombe 2007). There were a variety of other sampling approaches that could have been taken. However, the purposeful sampling approach was taken in order to maximise the use of the context (Popay et al 1998) of accessing hospice patients who were in the last days, weeks or months of their lives and as such were likely to have relevant (Popay et al 1998), likely to occur (Denzin and Lincoln 1994) and valuable data (Denscombe 2007) about their thoughts on advance care planning.

The parameters (Silverman 2010) of the purposeful sample were that of being a hospice patient (receiving any part of the service), incurable diagnosis (cancer or non-cancer), either gender, adult (above 18 years), voluntarily taking part with or without their carer or person of choice. Gysels et al (2008) point out the importance of considering joint interviews early in the design stage, identifying other issues such as the gatekeeper role of carers as well as the challenge of discussing sensitive issues together. Participants were invited to be interviewed with someone if they chose. Only two participant carers could have been described as gatekeepers to the interview, in the context of acting as the coordinator of participation in the study through arranging dates and times for me to meet them.

The research site

The research site was an independent adult (age 18 years and over) hospice in the East of England providing a spectrum of education, inpatient, outpatient, outreach, rehabilitation and community services for adults (and their families) with life threatening illnesses. The site was registered as a charity, regulated by the principles of the Charity Commission and national, regional and local end of life strategic priorities (including the local Clinical Commissioning Groups) and inspected yearly by the Care Quality Commission. It is overseen by a board of volunteer trustees, managed by a clinical and non-clinical senior management team and has an established clinical governance forum. It is a member of the regional clinical research network. My relationship to the research site was as a member of the senior management and lead for the education team.

Recruitment

Participants were invited to voluntarily take part in the study through flyers distributed throughout the hospice setting for example. reception area, outpatient area, inpatient unit, and bistro area. The hospice clinical and reception teams were informed through team meetings of the research and provided with information packs about the research and copies of the invitation flyers. This pack contained; sample invitation flyer (appendix 12), participant (appendix 13) and hospice staff information sheet (appendix 14), examples of both consent forms (appendices 15 and 16). The research information sheets and consent forms were based upon similar studies which had been used elsewhere in the United Kingdom in qualitative palliative care studies as well as conforming to national guidelines such as the NHS Health Research Authority (or National Research Ethics service as it was known at the beginning of the study). The recruitment and consent process is illustrated in figure 4.

Figure 4: recruitment, consent and interview process



Consent

Consent was sought during a face-to-face meeting with the participant (following receipt of the information sheet). The details of the consent form and in particular reference to how their visual still or moving images, audio recording and quotes would be used was discussed, agreed and consented to. There were two consent forms from which the participants could choose. Consent Form One was for both video and audio recording, analysis and dissemination (appendix 15). Consent Form Two was for audio recording only (no visual images) and analysis and dissemination (appendix 16). Most participants opted for Consent Form One with a cool off period before their interview. There were four variances to this process illustrated by figure 5.

Figure 5: participant consent variances
<p>Variance One: Andrew (pseudonym)</p> <p>Andrew wished to see consent forms with the information sheet. Both sent prior to consent meeting. At consent meeting, Andrew wished to carry out interview immediately. Discussed and agreed as Andrew was able to articulate clearly his understanding of the use of his words and images. Consent form one signed. Interview carried out with an agreed follow up telephone call 48 hours later to confirm if still permission to use interview (post interview cool off period). Interview included in the study.</p>
<p>Variance Two: Keith (pseudonym)</p> <p>Keith wished to see consent forms when I visited him to provide him with information sheet (his request). He asked for me to stay whilst he read both and then insisted that I carried out the interview immediately. Consent form one signed. Interview carried out with an agreed follow up telephone call 48 hours later to confirm if still permission to use interview (post interview cool off period) had. Interview included in the study.</p>
<p>Variance Three: Liv (pseudonym)</p> <p>Liv asked to see the consent forms with the information sheet. Both sent prior to consent meeting. At consent meeting Liv asked to adapt consent form one to add in that images could only be used with her permission. Permission to be asked each time I wished to use an image. Agreed and consent form adapted in her handwriting and signed off by both of us. Interview date agreed for three days' time. At interview, adapted consent form one reinforced in interview recording. Interview included in the study.</p>
<p>Variance Four: Frank (pseudonym- not included in study)</p> <p>Frank sent information sheet as per protocol. At consent meeting, details of study discussed and interview date confirmed for 2 days' time. Consent form one signed. On interview date I had concerns if Frank still understood how his words and images would be used as his copy of paperwork and information sheet had not moved from where I had left them and he seemed vague and unclear about how I would use them saying '<i>I trust you</i>'. Interview carried out but not used due to my concerns about his current understanding. Frank died 3 hours after the interview. Interview not included in the study.</p>

Conducting the video interviews

Every interview was carried out in the participants' choice of pre-agreed venue, date and time. On arrival, the consent was confirmed as well as the practicalities of the interview. An interview schedule reminder was used for each interview (appendix 17). The participant chose which room they wished to be interviewed and the Flip video™ was set up in order to be able to record their face and upper body. During this process, it was not uncommon for participants to ask to see or experiment with the Flip video™ device. General conversation occurred during this time. The participant was asked if they were ready to begin, and reminded that they could stop or withdraw at any time. Each participant was asked the opening question (question 1) followed by questions 2, 3, 4 and 5. Every participant was asked the final question (5) at the end of the interview (figure 6).

Figure 6: questions asked in all the interviews	
1	Opening Question: <i>Tell me how you came to know [name of hospice]</i>
2	Questions asked during the interview: <i>What would influence you to discuss these type of things [end of life care and advance care planning]</i>
3	<i>What do you think is important about how doctors and nurses talk to you about these things?</i>
4	<i>How does it feel to be video interviewed about this topic?</i>
5	Final Question: <i>Is there anything else that you would like to say?</i>

In between questions 1 and 5, follow up questions, conversation nudges, clarification, check and housekeeping statements responded to the individual participant's interviews. This open interview approach enabled the participants to follow the order of their thoughts in a way that made sense to them; an observation noted elsewhere (Gysels et al 2008). The intent of follow up questions was to encourage further explanation for example. *'tell me more, what do you mean, say a bit more'*. Nudges and encouraging prompts were to encourage the continuation of the participants' thoughts or words for example. *'go on, mmm, and'*. Clarification statements sought clarification or confirmation of the participants' thoughts for example. *'can you clarify; can you explain a bit more''*. Check statements monitored if the participant wished to carry on or to recognise if they appeared distressed for example. *'are you ok to go on? Do you want to stop/carry on?'* Housekeeping statements provided organisation to the conversation for example. *'we have been talking for about 20 minutes, we*

have about 10 minutes left, we are nearing the end'. Once the Flip video™ was turned off there was a buffer period between conclusion of the interview and departure which often turned to answering clinical questions they had asked in the interview or consciously providing an empathetic or therapeutic response to thoughts in their interviews as well as acknowledging their conversations.

Transana™ and video interviews

After the interviews, had been carried out, they were downloaded and stored onto two separate password protected personal laptops using the Flip video™ programme. Laptop one contained the Flip video™ and the Transana™ programme; coding and analysis was carried out on this laptop. Laptop two contained the Flip video™ programme and writing of the thesis and secondary safety storage of the video interviews. Saving the participants videos on two password-protected laptops was a safety measure in case the videos interviews were lost on one of the laptops. The Flip video™ and personal laptops were purchased and owned by myself. The original videos on the Flip video™ camera were erased. An identity number and pseudonym known only to myself identified the participants. Transana™ also is password protected, so any access to the interviews would have to go through two password protected processes (my lap top and Transana™). Once the interviews had been saved in the Transana™ programme, every interview was transcribed fully by myself into that programme. Field notes, reflections and memos were also saved within the Transana™ programme as well as on the password-protected laptop.

Follow up

Each participant was sent a personal thank you letter within 48 hours of his or her interview (appendix 18). Their key hospice worker was informed that the interview had been carried out and a note made in their hospice records of the interview date and time. Out of the interviews, two key hospice workers were contacted immediately (with participants' permission) after the interview. One (Alfred) was because of an urgent symptom control issue, which the participant had directly asked intervention in (in terms of asking me to ask their hospice nurse to phone them). I did contact the hospice nurse immediately after the

interview with the request as I felt that the participant (who was alone) was unable to do so themselves because of pain and breathlessness. The second contact was immediately after his interview to ask the ward nurse to assess him and ensure the family knew the interview was concluded. This was because he appeared close to death and I had concerns about his comfort and ensuring his family could be with him if they wanted to.

Participants’ experience of taking part in the interviews

Fourteen participants were asked how they felt about being video interviewed about the topic. This was motivated by therapeutic and scientific curiosity to understand the potential impact on the participants of the topic and interview method and to provide an opportunity for participants to express or share their thoughts. One participant was not asked because his physical symptoms drew the interview to a swift close. Figure 7 summarises the themes of the participants’ experiences.

Figure 7: participants’ views on being video interviewed	
Theme	Illustrative Quotes
Therapeutic value	<i>“I mean it’s been sometimes it’s quite nice actually to talk it sounds kinda bizarre...but sometimes it’s quite cathartic...to talk to people about...um about what’s happened in my life in a non-emotional setting” (Mandy)</i>
	<i>“Because I have never been able never felt free to do it before ...I have never felt free to discuss this So that’s why” (Anne)</i>
	<i>“I’ve been quite relaxed...you know...actually I have enjoyed it. Because it has brought more things out.... it’s brought more things out ...and be able to discuss things easier” (Liv)</i>
Wanting to help others	<i>“If this can be of any help to any other people in the future then fantastic” (Keith)</i>
	<i>“You know can be a help to you know my experience ...is of help to other people that might have younger children leaving people that are vulnerable or whatever then I think that’s useful ...that’s useful” (Mandy)</i>
Wanting to help the hospice	<i>“I think the hospice does great stuff and all hospices all of the charities that are trying to help people with cancer so you know anything that I can do to help is great” (Edward)</i>
Interviewer skill	<i>“You have created the right environment for it... probably I’ve put a lot more thought to that then I’d realized I’d done ...in the short time you’ve got a lot” (Florence)</i>
	<i>“I could probably talk to you easier about it” (Andrew)</i>
Novelty of being video interviewed	<i>“novel (laugh)” (Mabel)</i> <i>“is that the video or is that the subject?” (Sarah)</i> <i>“oh no it (pointing at flip video) puts you on the back foot...that’s all but you soon get used to it I mean its only tiny interview not for hours” (Mabel)</i>

The conclusion that I drew from the answers to this question is that person-centred video interviews are a possible interview method in sensitive topics such as advance care planning. The participants described a therapeutic value in taking part in the interview. They were motivated by a desire to help others or the hospice, and being videoed was a novelty rather than a burden.

Thematic analysis

Thematic analysis is a catch all term (Payne 2007) and one of the many approaches that can be used (Aronson 1994). It is the search for themes that emerge as being important to a phenomenon (Daly et al. 1997). Acknowledging the arguments that there is no clear agreement about what thematic analysis is (Guest et al. 2012; Clarke and Braun 2013) and the importance of making (epistemological and other) assumptions explicit (Avis 2005), the approach taken in this study was data driven thematic analysis influenced by (Braun et al. 2014). Whilst recognising issues with reliability in terms of coder interpretation; thematic analysis remains useful to capture the complexities of meaning within a textual data set (Guest 2012). Appendices 7a to 7d illustrate some of the thematic analysis process.

The approach was taken as the research method (interviews), question (influences) and motivation (why?) required an analytical method that could *“move beyond counting explicit words or phrases and focus on identifying and describing both implicit and explicit ideas within the data, that is, themes”* (Guest et al 2010:10). Thematic analysis is an inductive search for themes that emerge as being important to the description of the phenomenon (Daly et al. 1997) and arguably is appropriate for a study that seeks to discover using interpretations (Alhojailan and Ibrahim 2012). Using an approach that could explore and interpret the context of the participants’ advance care planning influences was important to the interpretative and hypothesis generating nature of the research question.

The approach was used with caution. Criticisms of thematic analysis observe that this approach is informed predominately by interviews and focus group gathered data (Flicke

2014). There are observations of the lack of published guidance about how to carry out thematic analysis (Flicke 2014; Marks and Yardley 2004); for example. there are generally no standardised categories for coding (Marks and Yardley 2004). However, attention was paid to not only to fully transcribe each interview but also to code line by line every one. The thematic coding and analysis process was based upon Clarke and Braun (2013) as detailed in figure 8.

Figure 8: phases of thematic analysis		
Phase	Description	My Process
1	Familiarising yourself with your data: Transcribing data, reading and rereading the data, noting down initial ideas.	<i>Pre interview (recruitment & consent process) field notes, reflection and memos Full transcription, reading of each individual transcription, field notes, memos, reflections</i>
2	Generating initial codes: Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.	<i>Coding (initial) line by line of all interview data using participants own words as code headings, rereading data and assigning data extracts to multiple codes if necessary</i>
3	Searching for themes: Collating codes into potential themes, gathering all data relevant to each potential theme.	<i>Collating codes into general themes, rereading, reassigning or adding to codes if necessary</i>
4	Reviewing themes: Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.	<i>Reviewing themes across individual interviews (to interpret for example. meaning or relationship of theme to rest of interview) Reviewing themes across all interviews Initial analytical themes developed</i>
5	Defining and naming themes: On-going analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.	<i>Reviewing initial analytical themes, revisiting frequency of patterns of themes or confidence of strength of 'meaning' of single data extracts using video as an aide memoir and reviewing written transcript. Testing initial analytical themes against each other.</i>
6	Producing the report: The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.	<i>Rereading findings and relevance to topic literature, review 3 key analytical themes and their subthemes, selection of representative extracts, review of dispersion of selected extracts across all interviews, relate back to question.</i>
<i>On-going reflection, field notes and memos reflecting on process, relevance to topic literature and rereading of methodology literature to check process.</i>		

In addition to the process or steps of the thematic analysis, explicit decisions were made for where some participants provided only one response to the research questions and not within the rest of their interview. I still interpreted that they attached meaning to their single answer, which provided data for the subsequent analytic coding and themes. The video aide

memoir and transcription aided this in terms of their norms of body language or the verbal and non-verbal emphasis that they used to make their point. Alternatively, within an individual interview or across several interviews the participants gave examples of what was important to them for example. how doctors and nurses talked with them – but not in response to that specific question.

Consideration was given to the coding, analysis and naming of themes. Appendix 7d illustrates how by using Transana extracted quotes were grouped, organised and named. Participants offered a variety of thoughts and experiences not specifically related to the generic questions. Whilst taking a data driven approach to coding, this was challenging at times as I was consciously aware that my contemporaneous literature review, twenty years' experience as a palliative care nurse and ten years as a communication skills and advance care planning educator might influence what I saw or heard in the interview data. For example, blocks and barriers is a common heading in communication skills literature and it would have been easy to use them as a pre-existing framework for coding. I purposefully used the words of the participants to describe the initial and emerging themes and only in the final analysis titled some of the themes into recognisable clinical, communication and advance care planning titles. This final sanitising of the titles into recognisable clinical titles was a conscious pragmatic decision in terms of visualising the accessibility of the thesis and future formal or informal publications audience. An audience I wanted to reach in terms of influencing how future education programmes would be designed.

Participants' previous advance care planning activity

There was no prior knowledge of the participants' advance care planning activity before the interviews were carried out. However, after the interviews a brief survey of their hospice notes of; evidence of assessment of being in last year of life, advance statements, ADRT, DNACPR or preferred place of death was carried out. This survey was carried out after the interviews; firstly, to not provide any prior knowledge at the interview of advance care planning activity and secondly to provide insight after the interview as to whether any activity

had taken place. The survey revealed no evidence of documentation of advance care planning in the participants' notes which maybe illustrative of recording practice rather than activity.

The participants

Recruitment to the study took place between July 2009 and February 2011. The prolonged recruitment period was due to unexpected suspension of the study due to personal reasons. Twenty people made an initial response to the invitation to participate during this time. Seventeen interviews were carried out in two phases, July 2009 to July 2010 and November 2010 to February 2011. Fifteen interviews were used which are detailed in figure 9. Out of the original twenty responses, two people withdrew after reading the information sheet, citing reasons that they did not have time to do. One person was excluded as they did not meet the sample criteria as the family wanted to be interviewed not the hospice patient. Of the remaining seventeen people, all of which were interviewed, two interviews were excluded from the study after their interviews. Both were because of informed consent concerns as described earlier in this chapter.

Fifteen video interviews were transcribed and analysed (five men and ten women). Seven women and five men were married or in relationships, one woman was separated and two women were widowed. Three of the women participants and one man had young children. Four of the male participants and six of the women participants had adult children. One of the women participants had no children. All described themselves as either British White or Irish.

The age range for the women was 35 to 83 years. The age range for the men was 52 to 78 years. Six women and three men had a diagnosis of cancer, two women had a non-cancer respiratory diagnosis, two men had a cardiac diagnosis, one woman had a neurological condition and one woman had end stage renal disease. Six women and four men were interviewed at home (one man and two women had their partners present during the interview). Two women and one man were interviewed in the hospice day care. One woman was interviewed in the hospice ward and one woman at a hospice outpatient appointment.

The average length of interview was 39 minutes with a range of 15.49 – 55.14 minutes. The participants lived from 1 to 23 ½ months after the interview. Figure 9 provides details of the fifteen participants included in the study.

Figure 9: participant details

Pseudonym	Mary	Mabel	Florence	Frances	Keith	Alfred	Andrew	Sally & Jane	Liv
Age at interview	77	80	76	67	52	69	78	67	35
Gender	Female	Female	Female	Female	Male	Male	Male	Female	Female
Marital status	Married: adult children	Married: adult children	Widow: adult children	Married: adult children	Married: adult children	Married: adult children	Married: adult children	Unmarried: strong friendship	Partner: young children
Diagnosis	Cancer	Renal disease	Cancer	Cancer	Cardiac	Cancer	Cancer	Neuro	Cancer
Ethnicity	British white	British white	British white	Irish	British white	British white	British white	British white	British white
Consent form	One	One	One	One	One	One	One	One	One (adapted)
Interview venue	Home	Home	Home	Hospice Day Care	Hospice Day Care	Home	Home	Home	Hospice OPA
Interview length	48:46	48:54	53:45	47:28	35:42	15:48	55:14	36:34	39:41
Carer present	No	Yes (John-husband)	No	No	No	No	No	Yes (Jane-carer)	No
Time until death	7 ½ months	6 ½ months	8 months	9 months	1 month	2 ½ months	6 ½ months	11 ½ months	13 months

Figure 9: participant details continued

Pseudonym	Anne	Christine	Mandy	Ernest & Bobby	Jacky	Edward
Age at interview	76	83	37	74	50	58
Gender	Female	Female	Female	Male	Female	Male
Marital status	Widow: adult children	Married: adult children	Married: young children	Married: adult children	Separated: young children	Married: young children
Diagnosis	Respiratory	Respiratory	Cancer	Cardiac	Cancer	Cancer
Ethnicity	Irish	British white	British white	Irish	British white	British white
Consent form	One	One	One	One	One	One
Interview venue	Hospice ward	Hospice day care	Home	Home	Home	Home
Interview length (minutes: seconds)	17:39	30:09	62:37	54:00	40:54	44:22
Carer present	No	No	No	Yes (Bobby -wife)	No	No
Time until death	3 ½ months	7 months	10 ½ months	23 ½ months	4 months	2 ½ months

Chapter 4 Results: Living with Dying

Introduction

The following chapters present the results that emerged from thematic analysis of the fifteen interviews. Chapter four presents the first finding of *Living with dying*. Chapter five discuss the finding of *Preparing and planning for dying*. Chapter six reports on the impact of *Communication with clinicians'* in conversations.

As the study was concerned with the participants' unique and individual views and experiences, the properties of each finding are represented using selected illustrative examples from the interviews. Where necessary, the context to participants' words and illustrative quotes are drawn from either the interview transcript itself or from the field notes and memos taken throughout the research process. Added clarification of participants words or meaning has been noted using [] to clarify the fact they were describing, underlining if the participants emphasised a point within the conversation and grammar such as commas to increase the ease of reading. Where participants have paused in their interviews three ... are used to represent a pause (of any length or type for example. silence, umm or err) in talking. Pseudonyms are used throughout the text for the participants, carers, family members, clinicians (for example. health or social care clinicians in any setting and role) as well as organisations such as hospitals and hospices. Throughout the text, unless clarified otherwise, references to children by participants refers to children under 18 years old.

Living with dying

The first finding was *Living with dying*. This referred to the context within which the participants lived with the knowledge that they would inevitably die from their incurable illness at an uncertain time in the future. The interviews reported four common themes:

- Unfamiliarity with the term advance care planning
- Living with the knowledge of inevitable death
- Living with the uncertainty of when death would occur
- Emotional resilience.

Unfamiliarity with the term advance care planning

Unfamiliarity with the term advance care planning refers to the gap between the formal definition found in clinical literature and how the participants described discussing, preparing and planning for their future dying. Common to all the interviews was a lack of familiarity with the formal national advance care planning term regularly used within the clinical and patient literature for example. NEoLP (2011). Mabel illustrated this:

I'm not sure that I know much about them ...but it's...it's...as far as I know ...it's an opt out if you want...if don't want to be revived.... am I right?

Furthermore, from the first interview there was confusion from the participants about the term:

Sarah: What would influence you to discuss advance care planning?

Mary: What?

Sarah: Things that are important to you if you were dying.

Other early interviews illustrated similar confusion:

Florence: Advanced what?

Sarah: If you were at the end of your life.

Florence: What? Do you mean dying?

By the fourth interview the question was changed to:

What would influence you to discuss things that were important to you if you were dying?

The change of wording to dying as well as focus on what was important to participants appeared to result in less confusion and more ease in answering from the participants about the question they were being asked. Furthermore, all the participants did talk about what mattered most to them at the end of their life, indicating that it was the wording not the topic that was inhibiting answering the question in these interviews. Threading its way throughout all the interviews there were simultaneous expressions of thoughts and wishes about for example. where they would like to die, treatments that they did not want etc. which fitted into the advance care planning definition found in national patient information documents for example. N EoLP (2011).

Furthermore, there was little evidence in a post interview survey of the participants' hospice notes of their advance care planning documentation of wishes and decisions apart from evidence in two participants' notes of a DNACPR decision. This was despite participants reporting that they had talked to hospice staff about advance care planning:

Keith: I have talked to the [hospice] doctor about this.

Anne: They [hospice staff] know what I want...we have talked about it.

At the time the hospice was in the process of updating its advance care planning record keeping policy and practice in response to internal audits with a change from written to electronic records. The internal audit had identified a gap between records and clinical practice (Taylor 2013). The lack of familiarity (and documentation) of the national term combined with an openness of the participants to talk about their own dying suggested a gap between national terms used within the clinical literature, practice (or at least documentation) and the daily-lived experience of the participants.

Living with the knowledge of their inevitable death

Participants referred to how they lived daily with the knowledge of their inevitable death from an incurable illness. All provided evidence that they knew that their illness was incurable and that they would die from it. There were two regular themes of how the participants managed this knowledge in their daily lives, a constant companion and their own personal context. These themes provided an insight into how the participants lived with and faced their inevitable death and why they may or may not talk about advance care planning.

A constant companion

At the beginning of each interview, participants were invited to tell their story of why and how they had been referred to the hospice:

Tell me how you came to know [name of hospice].

All the participants included in their answers or within their interviews factual information to indicate that they knew their diagnosis and prognosis of an incurable illness, for example:

Keith: I have an illness that can't be cured and I will die from it...that's why they [General Practitioner] referred me to the hospice.

Mary: Oh...I have this thing [points to stomach]...it can't go away...it will be the death of me...eventually [laughter].

Alfred: It's my...lungs....my lungs...that's why I know [name of hospice]...it's where they send people who...you know...won't make it.

All of the participants described how the knowledge of their future death was a constant companion in the participants' lives. For example:

Anne: It is what it is...it's inevitable...it's always there...I know that.

Sally: Always there...always...always coming...along the...the...road.

Others described how they could never forget that they were going to die:

Jacky: Oh I always knew I'm going to die...eventually from this...I can never forget that.

There were frequent examples of how the participants daily lived with the constant knowledge of their inevitable death:

Mandy: My condition has sort of become part of me and become part of my normal life. It's always there...at the back of my mind like...but...but I can't spend all my time thinking about dying...I've got other things to do before then.

Mabel: You just have to get on with it...it's going to happen isn't it...so you...have...have a choice...live with it or live by it.

Andrew: I am just getting on with it until it [death] happens...you can't spend all your time brooding over your death...I mean I do think about it about what's to be done...but not all the time...no not all the time.

Other examples of it how was a constant companion included participants' descriptions of how other people's actions reminded them of their own inevitable death. Mary explained how she felt after seeing a friend whose husband had recently died:

I sometimes forget that one day I'll...not be here...but then I saw a friend at the post office who started to talk about her husband and it all came flooding back.

Participants also described a variety of physical reminders of the inevitability of their death. Bobby and Ernest illustrated how the physical presence of his medical device reminded him (the outline of his implantable defibrillator was visible to the naked eye):

Bobby: He...he had had it [implantable defibrillator] for such a long time that

Ernest: You kind of forget about it...but.

Bobby: It never goes away...it's constantly there [points to chest].

Constant physical reminders of inevitable death were echoed elsewhere such as the presence of buildings:

Andrew: I used drive past the hospice [old building in town centre] and think...aww...awful place....shudder even...I never ever ever thought I would end up under their auspices...so to speak...never thought I would be sitting here and singing

their praises...never thought that...but the thing is Sarah...it doesn't matter how wonderful the people are...how beautiful the building is...and it is a wonderful building...you still know it is for dying people...and now I am one of them...so...you can never get away from that fact...I'm now one of them.

Keith: *I know it sounds daft...very daft...I love coming to the hospice...they have done so much for me...I love it...but...but...well...it's a hospice isn't it...it does rather remind you.*

Sarah: *mmm.*

Keith: *Remind you that death is coming...so...does rather put you in your place.*

Physical symptoms and medical interventions also reminded the participants of the inevitability of their death:

Christine: *I don't want to think about it all the time...some days...just for a moment...it kind of slips out of my mind...but then...then I cough...and cough...and...well [points to portable oxygen]...well I can't really forget can I strapped to that.*

Anne: *When I...I...get really breathless...it does get me a bit down...like...you know...bit in your face like about...it...you know...the [points to chest]...you know...reminding you.*

These personal and physical reminders were examples of how death was a constant companion in the participants' lives, living with dying involved constant reminders of ones own mortality.

The personal context

Participants gave descriptions of how their personal context influenced their management of the knowledge of their inevitable death. This provided insights into the importance of taking into account the personal context of dying.

Mary: *Everyone does it their own way...don't they... we all have to face it in our own way...don't we. It's a bit like that song isn't it...do it your way.*

Keith described the difference between how he lived with his incurable illness and his sibling who had died a few years earlier:

Well I'm me...and he was he...we are all individuals aren't we.

Sally illustrated further the importance of understanding the personal context of dying:

Sorting things...everything...everything...depends upon the sort of person you are ...because...because everyone's individuals aren't they ...some people don't want the truth ...can't face it [dying] ...they fall to pieces...inside ...if they knew, so it's an individual thing ...very much so.

Florence was another example:

Florence: We are all different I suppose...but I think...I think...well I...we all know it is going to happen...so I just push it to the back of my mind and get on with it

The inevitability of the death was not always pushed to the back of participants' minds. Liv explained how she would fight until the very end. Describing how she was balancing traditional and alternative treatments Liv commented:

I don't bloody care what the medical reports say...and there is one part of me that knows it to be probably true [incurable] ...but I'm still going to fight it...so I will talk about the cancer but I won't talk about my death...I know it's coming but if I say it...it...it becomes real doesn't it...and not until it becomes real will I think about it.

Florence, Anne and Jacky illustrated a more reflective tendency:

Florence: It's the type of person I am I think ...whenever I have problems ...I don't talk about it ...straightway...I go through it in my head...work it out what I can do...how is it ...or all sorts of things ...if there's anything I can do...anything I can't do ...my way accept it ...so I mull it all over...then do something.

Anne: It's my job to. ...think about...you know...think about when it happened...who knows when that will be...but it will...so I've said to [name of adult child] I want to do my will.

Jacky: *I've had to...had to think about what happens...happens when I die...it's going to happen so I have to think about it...for their sakes [children].*

Other participants gave different personal examples of how they lived with the knowledge of their inevitable death influenced by what mattered to them. For example, Mandy illustrated how the needs of her young children motivated her to think about her dying:

I've had to do all those other things...things that I hated to do...but I had to...I can't just leave them to it all.

For others, wanting to be in control was important to them. Frances was an example of this:

I have always liked to be in control...you could describe me as a project manager...and I will manage this how I want to...that's the only way I know how.

In contrast, Edward reported that he liked to work it out as he went along:

Well I am still working it out as I go along you know. I don't know really because I am still you know on the path of discovery of all this if you like.

Some participants had made plans as a way to live with the knowledge of their inevitable death. Keith commented:

We have talked about it...decided what will happen...so that we know what we will do.

Others were more philosophical. Edward talking about when he would die reported:

I don't suppose I will be able to control this in any way at all...so I will do what I can...now...but I suppose it will all be taken out of my hands anyway.

Sally had similar feelings describing how she would trust her carer Jane to implement the plans they had made:

I...I...will do ...what I can...but...but...I will have...to...trust...Jane.

Mary had faith in her spiritual beliefs:

We all have what we deserve in the end...it is a fate...I hope that I have done enough for...for when the time comes...there isn't much I can do now is there [laughter] so no point starting now.

The diversity of examples of the personal context of living with the knowledge of inevitable death illustrated the value of understanding from each individual person what was important to them as they faced this knowledge. All the participants had provided evidence that they knew their illness were incurable. However, there were a variety of ways in which they lived with this knowledge illustrating the importance of taking into account the personal context of how each individual faces their future death. In addition, there were also examples of how participants balanced the knowledge of their inevitable death with the uncertainty of when death would occur.

Living with the uncertainty of time of death

Living with the uncertainty of when death would occur was concerned with managing the vagaries of how much time the participants' had to live. Understanding how each participant managed this gave further insight into they lived with their dying. Common across the interviews were descriptions of the participants' personal strategies of how they faced and coped with the uncertainty of when they were going to die and a relationship with how they planned for their death.

Participants described facing the uncertainty of when they would die. Sally's carer Jane demonstrated how difficult it was juggling the knowledge of her inevitable death with the uncertainty of when it would happen:

You've got a big black cloud up there ...at the moment it's just tricky working it [how long she has to live] out.

Juggling uncertainty and inevitability was echoed elsewhere:

Edward: I am new at this...and you've got a death sentence but don't know when it [death] is going to happen.

Keith: I'm just in between...do you know what I mean? In between life and death.

Christine: It's all up in the air...I don't know when [death] but you just get on with it.

Jacky: It's really difficult not knowing...knowing when.

Frances: *It's horrible...just not knowing.*

Liv: *When you see the bus heading towards you, when you are about to be run over ...or when your health deteriorates ...or when...someone comes up to you with a gun...you know ...how do we know when we are going to die?.*

The uncertainty of when they would die could trigger participants to make plans for their dying. Mandy illustrated this:

Mandy: *Do feel sometimes ...that I'm still in this sort of no man's land ... where I don't know how long it's gonna take to recur [the cancer] but I can't forget about it [the possibility of dying].*

Sarah: *ummm*

Mandy: *And because I don't know and because of the children...well you have to think about things...you know...just in case...plan things...in case it happens sooner rather than later.*

Alfred was a further example, illustrating that the uncertainty of the time rather than inevitability of his death was what mattered most to him:

Alfred: *I don't like knowing this [incurable illness] I don't want to die and...and...I...I hate not knowing when this [illness] is going to end...I hate...knowing what I know...but...but more than anything I hate not knowing when it is all going to end...it's...it's...like being on a see saw...you know.*

The uncertainty of when death would happen motivated other participants to make plans for when they were dying. Edward described how the uncertainty of when he would die triggered his plans:

We all know we are going to die...don't we...it would be stupid to deny that...but...I find it very very hard all this...not knowing...so I have made arrangements...sorted things...because...well I can do that can't I...that bit I can do.

Andrew was another example. Talking about his wife and adult children Andrew reported:

Who knows....who knows how long a piece of string is...but what I do know is that that string will be cut off...snip...broken...two pieces...and on one side is life and the other side death...and I'm moving towards that side now [indicates 'death' side of string]...so it would be silly of me not to think about her and the children.

Keith provided a further example of how the uncertainty of the time of his death influenced his planning:

I've made plans to...to go to the hospice...because I don't know when it will happen...so I'd rather be there...be much easier for her [wife].

Anne's choice of preferred place of death (the hospice) also indicated a relationship with the uncertain timing of her death:

I want to die here [hospice]...because they [family] can get all the support from them here...whilst they hang around...you know...waiting for me [laughter] to pop my clogs.

These examples illustrated how the uncertainty of when they would die motivated the participants to make plans for their death.

Participants described personal strategies to cope with the uncertainty of when they would die. These strategies did not reflect a denial of their future death, but were more concerned with how they daily lived with the uncertainty of when they would die. These indicated that the participants juggled their day-to-day lives with the knowledge of their death at an uncertain time.

Mary: I don't let those thoughts into my life...not if I can help it.

Mandy: I get into a mind-set where you kind of forget about it [death] because I'm really busy with two very small children and a job that's three days a week but still five.

Florence: I just don't let myself think about it...and the only times I do is when...[laughter] people like you ask me...or the sickness comes back again.

Sally: I...I...can't...can't think about...it...it...all the time...it's...too too much...too much.

Ernest and Bobby illustrated how not talking about dying was their way of coping with the uncertainty of when it would happen:

Bobby: *We don't talk.*

Ernest: *About it all the.*

Bobby: *Time because that would be too.*

Ernest: *Sad...and we want.*

Bobby: *Happiness, laughter, fun.*

Ernest: *In our lives.*

Bobby: *Yes so...so.*

Ernest: *We don't.*

Bobby: *Talk about it all the time.*

Ernest: *No.*

However, at times the uncertainty of the timing of their death crept back into participants' daily lives, illustrating that facing and coping with uncertainty was an on-going experience.

Jacky: Sometimes the uncertainty gets to me...for example we were looking at GCSE options and I...I...kept thinking I don't know if I will be here when [name of child] does them...I could feel this big wave of sadness...but then thought 'shut up Jacky' just get on with this.

Mandy: But there are times when it is really difficult to forget...they kind of creep up on you...like the other day I was at the school gate and it suddenly hit me...I don't think I will ever pick them up from their big school...you know...when they are eleven...that was really hard.

There were other coping mechanisms described by the participants. Frances managed by trying to control how she died:

I do like to be in control...but I know I will have little say on when...when I 'go over' [die]...but I will make sure I've organized as much as possible until then.

Andrew described how he took control of the uncertainty of when he would die:

I said to myself...'what do you want to do Andrew? Do you want to be useless and just be a useless waste of space?' so I am determined on this, because that's the way I live now and I wake up in a morning and say every day's not perfect... but it's always wonderful.

Negotiating the challenge of the uncertainty of the time of death took other forms including managing the confusion as to what end of life actually meant. Keith explained:

He [hospital consultant] told me I was end of life...terminal...so I talked to my wife...the doctor [hospice doctor]...decided I wanted to die in here [the hospice]....but now he [General Practitioner] says I am only palliative...I don't know what that means...I feel really guilty that I put my wife through all that when I am only palliative...does that mean I can't come here [the hospice] no more?

For some, whilst not challenging the inevitability of their future death, they simply did not define themselves as being at the end of their life yet. It was in the distance rather than the present. Mary described that she did not think she was at the end of her life because:

No I don't think so no ...no I don't think there is anything, maybe because I haven't got there yet.

Mary's thoughts demonstrated the space between formal clinical or policy definitions and the daily experience of living with dying. Recorded earlier in the interview, Mary had openly discussed her incurable cancer and that she knew she would die from it. Field note reflections commented on her diagnosis and prognosis candour during the recruitment and interview process. A review of Mary's hospice notes revealed little evidence of formal advance care planning documentation. A corridor chat (recorded in field notes) with her hospice nurse reported that the nurse was unconcerned about the lack of documentation because:

We [hospice team] all know Mary...she's completely aware [of dying]...but she knows that I know that she knows [dying] and will talk to me when she wants to.

End of life meant to Mary the very last days or hours of her life (rather than the last years) and in her opinion (proved to be correct), she was still months away from her death. Therefore, in her view, whilst accepting the inevitability of her future death, her personal timeframe for managing the uncertainty of her time of death was measured by her own definition of end of life (days or hours) rather than formal clinical definitions of months or years. Mary illustrated that managing the uncertainty of timing of death was not only concerned with individual coping mechanisms but also personal definitions.

The participants' experiences offered a perspective that in addition to managing the knowledge of ones' own inevitable death, living with dying also included balancing this with the uncertainty of when death would occur. These were two separate aspects: the factual knowledge of their inevitable future death and managing the uncertainty of when this would occur. The participants balanced the knowledge and uncertainty of their deaths with the day-to-day experience of their lives, which in turn could influence their future planning for dying activities. The balance was also influenced by the participants' emotional resilience.

Emotional resilience

Emotional resilience referred to what increased or decreased the participants' ability to live with the knowledge of their inevitable death at an uncertain time. Common was the influence of physical symptoms and family relationships. A relationship was described between resilience and the daily highs, lows and lengths of physical symptoms. Christine describing the effects of the breathlessness from her long term respiratory disease, illustrated the relationship between physical symptoms and resilience:

It wasn't a good day yesterday ...it was horrible day yesterday ...day before was a good day ...you take those [good and bad days] sort of things.

When asked to clarify the difference between a good and bad day, Christine explained:

On a bad day ...the breathing. You can't breathe properly even with this [portable oxygen] you can't breathe properly you are fighting trying to make it [life] work.

At times, Christine's bad days influenced her in thinking about wanting to die:

I suppose it's because of...sometimes what you've got wrong with you...is a little too much to bear...you can take it sometimes, other times you can't ...sometime, sometimes you just wish you weren't here [alive].

Asked to explain more Christine reported:

It's too much to bear sometimes...I don't know really...but...but...I know that when I am very breathless everything is worse...so I am learning...yes learning...to look after myself on those days...and I wait until I come here [the hospice] ...before...deciding anything and talk to them...yes that helps.

Christine's experience illustrated the impact of changes in her physical symptoms on her emotional resilience and thoughts about dying. This was echoed elsewhere in the interviews.

Florence commented on how the side effects treatment affected her:

Florence: When I felt ill...really ill you know...with the vomiting and the sickness and the tiredness...I didn't want to see anyone...I just could not be bothered...it was all too much...I plotted...plotted you know how...how to...to end it...but when [name of hospice nurse] sorted it out [vomiting]...then everything was different.

Sarah: Different?

Florence: Well...you know...more manageable.

The length of time of physical symptoms and affect it had on people's emotions influenced others. Mandy illustrated this.

Mandy: I've been doing it for so long...I was tired of falling apart ...I actually couldn't do it anymore it was too exhausting.

Alfred described a relationship between the length of his physical symptoms (2 years) and his emotional resilience:

Alfred: *Some days...some days don't seem no different...other other days are in a different league...on those days.*

Sarah: *...Those days?*

Alfred: *Those days...bad days life don't seem worth living...it's this you see [points to chest] when this is bad...then I can't face it...no can't face it at all.*

Sarah: *ummm.*

Alfred: *Can't face living.*

Sarah: *ummm.*

Alfred: *You try dealing with this all the time.*

Jacky described a rollercoaster of coping with investigations, treatments, and side effects. She was not denying the inevitability of her future death. Instead she was worn down by the daily experience of having to live with the knowledge. Talking about death was an emotionally draining experience:

Jacky: *I'm struggling not to burst into tears when I ...you know when I talk about that sort of thing but I think it's because it's [living with incurable cancer] been quite a roller coaster over the last year, nearly 2 years now.*

Sarah: *ummm.*

Jacky: *I mean some days you think 'I feel ok today' and talk but some days...you know there was one day when I was so sick...so sick...really sick and [name of hospice nurse] was here and I really thought...I can't face this now and no one...no one can talk about it all the time can they...that's crazy...you have to put it aside once in a while...otherwise you would go mad.*

Family relationships could influence the participants' resilience in terms of giving or receiving support. Common across the interviews were examples of how the participants had thought about how they received or gave support. This influenced the participants' emotional resilience in terms of who or how they gained support for themselves or how draining it was

for them to give support to others. Jacky described whom she chose to get support from within her family:

Everyone's different, everyone's situation is different ...and you know I think in diagnosis which is quite serious you know people have got different amounts of time left... their family set up so what they may need or want won't be the same...so I have to think all the time...who is helping who?

Ernest and Bobby illustrated similar views:

Bobby: *Family...family...family.*

Ernest: *Yes family...they.*

Bobby: *Are all different aren't.*

Ernest: *Yes they are so we use them differently.*

Sarah: *Can you say more?*

Bobby: *Depending which [adult] child it is...depends upon what we say.*

Ernest: *And depends whether we are helping them.*

Bobby: *Or they are helping us.*

Other participants described why they did or did not have conversations with different members of their family, illustrating the complexity of family relationships. Some of the reasons were because of family member's reticence:

Mabel: *She [daughter] doesn't like me being ...ill...she started off when I was first ill by saying there are people worse off than you...she doesn't believe in depression...so I've learnt that I've got to be cheerful when I talk to her.*

Sarah: *mmm.*

Mabel: *It's a shame really as I would like to talk to her about these things.*

Florence: *I suppose it is only natural in it they can't bear the thought their Mum...dying, can they, you know ...and...I say to them you've got to face up to it ...and and as I say I felt so ill I was trying to prepare him...but he [adult child] wasn't going to have it.*

Ernest and Bobby illustrated how the participants negotiated the intricate nature of family relationships. They explained how important it was for them to know the individual nature of their adult children when discussing Ernest was dying and the type of support that they (Ernest and Bobby) might need:

Ernest: You know your child.

Bobby: With certain children ...you know cannot listen to it [talking about dying].

Others gave similar examples. Mary reported how she wore different hats for different members of her family when discussing her dying. Describing the emotional impact that such conversations might have on her different family members Mary commented:

Well I think it's like you're different people like we wear a different hat at times don't we, when you're talking.... to your grandchildren or your children...you don't speak to them in the same way.

Mary continued, illustrating the relationship between her own emotional resilience needs and her family emotional support needs:

It's not just for them...the hats...it's for me...if I get it wrong then I spend all the time consoling them...and I can't keep doing that every day.

Anne was another example of how participants juggled the needs of their families and their own needs:

I don't tell them anything because then they [adult children] all start crying...its bad really as I want to talk about it but I'm the Mum so I need to look after them don't I.

Andrew expressed similar thoughts. Explaining why he felt supported by one of his adult children, Andrew commented:

Because we [name] are rather similar in make-up... is when I talk to her and say [name] this this and this...she comes back and says 'well Dad we could do this this and this' [name] has this toughness to overcome the problem.

Participants' emotional resilience was further affected by the on-going needs of family or friends. Edward explained:

It can start to get pretty tedious you know because you've got loads of emails, that you feel you should be responding to everybody but actually you don't want to be talking about it [death] all the time you know...it really drains you.

The draining nature for the participants of other people's informational or emotional needs was repeated elsewhere in the interviews.

Liv: And when I get back [from the hospital] they [family] always ask so much so quickly...and it really annoys me...I have barely got in the door and they are asking me questions...so now I don't tell them when I have my appointments [hospital].

However not all the participants described a negative effect, illustrating the value of understanding the dynamics of each person and their families:

Bobby: So when Ernest got back [from the hospital], they [one of the adult children and family] were there and we told them everything...and there were tears and hugs and questions and noise and laughing and crying...well that's family isn't it?

Ernest: Yeah.

Bobby: And you liked that didn't you Ernest?

Ernest: Yeah...yeah...it was good.

Concerns over the emotional impact on their families when talking about dying was common across the interviews. Liv commented on her awareness of the emotions that conversations about her death might have on her family:

And for them it's absolutely terrifying that they will think that I am going to die...and that's you know a...big fear, I imagine that they talk about it [her death] amongst themselves...I haven't really talked to them about it and in fact I've said I don't want to engage with that [talking about her inevitable death].

Conversations could bring new types of family relationships and unexpected benefits to participants. Mandy described how the relationship with her mother had changed:

I mean it's [talking about dying] brought me and my Mum much closer together... everything I've been through has brought me and my Mum much closer together over the years.

The interviews offered a perspective of the importance of understanding the influence of family relationships on emotional resilience especially in terms of when dying people needed support for themselves or to support or think about others.

Living with dying summary

The interviews illustrated that the participants lived with the knowledge of inevitable death at an uncertain time in the future. There were four common themes: Firstly, that advance care planning as a term was unfamiliar to the participants demonstrating a gap between their lived experience and clinical terms. Secondly, there were insights into how people lived with the knowledge of their inevitable future death; it was a constant companion through everyday life, physical reminders and personally approached depending upon the context of each person. Next, there were insights into how people faced and coped with the uncertainty of the timing of their deaths including personal strategies. Finally, emotional resilience to living with dying was increased or decreased by the daily highs and lows, length of time or rollercoaster effect of physical symptoms as well as family relationships with questions over who was helping who.

Chapter 5 Results: Preparing and Planning for Dying

Introduction

The second finding of the study was concerned with how the participants prepared or planned for their dying. There was evidence that preparing (what did they need to do for themselves) and planning (what did they need to do for others) held different intents.

Preparing for dying

Preparing for dying referred to how the participants personally readied themselves for their future death. Initially preparing for dying appeared to be an overarching theme including both planning (or making death arrangements) as well as personal preparation. However, in the interviews there were descriptions that identified that preparing for dying was concerned predominately with the participants own individual preparation were in terms of what they needed to do for themselves rather than for others. When others were involved; preparing for dying was led by what the participants felt were their responsibilities towards them in order for the participants to feel better prepared for their own dying. In other words, the intent for preparing for dying was the participant's own wellbeing needs rather than the needs of others. Mandy illustrated this:

At the end of the day...it's all about me...what I need to do...for me...before I die...if I don't look after me then I can't look after anyone else.

The interviews identified four common themes:

- An individual approach,
- Mental preparation
- Friendships
- Family responsibilities

An individual approach

There was evidence of the importance of identifying for each participant what individually mattered to him or her to prepare for their future death from practical to emotional and self-identity matters. This focus gave insights into how or what people wanted to do to prepare themselves for dying. Andrew explained:

We are all different aren't we...what I need is different to [name of wife] or [name of adult child] or [name of adult child].

Others expressed similar thoughts, illustrating that preparation for death was personal:

Florence: I remember when [name of husband] passed that it was really important to him to know what was happening...he used to...god he asked all these questions...every time the doctor came he would ask and ask and ask...I'm not sure I feel the same way...I'm not sure I want to know all that...before....before I pass.

Frances: It's not that they [adult child and husband] don't care...it's just that they don't want to face it...but that's not me...I do want to...I do...because that is who I am...I'm the type of person who needs to...know...to think...to work out what's best for me...me.

The underpinning theme to an individual approach to preparing for death was that it was unique to each participant. This indicated the importance of identifying what mattered most to each person. This is illustrated by the variety of personal preparation needs reported by the participants. Frances illustrated the importance of planning to her:

The end of your life is as important as the beginning of your life really ...you know when you are expecting a baby you prepare for it ...don't you, so that everything goes as smoothly as possible ...and I think you should be able to do that for your end of your life.

However, Frances also illustrated that planning was not solely about practical matters it was also about self-identity:

When I had [name of adult child] I did all the practical things like room, clothes, cot and so on...but I needed to prepare myself for what I was going to be once I became a mother...what did I think...who would I be? Because I wouldn't be able to work in the same way. It's a bit like that when you prepare for death...putting all my ducks in a

row...my ducks in the row are also my feelings...I am working out what they are about it [feelings about death] and who I am in the family...who I will be...when I have gone.

Some participants gave descriptions of the importance for them about knowing about the dying process, what happened and how long it would take. Jacky explained how preparing in the form of knowing the physical detail of dying helped her to mentally prepare herself so she could then consider and plan for the needs of her school age children:

I need to know this stuff for myself...it helps me prepare... I run things through in my mind...what might happen...who could help...it makes me feel better if I can start thinking about what I must do...it's horrible isn't it talking about this stuff...but I must do it...I need to know for my children and then I can relax.

After her interview and recorded in the field notes was a comment from Jacky about how helpful the interview had been for her in terms of being able to say out loud some of the things she had been thinking about what happened as she died (for example. how long would it take, changes in breathing, body temperature and skin colour).

Knowing the detail of dying was not a universal to all the interviews, however it did indicate how important it was to understand each participant's context. For example, Jane talking about Sally's long-term condition discussed how they used the hospice nurse as a point of support and contact as and when events in their lives happened. Their preparation was concerned with the reassurance of knowing who to contact when they reached a point beyond their coping strategies rather than planning what to do in particular circumstances.

Jane: It is one of those things that ...until it actually happens ...or you are going down that road ...I mean we are gradually going down a road that we know very little about but because it is so gradual ...you cope with it... if it was a sudden ...okay not okay that's a shock to the system ...but we cope with what's going on because of gradual process that we hardly notice it ...occasionally when Sally is quite bad that's when we most think...hang on this is getting worse we are going to have to do something let's get [name of hospice nurse] ...and that's what happens doesn't it.

Sally: It works...works...for...for us...it really...really...helps me...to...to...know that.

Jane: *Yes ever since [name of hospice nurse] said 'that's fine' it took the weight of our minds...didn't it...we started thinking about your funeral songs didn't we.*

Jane and Sally's example illustrated that for them, their personal preparation needs were concerned with the reassurance of a relationship with the hospice nurse rather than a specific plan. However, for a few participants an individual approach included a lack of clarity:

Edward: *Not really sure what else there is really...[name of hospice nurse] keeps asking me how I feel...is there anything that matters to me...but I'm not sure really...what else is there to say...I'm going to die...see...nothing really gets you ready for that does it.*

These examples illustrated that whilst there was no consistency as to what mattered to each of the participants as they prepared themselves for their own death, there was a constancy in the importance of finding out what mattered to each person as they prepared themselves for their future death.

Personal mental preparation

A type of preparation that was repeated across all the interviews was personal mental preparation for dying. Preparing oneself mentally was reported as a means to manage how participants lived with the knowledge of their future death. For example, Florence explained:

Well I think that we all have to prepare mentally for it really don't we...if we don't prepare for it then how are we going to manage...I know...I know that I have in my own way...I mean mean I have to find some way to manage this...I can't be weeping and wailing all over the place can I...so I have to find a way for me to prepare for it...don't you see?

A motivation for preparing themselves for their future death was so that the participants' could think about the needs of others:

Jacky: *As I said earlier...now I know what it is like...I've...I've got a picture in my mind...what it will be like...I needed to get my head round that first...I had a little tear...you know.*

Sarah: *Go on.*

Jacky: *Well...obviously...the kids...that's what's important...and...and if I have sorted out it my head what will happen to me when...it...it happens and what to expect then then...it doesn't bother me where I am cos I can get them ready.*

The desire to mentally prepare oneself in order to support others was illustrated by others:

Mandy: *I do think that I have a responsibility...a responsibility to prepare myself mentally [laughter] because of the children...how can I help them if I haven't helped myself? I do and I have thought about how I feel when I eventually...you know...you see as a Mum I think it's very important that I think about myself for them...bit like those oxygen things in planes...you know where they tell you to put on the oxygen before your children.*

Liv: *Actually the only time I will talk about it is because of [name of partner] children...it's not fair on them to not answer their questions...they are only little and...I don't think I could live with myself if I died not answering their questions... [prolonged laughter] ...they are young...and...we need to make sure they are okay...yes...that's the only time...and I need to do that...for myself as much as anything. I don't want to think about it [death]...but...but for them I will...and I have thought all about it...had the feelings, prepared myself, had the talk and now I have wrapped it up in box...and I don't intend opening it.*

Mentally preparing oneself for future death did not take one form; it depended upon the context of what was important to each participant. However, there were consistent indications that all the participants sought a way to mentally prepare themselves for their own dying. Many of the examples were influenced by their family relationships:

Christine: *I told him [husband]... I would like to be with my husband. Until I had told him that...I...that I couldn't cross of it off my list...I needed him to know that so that I could stop worrying about it...I couldn't get it out of my head until I had told him.*

Keith: *As I say...I want to die here [hospice]...but I want [name of wife] to be with me...that's what's most important to me...that's what I needed to talk to her about...needed her to know that she being with me was what was most important...I*

had had to have that talk with her...and when we did...well beautiful...beautiful to feel that we had had that talk.

Andrew: So...as I was saying....I came back [from the hospital] phoned [name of adult child] and told her the news and there was silence...silence silence at the other end...nothing...she didn't say a word and then she said 'ok Dad' and I knew...I knew that she understood...understood that I didn't want to go through it all again that that wouldn't help me...and I thought 'good' there is someone else in this family...someone I can lean on...someone who understands...me...and that really helps really helps knowing that...helps me...you know for the future.

However, talking about dying was not without its challenges and many of the participants highlighted how they had to juggle their own and others mental preparation:

Mabel: Sometimes you know...middle of the night stuff I do...do think to myself...what do I need, what will help me...not what others need...what do I need...do you think that's selfish?

Sarah: Go on.

Mabel: I just sometimes want to think about what I need...but do think maybe maybe I am being very selfish.

Mary explained why she did not always respond to her adult children's emotions:

Mary: Maybe you have to put yourself first...what things make you manage...after all...after all...it's me who is going to go...not them...so...I do put myself first at times.

Sarah: Can you say more?

Mary: I don't always look after them...I should...I am their mother you see...but not always...maybe I can't don't want to see them cry...so I put myself first and change the subject...say 'I am fine' so that they don't cry...and then I can manage.

There were some descriptions of how emotional support could be challenging for the participants themselves. Edward commented on the conversation he had had with the hospice doctor:

Edward: I don't think I could face it if I hadn't faced it.

Sarah: *Can you say more?*

Edward: *You know face it.*

Sarah: *mmm.*

Edward: *Ok, ok...I don't want to die...I am terrified...absolutely terrified...but what I do know is that if I face it...I will cope better with it. That doctor [hospice doctor] she and I... she asked me what was I most afraid of and I told her...dying...dodo...stupid question...but it did help saying the words out loud...it did it did help and I said to [name of wife] I said...'funny but that's helped' facing it that way...it did help facing it.*

Alfred shared a similar experience:

I don't think anyone wants to talk about how they feel ...but in a bizarre way I think it does help. I did talk to [name of hospice nurse] and she she was very good...because she said the words I didn't want to say.

Alfred continued:

She said things like 'death', 'where do you want to die', 'what if you heart stops'...that's why I've got this form [DNACPR form] but it does help saying those awful words...you stop stop and think...how do I feel now...I suppose it makes you stronger.

These examples identified the value of discovering what was important to each person as they mentally prepared for their dying

Friendships

The role of friendships was often described by the participants. Friendships provided a supportive space by listening. This facilitated the participants to discuss their thoughts and feelings in an unencumbered way. Anne explained why she talked to her friends about how she felt about dying:

With my family I have to think about them...with the girls [friends] I don't.

Andrew commented how a friend at work helped him think about his future dying:

There is this bloke at work, very good at his job and every once in a while we go for a drink, you know after work...and I don't know what it is about him...but I do enjoy our drinks, he asks about the treatment and I tell him, I told him about how far the cancer was and and he sits there and says 'another pint?' and you can tell him stuff and it is good to be able to tell someone all matter of fact like yes, yes I look forward to those pints and just talk about it all straightforward like.

Friendships provided a way for the participants to think and talk about their future dying without being concerned with their friends' emotions:

Anne: I have this one friend...she doesn't say much...known her for years...since we moved here...but she is really, really good ...when everyone else is flapping and flapping...she just sits there and and looks me in the eye 'love what's up' is all she says...and when when this [points to chest] got worse and the doctor told me how long I said to her...I said to her 'you are like my rock'...all stoic and like and she laughed...but she is...she is...she really helps me because I can be upset with her and she doesn't get upset back.

Jacky: I can talk with them about all the horrible stuff...and I do I really do...some days they have rescued me from those dark dark feelings and I try you know to do the same back...you know ask them about what's up...because that's what friends do isn't it...look out for each other.

Sarah: Go on.

Jacky: Friends my friends...actually I think it is because I can tell them stuff and they don't get upset...or don't seem too.

Mary: My friends help me...they...they don't seem to need consoling themselves...maybe it is because we are all so old [laughter] and are all on our last legs [laughter] but but the fact I don't need to console them means I can really say what I mean...about...about...being gone.

For others, friends provided a supportive space to discuss the inevitability and uncertainty of death.

Mandy: *What I love about them [friends] is that they don't fuss...there is no fussing do you know what I mean? So when we sit down and talk about it and who is doing what there is no fuss...I mean it can't be easy for them as well but there is no fuss and that helps.*

Mary illustrated how death and dying conversations with her friends were unplanned but regular:

My friends that are the same age as me about...we haven't made a point of specially talking about it....it [dying] just crops up...and it is...good...yes good to talk about it...but in a random way...rather than planned way...if you see what I mean...I always feel better.

Mary made a further point demonstrating that talking about dying was a habitual part of her relationships with her friends:

I do have conversations with friends about things [dying]...we talk about it you know, in depth, often how we feel and also how we are coping with different things, cos most people when they are old have got something [illness] else we'd be on [alive] for ever wouldn't we... wouldn't we, there wouldn't be any old age...yes so we do delve into things how we are thinking.

Mary continued, explaining why such conversations helped her:

Sometimes...sometimes it just really helps being able to say all this...with each other...without upsetting anyone...yes it really helps me...gets my thinking...talking about all that.

Others described similar experience with their friends, illustrating how valuable the participants found their friendships when thinking about or discussing dying:

Frances: *I do love her...she comes round here, brings a cake and we talk and talk but what I like most is that we talk about you know...this stuff all natural like...it is just talk and there is no crying or tears or 'have you asked another doctor' or 'what if they are wrong' she just talks and we talk.*

Anne: *When I spoke to a couple of my very good friends ...I told them what [name of hospice doctor] said she give me 6 months oh yeah you know and their faces dropped you know 'how did you cope with it'... and I said 'well we've all got to die ... I've had a good innings ...and I'd sooner know and then II can use what time I've got. It felt ok telling them...they just listened...and that really helped me...cos...it made it seem less terrible...just saying it and then [name of friend] said 'better get a bottle out then whilst we can still drink it' [laughter].*

However, not all participants felt that conversations with their friends about their future death were helpful, illustrating the importance of not making assumptions about the role of friendships. Edward commented:

Actually it pisses me off quite a bit...I don't want to talk about it but some do [name of friend] does all the time...but [name of friend] doesn't...we talk about the band and next year's tour and...well that's good...better than [name of friend].

Friendships also helped the participants prepare for death in practical ways. Mandy had a neurological illness that at times made her reasoning and perception variable. Mandy used her friends to help her benchmark if there were any changes in her mental function. This was important to her, as earlier in her interview Mandy had explained:

What I am really worried about is how am I going to know if things are changing...how will I know...it's really important to me that I know...because it means things are changing...and it terrifies me that I won't notice...and if I don't notice then I won't be ready.

When asked to clarify Mandy continued:

You know...be ready for dying...me, the kids, [name of husband], Mum, Dad...you know...I can't do it if I don't know to be ready for it.

As part of her preparation Mandy identified a group of friends who could help her monitor herself:

There have been some a couple of work friends that knew me before and after [diagnosis] who have been brutally honest...not harshly and unkindly but ...what I seek actually which is real honesty where they say: no you are different I see a difference in you...you aren't quite as decisive as you were.

The interviews indicated that friendships played an important role in the participants preparing for dying by providing a support for the participants. This support could take different forms, providing a reminder of identifying what support each participant was looking for in their friendships.

Family responsibilities

Another aspect reported which influenced the participants preparing for dying was their perception of their responsibilities towards their family. Initially it seemed that the participants were motivated to meet the needs of their families (rather than their own). However, looking more closely there were examples that participants' perceptions of their practical and emotional responsibilities towards their families were a catalyst for their personal preparation. Predominately this revolved around participants identifying actions that they wished to complete before they died. The completion of such actions helped the participants feel better prepared for their forthcoming death. The intent of the actions was to be of benefit to the participant, but commonly motivated by what they saw as the needs of their families.

Sorting out practical considerations for family members were one aspect. Frances explained why it was important to organise her own funeral, will and care before she died:

I can't stop thinking about it ...it keeps me up at night...I need to sort it so that I can concentrate ... on what happens next. When they [husband and adult child] ever have any emotional problem they come, they rely on me to sort them out ...so therefore I'm not going to be there ...if they get emotional about me dying ...so I've got to sort it out to make it as ...easy on them as I possibly can...it's for me as much as anything.

Anne commented on how hard it was for her to prepare for dying with her family, because they would not talk to her about it, something she wanted to do. Anne felt responsible towards her family:

I wanted to talk about it [funeral]...I mean I really wanted to talk about it with them about it...Well ...they don't [talk about dying]...if I say, I don't think... I mean like a couple of weeks ago I felt so ill and I said to my eldest son. 'I really think this is it, I'm coming to the end now' I felt like that ... 'oh don't start talking like that' he said 'you've got a chest infection ...you'll get over it' ...swept it under the carpet...that's what they do ...you know mention anything like that ...they don't want to know they can't cope with it.

There were other examples. Practical arrangements were a consideration for both Edward and Keith. They explained the importance of considering others before they could think of themselves.

Edward: I have...to accept that there is a good chance that at some point I have got to sort this out...you know I can't just dump this on the wife and kids...I don't want that...I worry about that all the time...so for me I need to sort this out...not just for them but for me, I don't want to...but I need to for my own sake...so that when I go I have sorted it.

Keith: Before I can think of me...I need to think of her [wife] ...it's selfish really...it's all about me really...what I need to do to still feel like a proper husband...you know taking care of the family...I feel better if I can still be the husband in all that. It's important to me to be a husband right up to the very end...take care of her be a man about it...if I'm a man about it then it won't seem so bad...dying you know.

For some participants meeting the emotional needs of their families were a consideration. Andrew shared his experiences about going home and talking to his family after his hospital outpatient appointment and investigation results. Andrew's preparation included the decision to censor the amount of information he gave to his family because he did not feel

prepared to manage both their and his reactions:

Andrew: *But this is the most difficult because I think... am I being fair to them by not discussing with them in detail [diagnosis and poor prognosis].*

Sarah: *Go on.*

Andrew: *Most difficult because I can't prepare myself if I am looking after them...so...so...you have to make a decision.*

Sarah: *umm.*

Andrew: *So you make the decision not to say everything...so that you can manage your own thoughts and actions about...about...it.*

Other participants gave examples of how their preparation was influenced by what they considered to be the emotional needs of their families. Mary explained:

Mary: *Well I am never going to do something without thinking of them.*

Sarah: *mmm.*

Mary: *They are ...I love them and if I don't think about them...well what does that make me? I couldn't go with that on my conscience...I couldn't live with that...I couldn't go like that.*

Christine described how her preparation was influenced by the needs of her husband:

I am trying trying to get him to talk about it...because...I know him...I know him...I know he won't manage if we don't talk talk about it...but he won't and so so...I will go without talking to him about it [cries].

Mandy and Jacky shared how the needs of their young children influenced their preparation for dying:

Mandy: *As a mother I have to think about what they need because if I don't look after them I don't think I can manage with what happens in the future...it's for me I need to do this for them for me.*

Jacky: *It's not just about them [children] it's also about me...I can't go until I know everything is ready.*

The interviews provided examples that preparing for dying included concern of the participants to prepare themselves for their inevitable death in the context of an individual

approach, mental preparation, friendships as well as family responsibilities. Considering the personal context of these influences illustrated that there was a wide variety of what mattered to each participant in their preparing for dying. There was also a constant need to inquire and respond to individual needs. Preparing for dying was unique to each participant.

Planning for dying

Planning for dying related to how the participants' felt they needed to plan because of others needs rather than their own. These concerns motivated participants to make specific plans or arrangements for dying. Within the interviews there were three common themes, which motivated the participants to make specific plans for their dying:

- Dying at home
- Future needs of children
- Planning for suicide

Dying at home

The participants reported the influence of practical issues of dying in the home space and the effect this might have on their families. Participants shared worries about the dying period, moment of death and the immediate post death period in their own homes. This in particular motivated specific planning decisions about where participants wanted to die with an intent to relieve any potential distress for their families.

The witnessing of the dying period was one example of an influence on the decision about place of death. Jacky demonstrated how the needs of her children and the space in her home influenced her choice of where she wanted to die. After visiting the hospice, Jacky explained:

It made me also think about if I was at home ...you know you don't have that equipment at home. [Talks about hospital beds, baths, hoists and commodes that she had seen in the hospice]...and if you are in that much of a state ...that you can't get to the loo ...etc...and I am at home alone with my kids ...then...you know where does that

*lead...do they want to see me on that state? Is it fair for them to see me in that state?
I don't want that so I'm not going to die at home.*

Others had similar thoughts about her young children witnessing her dying at home:

*Mandy: I'm not sure if I want all that going on around them at home...to see their Mum
like that...ummm not sure.*

Concerns about witnessing the dying period was not confined to younger children. Frances talking about her adult child and husband explained why she did not want to die at home:

*They [family] wouldn't cope with me at home...they would go to pieces seeing me in
bed all the time...so no not there...It just wouldn't work...I know...I'm the doer in the
family...I'm the one who looks after everyone...so they would not be able to cope...they
are just not used to it.*

Considerations about space within the home could trigger decisions about place of death. Anne explained that concerns about medical equipment that she might need was the reason she did not want to die at home:

*Where I live there wouldn't be ...enough room, you know I felt that it would be nicer
for them.*

Keith was concerned about how his extended family would manage in the confines of his small home:

*Well you know as things gets worse...well...this house is very very small and we have a
big family...so...here [home] would not be good.*

The combination of medical equipment and abundance of health care professional visits was cited by others as to why they did not plan to die in the home space. Andrew illustrated this:

*She [wife] just wouldn't be able to cope...everyone invading the house day and
night...all the mess...the kettle on all the time...no...no I couldn't put her through
that...so no I won't die at home.*

However, not all the participants saw space within the home as a concern. Ernest and Bobby reflected:

Ernest: *When it.*

Bobby: *Happens.*

Ernest: *Everyone will be here and.*

Bobby: *The house will be full to the roof.*

Ernest: *And that will be.*

Bobby: *Great.*

Ernest: *Yes great.*

Bobby: *It will be.*

Ernest: *Like Christmas [laughter]...well sort of.*

These examples were illustrations that the home space as a place to die motivated the participants planning decisions about a preferred place to die.

Participants reported the impact of the caring role of families as they died at home and the influence that had on their planning. Concerns about being a burden to families in terms of care provision was repeatedly described by the participants:

Florence: *I live alone...and I can't see the boys being able to stay for who knows how long...so...I've told [name of hospice nurse] I want to die at the hospice.*

Mabel: *It won't happen here [home] because he [husband] needs care himself and I'm his main carer so it won't happen here.*

Andrew: *I'm not sure how [name of wife] would cope...because I look after her really...I think she would be fine for a while...but if it took a long time...I'm not so sure.*

The outcome of concerns over families caring roles was that participants did not plan to die at home:

Christine: *He [husband] can't do the caring thing...he's useless when I have a cold...so I can't expect him to look after me at home...so...so...that's why I won't die at home.*

As well as participants' concerns over the dying period, there were examples about the effect of the moment of death on families influencing decisions. Uppermost in many participants' descriptions were concerns of the lasting effects on their families of seeing their dead body in the home space. These concerns appeared to influence their planning. Edward explained:

I don't want to die at home...well actually I do want to die at home but it wouldn't work with the stairs and I don't want the kids to come home from school one day and find everyone weeping and wailing...so no I won't die at home.

Mandy gave another example:

I don't want the kids to remember me dead in the bed...it would be horrible for them...so I don't want to die here [home].

The lasting memories for families of the moment of death influencing the participants' planning for dying was illustrated by Liv who explained how she felt about her changes of body image due to cancer treatment:

What also bothers me is how I will look when I die. All those scenes in films and books is bullshit...it doesn't look like that...I'm not going to be some fading Victorian heroine...I'm going to look crap...I look crap now and I'm pretty sure I will look crap then...that does bother me because I don't want to put them [partners' children] through that...so I guess I will have to think about that.

Concerns about lasting memories were not confined to younger children. Sally explained why did not want to die at home:

I do worry...worry...worry about J...Jane...I don't want...want...her...to remember...me as dead...dead...I...I...want...to...her...to...remember me...me...as living.

Alfred expressed a similar view:

What I hate is that she [wife] will mainly remember this [points to body]...not that [points to wedding photo]...when I go...all she will see is this [points to body]...and she will hate that...but I don't suppose you can do anything about that can you.

The participants' planning was influenced by both the dying period and moment of death but

also for after they had died. Concern over how their families would cope after they had died was reported by the participants. This motivated them to have conversations and make plans. Christine explained how she had tried to talk with her husband about her future death:

Christine: I've had time to explain ...and he [husband]... that there are other things after ...which he will need help with ...which he won't be able to do all on his own he will need help ...but he clams up.

Sarah: Go on.

Christine: I say to him...you know...everything [after she has died] would be alright everything would be alright...when I'm gone ...you will cope in the end you will cope ... but he clams up just the same as he doesn't want to talk about it ...he doesn't want to talk about it.

Others echoed similar concerns:

Anne: I am worried about them [adult children] how they will cope when I have gone...I try to talk to them about it...to look after them.

Mary: It's the mothers' job isn't it...doesn't matter how old they are...you still worry about them...I have talked to [name of adult child] about some stuff...but I could tell it was upsetting her.

The participants' views illustrated that the home space within the context of the dying period, moment of death and after death period influenced specific planning decisions. Although within the interviews the question was not specifically asked where they would like to die (preferred place of death), each interview provided examples that home as a preferred place to die was conflicted for the participants.

Future needs of children

Concern for the future emotional and practical needs of children of all ages influenced the participants' planning for dying. The motivation of the participants planning appeared to revolve around anticipating what their children's needs might be after they had died. In other words, planning for dying was not an individual action it was rooted in relationships to others.

Mandy talking about her primary school age children illustrated this:

My children are definitely a trigger for thinking. I don't want to leave some of these things to chance they are far too important.

Mandy continued, illustrating that her personal planning for dying was concerned with the social and emotional needs of her children:

I do know that we [describes herself and her husband] have very different... We provide different things to our children ...you know there are traits to do with being male and female and ...not having me in their lives at a certain point in in life ...you know I struggle to think about certainly with a daughter, about her ever getting married...because I'm fairly sure I wouldn't be around then...and I know it's a silly thing but even going to parents evenings. My husband will go to a parents evening and he will ask about Math's and English and reading and writing...and how are they doing and what are their marks and where are they ranked... and it's a kind of a competitive thing...whereas I go along and I ask 'are they happy, who are their friends...how do they seem to be socializing in the group...and are they outgoing... will they ask a question'... it's far more about the rounded individual...and neither one of those is wrong ... but I know... if you struck me out of the picture [died]...I do think to myself...well where will they get that from?.

Mandy's example illustrated how her planning for dying revolved around the future needs of her children, rather than her own needs. The motivation to plan for their own death because of the needs of children was echoed elsewhere. Liv explained why she had done some planning (even though she didn't want to):

As I say I don't want to think or plan about my death...but the kids are young and [name of partner] and I have talked about it [death] and what we must do to look after them...so I've done wills etc., sorted out the bank, the money, the house so if I die and that's a big if...I can go knowing that I have done what I should have done for them.

Jacky had turned to her friends to plan for the future needs of her children:

So I have talked to my friends...and worked out who will be what...you know football on Saturdays, swimming, parents evening...who is the science friend...who is the you know...oh lots of them.

Older children were also a motivation for planning. Edward described how he planned his will and financial arrangements in order to help his children (secondary school age) after his death:

You know cos obviously if you have got family [referring to children] you want to...help them [children] as much as possible...so I've sorted the will...taken care of them when I've passed on...I need to do this for them...that's important.

Adult children were also a consideration. Frances talked about trying to share her planning for dying with her adult daughter and husband:

Well...facing up to the fact that ...I am going to die and I might be going to die sooner rather than later...and so ...I want to know that ...I want to try and make sure in the time that I have got left this sounds dreadful ...in the time that I have got left ...that I have got things sorted out for my husband and my daughter ...as far as I possibly can ...so that they don't have to go through...quite so much...stress and upset and emotional upheaval as you do when somebody dies.

Ernest and Bobby expressed similar thoughts about how they planned for their adult children. Sharing how they had decided to tell Ernest's family when he died they reported:

Bobby: *So we have.*

Ernest: *Talked about it...it when I.*

Bobby: *Pass.*

Ernest: *And how we will tell the children.*

Bobby: *[name of one child] will take it bad so so.*

Ernest: *We have told [name of other child] that we will phone them first so that.*

Bobby: *He can get here first...before [name] and be here to.*

Ernest: *Help Bobby break the news.*

These examples illustrated that the participants planning for dying was not an independent action. Planning was influenced by the relational aspects of both practical and/or emotional needs of the participants' children (adult or young).

Planning for suicide

One aspect of planning for dying, that was highlighted by the participants, was their wish to control the time of their death through suicide. There were reports that participants' concerns of being a burden to families or society and living an unbearable life motivated them to think about suicide. Suicide is the act of deliberately killing oneself (World Health Organization 2014), assisted suicide is where patients are assisted to end their own lives (BMA Ethics Department 2009). The original purpose of this study was not to explore participants' views and experiences about wanting to die through suicide or assisted suicide. However, ten of the fifteen participants spontaneously shared their thoughts and wishes on this subject and it emerged as a theme in how they planned for their death. During the time of the interviews there were television programmes as well as media coverage of assisted suicide in the United Kingdom. It is unclear if or how much influence these had on the participants but some participants mentioned them in their thoughts about wanting to die through suicide. There was evidence of three reported themes for the participants' motivation of a wish for suicide; being a burden, an unbearable life and wanting to control the time of their death.

Being a burden

Wanting to control the timing of their death, influenced by thoughts about being a burden was a motivation for the participants to think or talk about suicide. Andrew illustrated this:

Andrew: It will be all too much for her.

Sarah: Go on.

Andrew: Too much...looking after this old body...I don't want her to have to do that...so it's not going to happen.

Sarah: mmm.

Andrew: I'll do a 'Julie Walters' [reference to recent TV programme about the suicide clinic Dignitas].

Alfred illustrated the importance that participants' put upon controlling when they died:

I worry for her [wife] ...she's not getting any younger [laughter] but...but...she's already looked after her sister in all this [reference to his sister in laws recent death from cancer]...and...and I don't want to put her through all that...again...so...I...I...think [hand gesture across throat indicating death].

The participants repeatedly reported that they wanted to control the time of their death by suicide was related to concerns for those that they cared about. Frances discussed how her husband would cope looking after her if she was bedbound:

Frances: You know quick...die quick...make it happen quick...so that he doesn't have to put up with me dying.

Keith explained why he had thought of suicide:

It's the missus...I need to think about her...what's right for her...that's why I think about it.

Florence shared her thoughts about not wanting to be a burden to her adult children:

I just don't want...they are all grown up now...and I am such an incubus...such a nuisance...I just think it would be easier for everyone if I wasn't here.

Suicide talk could cause friction within relationships indicating it was not a neutral discussion.

Sally and Jane illustrated this:

Sally: I do...do...think about...it...killing...killing... myself.

Jane: [interrupting] But we have talked about this and it doesn't bother me...I'm here right to the end...we have already decided that.

Sally: But...but.

Jane: It's fine...I'm here.

Sarah: Go on Sally.

Sally: It's just...just...what if it it gets...gets...too...too...much for...for...you...I.

Jane: It won't.

Sally: It might and it might might ...be better if...if...I...just...finished...finished it all.

After the interview and recorded in the field notes was a memo to myself documenting that Jane walked to the door with me and explained that Sally and her often had this conversation. Jane described how that it upset her to hear Sally repeating her suicide ideas, which is why she had interrupted her.

There were other examples of how talking about suicide caused friction within families. A few participants hid their suicide thoughts from their families because of how it would change their identity within the family:

Andrew: I'm the man in the family...the fixer...the go to guy and if I told her...she would spend all day checking up on me.

Others expressed concern over the effect of talking about their suicide thoughts to those that they cared about:

Keith: I did once try to talk to her [wife] about it [suicide]...see what she thought...but then the tears came and I thought 'god no...this won't work' so I haven't brought it up again.

Alfred: We [wife] did talk about it once...but she got so angry...really angry...I couldn't work it out.

Sally: She [Jane] gets...gets really up...upset if I mention it.

Mabel: No...no I don't talk to them [children] about it...it would just upset them...and what good would that do.

Christine: Oh no I couldn't talk to him [husband] about it ...he would change the subject...turn over the telly or something...he won't talk about it...never talk about it.

Whilst suicide talk could cause friction, many of the participants expressed regret that they could not talk to their families about it indicating that conversations would have been of value to them. For example, Sally whispered to me when Jane had gone out of the room:

I...just...I wish...she would...talk about it...I don't know what she...she...really thinks.

Mabel and her husband John (who had been quietly present throughout the interview) started a conversation with each other:

Mabel: *Well what do you think...about what I've said?*

John: *umm.*

Mabel: *We've never really discussed it...what do you think?*

John: [turns to me] *Am I allowed to say?*

Sarah: *Yes of course.*

John: *I don't really know...I don't like to think about it.*

Mabel: *But John I'd really like to know what you think.*

Recorded in the field notes is a hospice corridor conversation a few weeks later with Mabel's clinical nurse specialist who commented that Mabel's interview had started her and John talking about what would happen when she started to die.

Future concerns for participants' partners and children also influenced their suicide thoughts. Mandy commented that committing suicide had crossed her mind even though she wanted to live as long as possible for her young children:

Don't get me wrong...I don't want to die...I mean I want to live for as long as possible...but occasionally ...just occasionally I do wonder...you know middle of the night stuff...what if this is all too much for [name of husband]...and...if...I would make it happen faster.

Asked to clarify what she meant Mandy continued:

You know...make it happen...die...so that they can get on with their lives.

There were examples that children of all age's motivated participants to consider suicide as a specific plan:

Florence: *Frankly, I don't want to be a bother to them [adult children] so when it is time...I just want to go and do it...you know...do it...end it.*

Andrew: *I don't think it matters how old they are [adult children] you don't want them to be around looking after you...they have their own lives to live.*

Christine: *They [adult children] don't want me hanging around...forever...not like this anyway...it's not fair on them.*

Frances who also had an adult child shared similar thoughts:

I do think sometimes...I really do think sometimes...when will this be too much for them [adult child]...and what should I do then...if I should just 'go away'.

Another aspect influencing the participants' suicide thoughts was concern over being a burden on society as a whole (rather than just their families). Andrew discussing how he felt about Dignitas illustrated how some participants did not want to be a burden; to either family or society:

The world is full of old people....and the sad part is is that as medicine gets better they going to live longer and longer ... and I don't... and this may sound silly...but I don't want to feel I'm using resources up that someone else who needs them better than me...I am very proud of the health service.

There were other expressions of concerns over being a burden to society. Mabel commented on all the nursing and medical teams she had seen:

We all get old...I'm old...I don't know how long this is going to go on for...but it can't go on forever...I wish I could hurry it [death] up...all these people seeing me...there are others who need it more than me...I've had my time... now it's time for others.

Christine reported:

I do wonder sometimes...sometimes how much I cost [points to portable oxygen cylinder] and if it's right that I have it...makes me think about if you should go on.

When asked to clarify Christine continued:

Well ...live...live really...I'm sure they could do something to end it all if they wanted too...and that might be the right thing to do you know for everyone.

Other participants expressed thoughts about being a burden on society as a whole:

Alfred: There are some days when I think 'I've had my time now, now it's someone else's turn'...I mean I've had a lot from the NHS...so...so...maybe I should just 'move on'.

Keith: We all have to go sometime...and I'm not getting any younger...I'm only going to get older you know...so...it's not a stupid idea to get rid...get rid of people like me...people like me...we've had our time...we can't do anything no more for anyone...so getting rid is good for everyone.

Being a burden to both families and society appeared to be one motivation for participants' desire to commit suicide. Controlling the time of their death through suicide was a means for the participants to relive the burden of their dying on those that they cared for. As well as evidence for a relationship between being a burden and thoughts about suicide, there were also aspects of how an unbearable life affected the participants. The ten participants described a relationship between an unbearable life and a wish to die through suicide.

An unbearable life

In addition to self-perceived burden to others or society, there were indications that anticipation of an unbearable life motivated ten participants to plan for dying through suicide. For example, Florence commented on how at one point in her medical treatment she had felt life was unbearable:

It was unbearable...I mean...because it was sort of like being on another planet... I just didn't want to be here ...nothing mattered.

What constituted an unbearable life was unique to each participant. One aspect was a decline in physical function, which affected the ability of participants to carry on with their usual life. Keith explained how his life was becoming unbearable measured by his social activities:

I mean for me I was...day before yesterday was it yes... I was in the pub with my wife where I quite like a couple of pints of real ale but I struggled to drink one. Usually I am a three-pint merchant.

Keith explained more:

I mean what's the point...what's the point when you can't even enjoy even the little things in life...it's times like that which make me think...I want to end it all now.

Sally explained how reduced function influenced her:

Oh if I...I... got totally totally paralyzed bed ridden...couldn't couldn't speak, couldn't eat or drink ... a cabbage...I wouldn't want to live.

Others described how their physical function influenced their planning for suicide. Andrew explained:

It's okay now...because I am still working...can still get around...I'm still driving...still working...but if this [points to pelvis] pain gets worse and I have to take more stuff [points to morphine]...and I can't work...then it will be curtains for me...I'm not going to stick around...as I said I'm doing a Julie Walters.

Christine had similar thoughts:

I know I can't do very much because of this [points to portable oxygen cylinder] ...but I am still useful...I can still do things...I mean I know it is a bother...but I still get up here [hospice] don't I...I mean I am still here...but if that stopped...then I don't think I would want to carry on.

Asked to clarify what she meant Christine continued:

Getting up here [hospice] means that I am still able to do things...if I can't even get up here...then well it means I am on the way out doesn't it.

Others provided examples how physical function influenced their thoughts about suicide:

Mary: *At the moment I am up and about as normal...well almost normal...but if I ended up like [recounts story of deceased relative] and in bed all day...needing help night and day...then I wouldn't want to go on.*

Frances: *I don't want to end up like [family name]...definitely not he couldn't do anything for himself...I am not ending up like that...I'll die before I end up like that.*

In addition to comments about the decline in physical function there was evidence of a relationship between day-to-day control of physical symptoms and wanting to die. For example, Andrew talking about his pain control commented:

I wouldn't want to go on if there were more bad days than good days...at the moment the good days are glorious...and the bad days...well they are ok because of this [points to morphine bottle].

Christine explained that on bad days she just wanted to die (recorded in the field notes was the observation that on the day that we met it was a good day so she did not want to die):

Christine: There was one Friday I just sat there and wished ...I really wish I wasn't here ...really did sat there and oh I found it...I wish I wasn't here and I meant it I really really meant it.

Sarah: Go on.

Christine: I just sat and thought I wish I wasn't here...it's all too much [gestures to portable oxygen]...I can't go on...I just want it all to stop...how can I make it stop.

There were repeated examples of the relationship between daily physical symptoms and suicide thoughts. Describing her experiences of nausea and vomiting during her chemotherapy Florence explained:

There were some days when it [vomiting] was so bad...that I just thought...I want to die...and I still do...if... if it [vomiting] comes back.

Florence continued:

If somebody had offered me a pill [to kill her] I'd have said thank you so much and not consulted my family my friends I would have just taken it because I just wanted to be off this planet.

Frances explained what motivated her suicide thoughts:

I just don't want to get to that stage where it is all about how ill I am...then I become someone else don't I...not me...so some days when the pain is a bit worse I think to myself...what shall I do if this carries on...do I still want to be here?

Alfred also reported how day-to-day physical symptoms influenced his thinking:

I just don't like being this way [points to his body] I don't want to be like this...so on some days I wish it would all end...bang...go...I disappear away...but then the other day...it was alright...[name of friends] came round...we had a laugh...a chat...and I thought 'this is alright'.

Constantly juggling how unbearable life was also influenced the participants in their thoughts about suicide. Describing her experience of long term dialysis Mabel explained:

Mabel: Now...having...felt near to death when I was first diagnosed ...I...I...I was so ill...on my initial entry before they did all the dialysis and tried to take biopsies and things... I did want to die ...because it's easier than not dying if you know what I mean.
Sarah: Can you say more.

Mabel: Before my dialysis I felt so ill...it was such a struggle...I just thought I can't live like this...I don't want to live like this...and don't get me wrong...having the dialysis is hard too...but I...I feel so much better each time...it's easier.

Mary and Christine hinted at similar thoughts:

Mary: Every day you have to decide...what you can cope with.

Christine: Sometimes it is a fine balance...you know between what's bearable and what's not.

As well as decline in physical function and physical symptoms influencing the participants' thoughts about suicide there were reports of the need to still feel useful or have purpose in life. Christine had already indicated that physical function was important to her as well as being useful. Later on in the conversation she commented:

I suppose it's all about feeling useful in life isn't it...I can still do something...I'm still useful...but if that stopped...then what's the point...I'm just a burden to everyone.

Andrew provided another example:

If you can't jump out of bed in the morning and do something productive you know be of some purpose then I don't want to be around.

Others shared similar examples. Mary discussed her role as mother and grandmother:

Mary: *It's okay now...because I'm still in charge...but if I had to hand that over...then.*

Sarah: *Go on.*

Mary: *Then...it means my time has passed...someone else is in charge [name of adult child] probably [laughter] ...and I'll just have to sit in the chair and wait to die...and I'm not having that.*

Mandy commented on how she felt about being a mother with young children:

Me and my Mum are much closer now...and the kids too...but sometimes I watch her with them...and think...what if ...what if...they don't need me anymore...and on one hand that would be great...but on the other hand...what would I do then? What would be the point of me? And that's when I think about it [suicide].

Purpose in life took other forms such as an expectation that every day was more than just medications and care. Sally and Jane discussed how they planned their time together:

Jane: *Sally and me still plan our days don't we?*

Sally: *Yes.*

Jane: *It's a hassle but we still go out...go out for lunch...trip in the car...to the shops...we went to [name of shop] the other day and bought new slippers.*

Sally: *Yes.*

Jane: *Sally still has a life don't you.*

Sally: *Yes [reaches out and clasps hand with Jane]...thank you.*

After Sally and Jane's interview and recorded in the field notes was a memo to myself reporting that Jane had reported on my way out that she purposefully planned Sally's week especially when Jane felt she was feeling 'low'. Jane explained that she felt that by providing Sally with a reason to go out (such as buying new slippers) that it helped Sally to feel like more like a person than someone sick.

The interviews illustrated that an unbearable life and being a burden were motivations for participants' desire to commit suicide. Furthermore, there were examples that participants planned to control the time of their death through suicide.

Controlling time of death through suicide

There were descriptions in the interviews that the participants saw suicide as a way to control the time of their death. Whilst the participants' motivations were concerned for example with being a burden or an unbearable life, their intent for the plan of suicide was to control the time of their death. All of the ten participants gave examples:

Andrew: *It suddenly hits you ...you know...that I laugh and joke about ... you know... but one day I'm gonna have to face it you know [death] ... and say it's there ... how do I do it...[suicide].*

Sarah: *Say more?*

Andrew: *When the time comes...I will have to face it and decide...no plan... how to die.*

Sarah: *ummm.*

Andrew: *I'm the one who will decide when I die...no one else.*

Florence commented:

I do wish I did have that pill...so that...so that...that...I decided when...I mean...I don't think I would have the courage...but I wish...wish I could decide when...when I die.

Other expressed similar thoughts about wanting to decide when they died:

Alfred: *When it gets too much...I want to decide...decide what happens.*

Sarah: *Happens?*

Alfred: *Yes...what happens...dying...what did you think I was talking about?*

Whilst Jane was out of the room making tea, Sally quietly said:

Sally: *I...I hope...when the...the time is...is right...I can find a way to end...end...it all.*

Sarah: *mmm.*

Sally: *I'm...I'm the only...only one who knows...when...when it will...will be right.*

Frances discussed how the death of a family member had influenced her thoughts about suicide:

Frances: *I don't plan to end up like him...not dignified...not good...so I will plan my exit strategy.*

Sarah: *mmm.*

Frances: *I will make my plan...go and do it quietly...without fuss...how I want it.*

Keith and Christine were also clear in their wish to be in control of when they died:

Keith: *When I've had enough...I'll be off.*

Christine: *In my ideal world...my dream...I will know when...when I am going to die...and...and...have everyone round my bed...and I will pat everyone on the hand...and say 'goodbye'...but it won't be like that will it [laughter]...so I will have to plan it differently.*

Mabel and Mandy had a view of wanting to control the moment of death based upon the needs of their families. Mabel discussing her children and grandchildren commented:

It's about them really...when I think there is too much to bear for them...I'll do something about it.

Mandy explained why planning the time of her death was important to her:

Actually I do think about it a lot...a lot...because they are only young...and I want them to have a good memory...so I think I would commit suicide without anyone knowing and make it look like...you know...a normal death...after all I do have cancer [laughter]...so it's to be expected [laughter]...but when I thought I was getting worse...you know as I said earlier...I think I would just quietly take some pills...tell everyone I didn't feel well...kiss the kids and take myself to bed...that way...it would be natural...normal...and they would be sad...but...but...sorry [wipes away tears]...it's just...just that I don't want to leave them...so all I can do is make sure when I do it is as good as possible for them.

Planning for suicide was a specific type of planning for dying described by ten participants motivated by concerns over being a burden and an unbearable life with the intent of controlling the timing of death.

Preparing and planning for dying summary

The interviews illustrated that as the participants faced their inevitable death at an uncertain time that preparing and planning for dying held different intents. Preparing for dying referred to what participants needed to do for themselves, to be ready themselves for their future death. There were three common themes. Firstly, preparing for dying was individual with no single approach. Secondly, emotional support was helpful for the participant's own mental preparation, with different types of support and challenges identified including the role of friends to provide rather than receive support through emotionally unencumbered conversations. Finally, family responsibilities such as participants' perceptions of their practical and emotional needs were a catalyst for them to carry out activities in order to feel personally prepared for death.

In contrast, planning for dying was predominately concerned with the participants' concerns for others rather than for themselves. These motivated participants to make specific plans or arrangements for dying. The interviews identified three common themes. Firstly, the home environment in the dying, moment of and after death period such as space and the caring role of families. Secondly, participants planning decisions were triggered by beliefs about the future emotional and practical needs of their children. Finally, ten participants described a desire to control the timing of death by planning for suicide because of concerns over being a burden to others or society and perceptions of an unbearable life because of declining physical function, physical symptoms and lack of purpose in life.

Chapter 6 Results: Communication with clinicians

Introduction

The final finding of the study was the catalyst role on conversations of clinician's communication behaviours. This chapter reports on the participants' direct answers to two specific questions in the interviews or thoughts expressed during their interviews, which gave examples of communication they had experienced. All the participants were asked in their interviews:

1. *What would influence you to discuss these types of things [end of life care/dying/advance care planning]?*
2. *What do you think is important when doctors and nurses talk to you about these things?*

All the participants commented on their thoughts and experiences on conversations with clinicians with two common themes: empathy and tailored conversations. Participants provided examples of how they saw these themes being operationalized and how its presence or absence acted as a catalyst for their conversations.

Empathy

The first theme described was the role of empathy (or the lack of it) in conversations. The willingness or ability of clinicians to show they were trying to understand or focus on another person's situation acted as a catalyst for participants to gain the information they wanted when considering their preparing and planning for dying. Participants defined empathy and described two behavioural elements that they found helpful in conversations with clinicians.

- Mutual connection as people
- Visible behaviour

Defining empathy and its benefits

Empathy was defined by the participants as showing willingness to understand or connect to the participants as a person as a whole rather than patients with a bio medical disorder. What

was commonly expressed was a feeling that the clinicians were trying to understand what it was like for the participant as well as helping in their clinical role.

Jacky: I would say a sort of understanding you know, thinking of, you know, putting themselves in your shoes.

Mabel: Somebody who shows they understand your feelings without you having to tell them.

Mandy: I think empathy ...for me is not just seeing the clinical ...condition...cos it [the cancer] has now ...infiltrated every part of my life.

When clinicians demonstrated empathy it made participants feel valued and important:

Alfred: It's a disinterested kind of love...they make you feel...like a person... that your life is importantno matter how long or short it's going to be.

Florence: You know that they are absolutely there for you 100% you know.

Empathy enabled participants to gain information that they needed for their own preparing or planning for dying. It empowered participants to have conversations with clinicians. For example, Mandy illustrated this explaining how her surgeons' empathy had empowered her to gain the information she wanted:

For me empathy is, and I felt that my surgeon had that. He understood that when I was asking him to be straight with me. I was asking him to be straight with me...because I had other things that I needed to do with the information...and other decisions to make.

The empowering nature of empathy to gain the type and amount of information that participants wanted was reflected elsewhere:

Mabel: With that one doctor...because of how he was I could you know...ask ask the questions.

Jacky: I mean when they are listening really listening trying to see from my angle...like [name of hospice nurse]...then they are the sort of people I can talk to you know find out what I need to know.

Mary: *Well you wouldn't want to talk to someone who didn't seem to care...about you...or...about what you thought.*

Keith: *They [hospice staff] treat me like a person not this...this...[points to chest] so I relate to them as people...can talk to them.*

Mutual connection

Reported in the interviews were descriptions of how empathy was demonstrated by participants and clinicians mutually connecting to each other as people rather than patient and health care professional. There were a variety of ways that this occurred, but when it did occur, it empowered conversations. The value of being connected to as a person rather than a patient was frequently described in the interviews. It enabled participants to have conversations about their future dying with clinicians as it increased their feeling that the clinicians were seeing them as people with other parts to their lives not just as patients with medical care to be administered to. Liv illustrated why this was important:

They relate to the ...patients as people ...um...so it just makes you feel better.

Liv continued:

My experience at the hospital ...is...what's that word...almost like people are disassociated ...from their, from their selves...so they bring their very large brains ...and their enormous experience and all those things of which ...I'm full of admiration ...but I want to connect to a person ...because I'm a person.

Liv's hospice experience had been different. Her hospice doctor had enabled her to discuss with more confidence her end of life treatment choices because she felt that the doctor was connecting to her as a person:

I wanted to connect...connect to a person not just the doctor...and I did...and that meant we were talking as people not as...you know...them and me or them and my failing body. Connecting as a person meant that I could explore things, ask things rather than feel judged, assessed, checked up on.

The distinction between being seen as a person rather than a patient was described elsewhere. Anne explained how being seen as a person by the hospice staff facilitated conversations:

Anne: I think my experience here at the hospice...is that...everybody the nurses, the volunteers...they are just people ...and they relate to the...patients as people ...so it just makes you feel better.

Sarah: mmm.

Anne: It's easier to talk to a person isn't it?

Frances gave another example from her hospital consultant:

He said...can you explain...how it [diagnosis and prognosis] really felt...he was asking me...as me...not as you know this [points to body].

Similarly, Mary discussed how hospice staff made a difference to her:

So you do like to feel like a person and the other persons considering you ...important to them in that moment.

There were other examples in the interviews of the importance of participants being seen as a person by the clinician. For example, not being seen as just a task for clinicians to complete encouraged conversations. Mary explained how she felt about some hospital staff:

And you see them...all there in their big groups...huddled round the beds...dishing out jobs...but they don't notice us...they don't notice us...the people they are here to see.

Mary continued:

I've come across one or two [clinicians] that I think ... they are not really thinking about me as a person ...I'm just somebody that they've got to deal with ... they are not considering me ...as an individual.

In contrast Mary explained how she felt when she was with hospice staff:

It's the fact that they [the hospice] recognize you as a person...not as a number on their chart...so I would talk to them about it [dying].

Florence illustrated how connecting as a person through simple acts facilitated conversations:

It's their attitude...sometimes I feel I want to talk, sometimes I don't and that's ok. The other day [name of hospice nurse] just came and sat with me...didn't have a reason to see me...just sat with a cuppa...so it [thoughts about dying] just all came out naturally.

Others echoed similar thoughts:

Frances: Just to have time...and to listen and to see me ...as a person and not just a name on a piece of ...paper where they tick things off and...scribble...on things down.

Jacky: They [hospital team] made me feel that I was just you know number 3 or number 27 on that day and that I wasn't Jackyand I am, I'm a person. So when you go [to hospital] it's just like we don't matter...they just have to get us 'done'...it's very hurtful...feeling like just a piece of their world...so I don't bother talking to them...why would you say anything to anyone like that?

The benefits of feeling connected to knowledgeable clinician was reported by the clinicians. This included those who combined their clinical expertise whilst remaining a person (rather than solely that of a health care role). Florence explained:

I want someone who knows what they are doing and talk to me kindly...I want both.

When clinicians were knowledgeable and mutually connected to participants as a person it encouraged participants to talk:

Sally: They have been such a help [the hospice]...and they are normal peopleand you know...some people...are full of themselves... aren't they ...but no the hospice people aren't ...they are knowledgeable ...and normal.

Alfred: You know someone like her [hospice doctor] knows a lot but talks with me as well.

The ways in which clinicians connected as a person and the benefits to the participants was illustrated by others:

Mabel: You see [name of hospital doctor] made you feel so at ease....so comfortable...he would always remember things and say 'how's the garden going?' or

'did you go out for mother's day?'...you felt like you were talking to someone who was really interested in you not just...just your illness not just your woes...so I always felt I could talk to him about things...because I felt...well it was a bit like talking to your clever nephew [laughter].

The benefits to the participants were repeated across the interviews.

Liv: I mean I do want them to know their stuff...but not lord it over me...still be a fellow human being for god's sake...who wants to talk to a lord?

Andrew: The boys, the top man, the really good ones are experts in their field but still still can talk to us as people...that's what I want an expert who I can talk to...who treats me equally whatever I do...that's what helps...that's when I will talk to them.

Sally: I like [name of GP] she...she is like...like... a friend because although...although she is a doctor she...she treats...treats me as a person...I am never afraid to ask her things.

Florence: There was not one person who you could not say was ...not nice or you couldn't trust...they were just so professional...they knew so much.

Keith reinforced the benefit of clinicians connecting as a person and being knowledgeable. Commenting on his DNACPR conversation with the hospice doctor Keith reported:

I know she knows what she is about.

A further aspect that the participants reported was that when clinicians showed their own fallacies or vulnerabilities as people, it could engender a feeling of trust enabling further conversations. Liv explained the moment that this had happened with one of her hospital doctors:

I think there was a turning point when I asked him about job satisfactionand he said he has to...somewhere in our conversation he said ...he has to leave his heart and his soul at home...and he comes and he just performs...a functional duty...and in the telling of that ...there was some human connection.

Further on in Liv's interview she clarified how that moment had facilitated their relationship:

That vulnerability that humanity...made me understand that he was under pressures too...and...and...and...made me want to connect with him.

Andrew expressed a similar thought when sharing how his consultant did not know much about the process of hospital admissions:

It did make me laugh...this big...very important consultant...just knows...knows so much...my fate is in his hands...and he just looked up at me all sheepish like and said 'I'll have to ask the nurse'...and I just thought...my god he is human...this top boy...this top expert is human.

Jane explained that it did not worry her or Sally when their hospice nurse forgot details:

Oh she [hospice nurse] is always phoning up saying 'I've got in a muddle...I meant to say this'...and we just look at each other but we know when the chips are down she knows what to do.

Mabel recalled how there had been a mix up in home appointment:

So [name of hospice nurse] was very very late and I I was worried so I phoned the hospice and she...you could tell that she had forgotten because there was a long silence...and she said 'oh my god I'm so sorry I wrote down the wrong day what can I do to fix this?' and and well it didn't matter and we all had a laugh about it...but now every time I say to her 'have you got it in the diary' ?

Later on in the interview Mabel commented on why she trusted the hospice nurse:

We like her because she is so so human...just like one of us and I don't mind when she forgets things because she's always always always there for when we really need her. She's always always apologises when she gets it wrong. She's always always always there when it matters...it's quite nice to not always be the one in the wrong [laughter].

Participants also shared the value of clinicians who insight into the boundaries of their own clinical knowledge. Edward explained:

Know what they know and know what they don't know.

Creating knowledge together empowered participant/clinician relationships. Mandy explained how reassured she felt when her GP was clear about her own knowledge

boundaries and the feeling it engendered that they would create together knowledge about Mandy's illness:

And she's telling me when she doesn't know something...or when she's gonna find something out...or when it's beyond her area of expertise...and it feels like...like we are doing it together.

Liv shared similar thoughts about the hospice doctor:

Liv: She looked at me put her pen down and said 'I have never heard of that before' so I said 'shall I show you' and we looked at it on the iPad there and then.

Sarah: And...

Liv: I thought it was amazing I was showing her and do you know it didn't matter one bit that she hadn't known about it because she was not afraid to find out with me.

Jane and Sally further illustrated the beneficial impact of participant and clinician creating knowledge together. The day after Sally had been diagnosed, her GP came to visit her at home:

Jane: We came back [from hospital OPA] and we just didn't know where to turn to next...did we?...it was so much to take on board...but [General Practitioner] came round the next day and said 'how did you get on'...cos she wanted to know too what was wrong...[further detail of hospital OPA]...and she said 'gosh I haven't heard of that for a long time'...and then she said 'I'll get you some more info and I'll ask [name of specialist nurse] to visit and I'll phone the hospital to check what's next'...and that was really good wasn't it...none of us had a clue.

There were other accounts:

Andrew: I was a bit surprised that he [consultant] knew so little about it [the hospice] and it did make me realise that they don't know everything...but as long as they know about this [points to body] I don't care.

Mandy explained how she and her GP had researched together the treatments and side effects for her uncommon cancer:

It feels like we are doing this together...discovering together what will happen next...well they can't know everything can they.

A different type of insight was an example from Florence. Florence shared her experience of chemotherapy in her local hospital. She had experienced copious side effects especially nausea and vomiting, diarrhoea and tiredness. During one hospital visit, a student nurse at the beginning of their training and career had cared her for. Florence explained how the student nurse's lack of knowledge had not inhibited Florence from feeling that they were a competent nurse:

And she just sat with me, listening to all this stuff coming out of my head...she was really still...just...being...there, witnessing it...I didn't...and she said 'I'm really sorry but I don't know much about this kind of stuff'...but she didn't leave, just held me hand until the sister came and, and I just thought...she is a really really good nurse.

There were other examples:

Keith: I know they are only [hospice] volunteers but it doesn't matter does it because when when you are ill you are ill and you just want a bit of kindness don't you.

Christine: She said to me 'I'm only the vol' and I said 'are you I would never have known' and she said 'yes' but but you see...when this this breathing gets on top top of you...all you want is someone who knows...knows what's like...and I think she did because she had seen it all before.

However, there were limits to participants' patience with clinicians' knowledge boundaries. Florence, talking about an occasion when the hospital staff seemed unclear about her treatment plan summed it up:

I don't mind all this dithering stuff...but I do want someone who knows what they are doing.

A further empowering element of connecting to a knowledgeable person were the benefits of mutual respect between the participants and clinicians. For example, Frances explained how mutual respect empowered her to have confidence to ask questions about her prognosis:

Respecting my wishes means people speaking to me...as a human being, as an intelligent human being. So they [the hospice team] listen to you and that in itself helps give you more confidence in the way you feel and how you feel about it...what you want to know about it.

Others gave similar examples:

Anne: You know they [hospice staff] talk naturally. So I can talk to them. Talk to the person as though they are an adult not a moron ...you know...cos that's how some some people do talk to you like that.

Liv: And if they [clinicians] can meet you in a place of mutual respect...so with the surgeon ...something happened ...and so I fully respected him ...and...you know hung on his every word ...felt really valuable that he really listened to me ...so we met in that place...as two people...that's what's important.

Liv followed an unconventional cancer treatment route. However, because her (conventional treatment) consultant surgeon had listened and heard her views, they were able to agree to disagree and for Liv to simultaneously receive different types of care. The door to conventional treatment remained firmly open for her because of the feeling of mutual respect facilitated by the surgeon demonstrating that he was trying to understand her choices and experience of living with an incurable cancer. Liv was able to use the surgeon as a sounding board and expert opinion rather than the owner of her care or the conductor of how she should live until she died.

Liv: The thing that has been most important for me is respect ...for my choices ...so regardless whether or not ...they agree with me or whether or not ...the science to back up ...what I'm ...doing...I would want them tolisten and offer me support ..and of course...part of their role is to use the best ...available evidence to...and make that available to meand so I guess time is really important ...so the most useful conversations I've had ...have been those where ...you know one persons on one side presenting their view and I'm on my side presenting my non-medical view ...but my beliefs and my hopes and myself and my...you know that all needs to be in the mix.

Other examples of the value that participants put upon mutual respect included Ernest and Bobby. Ernest and Bobby explained why they would talk to the hospice rather than community nurse about his end of life wishes:

Bobby: *What we liked.*

Ernest: *Was.*

Bobby: *When [name of hospice nurse] came and sat there [points to bed].*

Ernest: *And said.*

Bobby: *Right what can I do to?*

Ernest: *To help you...to help you.*

Bobby: *And we.*

Ernest: *Just felt she was very.*

Bobby: *Respectful.*

Ernest: *Respectful.*

Bobby: *She treated us like equals...not like some I could say.*

Ernest: *Yes.*

Bobby: *She was in our house...and I really respected her for that didn't.*

Ernest: *Yes...it was the first.*

Bobby: *Time that we felt we could talk with.*

Ernest: *Someone.*

Bobby: *Because she did not come into our house and tell us.*

Ernest: *What we thought.*

Ernest and Bobby's example illustrated the empowering nature of mutual respect. This was reflected in other participants' experiences, especially when it did not occur. Jacky explained why she did not start conversations with some clinicians:

If they don't bother with me why should I bother with them?

Mary commented on her feelings about some clinicians:

You can tell when they are just... you know going through...the motions...not really listening to what you are saying...and those aren't the people I talk to.

Mandy described how some clinicians had made her feel when she was asking questions about her illness:

I think that we should all you know respect each other don't you? Just because I'm not a doctor doesn't mean I am stupid...doesn't mean I can't make up my mind...doesn't mean I don't understand.

Mutual connection included being connected to a community of caring clinicians. Being connected to such a community increased the confidence of participants to be able to have conversations. Alfred explained:

I can't really explain it....but I feel that I am part of all this [the hospice].

Alfred continued:

All the staff here [hospice] are are inclusiveand they are all intimatewith all of... and you see ...it working...yeah not necessarily with...yourself but with other people ...I mean you do get ...things for yourself and you get better and better ...but when you see thisprogression of people you know ladies like [name of another hospice patient] I don't know if you know [name of another hospice patient]...who came in in utter despair ...bless her but...by the time she'd left ...she she'd got a whole life back...see...it's those examplesand you just think wow.

Mary illustrated further why feeling part of a community empowered her to talk about dying:

You're a nurse aren't you...you work there [the hospice] don't you...you see you are all like [name of hospice nurse]...you all care...I can talk to any of you...because you all treat me a like a person...so that's what I say...you all treat me like a person.

The benefits of mutually connecting as a person was repeated in the interviews. There was evidence that it empowered participants to discuss end of life. For example, Andrew reported

why he could ask his hospital consultant questions about his prognosis:

Bottom line I want to talk to a person about these things...an expert person...but a person.

Mabel commented:

And when these very clever people...clever people stop and they give you all that time...ask you about you...well well you can talk to people like that can't you.

Liv recalled:

The hospice doctor was great...she listened...she asked questions...and I really really felt that she was trying to understand my point of view and even though I could tell she didn't agree with me...that was okay because I felt she was trying to understand 'Liv the person'...so if and that's a big if I ever do have to talk about death...then she is the kind of person I would talk to.

Alfred reflected upon the benefits of connecting to him as a person:

They take away a lot of the burden of being ill ... it's like an oasis in a dessert reallyit can give you things here...that you can't get anywhere else...it can give youI suppose I've got to say love for want of better word ...then...a kind of love that you can't get from your family because they are too emotionally involved they are too close ...it's a disinterested kind of lovethey make you feel ...like a person.. that your life is important.

Jacky summed it up:

I choose who I talk to...with some of them [clinicians] I don't bother...but others like [name of hospice nurse] I can ask all the things I want because she treats me right.

The interviews provided a perspective that mutually connecting as people by seeing the 'person not the patient' and not being afraid to 'be the person in the clinician' facilitated conversations.

Visible empathy

The catalyst role for conversations of when clinicians' empathy was visible was reported in the interviews. Visible empathetic behaviour empowered (or disempowered when absent)

participants to carry out conversations with clinicians. There were a variety of examples in the interviews. Visible inviting behaviour was one such example. Liv commented on the inviting behaviour of her hospital consultant:

He [hospital consultant] was just great it was was like I was being invited to some meeting...he stood up, shook my hand invited me to sit down and said 'well where would you like to start?' and I just felt just felt that we were doing this as two people.

Liv explained why this aided her conversations:

And when it is like that...well it's easier to talk isn't it.

Alfred recalled his conversations with his hospice doctor when she visited him at home:

It's odd really...but but she always asks 'where would you like me to sit?' and I tell her and she always sits on the edge edge of the chair like this [demonstrates position] and she never has anything in her hands and and she always says 'what do you want to talk about?' and and it's always what I want to talk about what I am worried about.

Mabel commented how her hospital consultant used visible behaviours to indicate that this time with him was now hers:

He [consultant] always kept us waiting [in the outpatient clinic]...but that was alright because when you went in there [the room], he used to lean back in his chair as if he had all the time in the world.

After Mabel's interview and recorded in the field notes, Mabel explained how his behaviour had encouraged her to ask him questions about what would happen if her dialysis was withdrawn and how long would it take for her to die. This was in contrast to her comments about how the busy behaviour of day hospital doctors inhibiting her asking the same questions. Mabel explained how the clinicians' visible behaviours meant that she felt that she had to have a specific health related problem to talk to her doctors:

If you ask specifically to see, to see them they'll come to you, otherwise they wander round and go 'everything alright' and you feel though that they are in a bit of a hurry which they probably are ...and you don't like to bring things up.

In conversation with Mabel after her interview and recorded in field notes, Mabel revealed

that the conversation she really wanted to have with these clinicians was how long she would have to live when she stopped her renal dialysis. For her this was an important hypothetical question because she had no concept of whether she would die within minutes, hours, days or weeks. She wanted to ask this question so that she could plan for the needs of her family and prepare herself for when it happened. She felt that because she was seen as being 'alright' by her clinical team, that it was an inappropriate question to be asking them. She had therefore built up a picture (inaccurate) that:

They will give me something [meaning assisted suicide], cos they do that to everyone.

The importance of visible behaviours was reported elsewhere. Florence discussed the impact of when a student nurse had held her hand during a cancer treatment:

I just held onto that hand tight really tight and she didn't let go...she squeezed back...she didn't say anything...but I could feel that she cared...I could feel that she wanted to help and...that's what's important...showing you that you care...that what's important when talking to people.

Inviting behaviours encouraged or gave participants more confidence to have discussions with clinicians. Christine reported why she could talk to the hospice day care staff:

They always seem to have time for you...and that gives you confidence confidence that you can take your time...time to discuss things.

Sally and Jane explained how their hospice nurse made them feel more comfortable in their conversations with her:

Sally: I think it's it's the way she is...she...she is.

Jane: Very calm very still so Sally doesn't feel rushed.

Keith had similar thoughts:

It's about how they are with you...how...they make you think that they have all the time in the world...and that that helps it does it really does.

When asked to explain more Keith continued:

I suppose it's different here [hospice] but but when you are in [hospital] everyone is running around and lots of people and I feel bad...bad that I am taking up their time...so here it is different...I don't feel that I am in the way...that I'm part of everything.

Keith's insight into how the busy behaviour of clinicians did not invite conversations was reflected by other participants. Mary shared her thoughts about the behaviour of hospital staff:

Well they are all very busy so it's difficult to talk you see.

In contrast Anne reflected upon the behaviour of hospice staff:

I prefer it here [hospice]...she [nurse] comes back after our chats and asks if there is anything else...I don't feel I have to say everything all at once.

Visible listening also empowered participants to discuss end of life issues with clinicians. Liv explained how the actions of the hospice doctor influenced her:

I could see that she was listening because she had a pen and every so often would write a word down and then every so often she would circle a word and put a question mark by it or another word like 'feelings' or join up words that I said...and and I thought I can really speak to this woman...she is really listening to me...so when you ask me what is important when talking to me that's what I mean...showing me that she is listening.

Others gave examples of the empowering consequences of clinicians' visible listening behaviour. Andrew explained why he liked talking with his hospital consultant:

He's good...that's what I would say to you he's good because I know he is listening to me...because because he writes down what I say.

Mandy shared why the note taking and summary of their conversation by her hospice nurse helped her:

And and when we have finished she she says...'can I just check with you if I've got this right'...and she looks at her notes and reads it out to me...and that helps...sometimes I remember things I have forgotten to talk about [laughter].

Keith also valued visible evidence of the listening behaviour of clinicians:

Keith: *What I do like is when I can tell that they [clinicians] are listening to me.*

Sarah: *Go on.*

Keith: *[name of hospice nurse] is good...I know she is listening because it's written all over her face...I can see it...she's not very good at hiding her feelings that one [laughter]...but I do like it...I can tell she is listening and you know...that's why I can talk to her about it.*

Alfred shared the differences between his hospice and hospital doctor:

Now [name of hospice doctor] she she is very very good...she always stops what she is doing...writing and so on and listens to me...but [name of hospital doctor] he is always looking at his computer...I'm never really sure if he is paying attention...so when you ask me what's important I mean that...what [name of hospice doctor] does.

Whilst there was no commonality for one type of visible listening behaviour participants valued, there was agreement in that they valued such activity by clinicians. Edward commented why he felt he could talk to his hospice doctor:

I think what she does is important...that I can see that she is listening to me...that gives me confidence that she is paying me me attention not anything else.

Frances illustrated why visible listening behaviour encouraged conversations:

I do want to know that they are listening to me...if they do then I will listen to them.

Mabel explained why she spoke to one of her doctors about the end of her life:

Mabel: *So when I go back to the difference between [name of hospital consultant] and [name of day hospital doctor]...I could only ask questions about all this of [name of hospital consultant]....I would never ask [name of day hospital doctor].*

Sarah: *Go on.*

Mabel: *[name of hospital consultant] looked like he wanted to talk with you.*

However, not all participants had a positive experience of visible behaviours. Mary explained why she did not talk to some of the nurses who visited her:

Mary: *And you can tell...tell when they are doing it [nods head several times] by the manual like...suppose you taught them that...head...am I right?*

Sarah: *umm [shared laughter].*

Mary: *Well you can take it from me...don't...I can tell when you are doing it by the book and no no no don't.*

Mary had noticed a pattern of responses in the nurse's conversation, which she felt were neither genuine nor spontaneous to the conversation they were having. Mary commented that what she wanted was the nurse to be:

Listening to you and responding to you and responding because of what you've said not... not what's in the manual.

There was some evidence that the benefits of visible behaviours developed over time. Jacky commented on how her relationship with the hospice had evolved:

Jacky: *I think the hospice do make it clear that you do work together, you do work together and you've got your options and you make your own decisions...but you can change your mind at any time and I think that's always reassuring because you know if you are not happy not comfortable...that you feel comfortable to talk openly with them ...about that as well*

Sarah: *Can you say more?*

Jacky: *Well...well...every time I see [name of hospice nurse] she asks me 'can I check what you want to talk about' and and she never rushes me...never pushes me...never you know makes me feel she is in a hurry.*

Describing his experience of hospice day care Keith provided an example of taking time with people:

Reassurance and acceptance. The first time they asked lots of questions...but...but I didn't...could not answer all of them...it was...too too much...so next time I went...they

didn't...just sat me down and let me be. I was just unresponsive...for a couple of weeks mainly because I was fielding and trying not to engage with [talking about dying].

Frances described the impact on her of observing the behaviours of hospice staff over time:

Sometimes when I'm here [hospice] I sit and look and look at everything going on...the other day [name of day hospice nurse] was so kind so caring so lovely with [name of another patient] and she was so upset so ill and and...I thought to myself...that is how I want to be looked after...and I think that is because I had been here for so long...seen others...so it gives you confidence doesn't it...seeing them [hospice staff] with them [hospice patients].

The interviews provided some examples that empathy was not solely concerned with single conversations. It was also demonstrated by observing behaviours over a period of time.

When empathy was not visibly conveyed by clinicians, participants described the impact on their conversations. The lack of empathy led to participants not revealing or discussing issues that were important to them. Jacky explained:

If we were going to go back to the officious doctor types I wouldn't want to talk, to talk to them about it [dying].

Jacky described the impact of a doctor's lack of empathy in seeing her in the context of how she lived with dying whilst being a single parent of young children, one whose birthday was the following Monday:

On the day they were discharging me [from hospital] he said to me 'oh you need to come back next Monday ...and have the operation again' and you know ...and I felt that someone had hit me with a stick round the head.

The inability of the doctor to try to empathize with Jacky's world had a strong effect on her. Her planning for dying revolved about doing (as she saw it) the right thing for her children i.e. making sure that she was present for her son's birthday, creating happy memories – a birthday that she pragmatically realized would be the last that she would attend:

Because my children are quite young ...still and will be quite young still [when she dies],

are the ones who will be left with those last memories. It's those sort of people who...who you think...why are you a doctor? Because...because...well I am never going to discuss with him what I am worried about.

Frances described how the negative visible behaviours of a hospital doctor affected her conversations. The consequence of the behaviour was that she would not discuss what mattered to her (her emotional wellbeing and her prognosis) with the doctor concerned. Frances explained:

It was how he was so when I arrived at [cancer centre]...I was a little bit stressed wondering what had happened ...and the registrar ...comes and says 'now then, how are you?' 'Well I'm a bit stressed'...'Well I don't want to know that, I just want to know about your physical...health, are you eating have you got diarrhoea?' ...and I thought ...my first instinct was to say something really rude to him. I thought how you dare you say to me, because my mental state is more important to me than physical state. I can stand the physical bit... it's what goes on in my head ...that really ...really disturbs me... he paid no attention to that at all ...I cannot get a straight answer out of anybody there about anything ...so no way could I discuss anything important with them about what I have been talking to you about [referring to earlier conversation about suicide]...they wouldn't want to knowthat doesn't come into their scheme of things.

If Frances did not discuss anything of importance to her in terms of how she was living with her diagnosis, dying and thinking about suicide with her medical team the question then is; how much did that influence her preparing or planning for her dying? As discussed previously, if preparing is concerned with one's own individual preparation and planning's intention is the needs of others, then Frances's example showed how the blocking behaviour did not help her in either planning or preparing. Frances had already discussed that she liked to plan and she needed to plan to prepare:

What I really want to know is ...is how much time I've got, I mean I know they [clinicians] can never tell you ...but these people [clinicians] have been handling this sort of thing [cancer] for years ...and they ought to be able to give you a rough idea ...because I'm used you see in my job, my career ...I've always planned a year ahead

...and I can't get used to the idea of not knowing [how long she has to live] and if I only have got a limited amount of time ...then I want to know as soon as possible ...because there is a lot that I want to do ...and I can ...face up to this.

The negative impact of a lack of visible empathy was shown elsewhere. Mandy explained:

Mandy: I choose who I talk to and I only talk to them who I think care or can help...I don't have time to waste with those who don't...well [name of clinician] I don't have time for them because they never seem to be listening so I wait until I see [name of doctor] and ask them.

Sarah: umm what happens if you don't see [name of doctor].

Mandy: Then I don't ask the questions.

There were other examples of visible behaviour inhibiting end of life conversations. Liv reported how her hospital outpatient appointments seemed to be more about the performance of the consultant rather than her needs:

And as ever the room fills up with all these nurses and all these trainee doctors and things ...which is fine except for when someone [consultant] seems to be performing a show for them...so why he should think that I would discuss anything with him is beyond me...I'm not a performing monkey in his circus.

Others behaviours were described that inhibited conversations.

Anne: Some of them...only some of them mind...just seem to be going through the motions...so I wouldn't really want to talk to them.

Keith: Sometimes it does feel a bit you know step by step...I'm going in one end and coming out the other ...like some sausage.

The consequences of such behaviours was to inhibit conversations:

Mary: Well I'm not going to be inclined to someone who is not listening to me...you don't want someone to be ignoring you do you?

Andrew: *What's important is that you know that they are listening to you...that is that is what is important to me...that is the person I'm going to ask questions of...not anyone else...because they are listening to me.*

The participants also drew a picture that where discussions were concerned with the clinicians rather than participants' agendas, then conversations were inhibited. Florence described how she felt that conversations were often concerned with the needs of the clinicians rather than her own:

I did meet other patients of his [consultant] and in a funny way and I think he'd be mortified to know this...there was a certain pressure that went along...with needing to be positive with him and in front of him about it... there was a certain kind of commitment and a pressure... an additional pressure on top of everything else that patients of his did feel and I felt that as well ...like I had to be a positive as he was, even if I was maybe a bit more sceptical than he was.

Others echoed similar feelings:

Mabel: *Sometimes I do think...well with some of them that the meeting is all about them and...and...that's well very off putting.*

Christine: *When you get the good ones...it feels like it's all about you...but when you get the bad ones you can tell that all they want to do is to get to the end of the conversation...so what's the point?*

Mary: *I know they are busy and like...goodness me they work so hard...but but when they come and take your blood like or fiddle with your what not and ask alright?' you know they don't really want to hear anything...so I just say okay.*

Mandy: *With some of them it feels that they already know what they want to talk about and I'm just floating along.*

Liv explained why she felt her hospital consultants' fear of litigation got in the way of her conversations:

Liv: *So it's one thing having a doctor who generously ...writes a letter and copies you in so that you are informed ...but when you get the feeling this is...litigation prevention*

....you just thinkif you took the time to know me you'd know I'd never sue the NHS

Sarah: *mmm*

Liv: *So it stops you in your tracks really...stops you contributing anything to the conversation.*

Ernest and Bobby explained that for them, when their clinicians had discussed with them decisions about whether to discontinue specific treatments that the conversation order had been concerned with the clinicians concerns rather than theirs. Ernest and Bobby felt rushed into providing an answer about the decision to withdraw treatment because of the clinicians need to complete the tasks of advance care planning documentation. This had resulted in that they had been asked to make a decision and then asked what they thought about it. The clinicians' intent of the conversation was to make a decision rather than starting with what was important to Ernest and Bobby. Ernest and Bobby reported how it would have been more helpful to them to first think about it, ask questions and then decide. Ernest explained:

Think about it [withdrawing treatment] and then decide, not decide and then think about it...liked to have think about it first, not just fill in their boxes.

The effect that this had had on Ernest and Bobby was that they had not been able to think about what information they needed or ask the questions they wanted. Ernest reported:

Think about it first [specific treatment]...cos if you think about it as Bobby saidyou can think like you said, is there any questionsyou'd like to askis there is there any of this that you would like to knowand then in that respect cos if you are suddenly told ... and you haven't got time to think about it ...you don't know what you are going to answer or whether you are going to answer ...the way you really want to answer.

The interviews provided a perspective that clinicians empathetic behaviour (connecting as people and visible behaviours) had a direct impact and could empower or disempower conversations.

Tailored conversations

The effect of tailored conversations was reported in the interviews. Participants described how this played a part in how they could gain the information they wanted as they lived with their future death. The manner in which information was conveyed mattered. There were two elements described:

- Honesty
- The design and use of the environment

Honesty

Honesty referred to the amount of and how participants wanted information. Honesty included accessible and selective elements and when it did not include this, it could disempower conversations. Anne (who had been a seamstress in the past) explained why tailoring honesty to each individual person was important:

It's like...like when I was making a dress for someone they would bring me their pattern and I would measure them and ask them what the dress was for and and when it was finished it was tailored...tailored for them...someone else might have that pattern but no one had that dress...do you see? So when you talk to me about this [points to chest]...ask me...ask me...measure me up...do you see?

Tailored honesty was valued as it was seen as demonstrating that clinicians were led by the information and support needs of the person rather than solely conveying treatment, diagnosis or prognosis information. When done in an individual, personal way, it helped participants to find out information that was important to them. In contrast, when carried out in other ways, it inhibited discussions. Many of the examples that the participants described related to discussions about prognosis and diagnosis.

Common to the participants' descriptions was a recognition of the importance of clinicians identifying what were the information needs and style of communication of people. Andrew explained why he felt clinicians should size people up:

Andrew: The way they talk to you ...obviously and I think correctly depends on what kind of patient you are. He [hospital consultant] sized me up.

The concept of individually sizing people up was repeated across the interviews:

Liv: The most important thing, is to listen first of all...and... find out who it is you are talking to.

Christine: We are all different aren't we so you have to find out what so and so knows and what so and so wants.

Mary: The important thing is to ask people what they want to know...to discuss...to talk about...ask them first.

Sizing people up was important in order to personally tailor conversations. Jacky explained:

Jacky: Once they got to know me they have been very good.

Sarah: Very good?

Jacky: I mean I've been quite lucky in that certainly at the hospice people have endeavoured to be as up front and honest with me as they can...which is what I want.

Mabel provided another example:

I don't really like to talk about it...but they are very gentle here...so I don't feel forced into talking about it...but when we do...its very gentle like.

Mandy described three very different experiences of hospital consultations (diagnosis, second opinion and surgery consultation):

The first time...she was really good...she kept asking me if it was okay to go on...what did I want to know you know really thoughtful and when she told me [describes scan results of extensive disease] she never stopped checking up on me and though the news was terrible...devastating...I felt I could handle it...so she sent me to [name of another hospital consultant]...so that they could see if there was any other type of treatment and and I suppose she is brilliant...but...well it was awful...she just came straight out with it...didn't stop for a moment...never checked up on me like [name of

first consultant]...and I panicked...I couldn't remember a word she said...so when you ask me what's important that would be an example....please please please check with me what I want to know...I handled it first time round...but second time...well awful...awful.

In contrast, Mandy then went on to describe the consultation with her consultant surgeon. His tailored approach had provided her with the information that Mandy needed:

So he was quite honest with me he kind of gave ... and again I know it's not an exact science but he said it would be likely that it will come back in five years ...at some point it will come back in five years ... and that would be highly likely with the type of tumour I have...but obviously that's not a definite...but it does give me a rough time scale to work to and make me think well ok I don't need to stop work today.

Clarifying her first and third encounter Mandy commented:

I think the difference was that they both continually checked with me how and what information I wanted...and even when I got tearful they carried on...but only only because they checked if that was ok.

The persistent theme from the participants was that honesty was helpful to them as long as clinicians continually tailored their conversations. For example, Keith explained how his hospital consultant had told him about his disease. The consultant had found out from Keith first how he wanted the news:

Keith: For me he was great...he looked me in the eye and said 'ready?' and I said 'yes' and he told me...very simply very quietly and that's exactly what was right for me.

Sarah: Right for me?

Keith: Yes right for me...because he had found out about me first.

Jacky recalled a conversation she had had with the hospice nurse about what would happen when she started to die:

So we started to talk about what happens when...when you know...I'd been to see the hospice...decided...but although I wanted to know asked all these questions she could see that I was getting upset...so she stopped and waited and waited and then said 'do

you want to do this? do you want to stop?’ and and I did and I didn’t...but because she noticed because she stopped when she did because she asked me...properly asked me not one of those you know...properly asked me if I could go on and I did.

Edward had a further view, illustrating that tailored honesty was also concerned in the purpose of conversations. He felt that the conversations within outpatient appointments were only geared to the information and conversation structure needs of the doctors. He explained how at the end of his medical consultation he would only be asked if he had any more questions. For him it was less about medical questions and more about being able to consider and discuss the implications of his inevitable death at an uncertain time with his medical expert. Edward expressed clearly that he wanted to be able to have a conversation with the expert (in his case the oncologist). The conversation was about sharing information thinking time (preparing) with the consultant rather than decision-making. This time would help Edward as he thought ahead to his dying:

Well you know, they, you know, you are asked, like I said from the beginning ...its questions not information that is volunteered.

Edward continued:

I think it is also about being honest about how you want to use your time with them.

The benefit of honesty that was personally accessible was also reported by the participants. This referred to clinicians being able to carry out conversations in the way that meant sense to each individual person. It was tailored individually in terms of for example. content, terminology, depth or breadth. Mandy described what had helped her to make sense of her situation:

You want the truth told to you to to...to tell you that you are still able to at least able to access yourself ...realistically as well.

Anne clarified how a conversational approach had helped her when discussing her prognosis and what she wanted to subsequently prepare or plan:

But like I said when I’m talking to the nurses and doctors hereit can come out so

natural [discussing prognosis]...it's not a big conversation...just a chat.

Mandy explained why accessible honesty was important for her:

I'm...not wanting to know for just any old reason, I'm actually wanting to know certain time scales from you because I have fairly important decisions I want to make based on that...and... so he was quite honest with me.

Mandy continued:

I've always felt that they have treated me like an equal who could understand the same information as they you know they might know a bit more about it or they might know some of the more complex terms ...but...if given to me....I could disseminate that information ...and dissect it and work out ...what I needed to know.

Furthermore, accessible honesty included being led by the participant's agenda, especially in terms of the desire to and how to discuss dying. Ernest reported how important it was for him to work from his agenda in terms of how to discuss things with him:

The outcome is going to be...would you...like to talk about it [dying]...how would you like to discuss it?

Accessible honesty could take a variety of forms, one of which was clinicians recognising the need to provide information in a way that best helped individuals. Alfred explained why he had been able to discuss his prognosis with his hospice doctor:

She started off by asking me what was most important to me...well I didn't bloody know, it's obvious isn't it [points to his chest]...so she then said 'well why don't I start with what other people have asked me and see if that helps?'...and as she talked she kept stopping and asking me if it was ok to go on... I liked...that, found that...very helpful.

Alfred's example illustrated how the hospice's doctor had been able to make the conversation accessible through other people's experience, whilst keeping the focus on Alfred.

In addition to making conversations and information accessible, the participants also reported how selective honesty was of benefit to them. This referred to how participants continuously selected the type or amount of information they wanted and how clinicians assessed and provided that type of honesty. Edward describing himself as living on death row, explained how he wanted certain details so that he knew what the dying process might be like so that he could:

Well, avoid dying as much as possible.

Selective honesty was not static and some participants described how their honesty requirements could change depending upon how they felt, for example. when physical symptoms were not controlled. Christine explained how when she could feel her physical symptoms increasing that she felt compelled to start to plan for her husband's needs:

So when I...I...am really bad, I start to think about him [husband]...and what will happen when I ...die...so then I ask [name of hospice nurse] for more ...you know...more information about what happens when...cos...cos...cos...I have to think about him...what he needs...he'll be hopeless without me.

However, when Christine's physical symptoms were well controlled, her desire for detailed honesty for her preparing and planning needs lessened. Christine commented:

But when it is a good day, I don't want to talk about it [dying] at all.

Selective honesty could include partial or full disclosure. Sally explained that whilst knowing that her death was inevitable from her long-term condition, she did not want to prepare or plan for the details now:

Oh, blimey... not...not necessarily ...I know I know... it's going to happen ...but I don't need to know ...details...at this stage.

She was not the only one. Mary commented on why she did not want full honest conversations about her end of life yet:

No I don't think so no ...no I don't think there is anything maybe because I haven't got there yet.

However, some participants felt that full disclosure was relevant to their preparing and planning needs. Mandy described how being told her prognosis was not necessarily a negative

thing. It had empowered Mandy:

So I think sometimes there's an assumption that if you want to know it will be ... a negative thing to tell you... put time scales on things you might work to those and maybe not do things that you would otherwise have done and who knows if that time scale doesn't happen ... but it's not always negative things sometimes it... it throws up new opportunities and spins you off in a different direction ... and ok if it doesn't happen then so be it. I'm not going to turn around and sue anyone for it... for me having longer than somebody planned.

When tailored honesty was not carried out well, it had a negative effect on conversations. Participants did not gain the information in the way that they wanted. Mabel described an encounter with a hospital doctor:

Mabel: There was this one doctor and he just talked and talked and not once...not once did he stop to ask me what I wanted to know...not once.

Sarah: mmm.

Mabel: Silly thing is that I didn't find out anything.

There were other examples where the lack of tailored honesty inhibited conversations:

Jacky: You just kind of shut down really...see the mouth moving [laughter] and think I'll let them get on and find out another way.

Anne: I don't always know what I want to know...but but I do know that I want them to help me find out...and when they don't it's hard hard.

Mary: It sometimes feels as if it is their way or no way.

Liv explained how she felt about some clinicians' skills:

What annoys me is that it doesn't seem to occur to them to find out how much I want to know...if they did it would make life a lot easier for them.

The absence of tailored honesty could also have an emotional impact. Edward commented:

Usually I see [name of hospice doctor] and she she knows how we chat but this time I saw [name of different doctor] and I know I like keeping to the point but but...anyway I came away feeling feeling rather deflated...it was was too much too much all in one go.

Other indicated how they were affected by the absence of tailored honesty:

Andrew: You have to get it right...the right amount of information because if you don't it can get you down.

Florence: They don't always get it right...sometimes they go all round the houses and and they could just say it...I start to worry there is something else when they do that.

Mandy summed up the emotional impact of honesty. Reflecting upon her desire to know everything about her diagnosis and prognosis Mandy remarked:

I think its very important to think very very carefully about how you tell people stuff like this. It's important to me to know the facts about about all of this...but just because I want to know doesn't mean I don't get upset...I understand it...but I don't like it.

The examples of sizing people up, accessibility and recognising selectiveness illustrated the value the participants put upon tailoring honesty in conversations. When it occurred well, participants were able to gain the information and the support they wanted. When it did not occur they were unable to gain the information that they required.

The design and use of the environment

Examples from the interviews identified that the space within which clinicians carried out conversations influenced how participants discussed or talked about their future dying. In particular, this referred to the design of and use by staff of buildings and rooms. Tailoring the environment for conversations was reported as being important by the participants. There were descriptions of both the negative and positive impact of the environmental space on participants' conversations. The common consequence was that participants did not ask the questions or gather the information that mattered to them about their end of life if the physical space made it difficult to carry out conversations. For some there was a feeling buildings had not been designed for meaningful conversations. Mary shared her thoughts about the design of her local hospital:

They don't really design them for us do they. It's all very nice...new paint and all...but there used used to be this little coffee shop and benches in the garden where you could sit and wait and they would pop their head round the door when it was your turn...but

they changed all that...put a car park in [the garden] and changed it to [coffee shop chain] and...well it's not the same now...not so friendly.

There were other examples. Edward commented on the setup of his GP surgery:

So you sit there with your back against the wall looking at all these old bits of paper stuck to the wall...and this voice calls your name...don't even come out the door...just some box calling your name to some room...and you think 'has it come to this? That I have to talk to you...do you really expect me to talk to you like this, about this [points to body]?

Christine reflected upon how little information there was in her GP's surgery about booking double appointments and because of that she had not booked extra time to talk through her recent test results:

I felt so rushed...no time to talk...I was in and out of there in a jiffy...I didn't know I could ask for more time.

Other participants described how the environment affected them. Florence explained why she asked few questions when having her cancer treatment in hospital:

Urrrr...the room...the room...it's just so horrible...I can't bear it...it's a horrible room...I just want to get out of there as fast as I can.

Mabel commented on how her regular hospital visits affected her conversations:

You go there and sit there and sit and sit...and the magazines are all old...and you you see the paint coming off...and you just think...what a dreary dreary place...what a place to be and it drains...drains you of everything.

Liv described a similar experience in her hospital outpatient room:

I think it is dishonest. People are experiencing really really difficult things and sitting around with really full emotional responses ... you know if the staff are stressed or overwhelmed or busy but particularly again in ... cancer waiting area...it just feels like there has been an accumulation of ...fear anxiety which is almost palpable in the room.

How the clinicians interacted within the environment also influenced the participants' conversations. Jacky explained:

I think that you know where that's [the conversation] going when they are assembling those people in the room ...because when I had a friend with me ...he had another doctor in the room and I think a Macmillan nurse in the room and I ...you know common sense is saying to me well this isn't going to be good is it.

Other participants described examples of spaces, which did not enable conversations. Anne shared her experience in her local hospital when she had discussed with the hospice doctor about admission to the hospice. It was important to Anne to discuss this with her family after she had seen the doctor:

I had been there for a few days and [name of hospice doctor] came to see me and and I said 'yes I'll come in' [to the hospice] but I need to talk to [name of children] first...but oh the hoohar trying to phone [name of children] there was always a reason from the nurse why I couldn't phone and they [family] couldn't get in by visiting time...and I wanted to speak to them...you know face to face...so...so it was like it was just too much trouble.

Mabel provided an example of the way staff interacted within the day hospital environment:

So...as I was saying...they [clinicians] are all so busy...and they don't look at you as they rush past...eyes down...don't look at you...and it is difficult to catch their eye because of the way the chairs are.

Frances explained why she did not ask her hospital consultant questions about her prognosis:

Frances: So he sits by his desk and and looks at me over his glasses and I am used to being in control...being the boss but something happens when I go in there...I feel childish...I feel I'm going to be told off if I do something wrong...all those rules and notices everywhere...questions about have I done this...have I done that...it's not the sort of place I like going to.

Sarah: *mmm.*

Frances: *So I never ask him anything...not like here [hospice].*

Sarah: *mmm.*

Frances: *Here here you decide where you are going to sit...here you decide when you want to see the doctor...here you are in charge.*

Mandy described how she felt about the hospital ward setting and why she asked as few questions as possible:

I think I think you lose who you are when you go in there...I'm no longer Mandy ...I'm just another number on another list in another room...all lined up in chairs and people calling out your name...and and the place doesn't feel personal...I know they have to be sterile and all...but it's just all set up to 'do to you' so it doesn't really give you the confidence you know to speak...to ask...to be.

However, the environment did not affect all the participants. Explaining how he was told the news of his recurrence Andrew commented:

So the boss man shook my hand, sat me down, looked me in the eye...and told me. To be honest I didn't really notice anything else I was so busy listening to him.

Keith had a similar experience when the hospice doctor came to see him in his hospital ward. Having just described how busy the ward was Keith recalled:

When she came and sat down and talked to me...everything else went away... it was just her and me.

The environment could be beneficial with examples of how the hospice building itself (the research site) empowered conversations. The research site is a purpose built hospice combining clinical and office buildings, gardens and woodland. It was designed to use all of the buildings and land in a therapeutic manner. There is open visiting, overnight rooms for relatives, a restaurant and pets are welcome to visit. There are many spaces both in and outside of the building to sit or walk including a wheelchair accessed woodland walk. All of the participants had visited or been admitted to the hospice on a regular or irregular basis and therefore had experience of the building or grounds.

The conversation empowering nature of the hospice building space reported elsewhere in the interviews. For example, Liv articulated the impact of the hospice space on her:

I think the difference here is that it feels like it is a place for people with real people working here.

Liv continued giving examples of how the environment had been tailored to the needs of patients and families:

Well look...look at this room [one of the hospice small sitting rooms] look at the garden [points to group of hospice staff having coffee break sitting with some visitors]...look at the patient kitchen [point to china teacups and mugs]...look at the front door [designed as a domestic front door] look at this [indicates iPad and Wi-Fi] ...look...this is all about us...us the patients not the doctors or nurses or management or inspectors.

All of the participants gave examples of the benefit of the hospice space to them. There was a relationship between that and their potential for conversations. Anne who was an inpatient at the time of her interview illustrated how the design and use of the space supported her in her conversations:

So when they [adult child and granddaughter] are here...if the doctor comes in to see me...well [name of granddaughter] she pops outside to feed the birds and and then we can talk to the doctor proper.

The ability for the design and use of a building and space to engender a home like feeling was expressed by several participants. Keith described how he felt about the hospice site:

There is so much light and space and you can bring whatever you want in and it doesn't feel like a hospital.

Christine commented:

The other day I saw one of the nurses walking round with a horse and a little girl...walking around here! can you believe it! And and I asked her could my son meet him [the horse] and she said 'yes when shall I bring her in?'

Christine continued:

It is just so much nicer...you feel that you are part of a building and garden...not just a building...do you know what I mean...and I was talking to [name of another hospice

patient] *do you know them? And they said the same...it feels like home from home because it doesn't feel like a hospital.*

The use of building and space could incorporate the feelings or informality of home as well as maintain the participants' identity. Anne explained how she had been able to talk to one of her children about her future death:

I walked round with [name of adult child] and they [hospice staff] said...do you want tea outside...and we sat outside in the garden with tea and cake and and...it really helped us to talk...to talk about things [dying] because...because it felt we were at home...I mean I know we aren't at home but it felt like it.

There were other examples. Frances reflected:

It makes it easy to talk because there are so many places to sit...not just in your room...and you can make a cup of tea together or order lunch together.

Anne explained what happened when she had visitors from a long distance away:

So I was telling [name of hospice nurse] about [name of friends] coming to see me from [name of town] and she said 'well do you want to invite them for supper?' and I said 'what?' and she said 'invite them to supper I'll go find out what's on the menu' and and that's what happened and and they set it all up in the dining room...even put 'reserved' like a restaurant...things like that....I hadn't seen [name of friends] for months and I wanted to see them before before ...so [name of hospice nurse] helped me see them...and that that was [wipes away tear].

Keith described how he used the hospice space as a way to help his family to become accustomed to his wish to die there. The hospice runs a monthly film club. Keith commented:

They were showing [name of film] so I said to her [wife] shall we go? And we did and it was in the [name of day hospice area] they had set up all the chairs, there was wine, cheese and biscuits and some of the nurses and doctors were there...so next time I'm going to bring [name of adult child and partner]...you know to get them used...used to it.

The positive impact of the hospice environment was reflected elsewhere in the interviews, illustrating how the design and subsequent use of space by staff empowered a feeling of

community as well as encouraging conversations:

Andrew: *I always used to drive past here and think 'oh don't want to be there' and when I came when I came...it was wonderful...wonderful you drive up this big drive and and go into the front hall and immediately they smile say hello can I help and you sit down and they offer you a cup of tea and it's always like that.*

Keith: *I like that when you get there you get welcomed...the minute you come in [name of receptionist] says 'hello Keith how are you [name of hospice nurse] is waiting for you'...so you feel welcomed...expected...part of the family...and everyone smiles at you...even if you don't know them they say 'good morning or can I get you anything'...and and it's those sort of things that make the difference.*

Edward: *So I sit in the reception and I have noticed I have noticed...they treat everyone the same...the postman comes in and they say hello, the nurses come in and they say hello people come in and they say hello everyone is treated as a visitor a guest important.*

Christine: *So when you arrive and have had your cuppa and chat about what's on today...you then get on with whatever it is you are doing...now I like the spot by the window...where I can see everything...because on Tuesdays the gardeners come in...and as they do it...every so often they look up and wave at me...and I wave back...and well it just gives you this good feeling...that everyone cares...even the gardener...and I think that helps...that helps.*

The participants reported how the design and use of their hospital or hospice space could impact upon conversations. The hospice space through its design and use could engender a feeling of community, encouraged conversations as well as help maintain the identity of the participants as a person within their family networks. In contrast the hospital and GP surgery examples in these interviews did not facilitate conversations indicating that attention should also be paid to the architectural design of clinical buildings when considering the needs of people in their conversations.

Communication with clinicians' summary

The participants' interviews illustrated that clinicians' empathy and honest communication behaviours and the environment influenced participants' conversations as a catalyst for conversations by participants being able to gain the information they wanted for their future death.

Firstly, empathy was a catalyst for participants to be able to gain the information they wanted as they thought about their future death. This was illustrated by mutually connecting as people not a patient or task, connecting to a knowledgeable person who was human and had insight into the boundaries of their knowledge as well as mutual respect. In addition, visible behaviours benefited end of life conversations through inviting conversations, listening behaviours and behaviours over time. The consequences of negative visible behaviours were that participants did not reveal or discuss issues that were important to them, felt their emotional wellbeing was affected and that they were part of the clinicians' agenda rather than their own.

Secondly, tailored conversations helped participants gain information about their diagnosis, prognosis or treatments in the way that they wished. When this behaviour was absent participants did not gain the information they wanted to help them prepare or plan for dying. This was illustrated by tailored honesty, which included components of clinicians' sizing up what a person's information needs were, accessible and selected information. The environment or space for conversations was another aspect of tailored conversations reflecting the relationship between the intent of the design and use of the hospice and hospital setting. How these spaces were designed and used had both positive and negative impacts on participants' end of life conversations.

Chapter 7: Discussion

Introduction

The focus of the study was to explore what influenced fifteen adult hospice patients in their advance care planning including the clinician communication behaviours that the participants felt facilitated conversations. This chapter offers a critique of the study's findings in the context of the related literature. How the findings add to the advance care planning knowledge base is explored and a contribution to person-centred approaches through a model of *relational advance care planning* is proposed. Recommendations for future policy, education and practice are presented. The strengths and limitations of the study are considered and recommendations for future research are suggested.

Summary of study's findings

The study's first finding reports the influence on the participants' advance care planning activity and conversations of clinicians' considering the personal context of how people daily live with the knowledge of their future death. Living with and talking about dying is an ongoing experience for the participants influenced by their individual circumstances. In the study, contextual factors such as physical symptoms, reminders and the uncertainty of knowing when death would occur, family relationships and friendships influenced the participants advance care planning activity and conversations. A conceptual model that seeks to understand the personal and social context of how people live with dying provides insights into the motivations, intent, content and preferred style of advance care planning conversations and activity.

The second finding illustrates the differences between how people prepare (for themselves) and plan (for others) in their dying. Preparing and planning as terms can be used interchangeably, however, the study identified that whilst motivations (such as concern for others or self) may be similar, the intended outcome between them was different. The participants' intent in preparing for dying was concerned with their own personal preparation

(practical or emotional) whilst the intent for planning for dying was for the benefit of those that the participants cared for (for example. family). Advance care planning (rather than preparing) activity such as choices over preferred place of death and talking about suicide was motivated by the participants' perceptions of the impact and burden on others of their dying. The intended outcome of such decisions was for the benefit of others rather than the participants themselves. For example, the participants' concern of the effect on their family of their dying, time of and after death period illustrated the influence on participants' perceptions of family needs on choices about place of death. In this study, home as the preferred place of death was challenged as the participants reported that the potential effect on their families of them dying in the home space influenced their decisions not to die there. The impact of dying in the home space is less reported in the current literature and this study contributes to that evidence. Considering preparing and planning for dying as separate concepts with different intended outcomes provides insights into what influences for example. specific advance care planning decisions such as preferred place of death and talking about suicide as well as how to therapeutically support people as they prepare and face their own mortality.

The third finding reports how clinician communication behaviours such as empathy (by mutually connecting as people and visible behaviours) and tailored conversations (through accessible and selective honesty) empowered the participants in carrying out conversations. When these communication behaviours were not present, participants reported that they did not gain the information or support that they wanted as they thought or talked about dying. In addition, the design and use of buildings and clinical spaces could influence participants' discussions by for example. provoking or disempowering information giving, facilitating conversations by observing others as well as maintaining the participants' identity as a person (rather than patient) when talking about dying. Whilst the benefits of the use of empathy is an unsurprising finding, the emphasis on highly visible empathy behaviour and a mutual connection between the participants and clinicians serves to position advance care planning conversations as both contemplative spaces between people as well as decisions making ones about care and interventions. Moreover, the value that participants placed upon tailored conversations through selective and accessible honesty is a reminder of the benefit of

interactive conversations, which are geared around the emotional and information needs of each person.

The influence on participants' discussions of the design and use of buildings provided a different insight into how the physical environment influences conversations. Often communication skills education guidance will focus on considerations such as the environment, the layout of a room or a clinicians' spatial position in relation to the patient. There is less research on how the original design and on-going use of a physical space influences conversations through for example. enabling a feeling of wellbeing and safety through observation of others interactions or affirming the identity of the participant as a person rather than a patient. The study highlighted that the physical space in itself can be empowering (or disempowering) in conversations.

Contribution to the evidence base

The study situates advance care planning and conversations within the context of a person's life. It suggests evidence for the complexity of advance care planning, which extends beyond diagnosis, prognosis, death awareness, documents, organisational bureaucracy or a clinician's repertoire of communication skills. The study supports existing observations that current advance care planning practice and policy does not fully reflect the relational aspects of peoples' lives (Robinson 2011) or the complexity of future planning (Pollock and Wilson 2015). This resonates with other commentaries suggesting a reductionist approach to disease and suffering (Hynes 2014; Cassell 2013) or advance care planning (Thomas 2011) has lost sight of other dimensions to illness by focusing on technology (Hynes 2014) or medical expertise alone. For example, caution is advised to consider other aspects than just tools in advance care planning (Borgstrom 2015) with comments that the *'layers of institutional standardisation that frequent care planning'* (Van Mossel et al. 2011:286) prioritise the process or paperwork rather than the person in end of life care.

The study's findings report the value of taking into account of; firstly, the contextual nature of living with, preparing and planning for dying and secondly the impact of relational aspects such as empathy, visible behaviors, mutual connection and the design of an environment on conversations. A model of *relational advance care planning* which contributes to person centered advance care planning is proposed. *Relational advance care planning* offers a person-centered focus to advance care planning and conversations by focusing on the personal context of people's lives and positioning advance care planning to include the complexity of each person's life rather than solely decisions and documentation of future care.

Living with, preparing and planning for dying

The first finding suggests that situating advance care planning solely within a medical prognostication model does not represent the wider, more nuanced understanding of how people live with and plan for their dying. How the participants lived their lives and interacted with those who were important to them illustrated the relevance of the context of their relationships with themselves and others in their advance care planning. Not all the triggers for the participants' advance care planning were situated within a diagnosis or prognosis model of care and conversations.

Advance care planning is considered to be a key part of palliative care. However, commentators have reported that even hospice care has become reductionist, bureaucratic and routinized (Hynes 2014) with further suggestions that the management of dying has become the application of palliative care techniques rather than genuine care (Bradshaw 1996). For example, Frankl (1967) points out that not only should doctors treat the disease but that they should also care about the patient's attitude to the disease. This thesis suggests that participants' advance care planning was influenced by the individual context of how they experienced and lived with the knowledge of their certain death at an uncertain time. The example of Mary who had no record in her hospice notes of her advance care planning despite awareness between her and her nurse of the terminal nature of her cancer illustrated how both she and her nurse were not participating in the established clinical or bureaucratic

procedure for advance care planning. Mary demonstrated how her nurse was participating in a philosophy and attitude of care (with the focus on what matter most to Mary) rather than coordinating and implementing advance care planning as a process with a prescribed outcome (of a document or decision).

The notion of juggling the uncertainty of time of death with the knowledge of its inevitability in incurable disease has been present in the palliative care literature for some time. For example, Glaser and Strauss (1965) suggested that dying is a series of uncertain passages from the status of living to death and that the dying person and those around them may have different perceptions as to how that passage is legitimised (for example. expertise to prognosticate), announced (for example. inform of imminent dying) and co-ordinated (for example. care and communication). The afore mentioned example of Mary, illustrates her own way to legitimise, announce and coordinate her dying. The legitimisation, announcement and coordination of these passages is also seen in examples such as dying trajectories which have been used to help plot changes in health and functional status in incurable disease (see Murray et al. 2010; Lunney and Lynn 2010; Lynn and Adamson 2003), to identify the best timing for palliative care services (Murray and McLoughlin 2012) as well as communication examples which respond to questions about how long a person has to live (Back and Arnold 2006; Kiely et al. 2010).

The findings in the study suggest the individual ways in which the participants navigated the passages of uncertainty of living with dying with their choice and control over the time of their death. Whilst we will all die eventually there are comments that dying has “*blurred into a more disease-estimated view of dying*” (Kellehear 2009:389) and this is seen in a clinical and policy focus on prognostication of the last year of life being the trigger for advance care planning and palliative care. In this study, how the participants personally managed the knowledge of their inevitable death at an uncertain time shows a tension between a prognostication model of dying (with attempts to announce, coordinate, control or clarify the moment of dying through ‘last year of life’ announcements) with participants’ own experiences of living with dying (where the focus was on their control of how they wanted to

live until they died). The living with dying (rather than planning for death) experience appeared to hold more currency with the participants (for example, as they talked about managing their daily lives) and it is therefore unsurprising that they described their own ways to live and talk about dying within the context of their daily lives rather than through a medical gaze.

The perspective that people find their own way to live and manage their daily lives with the knowledge of incurable illness is found elsewhere (for example, Bury 1982; Reeve et al. 2010; Aoun et al. 2015; Hubbard and Forbat 2012). Dying is reported to be a unique individual relationship with death (Wright 2003) with observations that how one interacts with death is dependent upon the context of one's life (Graham et al. 2013; Hirai et al. 2006). The participants' examples of how they individually interacted with dying is found elsewhere with reports of the influence of for example, individual coping mechanisms at the end of life (Ellis 2013b; Kimbell et al. 2015).

The participants also described how physical function, symptoms and perceptions of suffering were a constant reminder to them of the inevitability of their death. This is seen in other literature (for example, Boerner et al. 2013; Deren 2011; Kahana et al. 2011; Pastrana et al. 2008; Ruijs et al. 2013; Monforte-Royo et al. 2012) illustrating the complexity of living with the inevitability of death. Furthermore, there are examples suggesting that living with dying involves finding ways to live daily in the present rather than focus on planning for death (see Halldorsdottir and Hamrin 1996; Landmark and Wahl 2002; Karlsson et al. 2014; Mathie et al. 2012a; Goodman et al. 2011; McTiernan and O'Connell 2015). The participants' descriptions of how they managed their own passage between living and dying indicates how the personal nature of living with dying did influence their advance care planning. For example, all of the participants indicated knowledge of the incurable nature of the illness (i.e. prognosis), but this was not necessarily the trigger for their advance care planning. Catalysts for the participants' advance care planning also came from other sources such as social interactions or encounters with family and friends and it was this personal context as much as diagnosis and prognosis which influenced their advance care planning.

A further example of how the personal context of the participants' lives influenced their advance care planning was the nature of their relationships with their family and friendships. For example, Andrew and Florence gave examples of how family dynamics influenced whom they talked to about their advance care planning. Mandy explained how her decisions were made from the context of future concerns for their children rather than consideration of her own needs. Jacky illustrated how friendships supported her as she lived with, prepared and planned for dying.

The influence of social networks (including friendships and families) at the end of life is described in other literature (see Gage 2014; Lewis et al. 2011; Leonard et al. 2015; Johansson et al. 2012; Horsfall et al. 2012; Abel et al. 2013a), especially in terms of the formal and informal support that they can give (Lewis et al. 2014). The findings of this thesis demonstrate that friendships appeared to be forums for discussion, entertainment, diversion, practical support and reality checks as well as part of individual participants preparing or planning for dying. For example, planning for the future emotional needs of Mandy's young children included thinking which friends could fulfil her nurturing role in the future. Jacky described how she used her friendships to talk about her own dying, supporting her as she emotionally prepared for her death.

The importance of friendships at the end of life is reported elsewhere. Friends and neighbors can provide a small but significant source of support for dying people in the community (Cartwright and Seale 1990; Young et al. 1998). However, the role of friendship is often underreported because dying is primarily seen as a family event as well as difficulties in defining the concept of friendship (De Vries and Johnson 2002). The importance of friendships at the end of life is reported especially in terms of individuals being able to continue to develop themselves through the active choice of friends, independent of family status and roles (De Vries and Blando 2000).

The value that the participants put upon their social networks of friends is supported by the literature which suggest social networks can be measured through the depth (rather than quantity) of connections (Leonard et al. 2015). The study illustrated that friendships supported the participants for example. as they lived with, planned and prepared for dying. If being a person is concerned with having a past, memories, life experiences, family, relationships and a role with oneself (Cassell 1991); then the participants illustrated that their living with, preparing and planning for dying was influenced by their on-going relationships with their friends. Friendships not only could help the participants prepare or plan for dying but also maintained their identity as for example. a friend or colleague rather than a sick patient. For example, Andrew discussed the supportive role of the friend who he shared a pint with and with whom Andrew remained the person he was before his diagnosis. For Jacky; it was her friends who were shoulders to cry on and with whom she had shared past experiences with. Mandy had friends who helped her monitor her symptoms and with whom she built up shared truths about the current and future impact of her illness on her. Mabel and Mary told how friends who they discussed dying with helped them to think about dying in an everyday way. These friendships provided the participants with an on-going dialogue about dying which was not controlled through the medium of a clinical conversation, services or intervention.

The study's finding regarding the role of friendships in advance care planning is seen in some of the emerging discourse concerning social capital as an individual and collective relational resource (Lin et al. 2001). This is also reported in the public health, community engagement and participation models approaches to palliative care (Kellehear 2013; Kellehear 2007; Higginson and Koffman 2005; Stjernsward 2007; Sallnow et al. 2015; Leonard et al. 2015a; Horsfall et al. 2012; Abel et al. 2013) which highlight the influence of social network (and friendship) relational aspects on the experience of dying. If death is both a social and health care experience (Sudnow 1967; Seale 1998; Lawton 2002) then the social elements of dying (including friendships) should not be subsumed by the bio medical focus of palliative care (Lewis et al. 2013). Furthermore, there are criticisms that end of life care is no longer positioned within the social context (Rosenberg 2011), an issue because *"the essential social nature of dying is such that social contexts, social support, and inclusion are imperative for*

quality care at the end of life" (Lewis et al. 2013:93). In the study, the participants explained how their social networks and in particular their family relationships and friendships were part of their living, preparing and planning for dying. Their friendship networks and relationships were forms of support, sources of emotional resilience, forums for discussion and deliberations influencing their living with, preparing and planning for dying.

The particular influence of family dynamics on the participants' end of life decision making was reported in the study and this is seen elsewhere (for example. Singer et al. 1998; Fins et al. 2005; Solomon and Hansen 2015; Broom and Kirby 2013; Hudson and Payne 2011; Grande et al. 2009). In the study the participants' decisions about their preferred place or timing of death was influenced by perceptions of self-perceived burden. Chochinov (2007) and Akazawa et al. (2010) describe similar considerations as does McPherson et al. (2007). This was seen in the study by the personal contextual nature of preparing and planning for dying. Preparing and planning for dying held different meanings and intents for the participants (Russell 2016). The participants described that the intent and decisions in planning for dying was situated within the needs and concerns about being a burden to others and what they needed to do for others (Russell 2016). This is compatible with the literature which reports that advance care planning should be seen within the context of personal relationships (Singer et al. 1998). Understanding better how people live their lives as they die is seen elsewhere (for example. Sudore and Fried 2010) with commentators highlighting the importance of a focus on the context of health, personal relationships, values, independence, in addition to physical symptoms (Prommer 2010; Doukas and McCullough 1991).

One example of the influence of family dynamics on participants' decision making was preferred place of death. The participants reported that their decisions about not dying at home were influenced by their perceptions of the effect it would have on their families. The suggestion that home may not always be the preferred place of death because of the impact on families of dying in the home space is found elsewhere (Pollock 2015; Collier 2013; Collier et al. 2015). This challenges common end of life policy that emphasises home as being the preferred place to die (Gomes et al. 2012). Dying at home has a variety of contextual

considerations. For example, Milligan et al. (2016) point out that most of the literature on home deaths has focused on geographical and statistical variables or specific disease characteristics rather than how the home space is experienced by the dying person and their family. Morris et al. (2015) point out that there are few studies that consider how the home space is affected by dying there. Moreover, there are observations that the focus on the place of death has detracted from how death is experienced (Pollock and Wilson 2015). The experiences of the participants in this study suggest that concerns for their family's experience within the dying period, moment of death and after death motivated planning choices about preferred place of death (not at home).

The study provided examples of participants not wanting children to remember home as the place of death or care of their parent. This is of interest when considering that the study reported that the dying period, moment of death and after death period in the home space (for example, being a burden, caring role of families, lasting memories and practicalities) was a trigger for participants' planning for dying (not at home). The study's findings is seen in other literature which comment upon the relevance of relational aspects of the dying experience in the home space and the challenges of the reorganization of the domestic space to accommodate health technologies (Milligan and Wiles 2010) as well as families witnessing suffering (Gott et al. 2004). Both of these types of experiences were reported by the participants in their planning for dying considerations. For example, both Florence and Jacky explained the reason they did not want to die at home was because of how much equipment might be used to care for them at home. Edward, despite wanting to die at home, did not want his children to witness his dying. The reporting by participants of their concerns over home becoming a clinical space to witness their dying and death is found elsewhere in the literature with examples of the physical and symbolic meaning of the home being constantly negotiated as both a site of care and of social and personal life (Payne et al. 2012).

The study illustrates the influence of the individual social context on choice and decisions about dying at home as well as other considerations such as the more reported accessibility to health care. The importance of understanding the social context of how people die is found

elsewhere in the literature (see Seale 1998; Kellehear 2013). For example, Broom and Kirby (2013) point out that it is necessary to view the dying process situated within the cultural and family environment, arguing that *“the focus on individual preferences and management of disease in palliative care contexts must be augmented with sophisticated and nuanced understandings of the family context”* (Broom and Kirby 2013:499). The study’s findings regarding the home space has further resonance with the literature reporting the effect of dying on families and patients (for example. Gott et al. 2004; Morris et al. 2015; Collier 2013) including how bodily decay affects relationships between the person who is dying and their families (Lawton 1998). Looking after a dying person can be hard as *“dealing with personal hygiene, vomit and faecal matter can be unpleasant”* (McCartney 2014:38). Furthermore, the concerns the participants reported of the effect of their dying on their family and the needs of carers supports a number of other studies (see Candy et al. 2011; Grande et al. 2009; Harding et al. 2012; Morris et al. 2015; Wong and Ussher 2009; Stajduhar and Davies 2005; Proot et al. 2003) which indicate that consideration should be given to how the home space is affected by dying (Morris et al. 2015).

In the study, the participants also described the influence of family relationships and friendships on their living with, preparing and planning for dying conversations. This supports the observation that one size does not fit all for a good death (Russell 2015c) and that a good death is determined by the way in which one is perceived, by self and others (McKechnie et al. 2007). The participants personal approach to how they prepared for their future death supports comments regarding the plurality of good death models (Toscani et al. 2003), ambiguity about what it is (Costello 2006) as well as different definitions between clinicians and patients (Payne et al. 1996; Semino et al. 2014). The beliefs and values of each individual can influence what they understand to be acceptable death (Wright et al. 2006) and the participants experiences support the suggestion that personal contextual factors influenced their perception of a good death or dying as they navigated their passages between living and dying. For example, Liv asserted how she did not want to contemplate her own death whilst also making plans for the needs of her partner’s children. Bobby and Ernest described how they would manage the news of his death.

The individual perception of a good death was reflected by ten participants who expressed a wish to kill themselves through suicide. Suicide was a means to control the uncertainty of the timing of their death and in response to personal motivations such as wanting to be in control, current or anticipated unbearable life and self-perceived burden to those they cared about or society in general. These motivations are compatible with existing literature which consider the context of the why and when of conversations about a wish to die (for example Gather and Vollmann 2014; Morita et al. 2003; Ohnsorge et al. 2014; Battin et al. 2007; Guirimand et al. 2014; Branigan 2015). Whilst expressing a wish to die or hasten death is not unique in the palliative care literature; the study does contribute towards an understanding of the personal motivations for planning for dying through suicide. In other words, recognising that choice is concerned with the how and when not just the where and with whom seen predominately in the advance care planning choice paradigm (Borgstrom and Walter 2015). This highlights a dilemma where the assisted dying movement competes with the palliative care movement for how a good death through choice and control at the end of life are defined and experienced (Russell 2015c). The participants' planning for dying through suicide represented advance care planning conversations, which included a type of autonomy and self-determination about their choice to control the timing of their death.

Person-centred conversations

This thesis reports the influence on the participants' advance care planning conversations of contextual considerations such as choice about discussing dying (rather than place of care or death) and unfamiliarity with the term advance care planning. The participants also described the catalyst influence on their conversations of clinicians' empathy, behaviours, tailored conversations (accessible and selective honesty) as well as the design and use of space.

Autonomy has been identified as a key component of palliative and end of life care provision (Wilson et al. 2014) and in particular in the current English national end of life strategy (Borgstorm and Walter 2015, Borgstorm 2015, Pollock and Wilson 2015). All of the participants reported an awareness of their diagnosis and prognosis but illustrated different expressions of personal autonomy in how they wanted to talk about, prepare or plan for

dying. Some wished to discuss and plan in detail their future dying – others did not. For example, Frances described herself as a ‘project manager’ and wanted to manage and plan in detail her death and funeral. In contrast, Sally took a less planned approach wanting to take things as they happened.

Such differences are challenging as *“information, consent and a desire to make future decisions with autonomy and self-determination is a corner stone of advance care planning”*. (Russell 2015c:161). The study illustrated that personal autonomy was concerned with choice and control over decisions to discuss dying as well as care or treatment choices over for example. place of death or refusal of future interventions. Whilst there is evidence within the literature (particularly in Northern American studies) that choice and control at the end of life are important (Kelner et al. 1993; Singer et al. 1998; Steinhauser et al. 2000), numerous authors have pointed out that open awareness of dying, control and individual autonomy is particularly linked to Anglophone countries (Seale et al. 1997; Borgstrom and Walter 2015; Zimmermann 2007). Furthermore, there is evidence that individualised models of autonomy may be inadequate in palliative care because of the complexity of cultural and social relationships (Wilson et al. 2014). For example, end of life decision making may emerge from interactions between patients, their families and health care team members (Epstein and Street 2011) and there are suggestions that autonomy is not always a solitary action as it is experienced with others (Lavoie et al. 2011). The study highlights that the motivation for the participants preparing and planning for dying was concerned with and related to the responsibilities for or impact on others (i.e. relationships and family dynamics). Personal contextual autonomy considerations such as relationships, friendships and considerations for others (rather than decisions made solely for themselves) influenced the participants in their advance care planning.

The participants’ unfamiliarity with the term advance care planning influenced their advance care planning decisions and conversations. The unfamiliarity illustrates that language has an effect on conversations about dying and consideration should be given to the words and meaning that people use to describe dying. This finding is found elsewhere in the current

evidence base with unfamiliarity with the term advance care planning regularly reported from the general public and clinicians (McLennan et al. 2015; Pollock and Wilson 2015; Michael et al. 2015; Thorevska et al. 2005; Habal et al. 2011; Upadya et al. 2002). It is of interest that the term (not the topic) was unfamiliar to the participants. The term advance care planning did not appear to be part of the familiar language of the participants (unlike dying or end of life), indicating a gap between clinician and participant language to describe preparing or planning for death.

Potter (1987) comments that language is not a neutral expression of an objective world. One consideration is the comment that the language of dying has been professionalised, with words and terms invoking professional social practices, knowledge and power, shaping the meaning and delivery of palliative care (O'Connor and Payne 2006; O'Connor et al. 2010). This suggests that the term advance care planning may not have the same meaning to participants and clinicians. A discrepancy of understanding and use of terms and words is seen elsewhere with arguments that hospice managers descriptions of a good death (different to those of their patients) are related to professional identity and self-worth (Semino et al. 2014) and professions use concepts, phrases, and keywords to provide a framework to help categorize phenomena and to work together (Cohen-Almagor 2000).

Furthermore, the historical development of advance care planning with its focus of planning for incapacity may be a reason why there is a gap between every day and clinical language. Whilst this may seem to be quibbling over semantics, even when the literature regarding advance care planning includes taking into account values, beliefs and preferences, the primary intent remains future decision making rather than the dying experience. Gysels et al. (2013) review of the diversity in defining end of life care make a point also relevant for advance care planning. They argue that definitions evolve over time reflecting changes in meaning as research and practice develops (Gysels et al. 2013). Moreover, (end of life) definitions and concepts represent historical, geographical, institutional, professional, personal and cultural developments (Gysels et al. 2013). It is not unreasonable to suggest that advance care planning has also experienced evolution of its meaning and understanding from

its original narrower clinician based focus on advance decisions and surrogate decision making to wider end of life considerations about living until death. The study's reporting of the lack of familiarity with the term advance care planning raise questions for future research to explore the efficiency of the current terminology as well as consensus between clinicians, patients, carers and the general public of its meaning and practice.

The participants reported the value they put upon and the positive impact it had when conversations were personally tailored to them especially in terms of information (honesty) and empathy. This is found elsewhere with systematic reviews reporting the importance of tailoring honesty, truth telling and information giving to each person in end of life conversations (Clayton et al. 2007; Hancock et al. 2007). This is also supported by other literature for example. person-centered approaches to conversations i.e. focusing on the person (and the context within which they live) rather than solely illness based decisions, information giving and documentation activity.

Person-centered care is not only about knowing what is important to a person but also concerned with the way individuals communicate and make decisions (Sanderson and Lewis 2012). Whilst acknowledging the definitions discourse about the differences and similarities between person and patient-centred care (Barry and Edgman-Levitan 2012; Epstein and Street 2011), patient-centred approaches (for example. a consideration of patients' needs, perspectives, individual experiences; provision of opportunities to patient to participate in their care; and enhancement of the patient-clinician relationship (Epstein and Street 2011), and person-centred care (a focus on "*activities which are based upon what is important to a person from their own perspective*" (Robertson et al. 2005:3), the experiences of the participants in the study supports a person centred approach to conversations. In other words, conversations that not only start with the concerns and needs of the person but also how they like to discuss issues. For example, Bobby and Ernest described how important it was for them in their conversations to be able to think together then decide (rather than vice versa). Liv, explained how the person centred behaviour of her hospice and hospital doctor enabled her to discuss the end of life issues that were important to her because they had

focussed on understanding how and what she wanted to discuss. Alfred valued how his hospice doctor took time to find out how he wanted to talk about his dying.

A focus on health care approaches that prioritise the person rather than the disease is seen in other areas such as health outcome approaches which advocate a 'what matters to you, rather than what's the matter with you' (for example. Bayliss et al. 2014; Barry and Edgman-Levitan 2012; Bisognano 2012). The 'what matters to you' (in topic and conversation style) approach is echoed in the communication findings where tailored honesty and visible empathy empowered conversations because conversations content and pace was geared around what mattered to the participants in terms of how and what they wanted to talk about in terms of living with, preparing or planning for dying. Other studies also argue for the relational rather than document and decision motivation to advance care planning conversations (Briggs 2004) with relational approaches which centrally position the person (rather than the disease) in conversations (Kimmel et al. 2015; Hilgeman et al. 2014).

The tailored conversation findings support the literature that take a perspective to advance care planning conversations by focusing on individual health behavior change rather than solely dying awareness, acceptance or clinician communication expertise. Behavior change theory argues that individuals proceed through a series of steps prior to action, including pre contemplation, contemplation, preparation, action and maintenance (Bandura 1977). There are observations in the advance care planning literature that greater attention should be paid to the individual stages of change and self-efficacy (Pearlman et al. 1995). It is suggested that behavior change theory plays a role in understanding the motivation of individuals to engage in advance care planning (Sudore et al. 2013; Fried et al. 2011). In addition other relational issues such as family based decision making, previous experiences, individual belief systems and personal barriers to care has been shown to influence health behavior change within advance care planning (Fried et al. 2011). This has relevance for the consideration of the timing and content of tailored conversations in terms of recognizing that advance care planning conversations include health behavioral elements such as a contemplative stage (Sudore et al. 2008). Furthermore, there is evidence that that people engage in a wide range

of advance care planning behaviors not just discussions about advance directives (Sudore et al. 2013), with arguments that advance care planning is more than ethical theory, law and advance directives (Fins et al. 2005).

The health behavior change models provide a perspective on advance care planning reflected in the study's findings that advance care planning is not only relational to the context of how people live with, prepare and plan for dying, but also conversations are related to individual health behaviors and not solely acceptance or awareness of dying. For example, Edward discussed how important it was for him to have reflective (contemplative) space with his hospital consultant, not necessarily just to ask questions or make decisions in. Similarly, Liv described the importance of thinking rather than decision making conversations and Ernest and Bobby emphasized the value of thinking then deciding discussions. These examples were on a backdrop of full awareness of the inevitability of death. This echoes the concept of the different stages of for example. pre contemplative and contemplative spaces found in the health behavior change models described by Sudore et al. (2013) and Fried et al (2011).

The study illustrated that clinicians' empathy and honesty communication behaviours were a catalyst for participants being able to gain the information they desired as they lived with, prepared or planned for dying. This supports reported evidence of the benefits of empathy to patients in end of life conversations (for example. Parker et al. 2007; Walczak et al. 2014; Hinton 1980; Barnes et al. 2012; Walczak et al. 2015). Furthermore, honest and accurate information, provided with empathy and understanding and tailored to the individual person is valued in discussions (Clayton et al. 2007; Hancock et al. 2007).

The participants reported that when empathy was both present and visible it facilitated them in their thoughts and conversations by acting as a catalyst for them to gain desired information from their clinicians'. This finding is also seen in existing literature regarding the benefits of the visible expression of empathy to both patients and clinicians'. Whilst there remains a lack of consensus in defining empathy (Hojat et al. 2002; Halpern 2003;

Hemmerdinger et al. 2007; Norfolk et al. 2007), there is robust evidence of its beneficial role (Kelm et al. 2014) and it is considered to be a basic component of all therapeutic relationships (Irving and Dickson 2004; Mercer and Reynolds 2002; Derksen et al. 2013). The participants reported that empathy facilitated them in giving and gaining information that they desired, illustrating that empathy empowers patients to give fuller histories and disclose more to physicians who are attuned to them (Halpern 2012). For example, there were several descriptions from the participants that the visible empathetic behavior of clinicians empowered them to ask questions and discuss more their future dying. There is evidence elsewhere that such empathetic communication enables patient led conversations (Andreassen et al. 2015) and improves health outcomes (Hojat et al. 2011; Decety and Fotopoulou 2014; Finset et al. 2003; Mercer and Reynolds 2002).

The participants reported that visible behaviours acted as a catalyst for deeper and wider conversations about their end of life. This highlights the benefit to the participants of visible expressions of empathy. These included clinicians' visibly showing that they were trying to understand, words used, listening, whole person approach, relationships, being connected, mutual respect, and a person focussed agenda about what is important to the person rather than the clinicians' agenda. This is similar to the reported findings in other literature which describe the empowering nature of empathy in conversations for patients (for example. Derksen et al. 2015; Mercer et al. 2008; Lelorain et al. 2012; Parker et al. 2007). The benefit of visible empathetic behaviours also indicates a line of inquiry (less visible in the palliative care but present in the neurological literature) where actions and visible behaviour stimulate empathy in clinicians (Gleichgerrcht and Decety 2013; Gleichgerrcht and Decety 2014; Gallese 2003; Carr et al. 2003; Singer and Lamm 2009).

The findings from this study adds further detail on the impact of when empathetic behaviours and attitudes are not present. These behaviours inhibited participants wanting to or being unable to discuss or reveal concerns that were important to them about their living with, preparing or planning for dying. It also inhibited information gathering, processing and disclosure of psychological concerns, reduced resilience, and increased inaccurate

assumptions about their future dying. This is seen in other evidence which report similar findings (for example. Wilkinson 1991; Parle et al. 1997; Pollak et al. 2007; Tulsky et al. 2011; Maguire 1985; Jassak 1992). This has implications for conversations where clinicians' behaviours shift the focus away from the person led agenda to that of the clinician and a task based, transfer of information, planning outcome approach to end of life conversations. The transactional nature of such conversations was not valued by the participants who were looking for a relationship, connection and conversation space to contemplate, think or decide.

The participants reported how they valued clinicians connecting to them as individual people (rather than patients or tasks). When this occurred it empowered conversations, enabling participants to gain the information they required as well as feeling more supported. This is reported elsewhere with comments that in order to deliver person-centred care, practitioners need to see the person behind the disease (Edvardsson et al. 2003) and by "*seeing the person behind the patient*" (Clarke et al. 2003:701). The participants reported the positive impact on their conversations of being connected to by a knowledgeable person (i.e. clinician) who was both expert in their role and empathetic. The empowering impact of mutually connecting as people reported by the participants is supported by existing literature. It is seen in examples such as the narrative medicine approaches of reciprocal recognition (Charon 2012) and narrative competence (Charon 2007), as well as the evidence that patients value the combination of an expert clinician who can also connect at a personal level (Decety and Fotopoulou 2014; Friedrichsen et al. 2000; Clayton et al. 2007; Kirk et al. 2004; Steinhauer et al. 2000).

In the study, the participants reported how they wanted to connect to and be viewed by the clinician as a person rather than a patient, illness or task; findings reported elsewhere (Johnston et al. 2015; Chochinov et al. 2015; Chochinov 2007). Furthermore, the benefits to clinicians' of connecting personally is seen in the evidence of increased clinicians' job satisfaction, sense of compassion (Gleichgerrcht and Decety 2013) including the possibility of "*reciprocal healing process, which occurs through meaningful caregiver-patient relationship, and inner self-reflection*" (Kearney et al. 2009:1158). The study suggests there is a value for

the clinician connecting as a person for both themselves and the participant; the knowledgeable clinician who is self-aware of their knowledge boundaries, unafraid of showing their vulnerabilities, willing to empathetically see the person not task as well as engage in mutually respectful behaviour.

The benefits to patients of assessing and titrating information (tailored honesty) to each person individually is already established in the literature (see Parker et al. 2007; Hancock et al. 2007; Clayton et al. 2007; Innes and Payne 2009; Deschepper et al. 2008; Hagerty et al. 2005). The study's findings regarding tailored honesty are supported by the wider body of evidence emphasizing the importance of an individualized, nuanced and titrated approach to end of life and advance care planning conversations (Parker et al. 2007; Hancock et al. 2007; Clayton et al. 2008; Innes and Payne 2009; Friedrichsen et al. 2011; Abdul-Razzak et al. 2014). The role of honesty or disclosure of for example. information, diagnosis or prognosis has had a mixed history with arguments that clinicians have swung between non-disclosure (for paternalistic reasons) and full disclosure (with a focus on accurate information giving, informed consent and autonomy) combined with different cultural approaches and best interest considerations (Field 1998; Sarafis et al. 2013; Gold 2004; Silva et al. 2003; Surbone 2004; Oliffe et al. 2007; Jotkowitz et al. 2006; Rosner 2004). However, the findings from this study emphasised that a focus should be concerned with tailoring content, structure and pace to each individual (for example. Mandy's descriptions of the differences between her oncology and surgical consultant in discussing her diagnosis and prognosis).

There is evidence regarding the benefits of honesty and truth telling in end of life care conversations, often concerned with breaking significant news, prognosis telling and retaining hope in the face of serious illness (Fallowfield et al. 2002; Reich and Mekaoui 2003; Butow et al. 2002; Hancock et al. 2007; Parker et al. 2007; Clayton et al. 2008; Hagerty et al. 2005; Baile et al. 1997). Moreover, there is evidence of a fine balance between telling the truth and nurturing hope (Clayton et al. 2005; Kodish and Post 1995; Porter 1999; Begley and Blackwood 2000; Clayton et al. 2008). The study's findings support the evidence base for tailored

honesty, reinforcing the need for an individual approach as well as emphasizing the consequences of when it does not occur.

Another consideration described by the participants was how the design and use of spaces were a catalyst for their conversations. Participants gave examples of how not only did the design (for example. the hospice building built for their needs) but the use of a building (for example. observing hospice staff interactions with others) influenced their conversations. This could be a positive or negative experience. This highlights a less visible area in the palliative care literature as it is tempting to consider only the teaching of communication techniques and practices as the road to successful conversations (Russell 2015b). There is a dearth of research into physical space and end of life (Collier 2013), with suggestions that the worlds of social geography (therapeutic landscapes), architecture, environmental psychology (hospital design) and social psychiatry (environments designed for care) all provide insights into the relevance of buildings (such as hospices, hospitals and GP surgeries) which provide care (Curtis et al. 2007). The study suggested a relationship between the participants' conversations with the design and use of a clinical space (for example. in hospice or hospital). For example, Mary and Edward described how the local hospital and GP surgery disempowered them in their conversations in contrast to Liv and Anne who reported how the hospice environment facilitated them in talking about dying.

There are observations in the literature that the design of space and place are dependent upon the thoughts and actions of human beings (Kellett and Collins 2009). Bromley (2012) comments that hospital designs reflect the sociocultural, economic, professional, and aesthetic priorities prevalent at a given time as well as assumptions about illness, care and healing, patient hood, and medical providers' roles (Bromley 2012). This was seen in the participants' experiences for example. Mandy described how the hospital ward was a place *"all set up to 'do to you' so it doesn't really give you the confidence you know to speak...to ask...to be"*. Furthermore, there are examples of how hospital design can make it unable to provide a homely, comfortable clinically effective, healing environment at the end of life (Gardiner et al. 2011; Gesler et al. 2004; Brereton et al. 2012). This was illustrated also in the

participants' experiences. For example, Keith reported how the use of light and space in the hospice made it home like rather than like a hospital.

The participants' interviews illustrated that the attitude and behaviour of clinicians within hospice, hospital or GP surgery spaces inhibited or encouraged conversations because they represented an approach to care. For example, Liv commented how the hospice felt to be a space populated by real people who cared and Keith gave examples of how his observations of hospice staff with other patients gave him the confidence to talk about his own dying. Christine described seeing a horse in the hospice grounds giving rides to children and the beneficial impact it had on her. These examples illustrated that the participants were observing the ebb and flow clinicians' movement and behaviour within a physical space and it was this as well as face to face conversations that empowered them to talk about dying.

The benefit of a building being purposively designed for both interventions and interactions is present elsewhere in the literature with observations that buildings can represent a value, philosophy of care or intervention (Collier et al. 2015; Worpole 2009). There are comments that palliative care architecture "*holds the power to revalidate the invalid as a human being*" (Verderber and Refuerzo 2003:4) as the design reinforces personal independence, autonomy and dignity. Furthermore, there are reports that for example, an accessible garden space as part of the physical care environment could serve as a place for privacy or for socialization (Cooper Marcus & Barnes 1999). The revalidation as a person by a building and surroundings was seen in the participants' experiences as well for example, Anne described how being able to sit at the head of a table (as the mother figure) in the garden with her family (rather than by her ward bed) enabled her to talk about dying. Anne's experience of returning to her identity as a mother (rather than a patient) illustrated the influence of the building and space on her conversations.

The focus on the design of clinical space as healing places as well as clinical interventions has been illustrated by policy initiatives such as the Kings Fund *Enhancing the Healing Environment Programme* (The Kings Fund 2013) where clinical interventions and healing are

seen as interacting together. The recent Hospice UK #notdingy campaign in response to television representations of hospices being dingy places resulted in a deluge of responses from hospices across the UK to show that the hospice buildings and spaces were therapeutic by design in terms of physical beauty and therapeutic usefulness. This highlighted the influence of buildings and space enabling conversations (Russell 2015b) because of the intentional therapeutic use of space (for example. clinical activities, privacy and dignity design), therapeutic purpose (for example. restful, peaceful, stimulating and homely social spaces) and designed for formal and informal interactions (between patients, families and clinicians).

Whilst the benefits of the hospice setting cannot be assumed (see Grande 2009; Addington-Hall and O’Callaghan 2009) and evidence that hospices are not always seen as a haven (Swarbrick et al. 2011). Hospices are often seen as therapeutic spaces both in design and use (Worpole 2009). The therapeutic benefit of a designed hospice space was illustrated in the participants’ examples of how the hospice site encouraged their conversations. There were examples of how the space both within and outside the building (for example. grandchildren feeding the birds outside when the consultant visited) was utilised by the participants in order for them to carry out conversations. Worpole (2009) argues that hospices are intentionally designed to be a domestic and clinical space, and this is demonstrated by examples in the interviews of for example. how the hospice dining room (situated within the inpatient unit) became a ‘restaurant’ for visiting friends enabling conversations about dying to occur in a social rather than clinical space. Commentators report that hospice clinical spaces by being homely or domesticated (through the intentional design to look like a home) encourages conversations because the home like setting is more familiar and comfortable for patients and their families (Kellehear et al. 2009; Rasmussen and Edvardsson 2007; Moore et al. 2013; Rigby et al. 2010).The participants’ perception of how the environments influenced their conversations highlights the context of the environment as a clinical, social, therapeutic and meaningful space. For example, complex clinical interventions (for example. blood transfusions and drainage of ascetic fluid) took place within the hospice space whilst a domestic atmosphere was encouraged (for example. family and pet visiting, sitting rooms, personal menus and mementoes). Whilst it might be “*a matter of perspective*” (Bond 2015) it

also illustrated that care and care relationships are located in, shaped by, and shape particular spaces and places (Milligan and Wiles 2010). These influences add to the consideration that advance care planning and conversations should also be seen from within the context of relationships with both clinicians and the environment.

Implications for communication education programmes

A motivation for carrying out the study was to influence the design of future education programmes. Whilst there remains a need for more evidence for specific communication tools, there are comments not to use an ad-hoc approach to end of life decision making (Oczkowski et al 2016). The participants in the study identified a form of structured conversations i.e. a person-centred approach (for example. seeing the person in the patient and being a person in the clinician) that facilitated their conversations. The catalyst elements of the conversation included empathy, visible behaviours, tailored conversations as well mutually connecting as a person. The emphasis on person rather than task orientated relationships is seen elsewhere, where being genuinely interested in each other is seen as important in conversations (Schein 2013). Furthermore there are observations that short term person-centred training interventions are as effective as longer terms ones in increasing patient-centred consultation process including levels of empathy; and patients' perception of providers' attentiveness to them and their concerns as well as their diseases (Dwamena et al. 2012). The study's findings suggest that an education programme that focuses on person centered care rather than communication skills or advance care planning documentation and legal knowledge may offer a different perspective. In other words, it supports understanding more the considering, contemplating and discussing side of conversations rather than a primary focus on the decision, documentation and implementation of advance care planning activity.

Designing and delivering person centred education programmes are not without its challenges. Communication and advance care planning education curricula can be inconsistent (Brown and Bylund 2011; Levinson and Pizzo 2011; Kelley and Kelley 2013;

Levinson et al. 2010). Much of the evidence for end of life communication interventions is lacking (Parry et al. 2014) or not based on robust studies (Walczak et al. 2015) despite appropriate and effective communication strategies being seen as a priority for practice, research and policy (Barnes et al. 2012). Whilst there is evidence that empathetic interactions between clinician and patient can be improved by training programmes (Bonvicini et al. 2009; Kurtz and Cooke 2011) there are also reports that empathy may deteriorate over time (Canale et al. 2012; Kurtz and Cooke 2011) benefiting from a helical rather than sequential linear approach to learning (Kurtz et al. 2005; Silverman et al. 2005). The study's findings suggest the value of a person centred rather than communication skills approach to education programmes.

A model of relational advance care planning

The aim of the study was to explore what influenced hospice patients in their advance care planning conversations and the clinician communication behaviours that they valued in such discussions. From the study's findings a model of relational advance care planning is proposed, contributing to person-centred approaches to advance care planning.

Relational advance care planning (figure 10) is concerned with how the context of a person's life influences their conversations and advance care planning. It starts with the person and their relationships rather than the prognosis, paperwork, process, decisions or diagnosis. The model of *relational advance care planning* suggests that advance care planning activity is influenced by the context of how people live with, prepare and plan for dying, the empathic and tailored communication behaviours of clinicians as well as the design and use of clinical spaces.

Relational advance care planning offers three theoretical contributions to the evidence base. Firstly, it focuses on the context of the person's individual life (what supports and motivates them as they live with dying) rather than solely making decisions in advance through an advance care plan. Moreover, the *relational advance care planning* model adds to the

literature which suggest that the focus on personal autonomy and decision making in advance care planning does not fully reflect the complexity of the experience of dying. The challenge of the home space as the preferred place of death is highlighted. Furthermore, *relational advance care planning* differentiates between preparing and planning for dying providing evidence for different intent.

The second theoretical contribution of *relational advance care planning* is through the communication behaviours of clinicians' and the impact on the participants' conversations. Whilst empathy and tailored conversations are not a new finding in the communication evidence base, the findings in the study reinforces the relational aspect of the patient-clinician relationship especially in terms of a mutual connection as a person, the visible behaviours of clinicians and tailored conversations that do not solely focus on decision making aspects of the end of life. This is found in other areas such as narrative medicine, personhood and dignity concepts, but this study suggests further the importance of relationships within communication, which provides a different lens for communication skills education focusing on 'how' and 'why' people want to communicate rather than the 'what'. Moreover, *relational advance care planning* suggests that the design and use of space is important in conversations (as places of social interactions and clinical interventions), an area less reported within the words of health and social care as well as social and political geography and social psychology.

Finally, *relational advance care planning* illustrates a gap between clinicians and the participants understanding of the professional clinical term of advance care planning. The unfamiliarity with the professional term not only highlights definition confusion but also suggests that the meaning of the term does not represent the participants' experience of living with, preparing or planning for dying. Advance care planning conversations about decisions and documents should be seen as only one aspect of end of life conversations; not the primary focus.

<p align="center">Figure 10: relational advance care planning <i>How the context of my life influences my advance care planning and conversations</i></p>		
<p>Living with dying: <i>How I daily live with dying</i></p>	Talking about dying whilst being unfamiliar with the term 'advance care planning'	
	Living with the knowledge of my inevitable death	A constant companion in my life
		The context of my life
	Managing the uncertainty about the time of my death	My personal strategies
My emotional resilience	The effects of my physical symptoms	
	The impact of my family relationships	
<p>Preparing for dying: <i>What I need to do for myself</i></p>	How I prepare myself for dying	My individual approach
		My mental preparation
		The role of my friendships
		My responsibilities to my family
<p>Planning for dying: <i>What planning and decisions I need to do for others</i></p>	Dying at home: the influence of the impact on my family	During dying
		At the moment of death
		After death
	How the future needs of my adult or younger children influences my planning	Their emotional needs
		Their practical needs
	Why I want to control the time of my death	Self-perceived burden on my family
Thinking about an unbearable life		
Talking about suicide		
<p>Clinicians' communication: <i>Effects on my advance care planning</i></p>	Empathy as a catalyst for my emotional and informational needs	Mutual connection between a clinician and myself
		Visible empathetic behaviours
	Conversations tailored around me	Accessible and selective honesty
		Impact of the environment on my conversations

Implications for policy, education and practice

There is a persistent call to understand more about the benefits and process of advance care planning including approaches to listening to and incorporating patient preferences in end of life care (PeolcPSP 2015; NIHR Dissemination Centre 2015). The study contributes to this call by supporting the evidence for a person-centred approach to advance care planning and conversations which focuses on the context of peoples' lives as they juggle the knowledge of their inevitable death at an uncertain time (rather than solely decision making and documents). The study seeks to understand more about what are the motivations and intents of preparing and planning for dying, supporting the use of empathy and tailored conversations as well as taking greater account of the impact of the design and use of space. Moreover, the study's findings challenge the home space as the consistent preferred place to die, or at least call to investigate more the motivations and experience of dying at home.

The study's findings and proposed contribution to person-centred care through *relational advance care planning* have policy, education and practice implications at individual practitioner, organisational and strategic/policy level.

At an individual level *relational advance care planning* embeds patients' preferences to talk or make decisions about dying in the context of their lives (living with, preparing and planning for dying) rather than solely their diagnosis or prognosis. Relational aspects of people's lives become the core catalyst, motivation and therapeutic intent of conversations and advance care planning rather than solely diagnosis, interventions and prognosis. For individual practitioners this means paying equal weight to a person within their social world as well as being a patient (with biomedical disruption to their body). Moreover, conversations include contemplative as well as decision making aspects. Whilst this may be challenging for clinicians' in terms of advance care planning conversations not solely being concerned with decisions and actions (and for example. valuing the contemplative side of conversations), it does present differently the complex context of how individuals live with, prepare and plan for dying.

At an organisational level *relational advance care planning* moves away from fixed death trajectory outputs such as decisions and documentation about preferred place of death, resuscitation, surrogate decision makers and measuring of clinical activity towards the experience of living with dying. This has implications not only for the design and use of clinical buildings as therapeutic spaces but also for care that equally priorities the individual experience of care (where values and principles of person-centred practice drives care) with the impact of commissioned, budgeted and reported upon clinical interventions. As the drive towards providing needs rather than diagnosis or prognosis based palliative care continues, *relational advance care planning* represents an alternative view of the complexity of the end of life experience.

Finally, at strategic and policy level *relational advance care planning* has implications to how society as a whole defines and operationalises advance care planning. Defining in more detail how people live with, prepare and plan for dying enables a wider, more detailed understanding about what influences advance care planning. In other words, is advance care planning solely concerned with accurate prognostication of the last year of life and subsequent clinical interventions and activity? Or is it concerned with an approach to the end of life where advance care planning contemplation and conversations are part of the everyday life cycle (and subsequent what matters most to each individual) rather than prognosis and diagnosis definitions. This study provides a perspective to move advance care planning away from solely prognosis trajectories, decisions and documents to seeing discussing end of life as an on-going conversation about how people choose to live with their dying and understanding the individual context of their preparing and planning motivations and intents.

Strengths and limitations of carrying out the research

A strength of the study lies in the video narrative interview method. The Flip Video™ was unobtrusive to the participants, easy to use and added to the coding and analysis process. In addition, the qualitative, narrative interview approach facilitated responses from the participants not confined to advance care planning decisions and documents. For example, this revealed unanticipated findings (for example, design and use of space). The study interviewed a small group of people with limited demographic or diagnoses diversity. Whilst qualitative studies are often small (and purposive sampling was planned), a larger, less heterogenic group will enable future research to explore more and generalise the findings. Moreover, it was solely hospice patients and their carers who were recruited which only gave insight from that group of individuals. However, it was a strength to be able to carry out in-depth interviews from people who were at the end of their lives. This enabled the findings to emerge from the participant's thoughts and experiences, with opportunities to explore rich or unforeseen lines of enquiry driven by the participants' narratives. This was valuable for generating the study's model and gaining perspectives on how people approached their future death.

Whilst a strength of the design for the participants was that they only took part in one interview thus lessening the potential burden for them of multiple interviews at the end of their lives; there were limitations in carrying out one off rather than serial or longitudinal interviews. Future research would take this into account in order to aggregate and explore more the findings. However, inquiry at the individual level of the fifteen participants did provide rich data providing a deeper understanding of their thoughts and experiences. A further strength of the study was to be a nurse researcher in practice, contributing at strategic and clinical level from both an evidence base and study's findings level. This enabled a continuous contribution to the care of patients and their families. For example, it enabled a challenging of local clinical commissioning groups of a focus on a 'plan' rather than 'planning' as well as influence end of life and advance care planning across a region through education, practice, policy and documentation.

Future research recommendations

This study represents one interpretation of the phenomena of advance care planning through the eyes of fifteen hospice patients and one nurse researcher. The study raised a number of areas for future research consideration.

Possible areas for research include understanding more of the role of friendships at the end of life because of the rich examples from the participants about how friendships influenced their advance care planning. This is a less described area in the literature and deserves further attention because of the possible influences on how people prepare and plan for dying. The impact on dying at home as both a clinical and social space in preferred place of death decisions is another area for future research considerations. Home as the preferred place of death plays a constant part in end of life policy and as such, how dying at home is experienced requires further interrogation to understand decision making, the dying experience and service planning.

Other areas for future research include investigating more the relationship of the design and use of space on conversations. The study illustrated that the environment could both empower and disempower conversations through its design and use. This deserves further attention to understand the relationships between buildings, clinical staff, patients and their families. A further step includes identifying in more detail the relationship between how people live with, prepare and plan for dying to test if for example, the components of living with the inevitability and uncertainty of timing of future death are generalizable to different settings and populations.

Further investigation in the implementing and evaluating person-centred communication skills education to understand if there is an importance on focusing on the relational aspects of people's lives rather than the tasks of communication would support people and reveal more of their concerns. We also must understand more what the term advance care planning means to clinicians, patients and their families as the study revealed a consistent unfamiliarity

of the term, counter posed with a willingness to talk about dying – this gap between clinical term and participants understanding is both curious and important to investigate more.

Final thoughts

This qualitative study of fifteen hospice patients adds to the knowledge base by suggesting a rationale for a person-centred model of *relational advance care planning*. The model is concerned with understanding the context of how people with an incurable illness live with (the knowledge of inevitable death at an uncertain time), prepare (for themselves) and plan (for others) for their dying; and what communication behaviours (tailored conversations and the environment) supports them as they live with, prepare and plan for dying. *Relational advance care planning* positions the person and the related context of their lives at the centre of advance care planning and conversations rather than the process, prognosis, physical illness or paperwork.

References

- Abbott, K.H, Sago JG, Breen CM, Abernethy AP, Tulsky JA, 2001. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Critical care medicine*, 29(1), pp.197–201.
- Abdul-Razzak, A, You J, Sherifali D, Simon J, Brazil K, 2014. “Conditional candour” and “knowing me”: an interpretive description study on patient preferences for physician behaviours during end-of-life communication. *BMJ open*, 4(10), p.e005653.
- Abel, J, Walter T, Carey LB, Rosenberg J, Noonan K, Horsfall D, Leonard R, Rumbold B, Morris D, 2013b. Circles of care: should community development redefine the practice of palliative care? *BMJ supportive & palliative care*, 3(4), pp.383–8.
- Addington-Hall, J. & McCarthy, M., 1995. Dying from cancer: results of a national population-based investigation. *Palliative medicine*, 9(4), pp.295–305.
- Addington-Hall, J.M., 2007. Introduction. In J. M. Addington-Hall et al., eds. *Research Methods in Palliative Care*. Oxford University Press, pp. 1–12.
- Addington-Hall, J.M. & O’Callaghan, A.C., 2009. A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliative medicine*, 23(3), pp.190–197.
- Adelman, R.D., Greene, M.G. & Ory, M.G., 2000. Communication Between Older Patients and Their Physicians. *Clinics in Geriatric Medicine*, 16(1), pp.1–24.
- Ahluwalia, S.C, Bekelman DB, Huynh AK, Prendergast TJ, Shreve S, Lorenz KA , 2015. Barriers and Strategies to an Iterative Model of Advance Care Planning Communication. *The American journal of hospice & palliative care*, 32(8), pp.817–823.
- Akazawa, T, Akechi T, Morita T, Miyashita M, Sato K, Tsuneto S, Shima Y, Furukawa TA, 2010. Self-perceived burden in terminally ill cancer patients: a categorization of care strategies based on bereaved family members’ perspectives. *Journal of pain and symptom management*, 40(2), pp.224–234.
- Alhojailan, M.I. & Ibrahim, M., 2012. Thematic Analysis : A Critical Review of Its Process and

- Evaluation. *WEI International European Academic Conference Proceedings*, (2011), pp.8–21.
- Al-Jahdali, H.H. Bahroon S, Babgi Y, Tamim H, Al-Ghamdi SM, Al-Sayyari AA., 2009. Advance care planning preferences among dialysis patients and factors influencing their decisions. *Saudi journal of kidney diseases and transplantation : an official publication of the Saudi Center for Organ Transplantation, Saudi Arabia*, 20(2), pp.232–239.
- Almack, K. Cox K, Moghaddam N, Pollock K, Seymour J, 2012. After you: conversations between patients and healthcare professionals in planning for end of life care. *BMC palliative care*, 11, p.15.
- Alonso-Babarro, A. Astray-Mochales J, Domínguez-Berjón F, Gènova-Maleras R, Bruera E, Díaz-Mayordomo A, Centeno Cortes C., 2013. The association between in-patient death, utilization of hospital resources and availability of palliative home care for cancer patients. *Palliative medicine*, 27(1), pp.68–75.
- Amjad, H., Towle, V. & Fried, T., 2014. Association of experience with illness and end-of-life care with advance care planning in older adults. *Journal of the American Geriatrics Society*, 62(7), pp.1304–1309.
- Andreassen, P, Neergaard MA, Brogaard T, Skorstengaard MH, Jensen AB., 2015. Talking about sensitive topics during the advance care planning discussion: A peek into the black box. *Palliative & supportive care*, 13(6), pp.1669–1676.
- Andrews, M., Squire, C. and Tamboukou, M., 2008. *What is narrative research*. London: Sage
- Aoun, S.M. Grande G, Howting D, Deas K, Toye C, Troeung L, Stajduhar K, Ewing G., 2015. The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial. *Plos One*, 10(4), p.e0123012.
- Aoun, S.M. & Nikolaichuk, C., 2014. Improving the evidence base in palliative care to inform practice and policy: thinking outside the box. *Journal of pain and symptom management*, 48(6), pp.1222–1235.
- Appleton, L. & Flynn, M., 2014. Searching for the new normal: exploring the role of language and metaphors in becoming a cancer survivor. *European journal of oncology nursing* :

- the official journal of European Oncology Nursing Society*, 18(4), pp.378–384.
- Aries, P., 1973. *Western attitudes toward death: From the middle ages to the present* 3rd ed., JHU Press.
- Aronson, J., 1994. A pragmatic view of thematic analysis. *The Qualitative Report*, 2(1), p.3.
- Arulkumaran, N., Szawarski, P. & Philips, B.J., 2012. End-of-life care in patients with end-stage renal disease. *Nephrology Dialysis Transplantation*, 27(3), pp.879–881.
- Atkinson, P., Coffey, A. & Delamont, S., 1999. ETHNOGRAPHY Post, Past, and Present. *Journal of Contemporary Ethnography*, 28(5), pp.460–471.
- Auriemma, C.L, Nguyen CA, Bronheim R, Kent S, Nadiger S, Pardo D, Halpern SD., 2014. Stability of end-of-life preferences: a systematic review of the evidence. *JAMA internal medicine*, 174(7), pp.1085–1092.
- Avis, M., 2005. Is there an epistemology for qualitative research? In I. Holloway, ed. *Qualitative Research in Health Care*. Open University Press, pp. 3–16.
- Azoulay, E., 2005. The End-of-Life Family Conference. *American Journal of Respiratory and Critical Care Medicine*, 171(8), pp.803–804.
- Azoulay, E. & Sprung, C.L., 2004. Family-physician interactions in the intensive care unit. *Critical care medicine*, 32(11), pp.2323–2328.
- Babgi, A., 2009. Legal issues in end-of-life care: perspectives from Saudi Arabia and United States. *The American journal of hospice & palliative care*, 26(2), pp.119–127.
- Back, A.L, Arnold RM, Baile WF, Tulsky JA, Fryer-Edwards K., 2005. Approaching difficult communication tasks in oncology. *CA: a cancer journal for clinicians*, 55(November 1950), pp.164–177.
- Back, A.L, Arnold RM, Baile WF, Fryer-Edwards KA, Alexander SC, Barley GE, Gooley TA, Tulsky JA., 2007. Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Archives of internal medicine*, 167(5), pp.453–460.
- Back, A.L. & Arnold, R.M., 2006. Discussing prognosis: “how much do you want to know?”

talking to patients who are prepared for explicit information. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 24(25), pp.4209–4213.

Badger, F, Plumridge G, Hewison A, Shaw KL, Thomas K, Clifford C., 2012. An evaluation of the impact of the Gold Standards Framework on collaboration in end-of-life care in nursing homes. A qualitative and quantitative evaluation. *International journal of nursing studies*, 49(5), pp.586–595.

Bagnasco, A. Pagnucci N, Tolotti A, Rosa F, Torre G, Sasso L., 2014. The role of simulation in developing communication and gestural skills in medical students. *BMC Medical Education*, 14(1), p.106.

Baile, W.F. Lenzi R, Kudelka AP, Maguire P, Novack D, Goldstein M, Myers EG, Bast RC Jr., 1997. Improving physician-patient communication in cancer care: outcome of a workshop for oncologists. *Journal of cancer education : the official journal of the American Association for Cancer Education*, 12(3), pp.166–173.

Baile, W.F. Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP., 2000. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *The oncologist*, 5, pp.302–311.

Bailey, C. Froggatt K, Field D, Krishnasamy M., 2002. The nursing contribution to qualitative research in palliative care 1990-1999: a critical evaluation. *Journal of advanced nursing*, 40(1), pp.48–60.

Bailey, P.H. & Tilley, S., 2002. Storytelling and the interpretation of meaning in qualitative research. *Journal of advanced nursing*, 38(6), pp.574–583.

Bandura, A., 1977. Self-efficacy: toward a unifying theory of behavioral change. *Psychological review*, 84(2), pp.191–215.

Barclay, S. Momen N, Case-Upton S, Kuhn I, Smith E., 2011. End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. *British Journal of General Practice*, 61(582), pp.49–62.

Barclay, S. Froggatt K, Crang C, Mathie E, Handley M, Iliffe S, Manthorpe J, Gage H,

- Goodman C., 2014. Living in uncertain times: trajectories to death in residential care homes. *British Journal of General Practice*, 64(626), pp.e576–e583.
- Bardsley, M., Georghiou, T. & Dixon, J., 2010. Social care and hospital use at the end of life. *London: The Nuffield Trust*.
- Barnes, K. Jones L, Tookman A, King M., 2007. Acceptability of an advance care planning interview schedule: a focus group study. *Palliative Medicine*, 21(1), pp.23–28.
- Barnes, S. Gardiner C, Gott M, Payne S, Chady B, Small N, Seamark D, Halpin D., 2012. Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. *Journal of pain and symptom management*, 44(6), pp.866–879.
- Baron, K., Hodgson, A. & Walshe, C., 2015. Evaluation of an advance care planning education programme for nursing homes: A Longitudinal study. *Nurse education today*, 35(5), pp.689–695.
- Barry, M.J. & Edgman-Levitan, S., 2012. Shared decision making--pinnacle of patient-centered care. *The New England journal of medicine*, 366(9), pp.780–781.
- Battin, M.P, van der Heide A, Ganzini L, van der Wal G, Onwuteaka-Philipsen BD., 2007. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in “vulnerable” groups. *Journal of medical ethics*, 33(10), pp.591–597.
- Bauer, A.W., 2009. [Chances and limitations of patients’ advance decisions at the end of life]. *Wiener medizinische Wochenschrift (1946)*, 159(17-18), pp.431–438.
- Bayliss, E.A, Bonds DE, Boyd CM, Davis MM, Finke B, Fox MH, Glasgow RE, Goodman RA, Heurtin-Roberts S, Lachenmayr S, Lind C, Madigan EA, Meyers DS, Mintz S, Nilsen WJ, Okun S, Ruiz S, Salive ME, Stange KC., 2014. Understanding the context of health for persons with multiple chronic conditions: moving from what is the matter to what matters. *Annals of family medicine*, 12(3), pp.260–269.
- Beard, W.L., Long, R.C. & Geraci, S.A., 2014. Palliative care for the terminal heart failure patient. *Journal of the Mississippi State Medical Association*, 55(1), pp.4–10.

- Beauchamp, T.L. & Childress, J.F., 2001. *Principles of biomedical ethics*, Oxford University Press.
- Becker, E., 1973. *The denial of death*, New York, Free Press.
- Van Beek, K, Woitha K, Ahmed N, Menten J, Jaspers B, Engels Y, Ahmedzai SH, Vissers K, Hasselaar J., 2013. Comparison of legislation, regulations and national health strategies for palliative care in seven European countries (Results from the Europall Research Group): a descriptive study. *BMC health services research*, 13, p.275.
- Beernaert, K, Deliens L, De Vleminck A, Devroey D, Pardon K, Van den Block L, Cohen J., 2014. Early identification of palliative care needs by family physicians: A qualitative study of barriers and facilitators from the perspective of family physicians, community nurses, and patients. *Palliative medicine*, 28(6), pp.480–490.
- Beernaert, K., Deliens L, Vleminck A, Devroey D, Pardon K, Block LV, Cohen J 2015. Is There a Need for Early Palliative Care in Patients With Life-Limiting Illnesses? Interview Study With Patients About Experienced Care Needs From Diagnosis Onward. *The American journal of hospice & palliative care*. p.1049909115577352.
- Beernaert, K, Cohen J, Deliens L, Devroey D, Vanthomme K, Pardon K, Van den Block L., 2013. Referral to palliative care in COPD and other chronic diseases: a population-based study. *Respiratory medicine*, 107(11), pp.1731–1739.
- Begley, A. and Blackwood, B., 2000. Truth-telling versus hope: a dilemma in practice. *International journal of nursing practice*, 6(1), pp.26–31.
- Bélanger, E, Rodríguez C, Groleau D, Légaré F, Macdonald ME, Marchand R., 2014. Initiating decision-making conversations in palliative care: an ethnographic discourse analysis. *BMC Palliative Care*, 13(1), p.63.
- Bell, C.L., Somogyi-Zalud, E. & Masaki, K.H., 2010. Factors associated with congruence between preferred and actual place of death. *Journal of pain and symptom management*, 39(3), pp.591–604.
- Bernacki, R.E. & Block, S.D., 2014. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA internal medicine*, 174(12), pp.1994–2003.

- Bevan, J., Fowler, C. and Russell, S., 2011. Communication skills and Advance Care Planning. In *Advance Care Planning in End of Life Care*. Oxford University Press, pp. 261–276.
- Billings, J.A., 2012. The need for safeguards in advance care planning. *Journal of general internal medicine*, 27(5), pp.595–600.
- Bingley, A.F. Thomas C, Brown J, Reeve J, Payne S., 2008. Developing narrative research in supportive and palliative care: the focus on illness narratives. *Palliative medicine*, 22(5), pp.653–658.
- Bischoff, K.E, Sudore R, Miao Y, Boscardin WJ, Smith AK., 2013. Advance care planning and the quality of end-of-life care in older adults. *Journal of the American Geriatrics Society*, 61(2), pp.209–214.
- Bisognano, M., 2012. “An Ounce of Prevention.” In *IHI International Summit 2012 Keynote*. Keynote Presentation at IHI 13th Annual International Summit on Improving Patient Care in the Office Practice & the Community, March 19, 2012. Available at: <http://www.ihl.org/resources/Pages/AudioandVideo/BisognanoSummit2012Keynote.a.spx>.
- Black, B.S. Fogarty LA, Phillips H, Finucane T, Loreck DJ, Baker A, Blass DM, Rabins PV., 2009. Surrogate Decision Makers’ Understanding of Dementia Patients' Prior Wishes for End-of-Life Care. *Journal of Aging and Health*, 21(4), pp.627–650.
- Black, K. & Reynolds, S.L., 2008. Factors associated with advance care planning among older women in Southwest Florida. *Journal of women & aging*, 20(3-4), pp.249–264.
- BMA Ethics Department, 2009. End-of-life decisions Views of the BMA. , (August).
- Boddy, J, Chenoweth L, McLennan V, Daly M., 2013. It’s just too hard! Australian health care practitioner perspectives on barriers to advance care planning. *Australian journal of primary health*, 19(1), pp.38–45.
- Boerner, K., Carr, D. & Moorman, S., 2013. Family relationships and advance care planning: Do supportive and critical relations encourage or hinder planning? *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 68(2), pp.246–256.
- Boland, J. & Johnson, M.J., 2013. End-of-life care for non-cancer patients. *BMJ supportive &*

palliative care, 3(1), pp.2–3.

Bold, C., 2012. *Using Narrative in Research* 1st ed., SAGE Publications Limited.

Bond, J., 2015. *Spectre*, Eon Productions, Metro-Goldwyn Mayer and Columbia Pictures.

Bonvicini, K.A, Perlin MJ, Bylund CL, Carroll G, Rouse RA, Goldstein MG., 2009. Impact of communication training on physician expression of empathy in patient encounters. *Patient education and counseling*, 75(1), pp.3–10.

Borgstrom, E., 2015. Advance care planning: between tools and relational end-of-life care? *BMJ supportive & palliative care*, 5(3), pp.216–217.

Borgstrom, E., 2014. Planning for death? An ethnographic study of choice and English end-of-life care. PhD Thesis <https://www.repository.cam.ac.uk/handle/1810/245560>.

Borgstrom, E. & Walter, T., 2015. Choice and compassion at the end of life: A critical analysis of recent English policy discourse. *Social Science & Medicine*, 136-137, pp.99–105.

Borreani, C, Miccinesi G, Brunelli C, Lina M., 2004. An increasing number of qualitative research papers in oncology and palliative care: does it mean a thorough development of the methodology of research? *Health and quality of life outcomes*, 2(January), pp.7.

Boud, D., 1985. Problem-based learning in perspective. *Problem-based learning in education for the professions*, pp.13.

Bowling, A., 2000. A good death. Research on dying is scanty. *BMJ (Clinical research ed.)*, 320(7243), pp.1205–1206.

Boyd, K. Mason B, Kendall M, Barclay S, Chinn D, Thomas K, Sheikh A, Murray SA., 2010. Advance care planning for cancer patients in primary care: a feasibility study. *British Journal of General Practice*, 60(581), pp.449–458.

Bradshaw, A., 1996. The Spiritual Dimension Of Hospice: The Secularization Of An Ideal. *Social Science & Medicine*,, 43(3), pp.409–419.

Branigan, M., 2015. Desire for hastened death. *Current Opinion in Supportive and Palliative Care*, 9(1), pp.64–71.

Brannen, J., 2005. Mixed Methods Research: A Discussion Paper. *ESRC National Centre for*

Research Methods, pp.1–30.

Braun, V., Clarke, V. & Terry, G., 2014. Thematic analysis. *Qualitative Research in Clinical and Health Psychology*, 95, p113.

Bravo, G, Arcand M, Blanchette D, Boire-Lavigne AM, Dubois MF, Guay M, Hottin P, Lane J, Lauzon J, Bellemare S., 2012. Promoting advance planning for health care and research among older adults: A randomized controlled trial. *BMC Medical Ethics*, 13(1), pp.1.

Breen, C.M. et al., 2001. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *Journal of general internal medicine*, 16(5), pp.283–289.

Breitbart, W., 2003. Reframing hope: meaning-centered care for patients near the end of life. Interview by Karen S. Heller. *Journal of palliative medicine*, 6(6), pp.979–988.

Brereton, L. Gardiner C, Gott M, Ingleton C, Barnes S, Carroll C., 2012. The hospital environment for end of life care of older adults and their families: an integrative review. *Journal of advanced nursing*, 68(5), pp.981–993.

Briggs, L., 2004. Shifting the focus of advance care planning: using an in-depth interview to build and strengthen relationships. *Journal of palliative medicine*, 7(2), pp.341–349.

Brinkman-Stoppelenburg, A., Rietjens, J.A. & van der Heide, A., 2014. The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*, 28(8), pp.1000–1025.

Bristowe, K. Horsley HL, Shepherd K, Brown H, Carey I, Matthews B, O'Donoghue D, Vinen K, Murtagh FE., 2015. Thinking ahead - the need for early Advance Care Planning for people on haemodialysis: A qualitative interview study. *Palliative Medicine*, 29(5), pp.443–450.

Brohard, C.L., 2012. *The feasibility and efficacy of an autobiographical memory intervention on advance care planning with people with terminal cancer* (Doctoral dissertation, The University of Utah).

Bromley, E., 2012. Building patient-centeredness: Hospital design as an interpretive act. *Social Science & Medicine*, 75(6), pp.1057–1066.

Broom, A. & Kirby, E., 2013. The end of life and the family: hospice patients' views on dying

- as relational. *Sociology of Health & Illness*, 35(4), pp.499–513.
- Brown, M.A. & Stetz, K., 1999. The labor of caregiving: a theoretical model of caregiving during potentially fatal illness. *Qualitative health research*, 9(2), pp.182–197.
- Brown, R. & Bylund, C., 2011. Theoretical models of communication skills training. In D. Kissane et al., eds. *Handbook of communication in oncology and palliative care*. Oxford: Oxford University Press, pp. 27–40.
- Bruera, E. & Hui, D., 2010. Integrating Supportive and Palliative Care in the Trajectory of Cancer: Establishing Goals and Models of Care. *Journal of Clinical Oncology*, 28(25), pp.4013–4017.
- Bryman, A. & Teevan, J.J., 2004. *Social research methods*,
- Buckingham, D., 2009. *Creative visual methods in media research: possibilities, problems and proposals.*, *Sage Visual Methods*, 1, pp.227-246.
- Bulpitt, H. & Martin, P., 2010. Who am I and what am I doing? Becoming a qualitative research interviewer: Helen Bulpitt and Peter J Martin discuss using reflexion to make research processes in studies transparent. *Nurse researcher*, 17(3), pp.7–16.
- Burgess, R., 1984. Methods of field research 2: Interviews as conversations. In *In the Field: An Introduction to Field Research*. Routledge, pp. 101–122.
- Burnard, P., Gill, P., Stewart, K., Treasure, E. and Chadwick, B., 2008. Analysing and presenting qualitative data. *British dental journal*, 204(8), pp.429-432.
- Bury, M., 1982. Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), pp.167–182.
- Butow, P., Dowsett, S., Hagerty, R. and Tattersall, M., 2002. Communicating prognosis to patients with metastatic disease: what do they really want to know?. *Supportive Care in Cancer*, 10(2), pp.161-168.
- Calanzani, N., Higginson, I. & Gomes, B., 2013. Current and future needs for hospice care: an evidence-based report. , *Help the Hospices* (January), pp.1–52.
- Caldwell, P.H., Arthur, H.M. & Demers, C., 2007. Preferences of patients with heart failure

- for prognosis communication. *The Canadian journal of cardiology*, 23(10), pp.791–796.
- Del Canale, S., Louis, D.Z., Maio, V., Wang, X., Rossi, G., Hojat, M. and Gonnella, J.S., 2012. The relationship between physician empathy and disease complications: an empirical study of primary care physicians and their diabetic patients in Parma, Italy. *Academic Medicine*, 87(9), pp.1243-1249.
- Candy, B., Jones, L., Drake, R., Leurent, B. and King, M., 2011. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *Cochrane Database Syst Rev*, 6.
- Cardona-Morrell, M. & Hillman, K., 2015. Development of a tool for defining and identifying the dying patient in hospital: Criteria for Screening and Triaging to Appropriate aLternative care (CriSTAL). *BMJ Supportive & Palliative Care*, 5(1), pp.78–90.
- Carpentier, N. & Van Brussel, L., 2012. On the contingency of death: A discourse-theoretical perspective on the construction of death. *Critical Discourse Studies*, 9(2), pp.99–115.
- Carr, L., Iacoboni, M., Dubeau, M.C., Mazziotta, J.C. and Lenzi, G.L., 2003. Neural mechanisms of empathy in humans: a relay from neural systems for imitation to limbic areas. *Proceedings of the national Academy of Sciences*, 100(9), pp.5497-5502.
- Cartwright, A. and Seale, C., 1990. *The natural history of a survey: an account of the methodological issues encountered in a study of life before death*. King Edward's Hospital Fund for London.
- Cartwright, C., Hughes, M. & Lienert, T., 2012. End-of-life care for gay, lesbian, bisexual and transgender people. *Culture, health & sexuality*, 14(5), pp.537–548.
- Casarett, D.J., Knebel, A. & Helmers, K., 2003. Ethical Challenges of Palliative Care Research. *Journal of Pain and Symptom Management*, 25(4), pp.S3–S5.
- Cassell, E., 2013. *The Nature Of Healing: The Modern Practice Of Medicine*, New York: Oxford University Press.
- Cassell, E., 1991. *The Nature Of Suffering And The Goals Of Medicine*, New York, Oxford: Oxford University Press.
- Chant, S., Jenkinson, T.I.M., Randle, J. and Russell, G., 2002. Communication skills: some

- problems in nursing education and practice. *Journal of clinical nursing*, 11(1), pp.12-21.
- Charles, C., Gafni, A. & Whelan, T., 2000. How to improve communication between doctors and patients. Learning more about the decision making context is important. *BMJ (Clinical research ed.)*, 320(7244), pp.1220–1221.
- Charmaz, K., 1980. *The social reality of death: Death in contemporary America.*, Addison Wesley Publishing Company.
- Charmaz, K (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.
- Charon, R., 2012. The reciprocity of recognition--what medicine exposes about self and other. *The New England journal of medicine*, 367(20), pp.1878–1881.
- Charon, R., 2006. The self-telling body. *Narrative Inquiry*, 1, pp.191–200.
- Charon, R., 2007. What to do with stories: the sciences of narrative medicine. *Canadian family physician Medecin de famille canadien*, 53(8), pp.1265–1267.
- Chavez, V., 2004. A Bridge between Communities: Video-Making Using Principles of Community-Based Participatory Research. *Health Promotion Practice*, 5(4), pp.395–403.
- Cheek, J., Onslow, M. & Cream, A., 2004. Beyond the divide: Comparing and contrasting aspects of qualitative and quantitative research approaches. *International Journal of Speech-Language Pathology*, 6(3), pp.147–152.
- Chen, C.Y., Thorsteinsdottir, B., Cha, S.S., Hanson, G.J., Peterson, S.M., Rahman, P.A., Naessens, J.M. and Takahashi, P.Y., 2015. Health care outcomes and advance care planning in older adults who receive home-based palliative care: A pilot cohort study. *Journal of palliative medicine*, 18(1), pp.38-44.
- Cheng, S.Y., Hu, W.Y., Liu, W.J., Yao, C.A., Chen, C.Y. and Chiu, T.Y., 2008. Good death study of elderly patients with terminal cancer in Taiwan. *Palliative Medicine*, 22(5), pp.626-632
- Chochinov, H.M., 2007. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ (Clinical research ed.)*, 335(7612), pp.184–187.

- Chochinov, H.M., McClement, S., Hack, T., Thompson, G., Dufault, B. and Harlos, M., 2015. Eliciting personhood within clinical practice: effects on patients, families, and health care providers. *Journal of pain and symptom management*, 49(6), pp.974-980.
- Chochinov, H.M., Tataryn, D.J., Wilson, K.G., Enns, M. and Lander, S., 2000. Prognostic awareness and the terminally ill. *Psychosomatics*, 41(6), pp.500-504.
- Christakis, N. a., 2006. Editorial: Advances in Palliative Care Research Methodology. *Palliative Medicine*, 20(8), pp.725–726.
- Christakis, N.A. & Iwashyna, T.J., 2003. The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social science & medicine (1982)*, 57(3), pp.465–475.
- Clancy, M., 2013. Is reflexivity the key to minimising problems of interpretation in phenomenological research? *Nurse researcher*, 20(6), pp.12–16.
- Clark, D., 2002. Between hope and acceptance: the medicalisation of dying. *Bmj*, 324(7342), pp.905–907.
- Clarke, A., Hanson, E.J. & Ross, H., 2003. Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of clinical nursing*, 12(5), pp.697–706.
- Clarke, A. & Seymour, J., 2010. “At the Foot of a Very Long Ladder”: Discussing the End of Life with Older People and Informal Caregivers. *Journal of Pain and Symptom Management*, 40(6), pp.857–869.
- Clarke, V. & Braun, V., 2013. Successful qualitative research: A practical guide for beginners. Sage Publications.
- Clarke, V. & Braun, V., 2013b. Teaching thematic analysis : Overcoming challenges and developing strategies for effective learning . *The psychologist*, 26(2), pp.120-123.
- Clayton, J.M., Butow, P.N., Arnold, R.M. and Tattersall, M.H., 2005. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer*, 103(9), pp.1965-1975.
- Clayton, J.M., Hancock, K.M., Butow, P.N., Tattersall, M.H. and Currow, D.C., 2007. Clinical

practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *The Medical Journal of Australia*, 186(12 Suppl), pp.S77-S79.

Clayton, J.M., Hancock, K., Parker, S., Butow, P.N., Walder, S., Carrick, S., Currow, D., Ghersi, D., Glare, P., Hagerty, R. and Olver, I.N., 2008. Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psycho-Oncology*, 17(7), pp.641-659

Clayton, J.M., Adler, J.L., O'Callaghan, A., Martin, P., Hynson, J., Butow, P.N., Laidsaar-Powell, R.C., Arnold, R.M., Tulskey, J.A. and Back, A.L., 2012. Intensive communication skills teaching for specialist training in palliative medicine: development and evaluation of an experiential workshop. *Journal of palliative medicine*, 15(5), pp.585-591.

Cleary, M., Horsfall, J. & Hayter, M., 2014. Qualitative research: quality results? *Journal of Advanced Nursing*, 70(4), pp.711–713.

Cohen-Almagor, R., 2000. Language and reality at the end of life. *The Journal of law, medicine & ethics : a journal of the American Society of Law, Medicine & Ethics*, 28(3), pp.267–278.

Colbourne, L. & Sque, M., 2005. The culture of cancer and the therapeutic impact of qualitative research interviews. *Journal of Research in Nursing*, 10(5), pp.551–567.

Collier, A., 2013. *Deleuzians of Patient Safety : A Video Reflexive Ethnography of End of Life Care*. PhD Thesis. Flinders University, Adelaide, SA, Australia: opus.lib.uts.edu.au.

Collier, A., Phillips, J.L. & Iedema, R., 2015. The meaning of home at the end of life: A video-reflexive ethnography study. *Palliative medicine*, 29(8), pp.695–702.

Collins, L.G., Parks, S.M. & Winter, L., 2006. The State of Advance Care Planning: One Decade After SUPPORT. *American Journal of Hospice and Palliative Medicine*, 23(5), pp.378–384.

Commission Audit, 1993. *What seems to matter? Communication between Hospitals and Patients*, London.

Conroy, S., Fade, P. & Schiff, R., 2009. CONCISE GUIDANCE TO GOOD PRACTICE A series of

- evidence-based guidelines for clinical management Advance care planning. , (12).
- Cooper Marcus C.C. & Barnes M. (1999) *Healing Gardens: Therapeutic Benefits and Design Recommendations*. John Wiley & Sons, United States of America.
- Cope, D.G., 2014. Methods and meanings: credibility and trustworthiness of qualitative research. *Oncology nursing forum*, 41(1), pp.89–91.
- Coppola, K.M. Bookwala J, Ditto PH, Klepac Lockhart L, Danks JH, Smucker WD, K., 1999. Elderly adults’ preferences for life-sustaining treatments: the role of impairment, prognosis, and pain. *Death studies*, 23(7), pp.617–634.
- Cornally, N., McGlade, C., Weathers, E., Daly, E., Fitzgerald, C., O’Caoimh, R., Coffey, A. and Molloy, D.W., 2015. Evaluating the systematic implementation of the ‘Let Me Decide’ advance care planning programme in long term care through focus groups: staff perspectives. *BMC palliative care*, 14(1), p.1.
- Costello, J., 2006. Dying well: nurses’ experiences of “good and bad” deaths in hospital. *Journal of advanced nursing*, 54(5), pp.594–601.
- Coulehan, J. & Block, M., 2006. *The Medical Interview: Mastering Skills for Clinical Practice* 5th ed., Philadelphia: F.A Davies Co.
- Coventry, P.A., Grande, G.E., Richards, D.A. and Todd, C.J., 2005. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. *Age and ageing*, 34(3), pp.218-227.
- Covinsky, K.E., Eng, C., Lui, L.Y., Sands, L.P. and Yaffe, K., 2003. The last 2 years of life: functional trajectories of frail older people. *Journal of the American Geriatrics Society*, 51(4), pp.492-498.
- Creswell, J.W., 2007. Understanding mixed methods research. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*, 11(2), pp.1–19.
- Creswell, J.W. & Clark, V.L.P., 2010. Designing and Conducting Mixed Methods Designing and Conducting Mixed Methods. , pp.1–2.
- Critical Skills Appraisal Programme (CASP). 2002. 10 Questions to help you make sense of qualitative research: Milton Keynes Primary Care Trust,

- Crossley, M., 2007. Evaluating qualitative research. In J. M. Addington-Hall et al., eds. *Research Methods in Palliative Care*. Open University Press, pp. 181–190.
- Crotty, M., 1998. The foundations of social research. *The foundations of social research*, 802, pp.1–17.
- Curry, L., Schwartz, H.I., Gruman, C. and Blank, K., 2002. Could adequate palliative care obviate assisted suicide?. *Death studies*, 26(9), pp.757-774.
- Curtis, J.R., Engelberg, R.A., Nielsen, E.L., Au, D.H. and Patrick, D.L., 2004. Patient-physician communication about end-of-life care for patients with severe COPD. *European Respiratory Journal*, 24(2), pp.200-205.
- Curtis, S., Gesler, W., Fabian, K., Francis, S. and Priebe, S., 2007. Therapeutic landscapes in hospital design: a qualitative assessment by staff and service users of the design of a new mental health inpatient unit. *Environment and Planning C: Government and Policy*, 25(4), pp.591-610.
- Daly, J., Kellehear, A. & Gliksman, M., 1997. *The public health researcher: A methodological approach.*, Oxford University Press.
- Daly, K., 1997. Re-placing theory in ethnography: A postmodern view. *Qualitative Inquiry*, 3(3), pp.343–365.
- Darbyshire, P., 2011. The business of nurse educators in troubled times. *Nurse Education Today*, 31(8), pp.723–724.
- Davies, N., Maio, L., Vedavanam, K., Manthorpe, J., Vernooij-Dassen, M. and Iliffe, S., 2014. Barriers to the provision of high-quality palliative care for people with dementia in England: a qualitative study of professionals' experiences. *Health & social care in the community*, 22(4), pp.386-394.
- Davison, S.N., 2010. End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease. *Clinical Journal of the American Society of Nephrology*, 5(2), pp.195–204.
- Davison, S.N., Jhangri, G.S., Holley, J.L. and Moss, A.H., 2006. Nephrologists' reported

- preparedness for end-of-life decision-making. *Clinical Journal of the American Society of Nephrology*, 1(6), pp.1256-1262.
- Davison, S.N. & Simpson, C., 2006. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ (Clinical research ed.)*, 333(7574), p.886.
- Dearnley, C., 2005. A reflection on the use of semi-structured interviews. *Nurse researcher*, 13(1), pp.19–28.
- Decety, J. & Fotopoulou, A., 2014. Why empathy has a beneficial impact on others in medicine: unifying theories. *Frontiers in behavioral neuroscience*, 8, p.457.
- Deloitte Centre for Health Solutions, 2014. *Transforming care at the end-of-life Dying well matters Contents*: <http://www2.deloitte.com/uk/en/pages/life-sciences-and-healthcare/articles/transforming-care-at-the-end-of-life.html>.
- Demmen, J., Semino, E., Demjen, Z., Koller, V., Hardie, A., Rayson, P. and Payne, S., 2015. A computer-assisted study of the use of Violence metaphors for cancer and end of life by patients, family carers and health professionals. *International Journal of Corpus Linguistics*, 20(2), pp.205-231.
- Dening, K.H., Jones, L. & Sampson, E.L., 2013. Preferences for end-of-life care: A nominal group study of people with dementia and their family carers. *Palliative Medicine*, 27(5), pp.409–417.
- Denscombe, M., 2007. *The Good Research Guide*, Open University Press.
- Denzin, N. and Lincoln, Y.S., 1994. *Handbook of qualitative research*, Thousands Oaks.
- Denzin, N. & Lincoln, Y.S., 2011. *The SAGE handbook of qualitative research*, SAGE Publications Limited.
- Department of Health, S.S. and P.S., 2010. “Living Matters:Dying Matters”. A Palliative and End of Life Care Strategy for Adults in Northern Ireland | Northern Ireland Supportive & Palliative Care Network. , (March), p.119.
- Deren, S.B., 2011. *Percieved illness burden, a key to understanding advance care planning in adults nearing the end of their life*. The State University of New Jersey.

- Derksen, F., Bensing, J., Kuiper, S., van Meerendonk, M. and Lagro-Janssen, A., 2014. Empathy: what does it mean for GPs? A qualitative study. *Family practice*, p.cmu080.
- Derksen, F., Bensing, J. & Lagro-Janssen, A., 2013a. Effectiveness of empathy in general practice: a systematic review. *British Journal of General Practice*, 63(606), pp.76–84.
- Derry, S.J., Pea, R.D., Barron, B., Engle, R.A., Erickson, F., Goldman, R., Hall, R., Koschmann, T., Lemke, J.L., Sherin, M.G. and Sherin, B.L., 2010. Conducting video research in the learning sciences: Guidance on selection, analysis, technology, and ethics. *The Journal of the Learning Sciences*, 19(1), pp.3-53.
- Deschepper, R., Bernheim, J.L., Vander Stichele, R., Van den Block, L., Michiels, E., Van Der Kelen, G., Mortier, F. and Deliens, L., 2008. Truth-telling at the end of life: A pilot study on the perspective of patients and professional caregivers. *Patient education and counseling*, 71(1), pp.52-56.
- Desharnais, S., Carter, R.E., Hennessy, W., Kurent, J.E. and Carter, C., 2007. Lack of concordance between physician and patient: reports on end-of-life care discussions. *Journal of palliative medicine*, 10(3), pp.728-740.
- Detering, K.M., Hancock, A.D., Reade, M.C. and Silvester, W., 2010. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *Bmj*, 340, p.c1345.
- Detmar, S.B., Muller, M.J., Schornagel, J.H., Wever, L.D. and Aaronson, N.K., 2002. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *Jama*, 288(23), pp.3027-3034.
- DH, 2008. *End of Life Strategy: Promoting High Quality Care for All Adults at the End of Life*, London.
- Dias, L., 2003. Breaking Bad News: A Patient's Perspective. *The Oncologist*, 8, pp.587–596.
- DiCicco-Bloom, B. & Crabtree, B.F., 2006. The qualitative research interview. *Medical Education*, 40(4), pp.314–321.
- Dickson-Swift, V., James, E.L., Kippen, S. and Liamputtong, P., 2007. Doing sensitive research: what challenges do qualitative researchers face?. *Qualitative research*, 7(3),

pp.327-353.

Ditto, P.H., Danks, J.H., Smucker, W.D., Bookwala, J., Coppola, K.M., Dresser, R., Fagerlin, A., Gready, R.M., Houts, R.M., Lockhart, L.K. and Zyzanski, S., 2001. Advance directives as acts of communication: a randomized controlled trial. *Archives of Internal Medicine*, 161(3), pp.421-430.

Ditto, P.H., Smucker, W.D., Danks, J.H., Jacobson, J.A., Houts, R.M., Fagerlin, A., Coppola, K.M. and Gready, R.M., 2003. Stability of older adults' preferences for life-sustaining medical treatment. *Health Psychology*, 22(6), p.605.

Ditto, P.H., Jacobson, J.A., Smucker, W.D., Danks, J.H. and Fagerlin, A., 2006. Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Medical Decision Making*, 26(4), pp.313-322.

Dixon, J., King, D., Matosevic, T., Clark, M. and Knapp, M., 2015. Equity in the provision of palliative care in the UK: review of evidence. eprints.lse.ac.uk

Dixon, J., Matosevic, T. and Knapp, M., 2015. The economic evidence for advance care planning: systematic review of evidence. *Palliative medicine*, 29(10), pp.869-884.

Doody, O. & Noonan, M., 2013. Preparing and conducting interviews to collect data. *Nurse researcher*, 20(5), pp.28–32.

Dooner, M., 2011. *Oxford Essential English Dictionary* M. Dooner et al., eds., Oxford University Press.

Doukas, D.J. & McCullough, L.B., 1991. The values history. The evaluation of the patient's values and advance directives. *The Journal of family practice*, 32(2), pp.145–153.

Dow, L.A., Matsuyama, R.K., Ramakrishnan, V., Kuhn, L., Lamont, E.B., Lyckholm, L. and Smith, T.J., 2010. Paradoxes in advance care planning: the complex relationship of oncology patients, their physicians, and advance medical directives. *Journal of Clinical Oncology*, 28(2), pp.299-304.

Dowsett, S.M., Saul, J.L., Butow, P.N., Dunn, S.M., Boyer, M.J., Findlow, R. and Dunsmore, J., 2000. Communication styles in the cancer consultation: preferences for a patient-centred approach. *Psycho-Oncology*, 9(2), pp.147-156.

- Drought, T.S. & Koenig, B. a, 2002. "Choice" in end-of-life decision making: researching fact or fiction? *The Gerontologist*, 42(lii), pp.114–128.
- DuFon, M.A., 2002. Video recording in ethnographic SLA research: Some issues of validity in data collection. *Language Learning & Technology*, 6(1), pp.40-59.
- Duriau, V.J. & Reger, R.K., 2004. Choice of text analysis software in organization research: Insight from a multi-dimensional scaling (MDS) analysis. *Journées Internationales d'Analyse Statistique des Données Textuelles*, 7, pp.382–389.
- Dwamena, F., Holmes-Rovner, M., Gauden, C.M., Jorgenson, S., Sadigh, G., Sikorskii, A., Lewin, S., Smith, R.C., Coffey, J. and Olomu, A., 2012. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev*, 12.
- Eardley, A., Cribb, A. & Pendleton, L., 1991. Ethical issues in psychosocial research among patients with cancer. *European journal of cancer (Oxford, England : 1990)*, 27(2), pp.166–169.
- Edvardsson, J.D., Sandman, P.-O. & Rasmussen, B.H., 2003. Meanings of giving touch in the care of older patients: becoming a valuable person and professional. *Journal of clinical nursing*, 12(4), pp.601–609.
- Elizabeth, M. et al., 2005. Interactive Health Communication Applications for people with chronic disease. *Cochrane Database of Systematic Reviews*, (4), pp.CD004274–CD004274.
- Elliott, R. & Timulak, L., 2005. Descriptive and interpretive approaches to qualitative research. *A Handbook of Research Methods for Clinical and Health Psychology*, pp.147–157.
- Ellis, J., 2013. Thinking beyond rupture: continuity and relationality in everyday illness and dying experience. *Mortality*, 18(3), pp.251–269.
- Emanuel, E.J. & Emanuel, L.L., 1998. The promise of a good death. *Lancet (London, England)*, 351 Suppl , pp.SII21–9.
- Engward, H. & Davis, G., 2015. Being reflexive in qualitative grounded theory: discussion and

- application of a model of reflexivity. *Journal of advanced nursing*, 71(7), pp.1530–1538.
- Entwistle, VA & Watt, I.S., 2013. Treating patients as persons: A capabilities approach to support delivery of person-centered care. *The American Journal of Bioethics*, 13(8), pp.29–39.
- Epner, D.E. & Baile, W.F., 2014. Difficult conversations: teaching medical oncology trainees communication skills one hour at a time. *Academic medicine : journal of the Association of American Medical Colleges*, 89(4), pp.578–584.
- Epstein, R.M. & Street, R.L., 2011. The value of patient-centered care. *Annals of Family Medicine*, 9(2), pp.100–103.
- Erickson, F., 2011. Uses of video in social research: a brief history. *International Journal of Social Research Methodology*, 14(3), pp.179–189.
- Erickson, F., 2007. Ways of seeing video: Toward a phenomenology of viewing minimally edited footage. *Video research in the learning sciences*, pp.145–155.
- Evans, C.J. et al., 2014. Place and cause of death in centenarians: a population-based observational study in England, 2001 to 2010. *PLoS medicine*, 11(6), p.e1001653.
- Evans, N., Bausewein, C., Menaca, A., Andrew, E.V., Higginson, I.J., Harding, R., Pool, R. and Gysels, M., 2012. A critical review of advance directives in Germany: attitudes, use and healthcare professionals' compliance. *Patient education and counseling*, 87(3), pp.277-288.
- Evans, N., Pasman, H.R., Deeg, D., Onwuteaka-Philipsen, B., Van den Block, L., De Groote, Z., Brearley, S., Caraceni, A., Cohen, J., Francke, A. and Harding, R., 2014. How do general end-of-life treatment goals and values relate to specific treatment preferences? A population-based study. *Palliative medicine*, 28(10), pp.1206-1212.
- Evans, N., Pasman, H.R.W., Payne, S.A., Seymour, J., Pleschberger, S., Deschepper, R. and Onwuteaka-Philipsen, B.D., 2012. Older patients' attitudes towards and experiences of patient-physician end-of-life communication: a secondary analysis of interviews from British, Dutch and Belgian patients. *BMC palliative care*, 11(1), p.1.
- Exley, C., Bamford, C., Hughes, J. and Robinson, L., 2009. Advance Care Planning: An

- opportunity for person-centred care for people living with dementia. *Dementia*, 8(3), pp.419-424.
- Fagerlin, A., Ditto, P.H., Danks, J.H. and Houts, R.M., 2001. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychology*, 20(3), p.166.
- Fagerlin, A. & Schneider, C.E., 2004. Enough. The failure of the living will. *The Hastings Center report*, 34(2), pp.30–42.
- Fallowfield, L., Jenkins, V., Farewell, V., Saul, J., Duffy, A. and Eves, R., 2002. Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *The Lancet*, 359(9307), pp.650-656.
- Fallowfield, L., Lipkin, M. & Hall, A., 1998. Teaching senior oncologists communication skills: results from phase I of a comprehensive longitudinal program in the United Kingdom. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 16(5), pp.1961–1968.
- Fallowfield, L.J., Jenkins, V.A. & Beveridge, H.A., 2002. Truth may hurt but deceit hurts more: communication in palliative care. *Palliative medicine*, 16(4), pp.297–303.
- Farrington, C.J., 2014. Blended e-learning and end of life care in nursing homes: a small-scale mixed-methods case study. *BMC Palliative Care*, 13(1), p.31.
- Feifel, H.E., 1959. *The Meaning of Death*, McGraw-Hill Book Company, Inc./The Blakiston Divis.
- Feinmann, J., 2002. Brushing up on doctors' communication skills. *Lancet (London, England)*, 360(9345), p.1572.
- Fellowes, D., Wilkinson, S. & Moore, P., 2004. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *The Cochrane database of systematic reviews*, (2), p.CD003751.
- Field, D., 1998. Special not different: general practitioners' accounts of their care of dying people. *Social science & medicine (1982)*, 46(9), pp.1111–1120.
- Field, D. & Copp, G., 1999. Communication and awareness about dying in the 1990s. *Palliative medicine*, 13(6), pp.459–468.

- Fielding, S., Fayers, P.M., Loge, J.H., Jordhøy, M.S. and Kaasa, S., 2006. Methods for handling missing data in palliative care research. *Palliative medicine*, 20(8), pp.791-798.
- Fink, A., 1998. *Conducting research literature review: from paper to internet*, Sage Publications, Thousand Oaks.
- Finlay, L., 2003. The reflexive journey:mapping multiple routes. In L. Finlay & B. Gough, eds. *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences*. Blackwell Publishing, pp. 3–20.
- Finlay, L. & Gough, B., 2003a. *Reflexivity: A Practical Guide for Researcers in Health and Social Sciences* L. Finlay & B. Gough, eds., Blackwell Publishing.
- Fins, J.J., Maltby, B.S., Friedmann, E., Greene, M.G., Norris, K., Adelman, R. and Byock, I., 2005. Contracts, covenants and advance care planning: an empirical study of the moral obligations of patient and proxy. *Journal of pain and symptom management*, 29(1), pp.55-68.
- Finset, A., Ekeberg, Ø., Eide, H. and Aspegren, K., 2003. Long term benefits of communication skills training for cancer doctors. *Psycho-Oncology*, 12(7), pp.686-693.
- Firth, S., 2001. Wider horizons: care of the dying in a multicultural society. *National Council for Hospice and Specialist Palliative Care Services.*, 100.
- Firth-Cozens, J. & Field, D., 1991. Fear of death and strategies for coping with patient death among medical trainees. *The British journal of medical psychology*, 64 (Pt 3), pp.263–271.
- Flicke, U., 2014. *An Introduction to Qualitative Research* 5th ed., SAGE Publications Ltd.
- Foucault M, 1973. *The Birth of the Clinic: An Archaeology of Medical Perception*, New York: Pantheon Books.
- Von Fragstein, M., Silverman, J., Cushing, A., Quilligan, S., Salisbury, H. and Wiskin, C., 2008. UK consensus statement on the content of communication curricula in undergraduate medical education. *Medical education*, 42(11), pp.1100-1107.
- Francis, R., 2013. *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*, The Stationary Office, 2013.

- Frank, A., 2013. *The wounded storyteller: Body, illness, and ethics*, Chicago: University of Chicago Press.
- Frank, A.W., 1994. Interrupted stories, interrupted lives. *Second opinion (Park Ridge, Ill.)*, 20(1), pp.11–18.
- Frankl, V., 1967. *Psychotherapy and Existentialism*, New York: Washington Square Press.
- Fried, T.R., Van Ness, P.H., Byers, A.L., Towle, V.R., O'Leary, J.R. and Dubin, J.A., 2007. Changes in preferences for life-sustaining treatment among older persons with advanced illness. *Journal of General Internal Medicine*, 22(4), pp.495-501.
- Fried, T.R., O'Leary, J., Van Ness, P. and Fraenkel, L., 2007. Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment. *Journal of the American Geriatrics Society*, 55(7), pp.1007-1014.
- Fried, T.R., Redding, C.A., Robbins, M.L., Paiva, A., O'Leary, J.R. and Iannone, L., 2010. Stages of change for the component behaviors of advance care planning. *Journal of the American Geriatrics Society*, 58(12), pp.2329-2336.
- Fried, T.R., Bullock, K., Iannone, L. and O'Leary, J.R., 2009. Understanding advance care planning as a process of health behavior change. *Journal of the American Geriatrics Society*, 57(9), pp.1547-1555.
- Friedrichsen, M., Lindholm, A. & Milberg, A., 2011. Experiences of truth disclosure in terminally ill cancer patients in palliative home care. *Palliative & supportive care*, 9(2), pp.173–180.
- Friedrichsen, M.J., Strang, P.M. & Carlsson, M.E., 2000. Breaking bad news in the transition from curative to palliative cancer care--patient's view of the doctor giving the information. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, 8(6), pp.472–478.
- Fritch, J., Petronio, S., Helft, P.R. and Torke, A., 2013. Making decisions for hospitalized older adults: ethical factors considered by family surrogates. *The Journal of clinical ethics*, 24(2), p.125.
- Froggatt, K., Vaughan, S., Bernard, C. and Wild, D., 2009. Advance care planning in care

- homes for older people: an English perspective. *Palliative Medicine*, 23(4), pp.332-338.
- Furer, P. & Walker, J.R., 2008. Death Anxiety: A Cognitive-Behavioral Approach. *Journal of Cognitive Psychotherapy*, 22(2), pp.167–182.
- Gadoud, A., Kane, E., Macleod, U., Ansell, P., Oliver, S. and Johnson, M., 2014. Palliative care among heart failure patients in primary care: a comparison to cancer patients using English family practice data. *PloS one*, 9(11), p.e113188.
- Gage, E., 2014. Social networks of experientially similar others: Formation, activation, and consequences of network ties on the health care experience. *Social Science & Medicine*, 95, pp.43–51.
- Gallese, V., 2003. The roots of empathy: the shared manifold hypothesis and the neural basis of intersubjectivity. *Psychopathology*, 36(4), pp.171–180.
- Gardiner, C., Ward, S., Gott, M. and Ingleton, C., 2013. Economic impact of hospitalisations among patients in the last year of life: An observational study. *Palliative medicine*, p.0269216313517284.
- Gardiner, C., Brereton, L., Gott, M., Ingleton, C. and Barnes, S., 2011. Exploring health professionals' views regarding the optimum physical environment for palliative and end of life care in the acute hospital setting: a qualitative study. *BMJ supportive & palliative care*, 1(2), pp.162-166.
- Gardiner, C., Brereton, L., Frey, R., Wilkinson-Meyers, L. and Gott, M., 2014. Exploring the financial impact of caring for family members receiving palliative and end-of-life care: a systematic review of the literature. *Palliative medicine*, 28(5), pp.375-390.
- Gates, M.F., Schins, I. & Smith, A.S., 1996. Applying advanced directives regulations in home care agencies. *Home healthcare nurse*, 14(2), pp.127–133.
- Gather, J. & Vollmann, J., 2014. [Physician-assisted suicide and advance care planning--ethical considerations on the autonomy of dementia patients at their end of life]. *Psychiatrische Praxis*, 41(7), pp.385–391.
- General Medical Council, 2010. End of life care: Guidance. GMC.
- George, R. & Harlow, T., 2011. Advance care planning:politically correct, but ethically

- sound? In K. Thomas & B. Lobo, eds. *Advance Care Planning in End of Life Care*. Oxford University Press, pp. 55–72.
- Gesler, W., Bell, M., Curtis, S., Hubbard, P. and Francis, S., 2004. Therapy by design: evaluating the UK hospital building program. *Health & place*, 10(2), pp.117-128.
- Gillett, G. & Chamberlain, J., 2013. The clinician's dilemma: two dimensions of ethical care. *International journal of law and psychiatry*, 36(5-6), pp.454–460.
- Gillick, M.R., 2010. The challenge of applying advance directives in hospital practice. *Hospital practice (1995)*, 38(3), pp.45–51.
- Girgis, A., Sanson-Fisher, R.W. & Schofield, M.J., 1999. Is there consensus between breast cancer patients and providers on guidelines for breaking bad news? *Behavioral medicine (Washington, D.C.)*, 25(2), pp.69–77.
- Glaser, B.G., & Strauss, A.L., 1974. *Time for Dying*, AldineTransaction.
- Glaser, B. G., & Strauss, A.L., 1966. *Awareness of dying*, Transaction Publishers.
- Glaser, B. G., & Strauss, A.L., 1965. Temporal aspects of dying as a non-scheduled status passage. *American Journal of Sociology*, pp.48–59.
- Gleichgerrcht, E. & Decety, J., 2013. Empathy in clinical practice: how individual dispositions, gender, and experience moderate empathic concern, burnout, and emotional distress in physicians. *PloS one*, 8(4), p.e61526.
- Gleichgerrcht, E. & Decety, J., 2014. The relationship between different facets of empathy, pain perception and compassion fatigue among physicians. *Frontiers in behavioral neuroscience*, 8, p.243.
- Gold, M., 2004. Is honesty always the best policy? Ethical aspects of truth telling. *Internal medicine journal*, 34(9-10), pp.578–580.
- Goldsteen, M., Houtepen, R., Proot, I.M., Abu-Saad, H.H., Spreeuwenberg, C. and Widdershoven, G., 2006. What is a good death? Terminally ill patients dealing with normative expectations around death and dying. *Patient education and counseling*, 64(1), pp.378-386.

- Gomes, B., Higginson, I.J. and McCrone, P., 2009. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *The Cochrane Library*.
- Gomes, B., Calanzani, N., Koffman, J. and Higginson, I.J., 2015. Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC medicine*, 13(1), p.1.
- Gomes, B., Higginson, I.J., Calanzani, N., Cohen, J., Deliens, L., Daveson, B.A., Bechinger-English, D., Bausewein, C., Ferreira, P.L., Toscani, F. and Meñaca, A., 2012. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology*, p.mdr602.
- Gomes, B., McCrone, P., Hall, S., Koffman, J. and Higginson, I.J., 2010. Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. *BMC cancer*, 10(1), p.1.
- Gomes, B., Calanzani, N. & Higginson, I., 2011. Local preferences and place of death in regions within England 2010. *Cicely Saunders International*, (August).
- Gomes, B. & Higginson, I.J., 2006. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ (Clinical research ed.)*, 332(7540), pp.515–521.
- Gómez-Batiste, X., Martínez-Muñoz, M., Blay, C., Amblàs, J., Vila, L., Costa, X., Espauella, J., Espinosa, J., Constante, C. and Mitchell, G.K., 2014. Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: a cross-sectional study. *Palliative medicine*, 28(4), pp.302-311.
- Goodman, C., Froggatt, K., Amador, S., Mathie, E. and Mayrhofer, A., 2015. End of life care interventions for people with dementia in care homes: addressing uncertainty within a framework for service delivery and evaluation. *BMC palliative care*, 14(1), p.1.
- Goodman, C., 2014. *Evaluation of the End of Life Care Train the Trainer (TTT) Education Model*, University of Hertfordshire, Hatfield.
- Goodman, C., Mathie, E., Cowe, M., Mendoza, A., Westwood, D., Munday, D., Wilson, P.M.,

- Crang, C., Froggatt, K., Iliffe, S. and Manthorpe, J., 2011. Talking about living and dying with the oldest old: public involvement in a study on end of life care in care homes. *BMC palliative care*, 10(1), p.20.
- Goodman, C., Froggatt, K. & Mathie, E., 2012. *End of Life Care. Methods Review 12*: http://www2.lse.ac.uk/LSEHealthAndSocialCare/pdf/SSCR-Methods-Review_12_web.pdf.
- Gott, M., Gardiner, C., Small, N., Payne, S., Seamark, D., Barnes, S., Halpin, D. and Ruse, C., 2009. Barriers to advance care planning in chronic obstructive pulmonary disease. *Palliative Medicine*, 23(7), pp.642-648.
- Gott, M., Allen, R., Moeke-Maxwell, T., Gardiner, C. and Robinson, J., 2015. 'No matter what the cost': A qualitative study of the financial costs faced by family and whānau caregivers within a palliative care context. *Palliative medicine*, 29(6), pp.518-528.
- Gott, M., Seymour, J., Bellamy, G., Clark, D. and Ahmedzai, S., 2004. Older people's views about home as a place of care at the end of life. *Palliative medicine*, 18(5), pp.460-467.
- Gough, B., 2003. Deconstructing reflexivity. In L. Finlay & B. Gough, eds. *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences*. Blackwell Publishing, pp. 21–36.
- Graham, N., Gwyther, L., Tiso, T. and Harding, R., 2013. Traditional Healers' Views of the Required Processes for a "Good Death" Among Xhosa Patients Pre-and Post-Death. *Journal of pain and symptom management*, 46(3), pp.386-394.
- Gramling, R., Stanek, S., Ladwig, S., Gajary-Coots, E., Cimino, J., Anderson, W., Norton, S.A. and Group, A.R.C.W., 2015. Feeling Heard and Understood: A Patient-Reported Quality Measure for the Inpatient Palliative Care Setting. *Journal of pain and symptom management*. 51(2), pp. 150–154.
- Grande, G., 2009. Palliative care in hospice and hospital: time to put the spotlight on neglected areas of research. *Palliative medicine*, 23(3), pp.187–189.
- Grande, G., Stajduhar, K., Aoun, S., Toye, C., Funk, L., Addington-Hall, J., Payne, S. and Todd, C., 2009. Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine*, 23(4), pp.339-344.

- Gready, R.M., Ditto, P.H., Danks, J.H., Coppola, K.M., Lockhart, L.K. and Smucker, W.D., 2000. Actual and perceived stability of preferences for life-sustaining treatment. *Journal of Clinical Ethics*, 11(4), pp.334-346.
- Green, M.J. & Levi, B.H., 2012. The era of “e”: the use of new technologies in advance care planning. *Nursing outlook*, 60(6), pp.376–383.e2.
- Greenhalgh, T., Vijayaraghavan, S., Wherton, J., Shaw, S., Byrne, E., Campbell-Richards, D., Bhattacharya, S., Hanson, P., Ramoutar, S., Gutteridge, C. and Hodkinson, I., 2016. Virtual online consultations: advantages and limitations (VOCAL) study. *BMJ open*, 6(1), p.e009388.
- Grimaldo, D.A., Wiener-Kronish, J.P., Jurson, T., Shaughnessy, T.E., Curtis, J.R. and Liu, L.L., 2001. A randomized, controlled trial of advance care planning discussions during preoperative evaluations. *The Journal of the American Society of Anesthesiologists*, 95(1), pp.43-50.
- Grimes, C., 2015. personal communication, January 22nd 2015
- Grundstein-Amado, R., 1992. Narrative inquiry: a method for eliciting advance health care directives. *Humane medicine*, 8(1), pp.31–39.
- Guba, FOR EXAMPLE. & Lincoln, Y.S., 1994. Competing Paradigms in Qualitative Research. *Handbook of qualitative research*, pp.pp. 105–117.
- Guba, FOR EXAMPLE. & Lincoln, Y.S., 1985. Establishing trustworthiness. *Naturalistic inquiry*, 289, p.331.
- Guest, G., Bunce, A. and Johnson, L., 2006. How many interviews are enough? An experiment with data saturation and variability. *Field methods*, 18(1), pp.59-82.
- Guest, G., MacQueen, K. & Namey, E., 2012. Introduction to applied thematic analysis. *Applied Thematic Analysis*, pp.3–20.
- Guirimand, F., Dubois, E., Laporte, L., Richard, J.F. and Leboul, D., 2014. Death wishes and explicit requests for euthanasia in a palliative care hospital: an analysis of patients files. *BMC palliative care*, 13(1), p.53.

- Gysels M and Higginson IJ, 2007. Systematic Reviews. In Addington-Hall JM and Bruera E and Higginson IJ and Payne S, ed. *Research Methods in Palliative Care*. Oxford University Press, pp. 115–136.
- Gysels, M., Evans, N., Meñaca, A., Higginson, I.J., Harding, R. and Pool, R., 2013. Diversity in defining end of life care: an obstacle or the way forward?. *PloS one*, 8(7), p.e68002.
- Gysels, M., Evans, C.J., Lewis, P., Speck, P., Benalia, H., Preston, N.J., Grande, G.E., Short, V., Owen-Jones, E., Todd, C.J. and Higginson, I.J., 2013. MORECare research methods guidance development: recommendations for ethical issues in palliative and end-of-life care research. *Palliative medicine*, 27(10), pp.908-917.
- Gysels, M., Shipman, C. & Higginson, I.J., 2008. Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Medical Ethics*, 9(1), p.7.
- Habal, M.V., Micevski, V., Greenwood, S., Delgado, D.H. and Ross, H.J., 2011. How aware of advanced care directives are heart failure patients, and are they using them?. *Canadian Journal of Cardiology*, 27(3), pp.376-381.
- Hagen, N.A., Howlett, J., Sharma, N.C., Biondo, P., Holroyd-Leduc, J., Fassbender, K. and Simon, J., 2015. Advance care planning: identifying system-specific barriers and facilitators. *Current Oncology*, 22(4), p.e237.
- Hagerty, R.G., Butow, P.N., Ellis, P.M., Dimitry, S. and Tattersall, M.H.N., 2005. Communicating prognosis in cancer care: a systematic review of the literature. *Annals of Oncology*, 16(7), pp.1005-1053.
- Hagerty, R.G. et al., 2005. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 23(6), pp.1278–1288.
- Halldorsdottir, S. & Hamrin, E., 1996. Experiencing existential changes: the lived experience of having cancer. *Cancer nursing*, 19(1), pp.29–36.
- Hallenbeck, J., 2003. *Palliative care perspectives*, Oxford University Press.
- Halpern, J., 2012. Gathering the patient's story and clinical empathy. *The Permanente*

journal, 16(1), pp.52–54.

Halpern, J., 2003. What is clinical empathy? *Journal of general internal medicine*, 18(8), pp.670–674.

Hamel, M.B., Davis, R.B., Teno, J.M., Knaus, W.A., Lynn, J., Harrell, F., Galanos, A.N., Wu, A.W. and Phillips, R.S., 1999. Older age, aggressiveness of care, and survival for seriously ill, hospitalized adults. *Annals of Internal Medicine*, 131(10), pp.721-728.

Hammersley, M., 2007. The issue of quality in qualitative research. *International Journal of Research & Method in Education*, 30(3), pp.287–305.

Hancock, K., Clayton, J.M., Parker, S.M., Butow, P.N., Carrick, S., Currow, D., Ghersi, D., Glare, P., Hagerty, R. and Tattersall, M.H., 2007. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliative Medicine*, 21(6), pp.507-517.

Hanratty, B., Lowson, E., Grande, G., Payne, S., Addington-Hall, J., Valtorta, N. and Seymour, J., 2014. Transitions at the end of life for older adults—patient, carer and professional perspectives: a mixed-methods study.

Hardie Boys, M., 1996. *Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights)*. Wellington: Health and Disability Commission, p.12.

Harding, R., Epiphaniou, E., Hamilton, D., Bridger, S., Robinson, V., George, R., Beynon, T. and Higginson, I.J., 2012. What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. *Supportive Care in Cancer*, 20(9), pp.1975-1982.

Harding, S.R., Flannelly, K.J., Weaver, A.J. and Costa, K.G., 2005. The influence of religion on death anxiety and death acceptance. *Mental Health, Religion & Culture*, 8(4), pp.253-261.

Hare, J., Pratt, C. & Nelson, C., 1992. Agreement between patients and their self-selected surrogates on difficult medical decisions. *Archives of internal medicine*, 152(5), pp.1049–1054.

Harrington, K.J., 2012. The use of metaphor in discourse about cancer: a review of the

- literature. *Clinical journal of oncology nursing*, 16(4), pp.408–412.
- Harris, D., 2007. Forget me not: palliative care for people with dementia. *Postgraduate Medical Journal*, 83(980), pp.362–366.
- Harris, J., 1985. *The Value of Life* 1st ed., London: Routledge and Kegan Paul.
- Hart C, 1998. *Doing a literature review: Releasing the social science research imagination*. Sage Publications, ed.,
- Hawkins, N.A., Ditto, P.H., Danks, J.H. and Smucker, W.D., 2005. Micromanaging death: process preferences, values, and goals in end-of-life medical decision making. *The Gerontologist*, 45(1), pp.107-117.
- Hawley, P.H., 2014. The Bow Tie Model of 21st Century Palliative Care. *Journal of Pain and Symptom Management*, 47(1), pp.e2–e5.
- Health Canada, 2007. Canadian Strategy on Palliative and End-of-Life Care: Final Report. Health Canada.
- Heath, C. & Hindmarsh, J., 2002. Analyzing interaction: Video, ethnography and situated conduct. In T. May, ed. *Qualitative research in action*. London: Sage, pp. 99–121.
- Heaven, C., Clegg, J. & Maguire, P., 2006. Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. *Patient education and counseling*, 60(3), pp.313–325.
- Hebert, R.S., Schulz, R., Copeland, V.C. and Arnold, R.M., 2009. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *Journal of pain and symptom management*, 37(1), pp.3-12.
- Heidegger, M., 1962. Being and time, trans. J. Macquarrie and E. Robinson.
- Helgesson, G., Ludvigsson, J. & Gustafsson Stolt, U., 2005. How to handle informed consent in longitudinal studies when participants have a limited understanding of the study. *Journal of medical ethics*, 31(11), pp.670–673.
- Hemmerdinger, J.M., Stoddart, S.D.R. & Lilford, R.J., 2007. A systematic review of tests of empathy in medicine. *BMC medical education*, 7, p.24.

- Henriksen, N. & Hansen, H.P., 2009. Marked bodies and selves: a literary-semiotic perspective on breast cancer and identity. *Communication & medicine*, 6(2), pp.143–152.
- Heyland, D.K., 2006. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal*, 174(5), pp.627–633.
- Hicks, F., 2012. Avoiding emergency stops in end of life care. *Clinical Medicine*, 12(2), pp.106–7.
- Higginson, I.J., Evans, C.J., Grande, G., Preston, N., Morgan, M., McCrone, P., Lewis, P., Fayers, P., Harding, R., Hotopf, M. and Murray, S.A., 2013. Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC medicine*, 11(1), p.1.
- Higginson, I.J. & Addington-Hall, J.M., 1999. Palliative care needs to be provided on basis of need rather than diagnosis. *BMJ (Clinical research ed.)*, 318(7176), p.123.
- Higginson, I.J. & Koffman, J., 2005. Public health and palliative care. *Clinics in geriatric medicine*, 21(1), pp.45–55, viii.
- Higginson, I.J. & Sen-Gupta, G.J., 2000. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *Journal of palliative medicine*, 3(3), pp.287–300.
- Hildebrand, L., 2012. Conversations About Care Wishes Can Ease Acute , Stressful Situations. (October), pp.202–204.
- Hilgeman, M.M., Allen, R.S., Snow, A.L., Durkin, D.W., DeCoster, J. and Burgio, L., 2014. Preserving Identity and Planning for Advance Care (PIPAC): Preliminary outcomes from a patient-centered intervention for individuals with mild dementia. *Aging & mental health*, 18(4), pp.411-424.
- Hinton, J., 1980. Whom do dying patients tell? *British medical journal*, 281(6251), pp.1328–30.

- Hirai, K., Miyashita, M., Morita, T., Sanjo, M. and Uchitomi, Y., 2006. Good death in Japanese cancer care: a qualitative study. *Journal of pain and symptom management*, 31(2), pp.140-147.
- HM Government, 1998a. *Data Protection Act 1998*, The Stationary Office
- HM Government, 1998b. *Human Rights Act*, The Stationary Office.
- Hockley, J., Watson, J., Oxenham, D. and Murray, S.A., 2010. The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation. *Palliative Medicine* 24 (8), pp. 828-38.
- Hojat, M., Gonnella, J.S., Nasca, T.J., Mangione, S., Vergare, M. and Magee, M., 2002. Physician empathy: definition, components, measurement, and relationship to gender and specialty. *American Journal of Psychiatry*.159, pp.1563-1569.
- Hojat, M., Louis, D.Z., Markham, F.W., Wender, R., Rabinowitz, C. and Gonnella, J.S., 2011. Physicians' empathy and clinical outcomes for diabetic patients. *Academic Medicine*, 86(3), pp.359-364.
- Holdsworth, L.M., 2015. Bereaved carers' accounts of the end of life and the role of care providers in a "good death": A qualitative study. *Palliative Medicine*, 29(9), pp.834–841.
- Holley, J.L., 2012. Advance Care Planning in CKD/ESRD: An Evolving Process. *Clinical Journal of the American Society of Nephrology*, 7(6), pp.1033–1038.
- Holley, J.L., 2005. Palliative care in end-stage renal disease: focus on advance care planning, hospice referral, and bereavement. *Seminars in dialysis*, 18(2), pp.154–156.
- Holloway, I. & Freshwater, D., 2007. Vulnerable story telling: narrative research in nursing. *Journal of Research in Nursing*, 12(6), pp.703–711.
- Holloway, I. & Wheeler, S., 1996. *Qualitative Research for Nurses*, Blackwell Science.
- Hollway, W. & Jefferson, T., 2007. *Doing qualitative research differently: Free association, narrative and the interview method*, SAGE Publications Limited.
- Hollway, W & Jefferson, T (2008). The free association narrative interview method. In:

Given, Lisa M. ed. *The SAGE Encyclopedia of Qualitative Research Methods*. Sevenoaks, California: Sage, pp. 296–315

- Hopkinson, J. & Hallett, C., 2002. Good death? An exploration of newly qualified nurses' understanding of good death. *International journal of palliative nursing*, 8(11), pp.532–539.
- Hopp F.P, 2000. Preferences for Surrogate Decision Makers, Informal Communication, and Advance Directives Among Community-Dwelling Elders Results From a National Study. *The Gerontologist*, 40(4), pp.449–457.
- Hopp F.P, Duffy S.A, 2000. Racial Variations in End-of-Life Care. *Journal of the American Geriatrics Society*, 48(6), pp.658–663.
- Hopper, M.J. & Quiñones, S., 2012. A Hunch Without a Sound: Co-Constructing Meanings of Nonverbal and Verbal Interactions in Video Data. *International Journal of Qualitative Methods*, 11(5), pp.547–572
- Horne, G., Seymour, J. & Payne, S., 2009. Advance care planning: evidence and implications for practice. *End of Life Care*, 3(9), pp.58–64.
- Horne, G., Seymour, J. & Shepherd, K., 2006. Advance care planning for patients with inoperable lung cancer. *International journal of palliative nursing*, 12(4), pp.172–178.
- Horsburgh, D., 2003. Evaluation of qualitative research. *Journal of Clinical Nursing*, 12(2), pp.307–312.
- Horsfall, D., Noonan, K. & Leonard, R., 2012. Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities. , 21(4), pp.373–382.
- Houben, C.H., Spruit, M.A., Wouters, E.F. and Janssen, D.J., 2014. A randomised controlled trial on the efficacy of advance care planning on the quality of end-of-life care and communication in patients with COPD: the research protocol. *BMJ open*, 4(1), p.e004465.
- Howarth, G., 2011. The emergence of new forms of dying in contemporary societies. *Death, dying, and social differences*, pp.8–18.

- Howlett, J., Morrin, L., Fortin, M., Heckman, G., Strachan, P.H., Suskin, N., Shamian, J., Lewanczuk, R. and Arthur, H.M., 2010. End-of-life planning in heart failure: It should be the end of the beginning. *Canadian Journal of Cardiology*, 26(3), pp.135-141.
- Hoy, E., 2004. Communication skills education for doctors : an update Editorial board. , (November).BMA.
- Hubbard, G. & Forbat, L., 2012. Cancer as biographical disruption: constructions of living with cancer. *Supportive Care in Cancer*, 20(9), pp.2033–2040.
- Hudson, P. & Payne, S., 2011. Family caregivers and palliative care: current status and agenda for the future. *Journal of palliative medicine*, 14(7), pp.864–869.
- Hulsman, R.L., Ros, W.J.G., Winnubst, J.A.M. and Bensing, J.M., 1999. Teaching clinically experienced physicians communication skills. A review of evaluation studies. *Medical education*, 33(9), pp.655-668.
- Hulsman, R.L., Ros, W.J., Winnubst, J.A. and Bensing, J.M., 2002. The effectiveness of a computer-assisted instruction programme on communication skills of medical specialists in oncology. *Medical Education*, 36(2), pp.125-134.
- Hunt, K.J., Shlomo, N. & Addington-Hall, J., 2014. End-of-life care and achieving preferences for place of death in England: Results of a population-based survey using the VOICES-SF questionnaire. *Palliative Medicine*, 28(5), pp.412–421.
- Hupcey, J.E., Kitko, L. & Alonso, W., 2015. Palliative Care in Heart Failure. *Critical care nursing clinics of North America*, 27(4), pp.577–587.
- Husserl, E., 1970. *The crisis of European sciences and transcendental phenomenology: An introduction to phenomenological philosophy.*, Northwestern University Press.
- Hynes, G., 2014. Revisiting the Contribution of Viktor Frankl to Palliative Care: viktorfranklireland.com
- Innes, S. & Payne, S., 2009. Advanced cancer patients' prognostic information preferences: a review. *Palliative medicine*, 23(1), pp.29–39.
- Institute of Medicine, 1998. Approaching Death: Improving Care at the End of Life. *Annals of Internal Medicine*, 128(11), pp.964-964

- Institute of Medicine (US). Committee on Approaching Death: Addressing Key End-of-Life Issues, 2015. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*.
- Irving, P. & Dickson, D., 2004. Empathy: towards a conceptual framework for health professionals. *International journal of health care quality assurance incorporating Leadership in health services*, 17(4-5), pp.212–220.
- Jack, B., 2010. Giving them a voice: the value of qualitative research. *Nurse researcher*, 17(3), pp.4–6.
- Jacobs, J.K., Hollingsworth, H. & Givvin, K.B., 2007. Video-Based Research Made “Easy”: Methodological Lessons Learned from the TIMSS Video Studies. *Field Methods*, 19(3), pp.284–299.
- Jankowski, J., 2014. *Bioethics, Clinical* Third Edition., Elsevier.
- Janssen, D.J., Spruit, M.A., Schols, J.M. and Wouters, E.F., 2011. A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure. *CHEST Journal*, 139(5), pp.1081-1088.
- Janssen, D.J., Spruit, M.A., Schols, J.M., Cox, B., Nawrot, T.S., Curtis, J.R. and Wouters, E.F., 2012. Predicting changes in preferences for life-sustaining treatment among patients with advanced chronic organ failure. *CHEST Journal*, 141(5), pp.1251-1259.
- Jassak, P.F., 1992. Families: an essential element in the care of the patient with cancer. *Oncology nursing forum*, 19(6), pp.871–876.
- Jenkins, V. & Fallowfield, L., 2002. Can communication skills training alter physicians’ beliefs and behavior in clinics? *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 20(3), pp.765–769.
- Jewitt, C., 2012. An introduction to using video for research An Introduction to Using Video for Research. *National Centre for Research Methods Working Paper*, pp.1–22.
- Jezewski, M.A. & Finnell, D.S., 1998. The meaning of DNR status: oncology nurses’ experiences with patients and families. *Cancer nursing*, 21(3), pp.212–221.
- Joffe, S., Cook, E.F., Cleary, P.D., Clark, J.W. and Weeks, J.C., 2001. Quality of informed

consent in cancer clinical trials: a cross-sectional survey. *The Lancet*, 358(9295), pp.1772-1777.

Johansson, S., Leonard, R. & Noonan, K., 2012. Caring and the generation of social capital: Two models for a positive relationship. *International Journal of Social Welfare*, 21(1), pp.44–52.

Johns, C. & Freshwater, D., 2009. *Transforming nursing through reflective practice.*, John Wiley & Sons.

Johnston, B., Pringle, J., Gaffney, M., Narayanasamy, M., McGuire, M. and Buchanan, D., 2015. The dignified approach to care: a pilot study using the patient dignity question as an intervention to enhance dignity and person-centred care for people with palliative care needs in the acute hospital setting. *BMC palliative care*, 14(1), p.1.

Johnston, B., Gaffney, M., Pringle, J. and Buchanan, D., 2015. The person behind the patient: a feasibility study using the Patient Dignity Question for patients with palliative care needs in hospital. *International journal of palliative nursing*, 21(2).

Johnstone, M.-J. & Kanitsaki, O., 2009. Ethics and advance care planning in a culturally diverse society. *Journal of transcultural nursing : official journal of the Transcultural Nursing Society / Transcultural Nursing Society*, 20(4), pp.405–416.

Josselson, R., 2007. The ethical attitude in narrative research: principles and practicalities. *Handbook of narrative inquiry*, pp.537–566.

Jotkowitz, A., Glick, S. & Gezundheit, B., 2006. Truth-telling in a culturally diverse world. *Cancer investigation*, 24(8), pp.786–789.

Jox, R.J., 2011. End-of-life decision making concerning patients with disorders of consciousness. *Res Cogitans*, 1(8), pp.43–61.

Kahana, B., Kahana, E., Lovegreen, L., Bhatta, T., Cronin, C. and Brown, J., 2011. Hoping for the Best and Preparing for the Worst: End-of-Life Attitudes of the Elderly. *BMJ supportive & palliative care*, 1(1), pp.93-93.

Kahana, B., Dan, A., Kahana, E. and Kercher, K., 2004. The personal and social context of planning for end-of-life care. *Journal of the American Geriatrics Society*, 52(7), pp.1163-

1167.

Karlsson, M., Friberg, F., Wallengren, C. and Öhlén, J., 2014. Meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: a life-world phenomenological study. *BMC palliative care*, 13(1), p.1.

Kastenbaum, R., 2000. *The psychology of death*, Springer Publishing Company.

Kayser-Jones, J., 2002. The experience of dying: an ethnographic nursing home study. *Gerontologist*, 42 Spec No(liv), pp.11–19.

Kearney, M.K., Weininger, R.B., Vachon, M.L., Harrison, R.L. and Mount, B.M., 2009. Self-care of physicians caring for patients at the end of life: “Being connected... a key to my survival”. *Jama*, 301(11), pp.1155-1164.

Kehl, K.A., 2006. Moving Toward Peace: An Analysis of the Concept of a Good Death. *American Journal of Hospice and Palliative Medicine*, 23(4), pp.277–286.

Kellehear, A., 2007. *A Social History of Dying*, Oxford University Press.

Kellehear, A., 2013. Compassionate communities: end-of-life care as everyone’s responsibility. *Qjm*, 106(12), pp.1071–1075.

Kellehear, A., 1984. Are we a “death-denying” society? a sociological review. *Social science & medicine* (1982), 18(9), pp.713–723.

Kellehear, A., Pugh, E. & Atter, L., 2009. Home away from home? A case study of bedside objects in a hospice. *International journal of palliative nursing*, 15(3), pp.148–152.

Kellett, P. & Collins, P., 2009. At home in hospital? Competing constructions of hospital environments. *International Journal of Architectural Research*, p.100.

Kelley, K.J. & Kelley, M.F., 2013. Teaching empathy and other compassion-based communication skills. *Journal for nurses in professional development*, 29(6), pp.321–324.

Kelm, Z., Womer, J., Walter, J.K. and Feudtner, C., 2014. Interventions to cultivate physician empathy: a systematic review. *BMC medical education*, 14(1), p.219.

Kelner, M., Bourgeault, I.L., Hebert, P.C. and Dunn, E.V., 1993. Advance directives: the views

of health care professionals. *CMAJ: Canadian Medical Association Journal*, 148(8), p.1331.

Kendall, M., Carduff, E., Lloyd, A., Kimbell, B., Cavers, D., Buckingham, S., Boyd, K., Grant, L., Worth, A., Pinnock, H. and Sheikh, A., 2015. Different Experiences and Goals in Different Advanced Diseases: Comparing Serial Interviews With Patients With Cancer, Organ Failure, or Frailty and Their Family and Professional Carers. *Journal of pain and symptom management*, 50(2), pp.216-224.

Kendall, M., Harris, F., Boyd, K., Sheikh, A., Murray, S.A., Brown, D., Mallinson, I., Kearney, N. and Worth, A., 2007. Key challenges and ways forward in researching the “good death”: qualitative in-depth interview and focus group study. *bmj*, 334(7592), p.521.

Kennedy, C., Brooks-Young, P., Gray, C.B., Larkin, P., Connolly, M., Wilde-Larsson, B., Larsson, M., Smith, T. and Chater, S., 2014. Diagnosing dying: an integrative literature review. *BMJ supportive & palliative care*, pp.bmjspcare-2013.

Kiely, B.E., Tattersall, M.H.N. & Stockler, M.R., 2010. Certain death in uncertain time: informing hope by quantifying a best case scenario. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 28(16), pp.2802–2804.

Kimbell, B., Boyd, K., Kendall, M., Iredale, J. and Murray, S.A., 2015. Managing uncertainty in advanced liver disease: a qualitative, multiperspective, serial interview study. *BMJ open*, 5(11), p.e009241.

Kimmel, A.L., Wang, J., Scott, R.K., Briggs, L. and Lyon, M.E., 2015. FAMily CEntered (FACE) advance care planning: Study design and methods for a patient-centered communication and decision-making intervention for patients with HIV/AIDS and their surrogate decision-makers. *Contemporary clinical trials*, 43, pp.172-178.

King, A. & Hoppe, R.B., 2013. “Best practice” for patient-centered communication: a narrative review. *J Grad Med Educ*, 5(3), pp.385–93.

Kirchhoff, K.T., Walker, L., Hutton, A., Spuhler, V., Cole, B.V. and Clemmer, T., 2002. The vortex: families’ experiences with death in the intensive care unit. *American Journal of Critical Care*, 11(3), pp.200-209.

- Kirk, P., Kirk, I. & Kristjanson, L.J., 2004. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ (Clinical research ed.)*, 328(7452), p.1343.
- Kitwood, T., 1997. *Dementia Reconsidered: The Person Comes First*, Buckingham, UK: Oxford University Press.
- Kitwood, T., 1992. Towards a theory of dementia care: personhood and well-being. *Ageing and society*, 12(3), pp.269–287.
- Kjervik, D.K. & Badzek, L., 1998. Legal considerations at the end of life. *ANNA journal / American Nephrology Nurses' Association*, 25(6), pp.593–597.
- Klingler, C., in der Schmitt J., Marckmann, G., 2015. Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. *Palliative medicine*, p.0269216315601346.
- Knauff, E., 2005. Barriers and Facilitators to End-of-Life Care Communication for Patients with COPD. *Chest*, 127(6), pp.2188–2196.
- Kodish, E. & Post, S.G., 1995. Oncology and hope. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 13(7), p.1817.
- Kohut, N., Sam, M., O'Rourke, K., MacFadden, D.K., Salit, I. and Singer, P.A., 1997. Stability of treatment preferences: although most preferences do not change, most people change some of their preferences. *Journal of Clinical Ethics* 8 (2), p.124.
- Kolarik, R.C., Arnold, R.M., Fischer, G.S. & Hanusa, B.H., 2002. Advance care planning. *Journal of general internal medicine*, 17(8), pp.618–24.
- Kolarik, R.C., Arnold, R.M., Fischer, G.S. & Tulsky, J. a, 2002. Objectives for advance care planning. *Journal of palliative medicine*, 5(5), pp.697–704.
- Korfage, I.J., Rietjens, J.A., Overbeek, A., Jabbarian, L.J., Billekens, P., Hammes, B.J., Hansen-van der Meer, E., Polinder, S., Severijnen, J., Swart, S.J. and Witkamp, F.E., 2015. A cluster randomized controlled trial on the effects and costs of advance care planning in elderly care: study protocol. *BMC geriatrics*, 15(1), p.87.
- Kubler-Ross, E., 1972. On death and dying. *JAMA : the journal of the American Medical*

- Association*, 221(2), pp.174–179.
- Kurtz, S. & Cooke, L., 2011. Learner-centered communication training. In D. Kissane et al., eds. *Handbook of communication in oncology and palliative care*. Oxford: Oxford University Press, pp. 583–596.
- Kurtz, S.M., 2002. Doctor-Patient Communication : Principles and Practices. *The Canadian Journal of Neurological Sciences*, 29(2), pp.23–29.
- Kurtz, S.M., Silverman, J. and Draper, J., 2005. *Teaching and learning communication skills in medicine*. Radcliffe publishing.
- Kutner, L., 1969. Due Process of Euthansia:The living Will, a Proposal. *Indiana Law Journal*, 44(4), pp.539–54.
- Kvale, S., 2008. *Doing interviews*, SAGE Publications Limited.
- Kvale, S., 2006. Dominance Through Interviews and Dialogues. *Qualitative Inquiry*, 12(3), pp.480–500.
- Kvale, S. & Brinkman, S., 2009. *Interviews: Learning the craft of qualitative interviewing*. 2nd ed., SAGE Publications Limited.
- Kwak, J. & Haley, W.E., 2005. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*, 45(5), pp.634–641.
- Laidlaw T.S, Kaufman D.M, Macleoad H., Sargeant J., & Langille D.B., Patients' satisfaction with their family physicians' communication skills: a Nova Scotia survey. *Academic Medicine*, 76(10), pp.S77-S79.
- Lambert, B.L., Street, R.L., Cegala, D.J., Smith, D.H., Kurtz, S. and Schofield, T., 1997. Provider-patient communication, patient-centered care, and the mangle of practice. *Health communication*, 9(1), pp.27-43.
- Landmark, B.T. & Wahl, A., 2002. Living with newly diagnosed breast cancer: a qualitative study of 10 women with newly diagnosed breast cancer. *Journal of advanced nursing*, 40(1), pp.112–121.
- Lavoie, M., Blondeau, D. & Picard-Morin, J., 2011. The autonomy experience of patients in

- palliative care. *Journal of hospice & palliative nursing*, 13(1), pp.47–53.
- Law Reform Commission, 2009. *Bio Ethics: Advance Care Directives*, Law Reform Commission, Dublin, Ireland. www.lawreform.ie
- Lawton, J., 1998. Contemporary Hospice Care: the Sequestration of the Unbounded Body and “Dirty Dying.” *Sociology of Health and Illness*, 20(2), pp.121–143.
- Lawton, J., 2002. *The dying process: patients’ experiences of palliative care*, Routledge.
- Lehto, R.H. & Stein, K.F., 2009. Death Anxiety: An Analysis of an Evolving Concept. *Research and Theory for Nursing Practice*, 23(1), pp.23–41.
- Lelorain, S., Brédart, A., Dolbeault, S. and Sultan, S., 2012. A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psycho-Oncology*, 21(12), pp.1255-1264.
- Leonard, R., Horsfall, D. & Noonan, K., 2015. Identifying changes in the support networks of end-of-life carers using social network analysis. *BMJ Supportive & Palliative Care*, 5(2), pp.153–159.
- Levi, B.H., Dellasega, C., Whitehead, M. and Green, M.J., 2010. What influences individuals to engage in advance care planning?. *American Journal of Hospice and Palliative Medicine*, 27(5), pp.306-312.
- Levi, B.H. & Green, M.J., 2010. Too soon to give up: re-examining the value of advance directives. *The American journal of bioethics : AJOB*, 10(4), pp.3–22.
- Levinson, W., Lesser, C.S. & Epstein, R.M., 2010. Developing physician communication skills for patient-centered care. *Health affairs (Project Hope)*, 29(7), pp.1310–1318.
- Levinson, W. & Pizzo, P.A., 2011. Patient-physician communication: it’s about time. *JAMA*, 305(17), pp.1802–1803.
- Lewins, A. & Silver, C., 2009. Choosing a CAQDAS Package. *CAQDAS Networking Project and Qualitative Innovations in CAQDAS Project - QUIC Working Paper*, (#001), pp.1–7.
- Lewins, A. & Silver, C., 2007. *Using software in qualitative research: A step-by-step guide.*, SAGE Publications Limited.

- Lewis, D. & Scullion, J., 2012. Palliative and end-of-life care for patients with idiopathic pulmonary fibrosis: challenges and dilemmas. *International journal of palliative nursing*, 18(7), pp.331–337.
- Lewis, J.M. et al., 2013. A Social Capital Framework for Palliative Care: Supporting Health and Well-Being for People With Life-Limiting Illness and Their Carers Through Social Relations and Networks. *Journal of Pain and Symptom Management*, 45(1), pp.92–103.
- Lewis, J.M., DiGiacomo, M., Currow, D.C. and Davidson, P.M., 2011. Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. *Journal of pain and symptom management*, 42(1), pp.105-118.
- Lewis, J.M., DiGiacomo, M., Currow, D.C. and Davidson, P.M., 2014. Social capital in a lower socioeconomic palliative care population: a qualitative investigation of individual, community and civic networks and relations. *BMC palliative care*, 13(1), p.30.
- Libert, Y., Merckaert, I., Reynaert, C., Delvaux, N., Marchal, S., Etienne, A.M., Boniver, J., Klastersky, J., Scalliet, P., Slachmuylder, J.L. and Razavi, D., 2007. Physicians are different when they learn communication skills: influence of the locus of control. *Psycho Oncology*, 16(6), pp.553-562.
- Lietz, C. a., Langer, C.L. & Furman, R., 2006. Establishing Trustworthiness in Qualitative Research in Social Work: Implications from a Study Regarding Spirituality. *Qualitative Social Work*, 5(4), pp.441–458..
- Lin, N., Cook, K.S. & Burt, R.S., 2001. *Social capital: Theory and research* N. Lin, K. S. Cook, & R. S. Burt, eds., Transaction Publishers.
- Lipkin, M., 2010. The history of communication skills knowledge and training. In D. Kissane et al., eds. *Handbook of communication in oncology and palliative care*. Oxford University Press, pp. 3–12.
- Lloyd-Williams, M., Kennedy, V., Sixsmith, A. and Sixsmith, J., 2007. The end of life: a qualitative study of the perceptions of people over the age of 80 on issues surrounding death and dying. *Journal of pain and symptom management*, 34(1), pp.60-66.
- Lobo, B., 2011. Advance Decisions to Refuse Treatment (ADRT). In Thomas K and Lobo B, ed.

- Advance Care Planning in End of Life Care*. Oxford University Press, pp. 101–112.
- Lock, A. & Higginson, I., 2005. Patterns and predictors of place of cancer death for the oldest old. *BMC palliative care*, 4, p.6.
- Lockhart K., Ditto P.H., Danks J.H., Coppola K.M., Smucker W.D., 2001. The stability of older adults' judgments of fates better and worse than death. *Death studies*, 25(4), pp.299–317.
- Loewenstein, G., 2005. Projection bias in medical decision making. *Medical decision making : an international journal of the Society for Medical Decision Making*, 25(1), pp.96–105.
- Loh, J., 2013. Inquiry into Issues of Trustworthiness and Quality in Narrative Studies: A Perspective. *Qualitative Report*, 18(33), pp.1–15.
- Lokker, M.E., van Zuylen, L., Veerbeek, L., van der Rijt, C.C. and van der Heide, A., 2012. Awareness of dying: it needs words. *Supportive Care in Cancer*, 20(6), pp.1227-1233.
- Lomax, H. & Casey, N., 1998. "Recording Social Life: Reflexivity and Video Methodology." *Sociological Research Online*, 3(2).
- Lovell, A. & Yates, P., 2014. Advance Care Planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008-2012. *Palliative medicine*, 28(8), pp.1026–1035.
- Low, J.T. & Payne, S., 1996. The good and bad death perceptions of health professionals working in palliative care. *European journal of cancer care*, 5(4), pp.237–241.
- Lowey, S.E., 2008. Communication Between the Nurse and Family Caregiver in End-of-Life Care. *Journal of Hospice & Palliative Nursing*, 10(1), pp.35–45.
- Lund, S., Richardson, A. & May, C., 2015. Barriers to advance care planning at the end of life: an explanatory systematic review of implementation studies. *PloS one*, 10(2), p.e0116629.
- Lunney, J.R., Lynn, J., Foley, D.J., Lipson, S. and Guralnik, J.M., 2003. Patterns of functional decline at the end of life. *Jama*, 289(18), pp.2387-2392.

- Lunney, J.R. & Lynn, J., 2010. Trajectories of disability in the last year of life. *The New England journal of medicine*, 363(3), p.294
- Lynch, H.F., Mathes, M. & Sawicki, N.N., 2008. Compliance with advance directives. Wrongful living and tort law incentives. *The Journal of legal medicine*, 29(2), pp.133–178.
- Lyne, M., 2010. The Mental Capacity Act 2005. , pp.33–36.
- Lynn, J. & Anderson, D., 2003. *Living well at the end of life. Adapting health care to serious chronic illness in old age*, Rand Health.
- Mack, J.W., Weeks, J.C., Wright, A.A., Block, S.D. and Prigerson, H.G., 2010. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology*, 28(7), pp.1203-1208.
- MacPherson, A., Walshe, C., O'Donnell, V. and Vyas, A., 2013. The views of patients with severe chronic obstructive pulmonary disease on advance care planning: a qualitative study. *Palliative medicine*, 27(3), pp.265-272.
- Mac Williams, J., Bramwell, M., Brown, S. and O'Connor, M., 2014. Reaching out to Ray: delivering palliative care services to a homeless person in Melbourne, Australia. *International journal of palliative nursing*, 20(2).
- Maguire, P., 1985. Consequences of poor communication between nurses and patients. *Nursing*, 2(38), pp.1115–1118.
- Maguire, P., Booth, K., Elliott, C. and Jones, B., 1996. Helping health professionals involved in cancer care acquire key interviewing skills—the impact of workshops. *European Journal of Cancer*, 32(9), pp.1486-1489.
- Maguire, P. & Pitceathly, C., 2002. Key communication skills and how to acquire them. *British Medical Journal*, 325(7366), pp.697–700.
- Mak, Y.Y.W. & Elwyn, G., 2005. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. *Palliative medicine*, 19(4), pp.343–350.
- Malcomson, H., & Bisbee, S., 2009. Perspectives of healthy elders on advance care planning.

- Journal of the American Academy of Nurse Practitioners*, 21(1), pp.18–23.
- van Manen, M., 1990. *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*, Ontario: Althouse Press.
- Marambe, K.N., Edussuriya, D.H. & Dayaratne, K.M., 2012. Attitudes of Sri Lankan medical students toward learning communication skills. *Educ Health (Abingdon)*, 25(3), pp.165–171.
- Margolis, E. & Pauwels, L., 2011. *The Sage handbook of visual research methods* E. Margolis & L. Pauwels, eds., SAGE Publications Limited.
- Marks, D.F. & Yardley, L., 2004. *Research methods for clinical and health psychology.*, SAGE Publications Ltd.
- Maschi, T., Marmo, S. & Han, J., 2014. Palliative and end-of-life care in prisons: a content analysis of the literature. *International journal of prisoner health*, 10(3), pp.172–197.
- Mason, M., 2010, August. Sample size and saturation in PhD studies using qualitative interviews. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* 11(3)
- Masso, M, Dodds, S, Filders, D, Yeatman, H. and Eagar, K2004. Ethical Research in Palliative Care: a guide through the Human Research Ethics Committee process, Centre for Health Service Development, University of Wollongong, 2004, 37p.
- Masso, M., Allingham, S.F., Banfield, M., Johnson, C.E., Pidgeon, T., Yates, P. and Eagar, K., 2014. Palliative Care Phase: Inter-rater reliability and acceptability in a national study. *Palliative medicine*, p.0269216314551814.
- Mathie, E., Goodman, C., Crang, C., Froggatt, K., Iliffe, S., Manthorpe, J. and Barclay, S., 2012. An uncertain future: the unchanging views of care home residents about living and dying. *Palliative Medicine*, 26(5), pp.734-743.
- May, P., Hynes, G., McCallion, P., Payne, S., Larkin, P. and McCarron, M., 2014. Policy analysis: palliative care in Ireland. *Health policy*, 115(1), pp.68-74.
- McCartney, M., 2014. *Living with Dying: finding care and compassion at the end of life*, Pinter and Martin Ltd.

- McCormack, B., 2004. Person-centredness in gerontological nursing: an overview of the literature. *Journal of clinical nursing*, 13, pp.31–38.
- McCormack L, Sheridan S, Lewis M, et al. Communication and Dissemination Strategies to Facilitate the Use of Health-Related Evidence. Rockville (MD): Agency for Healthcare Research and Quality (US); 2013 Nov. (Evidence Reports/Technology Assessments, No. 213.)
- McCormack, L.A., Treiman, K., Rupert, D., Williams-Piehot, P., Nadler, E., Arora, N.K., Lawrence, W. and Street, R.L., 2011. Measuring patient-centered communication in cancer care: a literature review and the development of a systematic approach. *Social science & medicine*, 72(7), pp.1085-1095.
- McKechnie, R., MacLeod, R. & Keeling, S., 2007. Facing uncertainty: The lived experience of palliative care. *Palliative & Supportive Care*, 5(03), pp.255–264.
- McLennan, V.E., Boddy, J.H., Daly, M.G. and Chenoweth, L.M., 2015. Relinquishing or taking control? Community perspectives on barriers and opportunities in advance care planning. *Australian Health Review*, 39(5), pp.528-532.
- McLeod-Sordjan, R., 2014. Death preparedness: a concept analysis. *Journal of advanced nursing*, 70(5), pp.1008–1019.
- McPherson, C.J., Wilson, K.G. & Murray, M., 2007. Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative Medicine*, 21(2), pp.115–128.
- McTiernan, K. & O’Connell, M., 2015. An interpretative phenomenological analysis exploring the lived experience of individuals dying from terminal cancer in Ireland. *Palliative & supportive care*, 13(3), pp.641–651.
- Meeker, M., 2004. Family Surrogate Decision Making at the End of Life: Seeing them Through with Care and Respect. *Qualitative Health Research*, 14(2), pp.204–225.
- Meeussen, K., Van den Block, L., Echteld, M., Bossuyt, N., Bilsen, J., Van Casteren, V., Abarshi, E., Donker, G., Onwuteaka-Philipsen, B. and Deliens, L., 2011. Advance care planning in Belgium and The Netherlands: a nationwide retrospective study via sentinel networks of general practitioners. *Journal of pain and symptom management*, 42(4),

pp.565-577.

Mellor, PA and Shilling, C., 1993. Modernity, self-identity and the sequestration of death. *Sociology*, 27(3), pp.411–431.

Mercer, S.W., Neumann, M., Wirtz, M., Fitzpatrick, B. and Vojt, G., 2008. General practitioner empathy, patient enablement, and patient-reported outcomes in primary care in an area of high socio-economic deprivation in Scotland—a pilot prospective study using structural equation modeling. *Patient education and counseling*, 73(2), pp.240-245.

Mercer, S.W. & Reynolds, W.J., 2002. Empathy and quality of care. *The British journal of general practice : the journal of the Royal College of General Practitioners*, 52 Suppl, pp.S9–12.

Merrell, J. and Williams, A., 1994. Participant observation and informed consent: relationships and tactical decision-making in nursing research. *Nursing Ethics* 1 (3):163-172

Michael, N., O’Callaghan, C., Baird, A., Gough, K., Krishnasamy, M., Hiscock, N. and Clayton, J., 2015. A mixed method feasibility study of a patient-and family-centred advance care planning intervention for cancer patients. *BMC palliative care*, 14(1), p.1.

Michael, N., O’Callaghan, C., Clayton, J., Pollard, A., Stepanov, N., Spruyt, O., Michael, M. and Ball, D., 2013. Understanding how cancer patients actualise, relinquish, and reject advance care planning: implications for practice. *Supportive Care in Cancer*, 21(8), pp.2195-2205.

Miczo, N., 2003. Beyond the “fetishism of words”: considerations on the use of the interview to gather chronic illness narratives. *Qualitative health research*, 13(4), pp.469–490.

Miles, A. & Mezzich, J., 2011. The care of the patient and the soul of the clinic: person-centered medicine as an emergent model of modern clinical practice. *The International Journal of Person Centered Medicine*, 1(2), pp.207–222.

- Milligan, C., Turner, M., Blake, S., Brearley, S., Seamark, D., Thomas, C., Wang, X. and Payne, S., 2016. Unpacking the impact of older adults' home death on family care-givers' experiences of home. *Health & place*, 38, pp.103-111.
- Milligan, C. & Wiles, J., 2010. Landscapes of Care. *Progress in Human Geography*, 34(6), pp.736–754.
- Ministry of Health, 2011. *Advance Care Planning: A Guide for the New Zealand health care workforce*, Wellington, New Zealand.
- Minto, F. & Strickland, K., 2011. Anticipating emotion: a qualitative study of advance care planning in the community setting. *International journal of palliative nursing*, 17(6), pp.278–284.
- Mishler, FOR EXAMPLE., 1991. *Research interviewing*, Harvard University Press.
- Mishler, FOR EXAMPLE., 1981. *Social contexts of health, illness, and patient care*, CUP Archive.
- Mitchell, B.L. & Mitchell, L.C., 2009. Review of the literature on cultural competence and end-of-life treatment decisions: the role of the hospitalist. *Journal of the National Medical Association*, 101(9), pp.920–926.
- Mitchell, M. & Egudo, M., 2003. *A Review of Narrative Methodology*, Edinburgh, South Australia.
- Moen, T., 2006. Reflections on the Narrative Research Approach. *International Journal of Qualitative Methods*, 5, pp.56–69.
- Moher D, Liberati A, Tetzlaff J, Altman D, 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine*, 151(4), pp.264–269.
- Monforte-Royo, C., Villavicencio-Chávez, C., Tomás-Sábado, J., Mahtani-Chugani, V. and Balaguer, A., 2012. What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. *PLoS One*, 7(5), p.e37117.
- Moody, L.E., Beckie, T., Long, C., Edmonds, A. and Andrews, S., 2000. Assessing readiness for death in hospice elders and older adults. *The Hospice Journal*, 15(2), pp.49-65.

- Moore, P.M., Wilkinson, S.S. and Rivera Mercado, S., 2004. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev*, 2.
- Moore, A., Carter, B., Hunt, A. and Sheikh, K., 2013. 'I am closer to this place'—Space, place and notions of home in lived experiences of hospice day care. *Health & place*, 19, pp.151-158.
- Moore, P.M., Rivera Mercado, S., Grez Artigues, M. and Lawrie, T.A., 2013. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database Syst Rev*, 2.
- Moriarty, J., 2011. *Methods Review 1*, eprints.lse.ac.uk
- Morita, T., Hirai, K., Akechi, T. and Uchitomi, Y., 2003. Similarity and difference among standard medical care, palliative sedation therapy, and euthanasia: a multidimensional scaling analysis on physicians' and the general population's opinions. *Journal of pain and symptom management*, 25(4), pp.357-362.
- Morris, S.M., King, C., Turner, M. and Payne, S., 2015. Family carers providing support to a person dying in the home setting: A narrative literature review. *Palliative medicine*, 29(6), pp.487-495.
- Morrison, R.S., Chichin, E., Carter, J., Burack, O., Lantz, M. and Meier, D.E., 2005. The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *Journal of the American Geriatrics Society*, 53(2), pp.290-294.
- Morse, J.M., Barrett, M., Mayan, M., Olson, K. and Spiers, J., 2002. Verification strategies for establishing reliability and validity in qualitative research. *International journal of qualitative methods*, 1(2), pp.13-22.
- Van Mossel, C., Alford, M. & Watson, H., 2011. Challenges Of Patient-Centred Care: Practice Or Rhetoric. *Nursing Inquiry*, 18(4), p.278—289.
- Mullick, A., Martin, J. & Sallnow, L., 2013. An introduction to advance care planning in practice. *Bmj*, 347(oct21 3), pp.f6064–f6064.
- Munday, D., Petrova, M. & Dale, J., 2009. Exploring preferences for place of death with

- terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England. *BMJ (Clinical research ed.)*, 339, p.b2391.
- Murray, L., Butow, P.N., White, K., Kiernan, M.C., D'Abrew, N. and Herz, H., 2016. Advance care planning in motor neuron disease: A qualitative study of caregiver perspectives. *Palliative medicine*.30, pp.471-478.
- Murray, S., Kendall, M., Boyd, K. and Sheikh et al., 2005. Illness trajectories and palliative care. *BMJ (Clinical research ed.)*, 330(7498), pp.1007–1011.
- Murray, S.A., Kendall, M., Boyd, K., Grant, L., Hight, G. and Sheikh, A., 2010. Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: secondary analysis of serial qualitative interviews. *Bmj*, 340, p.c2581.
- Murray, S.A., Boyd, K., Kendall, M., Worth, A., Benton, T.F. and Clausen, H., 2002. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *Bmj*, 325(7370), p.929.
- Murray, S and McLoughlin, P., 2012. Illness trajectories and palliative care: Implications for holistic service provision for all in the last year of life. In S. K. and A. K. L Sallnow, ed. *International perspectives on public health and palliative care*. pp. 30–51.
- Murtagh, F., 2013. Foreword. In S. Payne et al., eds. *Research in palliative care:can hospices afford to not be involved?*. Help the Hospices Commission, p. 3.
- Murtagh, F.E., Sheerin, N.S., Addington-Hall, J. and Higginson, I.J., 2011. Trajectories of illness in stage 5 chronic kidney disease: a longitudinal study of patient symptoms and concerns in the last year of life. *Clinical Journal of the American Society of Nephrology*, 6(7), pp.1580-1590.
- Murtagh, F.E.M., Addington-Hall, J.M. & Higginson, I.J., 2007. The value of cognitive interviewing techniques in palliative care research. *Palliative Medicine*, 21(2), pp.87–93.
- Nakanishi, M., Nakashima, T., Shindo, Y., Miyamoto, Y., Gove, D., Radbruch, L. and van der Steen, J.T., 2015. An evaluation of palliative care contents in national dementia

- strategies in reference to the European Association for Palliative Care white paper. *International Psychogeriatrics*, 27(09), pp.1551-1561.
- National End of Life Care Programme, 2010a. Capacity , care planning and advance care planning in life limiting illness. A Guide for Health and Social Care Staff.
- National End of Life Care Programme, 2010b. *End of Life Care: Achieving Quality in Hostels and for Homeless People - A Route to Success*,
- National Palliative and End of Life Care Partnership, 2015. *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*,
- Nauck, F., Becker, M., King, C., Radbruch, L., Voltz, R. and Jaspers, B., 2014. To what extent are the wishes of a signatory reflected in their advance directive: a qualitative analysis. *BMC medical ethics*, 15(1), p.1.
- Neergaard, M.A., Olesen, F., Andersen, R.S. and Sondergaard, J., 2009. Qualitative description—the poor cousin of health research?. *BMC medical research methodology*, 9(1), p.1.
- Neergaard, M.A., Vedsted, P., Olesen, F., Sokolowski, I., Jensen, A.B. and Søndergaard, J., 2009. Associations between home death and GP involvement in palliative cancer care. *Br J Gen Pract*, 59(566), pp.671-677.
- Neimeyer, R.A., Moser, R.P. & Wittkowski, J., 2003. Assessing attitudes toward dying and death: Psychometric considerations. *Omega: Journal of Death and Dying*, 47(1), pp.45–76.
- NHS England, 2015. Developing a new approach to palliative care funding : A first draft for discussion.
- NHS Scotland, 2008. *Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland*, NHS Scotland
- NHS Wales Health Board, 2013. *Together for Health: Delivering End of Life Care*, NHS Wales Health Board
- NICE, 2015. *Care of the Dying Adult*, NICE, London.

- NICE, 2011. *Quality Standard for end of life care for adults. NICE Quality Standard 13*,
- NIHR Dissemination Centre, 2015. *Better Endings: Right Care, Right Place, Right Time*, NIHR.
- Noah, B.A., 2013. Two Conflicts in Context: Lessons from the Schiavo and Bland Cases and the Role of Best Interests Analysis in the United Kingdom. *Hamline Law Review*, 36, p.239.
- Noble, H. & Smith, J., 2015. Issues of validity and reliability in qualitative research. *Evidence-Based Nursing*, 18(2), pp.34–35.
- Nolan, M.R., Davies, S., Brown, J., Keady, J. and Nolan, J., 2004. Beyond ‘person-centred’ care: a new vision for gerontological nursing. *Journal of clinical nursing*, 13(s1), pp.45-53.
- Norfolk, T., Birdi, K. & Walsh, D., 2007. The role of empathy in establishing rapport in the consultation: a new model. *Medical education*, 41(7), pp.690–697.
- Oczkowski, S.J., Chung, H-O., Hanvey, L., Mbuagbaw, L., You, J.J., 2016. Communication Tools for End-of-Life Decision-Making in Ambulatory Care Settings: A Systematic Review and Meta-Analysis. *PLoS ONE* 11(4): e0150671.
- O’Brien, M. & Fiester, A., 2014. Who’s at the table? Moral obligations to equal-priority surrogates in clinical ethics consultations. *The Journal of clinical ethics*, 25(4), pp.273–280.
- O’Connor, M., Davis, M.P. & Abernethy, A., 2010. Language, discourse and meaning in palliative medicine. *Progress in Palliative Care*, 18(2), pp.66–71.
- O’Connor, M. & Payne, S., 2006. Discourse analysis: examining the potential for research in palliative care. *Palliative medicine*, 20(8), pp.829–834.
- Ohnsorge, K., Gudat, H. & Rehmann-Sutter, C., 2014. What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliative Care*, 13(1), p.38.
- Oliffe, J. et al., 2007. “Truth telling” and cultural assumptions in an era of informed consent. *Family & community health*, 30(1), pp.5–15.

- On, R. et al., 2011. REPORT ON THE NATIONAL STRATEGY FOR PALLIATIVE CARE Coordinated by Lien Centre for Palliative Care , Duke-NUS Graduate Medical School.
- One Hundred and First Congress, 1990. *Patient Self Determination Act of 1990*, USA. United States of America Congress
- Pacquiao, D., 2001. Addressing cultural incongruities of advance directives. *Bioethics forum*, 17(1), pp.27–31.
- Parker, M. & Cartwright, C., 2004. Advance care planning and end of life decision making. *Australian family physician*, 33(10), pp.1–2.
- Parker, P.A., Baile, W.F., de Moor, C., Lenzi, R., Kudelka, A.P. and Cohen, L., 2001. Breaking bad news about cancer: patients' preferences for communication. *Journal of clinical oncology*, 19(7), pp.2049-2056.
- Parker, S., Clayton, J.M., Hancock, K., Walder, S., Butow, P., Carrick, S., Currow, D., Gherzi, D., Glare, P., Hagerty, R. and Tattersall, M., 2006. Communicating Prognosis and Issues Surrounding End of Life (EOL) in adults in the advanced stages of a life-limiting illness: A Systematic Review. *NHMRC Clinical Trials Centre and the University of Sydney*.
- Parker, S.M., Clayton, J.M., Hancock, K., Walder, S., Butow, P.N., Carrick, S., Currow, D., Gherzi, D., Glare, P., Hagerty, R. and Tattersall, M.H., 2007. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management*, 34(1), pp.81-93.
- Parkes, C.M., 1978. Home or hospital? Terminal care as seen by surviving spouses. *The Journal of the Royal College of General Practitioners*, 28(186), pp.19–30.
- Parle, M., Maguire, P. & Heaven, C., 1997. The development of a training model to improve health professionals' skills, self-efficacy and outcome expectancies when communicating with cancer patients. *Social science & medicine (1982)*, 44(2), pp.231–240.
- Parliament of South Australia, 1995. Consent to Medical Treatment and Palliative Care Act 1995., (26), pp.1–13.

- Parry, R., Land, V. & Seymour, J., 2014. How to communicate with patients about future illness progression and end of life: a systematic review. *BMJ Supportive & Palliative Care*, 4(4), pp.331–341.
- Pastrana, T., Jünger, S., Ostgathe, C., Elsner, F. and Radbruch, L., 2008. A matter of definition—key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine*, 22(3), pp.222-232.
- Patel, K., Janssen, D.J. & Curtis, J.R., 2012. Advance care planning in COPD. *Respirology*, 17(1), pp.72–78.
- Pattenden, J.F., Mason, A.R. & Lewin, R.J.P., 2013. Collaborative palliative care for advanced heart failure: outcomes and costs from the “Better Together” pilot study. *BMJ supportive & palliative care*, 3(1), pp.69–76.
- Pauwels, R., 2001. Global initiative for chronic obstructive lung diseases (GOLD): time to act. *The European respiratory journal*, 18(6), pp.901–902.
- Payne, S., Seymour, J., Grande, G., Froggatt, K., Molassiotis, A., Lloyd-Williams, M., Foster, C., Addington-Hall, J., Rolls, E. and Todd, C., 2012. An evaluation of research capacity building from the Cancer Experiences Collaborative. *BMJ supportive & palliative care*, 2(3), pp.280-285.
- Payne, S., 2007. Qualitative methods of data collection and analysis. In J. M. Addington-Hall et al., eds. *Research Methods in Palliative Care*. Oxford: Oxford University Press, pp. 139–162.
- Payne, S.A., Preston, N.J., Turner, J.M. and Rolls, L., 2013. Research in palliative care: can hospices afford not to be involved? Commission into Hospice Care, Hospice UK
- Payne, S., Brearley, S., Milligan, C., Seamark, D., Thomas, C., Wang, X., Blake, S. and Turner, M., 2012. The perspectives of bereaved family carers on dying at home: the study protocol of ‘unpacking the home: family carers’ reflections on dying at home. *BMC palliative care*, 11(1), p.1.
- Payne, S.A., Langley-Evans, A. & Hillier, R., 1996. Perceptions of a “good” death: a comparative study of the views of hospice staff and patients. *Palliative medicine*, 10(4),

pp.307–312.

Pearlman, R.A., Cole, W.G., Patrick, D.L., Starks, H.E. and Cain, K.C., 1995. Advance care planning: eliciting patient preferences for life-sustaining treatment. *Patient education and counseling*, 26(1), pp.353-361.

Pender, S. & Hardwick, K., 2011. When someone asks for your assistance to die. RCN Guidance.

Penrod, J., 2007. Living with uncertainty: concept advancement. *Journal of advanced nursing*, 57(6), pp.658–667.

Pentz, R.D., Lenzi, R., Holmes, F., Khan, M.M. and Verschraegen, C., 2002. Discussion of the do-not-resuscitate order: a pilot study of perceptions of patients with refractory cancer. *Supportive care in cancer*, 10(8), pp.573-578.

PeolcPSP, 2015. *Palliative and end of life care Priority Setting Partnership: Putting patients, carers and clinicians at the heart of palliative and end of life care research*,. James Lind Alliance/Marie Curie Cancer Care

Perkins, P., Barclay, S. & Booth, S., 2007. What are patients' priorities for palliative care research? Focus group study. *Palliative Medicine*, 21(3), pp.219–225.

Pessin, H., Galietta, M., Nelson, C.J., Brescia, R., Rosenfeld, B. and Breitbart, W., 2008. Burden and benefit of psychosocial research at the end of life. *Journal of palliative medicine*, 11(4), pp.627-632.

Pink, S., 2003. Interdisciplinary agendas in visual research: re-situating visual anthropology. *Visual Studies*, 18(2), pp.179–192.

Pinnock, H., Kendall, M., Murray, S.A., Worth, A., Levack, P., Porter, M., MacNee, W. and Sheikh, A., 2011. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *Bmj*, 342, p.d142.

Plummer, K., 2001. The call of life stories in ethnographic research. *Handbook of ethnography*, pp.395-406. Sage, London.

Polkinghorne, D., 1983. *Methodology for the human sciences: Systems of inquiry*, Suny Press.

- Pollak, K.I., Arnold, R.M., Jeffreys, A.S., Alexander, S.C., Olsen, M.K., Abernethy, A.P., Skinner, C.S., Rodriguez, K.L. and Tulsky, J.A., 2007. Oncologist communication about emotion during visits with patients with advanced cancer. *Journal of Clinical Oncology*, 25(36), pp.5748-5752.
- Pollock, K., 2015. Is home always the best and preferred place of death? *BMJ (Clinical research ed.)*, 351, p.h4855.
- Pollock, K. & Wilson, E., 2015. *Care and communication between health professionals and patients affected by severe or chronic illness in community care settings: a qualitative study of care at the end of life*, Southampton (UK).
- Popay, J., Rogers, A. & Williams, G., 1998. Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative health research*, 8(3), pp.341–351.
- Popay, J. & Williams, G., 1998. Qualitative research and evidence-based healthcare. *Journal of the Royal Society of Medicine*, 91 Suppl 3, pp.32–37.
- Porter, W.G., 1999. Truth-telling and hope. The dilemma of modern medicine. *North Carolina medical journal*, 60(3), pp.142–148.
- Potter, J., 1987. *Discourse and Social Psychology: Beyond Attitudes and Behaviors*, SAGE Publications Limited.
- Powis, J., Etchells, E., Martin, D.K., MacRae, S.K. and Singer, P.A., 2004. Can a “good death” be made better?: A preliminary evaluation of a patient-centred quality improvement strategy for severely ill in-patients *BMC Palliative Care*, 3(1), p.2.
- Prendergast, T.J., 2001. Advance care planning: pitfalls, progress, promise. *Critical care medicine*, 29(2 Suppl), pp.N34–9.
- Prendergast, T.J., Claessens, M.T. & Luce, J.M., 1998. A national survey of end-of-life care for critically ill patients. *American journal of respiratory and critical care medicine*, 158(4), pp.1163–1167.
- Prendergast, T.J. & Puntillo, K.A., 2002. Withdrawal of life support: intensive caring at the end of life. *JAMA*, 288(21), pp.2732–2740.

- Prommer, E.E., 2010. Using the values-based history to fine-tune advance care planning for oncology patients. *Journal of cancer education : the official journal of the American Association for Cancer Education*, 25(1), pp.66–69.
- Proot, I.M., Abu-Saad, H.H., Crebolder, H.F., Goldsteen, M., Luker, K.A. and Widdershoven, G.A., 2003. Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scandinavian journal of caring sciences*, 17(2), pp.113-121.
- Pyper T, Sawyer J, Pyper C Mayhew L., 2013 PHAST Evaluation of Three End of Life Care Training Pilots in East of England v58 Public Health Action Support Team (PHAST)
- Pyszczynski, T., Greenberg, J. & Solomon, S., 1999. A dual-process model of defense against conscious and unconscious death-related thoughts: an extension of terror management theory. *Psychological review*, 106(4), pp.835–845.
- Queensland, Health., 2015. Statewide strategy for end-of-life care 2015. Queensland Govt.
- de Raeve, L., 1994. Ethical issues in palliative care research. *Palliative medicine*, 8(4), pp.298–305.
- Raijmakers, N.J., Van Zuylen, L., Costantini, M., Caraceni, A., Clark, J.B., De Simone, G., Lundquist, G., Voltz, R., Ellershaw, J.E. and van der Heide, A., 2012. Issues and needs in end-of-life decision making: an international modified Delphi study. *Palliative medicine*, 26(7), pp.947-953.
- Raisio, H., Vartiainen, P. & Jekunen, A., 2015. Defining a Good Death: A deliberative democratic view. *Journal of palliative care*, 31(3), pp.158–165.
- Ramirez, A.J., Graham, J., Richards, M.A., Cull, A., Gregory, W.M., Leaning, M.S., Snashall, D.C. and Timothy, A.R., 1995. Burnout and psychiatric disorder among cancer clinicians. *British journal of cancer*, 71(6), p.1263.
- Ramirez, A.J., Graham, J., Richards, M.A., Gregory, W.M. and Cull, A., 1996. Mental health of hospital consultants: the effects of stress and satisfaction at work. *The Lancet*, 347(9003), pp.724-728.
- Randall, F. & Downie, R., 2006. *The Philosophy of Palliative Care* 1st ed., Oxford University Press.

- Rasmussen, B.H. & Edvardsson, D., 2007. The influence of environment in palliative care: supporting or hindering experiences of “at-homeness”. *Contemporary nurse*, 27(1), pp.119–131.
- Raudonis, B.M., 1992. Ethical considerations in qualitative research with hospice patients. *Qualitative health research*, 2(2), pp.238–249.
- Razavi, D., Merckaert, I., Marchal, S., Libert, Y., Conrardt, S., Boniver, J., Etienne, A.M., Fontaine, O., Janne, P., Klastersky, J. and Reynaert, C., 2003. How to optimize physicians’ communication skills in cancer care: results of a randomized study assessing the usefulness of posttraining consolidation workshops. *Journal of Clinical Oncology*, 21(16), pp.3141-3149.
- Razavi, D., Delvaux, N., Marchal, S., De Cock, M., Farvacques, C. and Slachmuylder, J.L., 2000. Testing health care professionals' communication skills: the usefulness of highly emotional standardized role-playing sessions with simulators. *Psycho-Oncology*, 9(4), pp.293-302.
- Razavi, D. & Delvaux, N., 1997. Communication skills and psychological training in oncology. *European journal of cancer (Oxford, England : 1990)*, 33 Suppl 6, pp.S15–21.
- Reeve, J., Lloyd-Williams, M., Payne, S. and Dowrick, C., 2010. Revisiting biographical disruption: Exploring individual embodied illness experience in people with terminal cancer. *Health*, 14(2), pp.178-195.
- Reich, M. & Mekaoui, L., 2003. [Conspiracy of silence in oncology: a situation not to be overlooked]. *Bulletin du cancer*, 90(2), pp.181–184.
- Reicher, S., 2000. Against methodolatry: some comments on Elliott, Fischer, and Rennie. *The British journal of clinical psychology / the British Psychological Society*, 39 (Pt 1), pp.1–10.
- Reyniers, T., Houttekier, D., Pasman, H.R., Vander Stichele, R., Cohen, J. and Deliens, L., 2014. The family physician’s perceived role in preventing and guiding hospital admissions at the end of life: a focus group study. *The Annals of Family Medicine*, 12(5), pp.441-446.

- Reynolds, K.S., Hanson, L.C., Henderson, M. and Steinhauser, K.E., 2008. End-of-life care in nursing home settings: do race or age matter?. *Palliative and Supportive Care*, 6(01), pp.21-27.
- Rhee, J.J., Zwar, N. a. & Kemp, L., 2013. Advance care planning and interpersonal relationships: a two-way street. *Family Practice*, 30(2), pp.219–226.
- Rhee, J.J., Zwar, N.A. & Kemp, L.A., 2012. Uptake and implementation of Advance Care Planning in Australia: findings of key informant interviews. *Australian health review : a publication of the Australian Hospital Association*, 36(1), pp.98–104.
- Rider, E.A.E.A., Hinrichs, M.M.M.M. & Lown, B.A.B.A., 2006. A model for communication skills assessment across the undergraduate curriculum. *Medical teacher*, 28(5), pp.e127–e134.
- Riessman, C., 2008. *Narrative methods for the human sciences*, SAGE Publications Limited.
- Rigby, J., Payne, S. & Froggatt, K., 2010. Review: what evidence is there about the specific environmental needs of older people who are near the end of life and are cared for in hospices or similar institutions? A literature review. *Palliative medicine*, 24(3), pp.268–285.
- Riolfi, M., Buja, A., Zanardo, C., Marangon, C.F., Manno, P. and Baldo, V., 2013. Effectiveness of palliative home-care services in reducing hospital admissions and determinants of hospitalization for terminally ill patients followed up by a palliative home-care team: A retrospective cohort study. *Palliative medicine*, 28(5), pp.403-411
- Rietjens, J., Korff, J. & van der Heide A., 2016. Advance care planning: Not a panacea. *Palliative medicine*, 30(5), pp.421-422.
- Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krijnen-Kemp, E., Towers, C., Romeo, R., Knapp, M.R.J. and Sanderson, H., 2005. *The impact of person centred planning*. Lancaster: Institute for Health Research, Lancaster University.
- Robinson, C.A., 2011. Advance care planning: re-visioning our ethical approach. *The Canadian journal of nursing research = Revue canadienne de recherche en sciences infirmieres*, 43(2), pp.18–37.

- Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J. and Exley, C., 2013. A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but...'. *Palliative Medicine*, 27(5), pp.401-408.
- Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., Howel, D. and Exley, C., 2012. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing*, 41(2), pp.263-269.
- Robson, C., 1993. *Real World Research: A Resource for Social Scientists and Practitioner-Researchers*, Massachusetts, Blackwell Publishers.
- Rolfe, G., 2006. Validity, trustworthiness and rigour: Quality and the idea of qualitative research. *Journal of Advanced Nursing*, 53(3), pp.304–310.
- Rolfe, G. & Davies, R., 2009. Second generation professional doctorates in nursing. *International Journal of Nursing Studies*, 46(9), pp.1265–1273.
- De Roo, M.L., Miccinesi, G., Onwuteaka-Philipsen, B.D., Van Den Noortgate, N., Van den Block, L., Bonacchi, A., Donker, G.A., Alonso, J.E.L., Moreels, S., Deliens, L. and Francke, A.L., 2014. Actual and preferred place of death of home-dwelling patients in four European countries: making sense of quality indicators. *PLoS One*, 9(4), p.e93762.
- Rosenberg, J., 2011. Whose Business is Dying ? Death, the Home and Palliative Care. *Cultural Studies Review*, 17(1), pp.15–30.
- Rosner, F., 2004. Informing the patient about a fatal disease: from paternalism to autonomy--the Jewish view. *Cancer investigation*, 22(6), pp.949–953.
- Rudestam, K.E. and Newton, R.R., 1992. Surviving your dissertation: A comprehensive guide to content and process. 1992. *Dissertations, Academic*.
- Ruijs, C.D., Kerkhof, A.J., van der Wal, G. and Onwuteaka-Philipsen, B.D., 2013. Symptoms, unbearable and the nature of suffering in terminal cancer patients dying at home: a prospective primary care study. *BMC family practice*, 14(1), p.1.
- Russell, S., 2014. Advance care planning: Whose agenda is it anyway? *Palliative Medicine*, 28(8), pp.997–999.

- Russell, S., 2015a. Do definitions matter in palliative care? *International journal of palliative nursing*, 21(4), pp.160–161.
- Russell, S., 2015b. It's like an oasis in the desert. *BMJ Supportive & Palliative Care*, 5(3), p.A77.
- Russell, S., 2015c. One size does not fit all for a good death. *International journal of palliative nursing*, 21(6), pp.306–307.
- Russell, S., 2012. Patient Centered Advance Care Planning. In *Current Issues in Palliative Care Spring Meeting, London*.
- Russell, S., 2016. Preparing and Planning for Dying: Whats the Difference? In *11th Palliative Care Congress*. Glasgow: Palliative Care Congress.
- Russell, S. et al., 2013. Real World Research: Challenges and Opportunities. In *Hospice Care: For the Future.*, Hospice UK Conference.
- Russell, S., 2015d. Why diversity matters in advance care planning. *International journal of palliative nursing*, 21(5), pp.234–235.
- Russell, S., Dickenson, A. & Thomas, H., 2016. Ethics, Reflexivity and the Continuous Conversation Framework. In *EAPC, Research Conference, Dublin - June 2016*.
- Russell, S. & Russell, R., 2007. Challenges in end-of-life communication in COPD Palliative care. , 4(2), pp.133–139.
- Ryan, F., Coughlan, M. and Cronin, P., 2007. Step-by-step guide to critiquing research. Part 2: qualitative research. *British journal of nursing*, 16(12), pp.738-745.
- Sabatino, C.P., 2010. The evolution of health care advance planning law and policy. *The Milbank quarterly*, 88(2), pp.211–239.
- Sallnow, L., Richardson, H., Murray, S.A. and Kellehear, A., 2015. The impact of a new public health approach to end-of-life care: a systematic review. *Palliative medicine*, p.0269216315599869.
- Sampson, E.L., Jones, L., Thuné-Boyle, I.C., Kukkastenvehmas, R., King, M., Leurent, B., Tookman, A. and Blanchard, M.R., 2011. Palliative assessment and advance care

- planning in severe dementia: an exploratory randomized controlled trial of a complex intervention. *Palliative Medicine*, 25(3), pp.197-209.
- Sampson, E.L. and Burns, A., 2013. Planning a personalised future with dementia: 'the misleading simplicity of advance directives'. *Palliative medicine*, 27(5), pp.387-388.
- Samsi, K. & Manthorpe, J., 2011. "I live for today": a qualitative study investigating older people's attitudes to advance planning. *Health & Social Care in the Community*, 19(1), pp.52-59.
- Sandelowski, M., 2000. Whatever happened to qualitative description? *Research in nursing & health*, 23(4), pp.334-340.
- Sanders, C., Rogers, A., Gately, C. and Kennedy, A., 2008. Planning for end of life care within lay-led chronic illness self-management training: the significance of 'death awareness' and biographical context in participant accounts. *Social Science & Medicine*, 66(4), pp.982-993.
- Sanders, S., Stensland, M., Dohrmann, J., Robinson, E. and Juraco, K., 2014. Barriers Associated with the Implementation of an Advance Care Planning Program in a Prison Setting. *Journal of social work in end-of-life & palliative care*, 10(4), pp.322-337.
- Sanderson, H. & Lewis, J., 2012. *A Practical Guide to Delivering Personlisation: Person Centred Practice in Health and Social Care*, London: Jessica Kingsley Publishers.
- Sandman, L., 2005. *A Good Death* 1st ed., Open University Press.
- Sarafis, P., Tsounis, A., Malliarou, M. and Lahana, E., 2014. Disclosing the truth: a dilemma between instilling hope and respecting patient autonomy in everyday clinical practice. *Global journal of health science*, 6(2), p.128.
- Schein, E., 2013. *Humble Inquiry: The Gentle Art of Asking Instead of Telling-*, Berrett-Koehler Publishers.
- Schell JO, Green JA, Tulsy JA, Arnold RM. Communication skills training for dialysis decision-making and end-of-life care in nephrology. *Clinical Journal of the American Society of Nephrology*. 2012 Nov 8:CJN-05220512.
- Schick Makaroff, K.L., 2013. The unsayable: a concept analysis. *Journal of Advanced Nursing*,

69(2), pp.481–492.

Schickedanz, A.D., Schillinger, D., Landefeld, C.S., Knight, S.J., Williams, B.A. and Sudore, R.L., 2009. A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers. *Journal of the American Geriatrics Society*, 57(1), pp.31-39.

Schofield, P.E., Butow, P.N., Thompson, J.F., Tattersall, M.H.N., Beeney, L.J. and Dunn, S.M., 2003. Psychological responses of patients receiving a diagnosis of cancer. *Annals of Oncology*, 14(1), pp.48-56.

Schon, D., 1983. *The reflective practitioner: How professionals think in action*, Basic books.

Schuck, S. & Kearney, M., 2006. Using digital video as a research tool: Ethical issues for researchers. *Journal of Educational Multimedia and Hypermedia*, 15(4), pp.447–463.

Seale, C., 2000. Changing patterns of death and dying. *Social science & medicine (1982)*, 51(6), pp.917–930.

Seale, C., 1991. Communication and awareness about death: a study of a random sample of dying people. *Social science & medicine (1982)*, 32(8), pp.943–952.

Seale, C., 2002. Quality Issues in Qualitative Inquiry. *Qualitative Social Work*, 1(1), pp.97–110.

Seale, C., 1998. Theories in health care and research: theories and studying the care of dying people. *BMJ (Clinical research ed.)*, 317(7171), pp.1518–1520.

Seale, C. & Addington-Hall, J., 1995. Dying at the best time. *Social science & medicine (1982)*, 40(5), pp.589–595.

Seale, C., Addington-Hall, J. & McCarthy, M., 1997. Awareness of dying: prevalence, causes and consequences. *Social science & medicine*, 45(3), pp.477–484.

Searight, H.R. & Gafford, J., 2005. Cultural diversity at the end of life: issues and guidelines for family physicians. *American family physician*, 71(3), pp.515–522.

Selecky, P.A., Eliasson, C.A.H., Hall, R.I., Schneider, R.F., Varkey, B. and McCaffree, D.R., 2005. Palliative and end-of-life care for patients with cardiopulmonary diseases:

- American College of Chest Physicians position statement. *CHEST Journal*, 128(5), pp.3599-3610.
- Selman, L., Harding, R., Beynon, T., Hodson, F., Coady, E., Hazeldine, C., Walton, M., Gibbs, L. and Higginson, I.J., 2007. Improving end-of-life care for patients with chronic heart failure: "Let's hope it'll get better, when I know in my heart of hearts it won't". *Heart*, 93(8), pp.963-967.
- Seminar, S.G., 2011. Salzburg statement on shared decision making. *BMJ (Clinical research ed.)*, 342(December 2010), p.d1745.
- Semino, E., Demjén, Z., Demmen, J., Koller, V., Payne, S., Hardie, A. and Rayson, P., 2015. The online use of Violence and Journey metaphors by patients with cancer, as compared with health professionals: a mixed methods study. *BMJ supportive & palliative care*, pp.bmjspcare-2014.
- Semino, E., Demjen, Z. & Koller, V., 2014. "Good" and "bad" deaths: Narratives and professional identities in interviews with hospice managers. *Discourse Studies*, 16(5), pp.667–685.
- Seymour J and Horne G, 2011. Advance Care Planning for the end of life:an overview. In T. K. and L. B, ed. *Advance Care Planning in End of Life Care*. Oxford University Press, pp. 16–27.
- Seymour, J., 2012. Combined qualitative and quantitative research designs. *Current opinion in supportive and palliative care*, 6(4), pp.514–524.
- Seymour, J., 2012. Looking back, looking forward: the evolution of palliative and end-of-life care in England. *Mortality*, 17(1), pp.1–17.
- Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S.H. and Clark, D., 2004. Planning for the end of life:: the views of older people about advance care statements. *Social science & medicine*, 59(1), pp.57-68.
- Seymour, J., Almack, K. & Kennedy, S., 2010a. Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC palliative care*, 9, p.4.

- Shah, A.B., Morrissey, R.P., Baraghoush, A., Bharadwaj, P., Phan, A., Hamilton, M., Kobashigawa, J. and Schwarz, E.R., 2013. Failing the failing heart: a review of palliative care in heart failure. *Reviews in cardiovascular medicine*, 14(1), pp.41-48.
- Shaha, M., Cox, C.L., Talman, K. and Kelly, D., 2008. Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of Nursing Scholarship*, 40(1), pp.60-67.
- Shalowitz, D.I., Garrett-Mayer, E. & Wendler, D., 2006. The accuracy of surrogate decision makers: a systematic review. *Archives of internal medicine*, 166(5), pp.493–497.
- Sharp, T., Moran, E., Kuhn, I. and Barclay, S., 2013. Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. *Br J Gen Pract*, 63(615), pp.e657-e668.
- Shatil, S.R., 2012. Terror management theory: Interplay between mortality salience, death-thoughts, and overall worldview defense. *Dissertation Abstracts International, B: Sciences and Engineering*, 72(7), p.4330.
- Shenton, A., 2004. Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22, pp.63–75.
- Shepperd, S., Wee, B. & Straus, S.E., 2011. Hospital at home: home-based end of life care. *The Cochrane database of systematic reviews*, (7), p.CD009231.
- Shrank, W.H., Kutner, J.S., Richardson, T., Mularski, R.A., Fischer, S. and Kagawa-Singer, M., 2005. Focus Group Findings about the Influence of Culture on Communication Preferences in End-of-Life Care. *Journal of General Internal Medicine*, 20(8), pp.703-709.
- Silva, C.H.M.D., Cunha, R.L.G., Tonaco, R.B., Cunha, T.M., Diniz, C.B., Domingos, G.G., Silva, J.D., Santos, M.V.V., Antoun, M.G. and Paula, R.L.D., 2003. Not telling the truth in the patient–physician relationship. *Bioethics*, 17(5-6), pp.417-424.
- Silva, E., Neves, M. & Silva, D., 2014. Nurses' perceptions of advance directives. *Atencion primaria / Sociedad Española de Medicina de Familia y Comunitaria*, 46 Suppl 5, pp.145–9.

- Silverman, D., 2013. *Doing qualitative research: A practical handbook*, SAGE Publications Limited.
- Silverman, D., 2006. *Interpreting qualitative data: Methods for analyzing talk, text and interaction.*, SAGE Publications Limited.
- Silverman, D. ed., 2010. *Qualitative research*. Sage.
- Silverman, D., 2013. What counts as qualitative Research? Some cautionary comments. *Qualitative Sociology Review*, 9(2), pp.48–55.
- Silverman, J., Kurtz, S.M. and Draper, J., 2005. *Skills for communicating with patients*. Oxford, UK: Radcliffe Pub..
- Simpson, M., Buckman, R., Stewart, M., Maguire, P., Lipkin, M., Novack, D. and Till, J., 1991. Doctor-patient communication: the Toronto consensus statement. *BMJ: British Medical Journal*, 303(6814), p.1385.
- Singer, P., Martin, D.K. & Lavery, J. V, 1998. Reconceptualizing Advance Care Planning From the Patient's Perspective. *Arch Intern Med*, 158, pp.879–884.
- Singer, T. & Lamm, C., 2009. The social neuroscience of empathy. *Annals of the New York Academy of Sciences*, 1156, pp.81–96.
- Sivell, S., Prout, H., Hopewell-Kelly, N., Baillie, J., Byrne, A., Edwards, M., Harrop, E., Noble, S., Sampson, C. and Nelson, A., 2015. Considerations and recommendations for conducting qualitative research interviews with palliative and end-of-life care patients in the home setting: a consensus paper. *BMJ supportive & palliative care*, pp.bmjspcare-2015.
- Skilbeck, J.K. & Payne, S., 2005. End of life care: a discursive analysis of specialist palliative care nursing. *Journal of advanced nursing*, 51(4), pp.325–334.
- Sleeman, K.E. & Collis, E., 2013. Caring for a dying patient in hospital. *BMJ (Clinical research ed.)*, 346(April), p.f2174..
- Smith, A., 2013. Unsettling the Privilege of Self-Reflexivity. *Geographies of privilege*, 11., p263.

- Smith, S., Brick, A., O'Hara, S. and Normand, C., 2014. Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative medicine*, 28(2), pp.130-150.
- Smyth, A. & Holian, R., 1999. The credibility of the researcher who does research in their own organisation: the perils of participant observation. In *Association of Qualitative research conference: Issue of rigour in qualitative research*. pp. 6–10.
- Solomon, D.N. & Hansen, L., 2015. Living through the end: The phenomenon of dying at home. *Palliative & supportive care*, 13(2), pp.125–134.
- Solomon, S., Greenberg, J. & Pyszczynski, T., 1991. Terror management theory of self-esteem. , (162), pp.21–40.
- Song, J., Ratner, E.R., Wall, M.M., Bartels, D.M., Ulvestad, N., Petroskas, D., West, M., Weber-Main, A.M., Grengs, L. and Gelberg, L., 2010. Effect of an end-of-life planning intervention on the completion of advance directives in homeless persons: A randomized trial. *Annals of internal medicine*, 153(2), pp.76-84.
- Sorsa, M.A., Kiikkala, I. & Astedt-Kurki, P., 2015. Bracketing as a skill in conducting unstructured qualitative interviews. *Nurse researcher*, 22(4), pp.8–12.
- Sparkes, A., 2002. Autoethnography: Self-indulgence or something more. In A. Bochner & C. Ellis, eds. *Ethnographically speaking: Autoethnography, literature, and aesthetics*. AltaMira Press,U.S, pp. 209–232.
- Stajduhar, K.I. & Davies, B., 2005. Variations in and factors influencing family members' decisions for palliative home care. *Palliative medicine*, 19(1), pp.21–32.
- van der Steen, J.T., Radbruch, L., Hertogh, C.M., de Boer, M.E., Hughes, J.C., Larkin, P., Francke, A.L., Jünger, S., Gove, D., Firth, P. and Koopmans, R.T., 2013. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative medicine*, p.0269216313493685.
- Stein, G.L. & Bonuck, K.A., 2001. Attitudes on end-of-life care and advance care planning in the lesbian and gay community. *Journal of palliative medicine*, 4(2), pp.173–190.

- Steinberg, S.M., 2011. Cultural and religious aspects of palliative care. *International journal of critical illness and injury science*, 1(2), pp.154–156.
- Steinhauser, K.E., Clipp, E.C., McNeilly, M., Christakis, N. a, McIntyre, L.M., et al., 2000. In search of a good death: observations of patients, families, and providers. *Annals of internal medicine*, 132(10), pp.825–32.
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., Grambow, S., Parker, J. and Tulsky, J.A., 2001. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *Journal of pain and symptom management*, 22(3), pp.727-737.
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., McIntyre, L. and Tulsky, J.A., 2000. Factors considered important at the end of life by patients, family, physicians, and other care providers. *Jama*, 284(19), pp.2476-2482.
- Stjernsward, J., 2007. Palliative care: the public health strategy. *Journal of public health policy*, 28(1), pp.42–55.
- Strauss AL and Corbin JM, 1990. *Basics of qualitative research. Vol 15* C. Newbury Park, ed., SAGE Publications Limited.
- Stuart, B., 2007. Palliative care and hospice in advanced heart failure. *Journal of palliative medicine*, 10(1), pp.210–228.
- Suchman, L., 1995. Making work visible. *Communications of the ACM*, 38(9), pp.56-64.
- Sundow, D., 1968. Passing on; the Social Organization of Dying. *Nursing Research*, 17(1), p.81.
- Sudore, R.L., Landefeld, C.S., Barnes, D.E., Lindquist, K., Williams, B.A., Brody, R. and Schillinger, D., 2007. An advance directive redesigned to meet the literacy level of most adults: a randomized trial. *Patient education and counseling*, 69(1), pp.165-195.
- Sudore, R.L., Stewart, A.L., Knight, S.J., McMahan, R.D., Feuz, M., Miao, Y. and Barnes, D.E., 2013. Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors. *PLoS One*, 8(9), p.e72465.
- Sudore, R.L., Schickedanz, A.D., Landefeld, C.S., Williams, B.A., Lindquist, K., Pantilat, S.Z.

- and Schillinger, D., 2008. Engagement in multiple steps of the advance care planning process: a descriptive study of diverse older adults. *Journal of the American Geriatrics Society*, 56(6), pp.1006-1013.
- Sudore, R.L. & Fried, T.R., 2010. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Annals of internal medicine*, 153(4), pp.256–261.
- Sulmasy, D.P., Terry, P.B., Weisman, C.S., Miller, D.J., Stallings, R.Y., Vettese, M.A. and Haller, K.B., 1998. The accuracy of substituted judgments in patients with terminal diagnoses. *Annals of Internal Medicine*, 128(8), pp.621-629.
- Surbone, A., 2004. Persisting differences in truth telling throughout the world. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, 12(3), pp.143–146.
- Swarbrick, P., Grinyer, A. and Payne, S., 2011. When a hospice is not a haven. *Progress in Palliative Care*, 19(1), pp.22-24.
- Swinglehurst, D., 2011. *The electronic patient record: a linguistic ethnographic study in general practice*. Doctoral Dissertation. Queen Mary University of London.
- 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, p.14.
- Tang, S.T., Liu, T.W., Lai, M.S., Liu, L.N. and Chen, C.H., 2005. Concordance of preferences for end-of-life care between terminally ill cancer patients and their family caregivers in Taiwan. *Journal of pain and symptom management*, 30(6), pp.510-518.
- Tang, S.T., 2002. Influencing factors of place of death among home care patients with cancer in Taiwan. *Cancer nursing*, 25(2), pp.158–166.
- Tang, S.T., Chang, W.C., Chen, J.S., Su, P.J., Hsieh, C.H. and Chou, W.C., 2014. Trajectory and predictors of quality of life during the dying process: roles of perceived sense of burden to others and posttraumatic growth. *Supportive Care in Cancer*, 22(11), pp.2957-2964.
- Tang, S.T. & McCorkle, R., 2002. Use of family proxies in quality of life research for cancer

- patients at the end of life: a literature review. *Cancer investigation*, 20(7-8), pp.1086–1104.
- Targum, S.D., 2011. The Distinction between Clinical and Research Interviews in Psychiatry. *Innovations in clinical neuroscience*, 8(3), pp.40–44.
- Taylor, B., 2013. *Advance care planning audit*, Berkhamsted.
- Teno, J., Lynn, J., Wenger, N., Phillips, R.S., Murphy, D.P., Connors, A.F., Desbiens, N., Fulkerson, W., Bellamy, P. and Knaus, W.A., 1997. Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention. *Journal of the American Geriatrics Society*, 45(4), pp.500-507.
- Teno, J.M., Lynn, J., Phillips, R.S., Murphy, D., Youngner, S.J., Bellamy, P., Connors Jr, A.F., Desbiens, N.A., Fulkerson, W. and Knaus, W.A., 1994. Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *The Journal of clinical ethics*, 5(1), p.23.
- Teno, J.M., Clarridge, B.R., Casey, V., Welch, L.C., Wetle, T., Shield, R. and Mor, V., 2004. Family perspectives on end-of-life care at the last place of care. *Jama*, 291(1), pp.88-93.
- Thai, V. & Cujec, B., 2010. Transitioning to end-of-life care for patients with advanced heart failure. *Journal of palliative medicine*, 13(7), p.796.
- The Independent Review of the Liverpool Care, 2013. *More Care: Less Pathway: A Review of the Liverpool Care Pathway*. Dept of Health, London.
- The Kings Fund, 2013. Patient-centred Leadership: rediscovering our purpose. *Kings Fund*, London.
- The Leadership Alliance for the Care of Dying, 2014. *One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life*, London.
- The Nuffield Trust, 2014. Exploring the cost of care at the end of life. Nuffield Trust, London.
- The Scottish Government., 2008. *LIVING AND DYING WELL: a national action plan for palliative and end of life care in Scotland*, Edinburgh: Healthier Scotland.

- Thomas, C., Reeve, J., Bingley, A., Brown, J., Payne, S. and Lynch, T., 2009. Narrative research methods in palliative care contexts: two case studies. *Journal of pain and symptom management*, 37(5), pp.788-796.
- Thomas, D.L. & Watson, J.M., 1998. Advance directives in a correctional setting. *Psychology, public policy, and law : an official law review of the University of Arizona College of Law and the University of Miami School of Law*, 4(3), pp.878–899.
- Thomas, J. & Harden, A., 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), p.45.
- Thomas, K., 2011. Overview and introduction to Advance Care Planning. In L. B. Thomas K, ed. *Advance Care Planning in End of Life Care*. Oxford University Press, pp. 4–15.
- Thorevska, N., Tilluckdharry, L., Tickoo, S., Havasi, A., Amoateng-Adjepong, Y. and Manthous, C.A., 2005. Patients' understanding of advance directives and cardiopulmonary resuscitation. *Journal of critical care*, 20(1), pp.26-34.
- Thorne, S., Reimer Kirkham, S. & O’Flynn-Magee, K., 2004. The Analytic Challenge in Interpretive Description. *International Journal of Qualitative Methods*, 3(1), pp.1–11.
- Tierney, W.M., Dexter, P.R., Gramelspacher, G.P., Perkins, A.J., Zhou, X.H. and Wolinsky, F.D., 2001. The effect of discussions about advance directives on patients' satisfaction with primary care. *Journal of General Internal Medicine*, 16(1), pp.32-40.
- Timmermans S, 1994. Dying of awareness: the theory of awareness contexts revisited. *Social Health Illness*, 3, pp.322 – 339.
- Tong, A., Sainsbury, P. & Craig, J., 2007. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), pp.349–357.
- Torjesen, I., 2008. End-of-life strategy to ensure quality care for dying patients. *Nursing times*, 104(30), pp.21–22.
- Torke, A.M., 2014. Building the evidence base for palliative care and dementia. *Palliative medicine*, 28(3), pp.195-196.
- Torrance, H., 2011. Qualitative research, science and government: Evidence, criteria, policy

- and politics. In N. K. Denzin & Y. S. Lincoln, eds. *The SAGE handbook of qualitative research*. SAGE Publications Limited., pp. 569–580.
- Toscani, F., Borreani, C., Boeri, P. and Miccinesi, G., 2003. Life at the end of life: beliefs about individual life after death and "good death" models-a qualitative study. *Health and quality of life outcomes*, 1(1), p.1.
- Trarieux-Signol, S., Moreau, S., Gourin, M.P., Penot, A., de Lafont, G.E., Preux, P.M. and Bordessoule, D., 2014. Factors associated with the designation of a health care proxy and writing advance directives for patients suffering from haematological malignancies. *BMC palliative care*, 13(1), p.1.
- Treloar, A., Crugel, M. and Adamis, D., 2009. Palliative and end of life care of dementia at home is feasible and rewarding Results from theHope for Home's study. *Dementia*, 8(3), pp.335-347.
- Tuffrey-Wijne, I., Whelton, R., Curfs, L. and Hollins, S., 2008. Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals. *Palliative Medicine*, 22(3), pp.281-290.
- Tulsky, J.A., Arnold, R.M., Alexander, S.C., Olsen, M.K., Jeffreys, A.S., Rodriguez, K.L., Skinner, C.S., Farrell, D., Abernethy, A.P. and Pollak, K.I., 2011. Enhancing communication between oncologists and patients with a computer-based training program: a randomized trial. *Annals of internal medicine*, 155(9), pp.593-601.
- Turner, M., Payne, S. & Barbarachild, Z., 2011. Care or custody? An evaluation of palliative care in prisons in North West England. *Palliative medicine*, 25(4), pp.370–377.
- Twycross, A., & Shields, L. (2005). Validity and reliability - what's it all about? Part 3 issues relating to qualitative studies. *Paediatric Nursing*, 17, pp.35-36.
- Ubel, P.A., Loewenstein, G., Schwarz, N. and Smith, D., 2005. Misimagining the unimaginable: the disability paradox and health care decision making. *Health Psychology*, 24(4S), p.S57-62
- Upadya, A., Muralidharan, V., Thorevska, N., Amoateng-Adjepong, Y. and Manthous, C.A., 2002. Patient, physician, and family member understanding of living wills. *American*

journal of respiratory and critical care medicine, 166(11), pp.1430-1435.

Vandervoort, A., Houttekier, D., Vander Stichele, R., van der Steen, J.T. and Van den Block, L., 2014. Quality of dying in nursing home residents dying with dementia: does advanced care planning matter? A nationwide postmortem study. *PloS one*, 9(3), p.e91130.

Verderber, S. & Refuerzo, B., 2003. *Innovations in hospice architecture*, Taylor and Francis.

Vig, E.K., Starks, H., Taylor, J.S., Hopley, E.K. and Fryer-Edwards, K., 2007. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *Journal of general internal medicine*, 22(9), pp.1274-1279.

Visser, C., Hadley, G. and Wee, B., 2015. Reality of evidence-based practice in palliative care. *Cancer biology & medicine*, 12(3), p.193.

De Vleminck, A., Pardon, K., Beernaert, K., Deschepper, R., Houttekier, D., Van Audenhove, C., Deliens, L. and Vander Stichele, R., 2014. Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences. *PloS one*, 9(1), p.e84905.

Vogel, L., 2011. End-of-life planning framework calls for fewer checklists. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*, 183(1), p.33.

Volandes, A.E., Paasche-Orlow, M., Gillick, M.R., Cook, E.F., Shaykevich, S., Abbo, E.D. and Lehmann, L., 2008. Health literacy not race predicts end-of-life care preferences. *Journal of palliative medicine*, 11(5), pp.754-762.

Volker, D.L., 2005. Control and end-of-life care: does ethnicity matter? *The American journal of hospice & palliative care*, 22(6), pp.442-446.

De Vries, B. & Blando, J.A., 2000. Friendship at the end of life. *Annual Review of Gerontology and Geriatrics*, 20(1), pp.144-162.

De Vries, B. & Johnson, C., 2002. The death of friends in later life. *Advances in life course research*, 7, pp.299-324.

Wahl, J., 2006. *Advance Care Planning in Ontario*. CBA Organisation. Ontario, Canada.

- Waite, K.R., Federman, A.D., McCarthy, D.M., Sudore, R., Curtis, L.M., Baker, D.W., Wilson, E.A., Hasnain-Wynia, R., Wolf, M.S. and Paasche-Orlow, M.K., 2013. Literacy and race as risk factors for low rates of advance directives in older adults. *Journal of the American Geriatrics Society*, 61(3), pp.403-406.
- Walczak, A., Butow, P.N., Clayton, J.M., Tattersall, M.H., Davidson, P.M., Young, J. and Epstein, R.M., 2014. Discussing prognosis and end-of-life care in the final year of life: a randomised controlled trial of a nurse-led communication support programme for patients and caregivers. *BMJ open*, 4(6), p.e005745.
- Walczak, A., Butow, P.N., Bu, S. and Clayton, J.M., 2016. A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work?. *Patient Education and Counseling*, 99(1), pp.3-16.
- Walker, R., 2008. A Neophyte 's Journey through Qualitative Analysis Using Morse ' s Cognitive Processes of Analysis., (1994), pp.81–93.
- Walling, A., Lorenz, K.A., Dy, S.M., Naeim, A., Sanati, H., Asch, S.M. and Wenger, N.S., 2008. Evidence-based recommendations for information and care planning in cancer care. *Journal of Clinical Oncology*, 26(23), pp.3896-3902.
- Walsh, D. & Downe, S., 2006. Appraising the quality of qualitative research. *Midwifery*, 22(2), pp.108–119.
- Walter, T., 2004. Body Worlds: clinical detachment and anatomical awe. *Sociology of health & illness*, 26(4), pp.464–488.
- Walter, T., 2003. Historical and cultural variants on the good death. *BMJ : British Medical Journal*, 327(July), pp.218–220.
- Walter, T., 2010. Jade and the journalists: media coverage of a young British celebrity dying of cancer. *Social science & medicine (1982)*, 71(5), pp.853–860.
- Walter, T., 1991. Modern death: taboo or not taboo?. *Sociology*, 25(2), pp.293–310.
- Walters, G., 2004. Is there such a thing as a good death? *Palliative medicine*, 18(5), pp.404–408.
- Webb, W.A., 2015. When dying at home is not an option: exploration of hostel staff views

- on palliative care for homeless people. *International journal of palliative nursing*, 21(5), pp.236–244.
- Weiner, S.J., Schwartz, A., Cyrus, K., Binns–Calvey, A., Weaver, F.M., Sharma, G. and Yudkowsky, R., 2013. Unannounced standardized patient assessment of the roter interaction analysis system: the challenge of measuring patient-centered communication. *Journal of general internal medicine*, 28(2), pp.254-260.
- Weissman, D.E. & Block, S.D., 2002. ACGME requirements for end-of-life training in selected residency and fellowship programs: a status report. *Academic medicine : journal of the Association of American Medical Colleges*, 77(4), pp.299–304.
- Weitzman, E.A. & Miles, M., 1995. Choosing software for qualitative data analysis: An overview. *Field Methods*, 7(2), pp.1–5.
- Wenrich, M.D., Curtis, J.R., Shannon, S.E., Carline, J.D., Ambrozy, D.M. and Ramsey, P.G., 2001. Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death. *Archives of Internal Medicine*, 161(6), pp.868-874.
- Westley, C. & Briggs, L., 2004. Using the stages of change model to improve communication about advance care planning. *Nursing Forum*, 39(3), pp.5–12.
- Whellan, D.J., Goodlin, S.J., Dickinson, M.G., Heidenreich, P.A., Jaenicke, C., Stough, W.G., Rich, M.W., Quality of Care Committee and Heart Failure Society of America, 2014. End-of-life care in patients with heart failure. *Journal of cardiac failure*, 20(2), pp.121-134.
- Wiles, R., Crow, G., Charles, V. and Heath, S., 2007. Informed consent and the research process: following rules or striking balances?. *Sociological Research Online*, 12(2).
- Wiles, R., Crow, G., Heath, S. and Charles, V., 2008. The management of confidentiality and anonymity in social research. *International Journal of Social Research Methodology*, 11(5), pp.417-428.
- Wilkie, P., 1997. Ethical issues in qualitative research in palliative care. *Palliative medicine*, 11(4), pp.321–324.
- Wilkinson, D.J., 2011. Shedding light on the gray zone. *The American journal of bioethics* :

- AJOB, 11(2), pp.W3–5.
- Wilkinson, S., 1991. Factors which influence how nurses communicate with cancer patients. *Journal of advanced nursing*, 16(6), pp.677–688.
- Wilkinson, S.M., Gambles, M. & Roberts, A., 2002. The essence of cancer care: the impact of training on nurses' ability to communicate effectively. *Journal of advanced nursing*, 40(6), pp.731–8.
- Williams, A., 2002. Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space. *Social science & medicine (1982)*, 55(1), pp.141–154.
- Wilson, F., Ingleton, C., Gott, M. and Gardiner, C., 2014. Autonomy and choice in palliative care: time for a new model?. *Journal of advanced nursing*, 70(5), pp.1020-1029.
- Winston, C.A., Leshner, P., Kramer, J. and Allen, G., 2005. Overcoming barriers to access and utilization of hospice and palliative care services in African-American communities. *OMEGA-Journal of Death and Dying*, 50(2), pp.151-163.
- Winter, L., Parks, S.M. & Diamond, J.J., 2010. Ask a different question, get a different answer: why living wills are poor guides to care preferences at the end of life. *Journal of palliative medicine*, 13(5), pp.567–572.
- Winterburn, S. & Wilkinson, S., 2011. The challenges and rewards of communication skills training for oncology and palliative care nurses in the United Kingdom. In D. Kissane et al., eds. *Handbook of communication in oncology and palliative care*. Oxford: Oxford University Press, pp. 425–438.
- Winzelberg, G.S., Hanson, L.C. & Tulsky, J.A., 2005. Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *Journal of the American Geriatrics Society*, 53(6), pp.1046–1050.
- Wise, J., 2014. Dying at home is not more expensive, Nuffield report finds. *Bmj*, 349(sep26 9), pp.g5902–g5902.
- Wong, W.K.T. & Ussher, J., 2009. Bereaved informal cancer carers making sense of their palliative care experiences at home. *Health & social care in the community*, 17(3),

pp.274–282.

Woods, S., 2007. *Deaths Dominion: Ethics at the end of life* 1st ed., Open University Press.

Workforce New Zealand., 2015. *Level 2 Advance Care Planning Practitioner Training Review Health Workforce New Zealand,*

World Health Organization, 2014. Preventing suicide. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*, 143(7), pp.609–610.

Worpole, K., 2009. *Modern hospice design: the architecture of palliative care*, Routledge.

Wright, A.A., Zhang, B., Ray, A., Mack, J.W., Trice, E., Balboni, T., Mitchell, S.L., Jackson, V.A., Block, S.D., Maciejewski, P.K. and Prigerson, H.G., 2008. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Jama*, 300(14), pp.1665-1673.

Wright, D.N., Hopkinson, J.B., Corner, J.L. and Foster, C.L., 2006. How to involve cancer patients at the end of life as co-researchers. *Palliative Medicine*, 20(8), pp.821-827.

Wright, K., 2003. Relationships with death: the terminally ill talk about dying. *Journal of marital and family therapy*, 29(4), pp.439–453.

Yardley, L., 2000. Dilemmas in qualitative health research. *Psychology and health*, 15(2), pp.215–228.

Yohannes, A.M., 2007. Palliative care provision for patients with chronic obstructive pulmonary disease. *Health and quality of life outcomes*, 5, p.17.

Young, E., Seale, C. & Bury, M., 1998. "It's not like family going is it?": Negotiating friendship boundaries towards the end of life. *Mortality*, 3(1), pp.27–42.

Zhou, G. et al., 2010. Knowledge, attitudes, and practice behaviors of oncology advanced practice nurses regarding advanced care planning for patients with cancer. *Oncology nursing forum*, 37(6), pp.E400–10.

Zimmermann, C., 2012. Acceptance of dying: a discourse analysis of palliative care literature. *Social science & medicine (1982)*, 75(1), pp.217–224.

Zimmermann, C., 2007. Death denial: obstacle or instrument for palliative care? An analysis

of clinical literature. *Sociology of Health & Illness*, 29(2), pp.297–314.

Zimmermann, C. & Rodin, G., 2004. The denial of death thesis: sociological critique and implications for palliative care. *Palliative medicine*, 18(2), pp.121–128.

Appendices

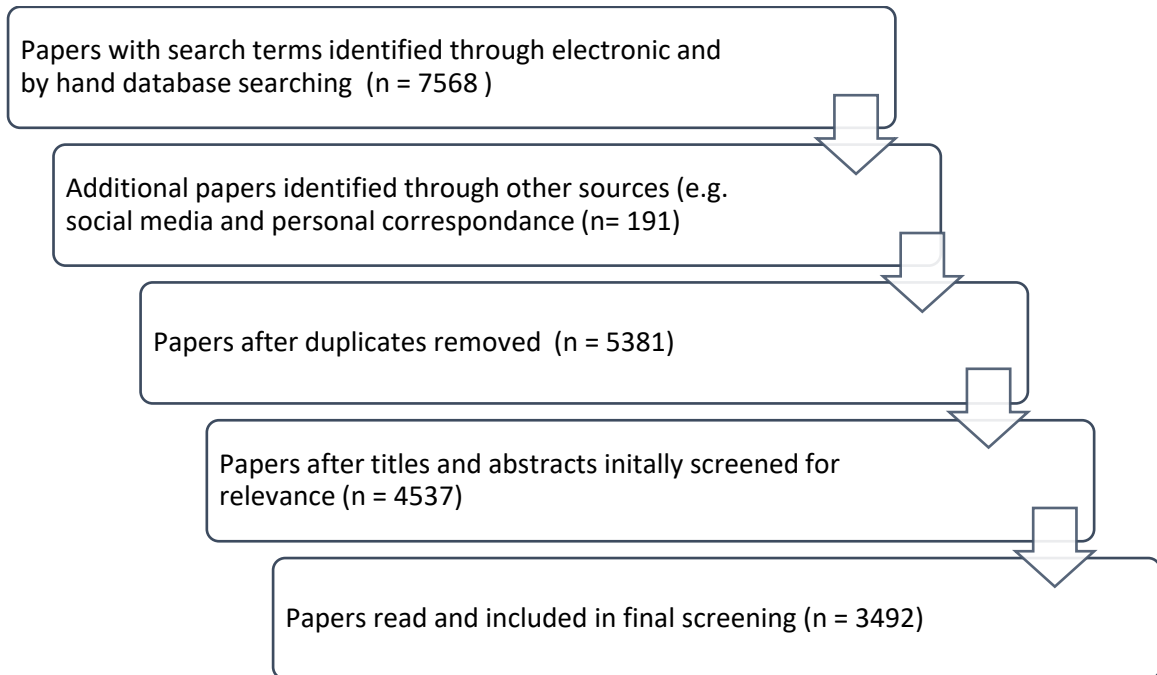
Appendix 1: examples of international terms for advance care planning

<i>These examples illustrate the variety of international terms and legal frameworks for advance care planning</i>					
Location	Overarching Terms			Legal Framework	
	<i>The Process</i>	<i>Preferences and wishes</i>	<i>Refusal of Treatment</i>	<i>Proxy Titles</i>	<i>Relevant Act or Statute</i>
England & Wales	Advance Care Planning	Advance Statements	Advance Decision to Refuse Treatment (ADRT)	Lasting Power of Attorney <ul style="list-style-type: none"> • Property & Affairs • Personal Welfare 	Mental Capacity Act (2005) implemented 2007
Scotland	Anticipatory or Advance Care Planning	Living Will Advance Directive Advance Decision		Power of Attorney <ul style="list-style-type: none"> • Financial/Property (Continuing Powers) • Personal Welfare 	Adults with Incapacity Act (2000)
Australia	Advance Care Planning	Advance Directive		Enduring Medical Power of Attorney Enduring Guardian	Medical Treatment Act (1988)
United States of America	Advance Care Planning	Advance Directives Living Will		Durable Power of Attorney	Patient Self Determination Act (1991)
Canada	Advance Care Planning	Living Wills Advance Directives, Personal Directive Health Care Directive		No overarching national federal law – locally developed provincial and territorial areas of responsibility	

Appendix 2: seminal cases in advance care planning history

<i>These seminal cases illustrate the drive to provide legislative and clinical frameworks when there was a need to plan for clinical decision making in the face of possible future incapacity</i>	
Karen Ann Quinlan	In 1975, Karen Ann, a 21-year-old American woman was in a persistent vegetative state following a cardio pulmonary arrest after the ingestion of drugs and alcohol. Her parents were eventually granted the right (on her behalf) to withdraw her from life support by the New Jersey Supreme court in 1976 and she lived breathing unaided until her death in 1985. One of the main issues in this case was whether surrogates could exercise the right to refuse treatments on behalf of others
Nancy Cruzan	In 1983, Nancy, a 27-year-old American woman from Missouri was in a persistent vegetative state following a car accident. The United States Supreme Court upheld the Missouri Department of Health's rejection of Nancy's parents request to withdraw her artificial feeding tube. Eventually in December 1990, Nancy's parents request was upheld due to 'clear and convincing' evidence that this would have been her wish and she died 12 days later after her artificial feeding was discontinued. One of the key issues in her case was the need to provide 'clear and convincing' evidence of an incompetent patient's wishes before removing life support
Terri Schiavo	In 1990, Terri Schiavo, a 26-year-old American woman was in persistent vegetative state following a cardiac arrest. In the years that followed until her death in 2005 (after the withdrawal of artificial feeding) there was a myriad of medical, ethical, and legal debates about what was known about her wishes and preferences and who had the right to speak for her. One of the key issues in her case was that the courts based their decisions on her previously expressed wishes, not on judgments on the value of her life
Tony Bland	In 1989, Tony, an 18-year-old English man was in persistent vegetative state (receiving artificial nutrition and hydration and showing no signs of brain activity) after being crushed at the Hillsborough football disaster. Tony Bland's parents, his consultant and Airedale NHS Trust applied to the English courts for the withdrawal of nutrition, hydration and other life sustaining measures. In November 1992 a legal ruling allowed the withdrawal of treatment and he died in March 1993. One of the consequences of the case was a hotly disputed debate as to whether withholding or withdrawing treatment constituted a form of euthanasia
(Jankowski 2014; Jox 2011; Noah 2013)	

Appendix 3: summary of literature search strategy based upon PRISMA (2009)



Appendix 4: dying and illness trajectories concepts

<i>Glaser and Strauss (1966) present the concept of a dying trajectory of:</i>	
certain death at a known time	certain death at an unknown time
uncertain death but a known time when certainty will be established	uncertain death and an unknown time when the question will be resolved

<i>Illness trajectories suggest various patterns of decline at the end of life: (Murray et al. 2005; Lunney et al. 2003; Lunney and Lynn 2010; Lynn and Anderson 2003)</i>	
Cancer	short period of evident decline
Organ failure	long term limitations with intermittent serious episodes
Frailty	prolonged dwindling

Appendix 5: dying awareness

<p><i>Dying awareness is the degree in which a person is aware of their impending death and or the extent to which their family share or deny this awareness</i></p> <p><i>(Glaser and Strauss 1966; Timmermans 1994)</i></p>	
Closed	Patient does not recognise or denies that they are dying, although everyone else knows
Suspected	Patient suspects what others know and attempts to confirm or negate it
Mutual pretence	Everyone knows that the patient is dying but pretend to each other they do not know
Open	Everyone admits that death is inevitable and behaves accordingly
Suspended open	Where the patient and family disregard the information given to them and are in denial – this may be a temporary coping reaction
Uncertain open	Where the patient and family overlook the negative aspects of information and hope for the best
Active open	The reality of the information about dying is accepted and everyone acts and behaves accordingly

Appendix 6: publication list

These examples illustrate on-going practice, policy, research and education interaction.

Books, Chapters and Patient Information:

Sanderson H and Russell S (eds) (in press due 2016) Personalization in End of Life Care, Jessica Kingsley Publications.

Russell S and Loney J (in press due 2016) 'Care in the last hours and days of life' in Johnston J, Preston N and Walsh N (eds) Book Chapter in Palliative Nursing: Principles and Evidence for Practice, Open University Press

Russell S and Sanderson H (June 2015) Advance Care Planning Trigger Cards, Helen Sanderson Associates and Fink Publications.

Russell S main author (2015) – 'Coping with the final stages of chronic lung disease' – British Lung Foundation (1st version 2008, updated 2015)

Russell S (2012) 'Thinking about the Future' in 'Looking after Me': Target Ovarian Cancer A Guide for Women with terminal ovarian cancer (Highly commended in BMA Patient Information Awards Sept 2014)

Bevan J, Fowler C, Russell S (2010) 'Communication Skills and Advance Care Planning' Book Chapter in Thomas K, Lobo B: Advance Care Planning in End of Life Care, Oxford University Press.

Russell S, Knowles V (2009) 'Palliative Care and COPD' Book Chapter in Palliative Care: Enhancing the Spectrum of Care, Blackwell Publishing.

Russell S (2006) 'End Stage Palliative Care' Book Chapter in Russell R, Ford P, Barnes PJ 'COPD: A guide to total patient care' Current Medicine Group, London.

Journal Publications:

Russell S, Middleton-Green L, Johnston B. (2016) 'Using social media to create discussion' International Journal of Palliative Nursing. 2015 Nov;21(11):525-6

Russell S (2015) 'One Size does not fit all for a good death' International Journal of Palliative Nursing, Vol 21, No 6:306-307

Russell S (2015) 'Why diversity matters in advance care planning' International Journal of Palliative Nursing Vol 21, No 5:234 - 235

Russell S (2015) 'Do Definitions matter in palliative care?' International Journal of Palliative Nursing Vol 21, No4:160-161

Russell S (2014) 'Advance Care Planning: Whose Agenda is it anyway?' Palliative Medicine 28 (8):997 - 999

Taylor R, Russell S, Richardson H (2014) 'We are marching in.' International Journal of Palliative Nursing Vol 20, No 2:96

Chadwick S and Russell S (2012) 'Providing Palliative Care in advanced respiratory disease – the experience of one hospice'. European Journal of Palliative Care. Vol 19 No 3: 110 – 114

Taylor R and Russell S (2010) 'Does the new GMC Guidance on good practice and decision making in end of life care go far enough?' International Journal of Palliative Nursing Vol 16, No: 264

Russell S (2008) 'Policy and non-cancer palliative care'. Practice Nurse 35(8):42-7

Russell SJF and Russell REK (2007) 'Challenges of end of life communication in COPD'. Breathe Vol 4 No 2:133 – 139

Russell S (1997) 'Dignity to the End' Nursing Times, Nov 26, Vol 93: 34 –5.

E learning and Videos:

@WeEOLC #WeEOLC launch video as part of the @WeCommunities

https://www.youtube.com/watch?v=SIQiTnckzQA&feature=em-upload_owner

Dementia Friendly Sway (Sept 2015) <https://m.youtube.com/watch?rel=0&v=Br3Gli5FZl8>

National E Learning for Health in End of Life Care (Planned for April 2016 onwards) Review of NHS East of England ABC End of Life Education Programme 7 Modules: update and reduce, produce pathway and evaluation methods, communication action plan.

National E Learning for Health in End of Life Care (2015) Review of ACP and different trajectories

National E Learning for Health in End of Life Care (2015) Review of ACP in practice: using end of life care tools

National E Learning for Health in End of Life Care (2015) Review of Culture and Communication

Russell S (2014) Bridging the Gap: Communication skills

www.heatherwoodandwexham.nhs.uk/bridging-the-gap

NHS East of England ABC End of Life Education Programme (EPIC) e learning modules (2014) Caring in the Last Days of Life: content and evaluation design of whole programme

<http://www.endoflifecarelearning.co.uk/login/index.php>

NHS East of England ABC End of Life Education Programme (EPIC) e learning modules (2010)

Advance Care Planning module: content and evaluation design of whole programme

<http://www.endoflifecarelearning.co.uk/login/index.php>

National E Learning for Health in End of Life Care (2010) e learning module: Communication for staff and volunteers <http://www.e-lfh.org.uk/projects/e-elca/index.html>

National and International Conference Presentations:

Russell S (2016) Person centred advance care planning at Inaugural End of Life Conference, Doncaster CCG.

Faull C and Russell S (2016) E-Elca Masterclass at 11th Palliative Care Congress, Glasgow <http://www.pccongress.org.uk/>

Noble B and Russell S (2016) Facilitating research in hospices Masterclass at 11th Palliative Care Congress, Glasgow <http://www.pccongress.org.uk/>

Russell S (September 2015) 'Having the Right words to say- communication skills in advance care planning' at 'No Decision about me- - without me' Gold Standards Framework Annual Conference, London.

Russell S (June 2015) 'Advance care planning: whose agenda is it anyway?' Independent Specialist Palliative Care Nurses Group, Manchester

Russell S (2012) 'Patient Centered Advance Care Planning', Current Issues in Palliative Care Spring Meeting, London

Russell S, Hemming L, Tshuma B (2012) 'Regional Approaches to good pain management'. 7th Annual Conference on Dementia and End of Life Care, National Council for Palliative Care, Dying Matters

Russell S (2011) 'ABC End of Life Care Education programme'. Presentation at National End of Life Care Celebrating Communication Conference, London.

Bevan J, Fowler C, Russell S (2011) 'Communicating Advance Care Planning', Oral Presentation to International Advance Care Planning Conference June.

Russell S, Fowler C (2011) 'Beds and Herts Advance Care Planning' Educational Model Workshop presentation to International Advance Care Planning Conference, London.

Chadwick S, Miller B, Russell S (2011) 'The Impact on the Place of Death through Advance Care Planning Documentation in Heart Failure and End Stage Respiratory Disease patients'. Oral Presentation to International Advance Care Planning Conference June.

Russell S (2009) 'Taking it Forward: Advance Care Planning'. Plenary Speaker at Iain Rennie Hospice at Home national conference.

Fernandes J and Russell S (2009) Spheres of Influence. Oral presentation to Help the Hospices conference, Harrogate.

Russell S, Hemming L (2008) 'Working together: Delivering Advanced Communication Skills Training' - Presentation to RCN Partners in Practice Conference, Blackpool.

Russell S (2008) Invited speaker 4th International Primary Care Respiratory Group (IPCRG) – 'Severe COPD. The final stage'

Russell S (2008) 'Celebrating successful partnership' University of Hertfordshire pre-registered Nursing Students conference.

Russell S (2007) Invited speaker to the European Respiratory Society Annual Conference – 'COPD and Palliative Care – The Patient and Carer Experience'

Russell S, Russell R (2004) 'Non Malignant Respiratory Care' – Invited speaker at Royal College of Nursing Respiratory Matters Annual Conference

National and International Conference Posters:

Russell S (2016) Preparing and Planning for Dying: What's the Difference? Poster at 11th Palliative Care Congress, Glasgow <http://www.pccongress.org.uk/>

Russell (2013) 'ABC of End of Life Education'. Poster at Future of Health: Meeting the Challenge of Long Term Conditions, NHS England

Russell S (2013) 'Blending Learning through an e-learning mentor support programme'. Poster at 13th World Congress of the European Association for Palliative Care, Prague.

Russell S, Loney J, Miller H, Nicell C, Willoughby J (2013) 'Making the Difference: An Alternative Care Home Education Approach': Poster at Hospice Care: For the Future Conference.

Russell S, Chadwick S, Hoddell K, Miller B, Nmeth E, Taylor R, McLaughlin K, Woodwark C (2013) Real World Research: Challenges and Opportunities: Poster at Hospice Care: For the Future Conference (awarded conference poster prize)

Russell S, Doyle C, Harris EJ, Convey V (2011) 'The ABC to Education: Collaborating, Coordinating and Contributing to End of Life Care'. Poster to Help the Hospices Conference, Bournemouth

Russell S, Fernandes J, Doughty J (2011) 'Fundraising Matters: Communication Skills Training for Non Clinical Hospice Staff ' Poster to Help the Hospices Conference, Bournemouth

Russell S, Willoughby J (2011) 'Documenting Advance Care Planning in the Hospice setting' Poster to Help the Hospices Conference, Bournemouth

Garrod L and Russell S (2011) 'End of Life Quality Matters (EOLQM): A Quality Improvement programme in Hertfordshire'. Poster at Help the Hospices conference, Bournemouth

Russell S, Carruthers L, Moss B, Alban Jones C (2011) 'End of Life Advanced Communication Skills programme.' Poster at National End of Life Care Celebrating Communication Conference, London

Russell S and Gontier J (2011) 'Palliative Care Competency Programme One: Collaboratively Sustaining and Developing Care'. Poster at European association for Palliative Care Congress, Lisbon.

Loney J, Miller H, Willoughby J, Russell S (2011) 'ACP: More than a burial or a cremation!' Poster at International Advance Care Planning Conference June.

Miller H, Nicell C, Loney J, and Willoughby J, Russell S (2011) 'Nursing Homes: How can we facilitate vital and effective end of life care and education to their staff and residents?' Poster at 3rd National Facilitator Conference, London

Russell S (2010) '1st Contact: The Video Interview Method in Advance Care Planning Research'. Poster at European association for Palliative Care Congress. Glasgow

Russell S, Ajuo C; Boyle S, Brown A; Bull M, Murray L, Pointu A, Whiting L (2009) 'Pathway to the future : The professional doctorate in health research (DHRes)'. Poster to RCN research conference, Cardiff

Russell S, Fowler C, Hemming L, Savage M, Plummer S (2009) 'Working Together: Challenges and Opportunities in delivering and designing Communication Skills Training across one UK Cancer network'. Poster to European association of palliative care conference, Vienna

Russell S, Taylor R, De Silva C, Satterwaite H, Ritter M (2009) 'Dying to talk – engaging the public in advance care planning' Poster to European association of palliative care conference, Vienna

Taylor R, Chadwick S, Russell S (Nov 2009) 'RAPT – Rapid Access Palliative Training – All you need to know about death and dying in 2 days!' Accepted poster to Help the Hospices Conference, Harrogate

Russell S, Fowler C, Hemming L, Savage M, Plummer S (2008) 'Working Together' Poster to Mount Vernon Cancer Network End of Life Conference

Chadwick S, Russell S (2008) 'Inspiring Care' Poster to International Congress on Palliative Care, Montreal, Canada

**Appendix 7a: summary of participants' contribution to the study themes:
living with dying**

Participants	Unfamiliar with term	Knowledge of inevitable death	Constant Companion	Personal Context	Uncertainty of timing of death	Emotional resilience
Mary	x	x	x	x	x	x
Mabel	x	x	x	x	x	x
Florence	x	x	x	x	x	x
Frances			x	x	x	
Keith	x	x	x	x	x	
Alfred	x	x			x	x
Andrew			x	x	x	x
Sally		x	x	x	x	
Liv		x	x	x	x	x
Anne	x		x	x	x	x
Christine		x	x	x	x	x
Mandy	x		x	x	x	x
Ernest	x	x	x	x		x
Jacky	x	x	x	x	x	x
Edward	x	x	x	x	x	x
	10	11	14	14	14	12

**Appendix 7b: summary of participants' contribution to the study themes:
preparing and planning for dying**

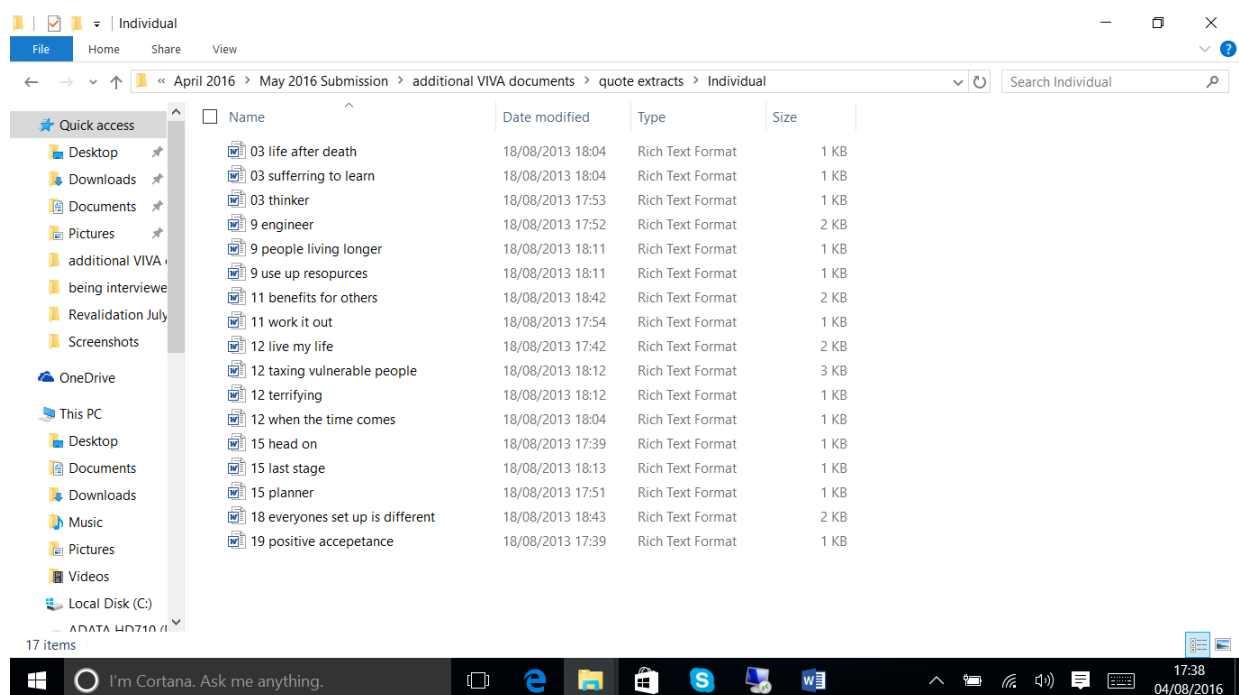
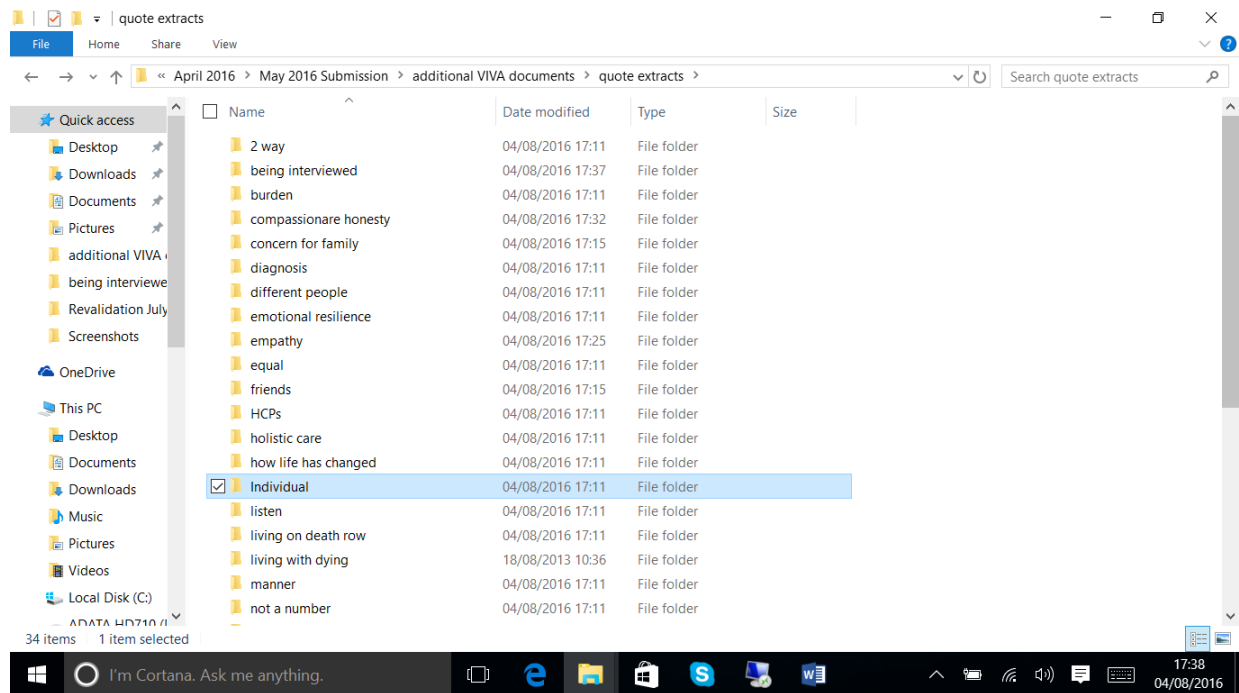
<i>Preparing for dying</i>					<i>Planning for dying</i>		
Participants	individual approach	Mental preparation	Friendships	Family responsibilities	Dying at home	Future needs of children	Planning for suicide
Mary	X	X	X	X	X	X	X
Mabel	X	X	X		X	X	X
Florence	X	X	X		X	X	X
Frances	X		X	X	X	X	X
Keith		X	X	X	X		X
Alfred	X	X	X		X		X
Andrew	X	X	X	X	X	X	X
Sally	X				X		X
Liv	X	X			X	X	
Anne			X	X	X	X	
Christine	X	X		X	X		X
Mandy	X	X	X	X	X	X	X
Ernest		X			X	X	
Jacky	X	X	X	X	X	X	
Edward	X	X	X	X	X	X	
	12	12	11	09	15	11	10

Appendix 7c: summary of participants' contribution to the study themes:
clinicians' communication

Participants	Empathy			Tailored conversations	
	Defining and benefits of	Mutual connection	Visible behaviour	Honesty	Design and use of space
Mary	X	X	X	X	X
Mabel	X	X	X	X	X
Florence	X	X	X	X	X
Frances	X	X	X	X	X
Keith	X	X	X	X	X
Alfred	X	X	X	X	
Andrew		X	X	X	X
Sally		X	X	X	
Liv	X	X	X	X	X
Anne	X	X	X	X	X
Christine	X	X	X	X	X
Mandy	X	X	X	X	X
Ernest		X	X	X	
Jacky	X	X	X	X	X
Edward		X	X	X	X
	11	15	15	15	12

Appendix 7d: examples of data driven thematic analysis process

Example of individual context



P15:

i by nature.. i said before i project manage . trained project manager means im a bit of a planner ... bit of an anal (laugh)planner

α<305890>S gantt chart woman

α<307017>P15 sl2 exactly so i .. it would be in my nature to want to know and control to some extent ↑what is going to happen in the future .

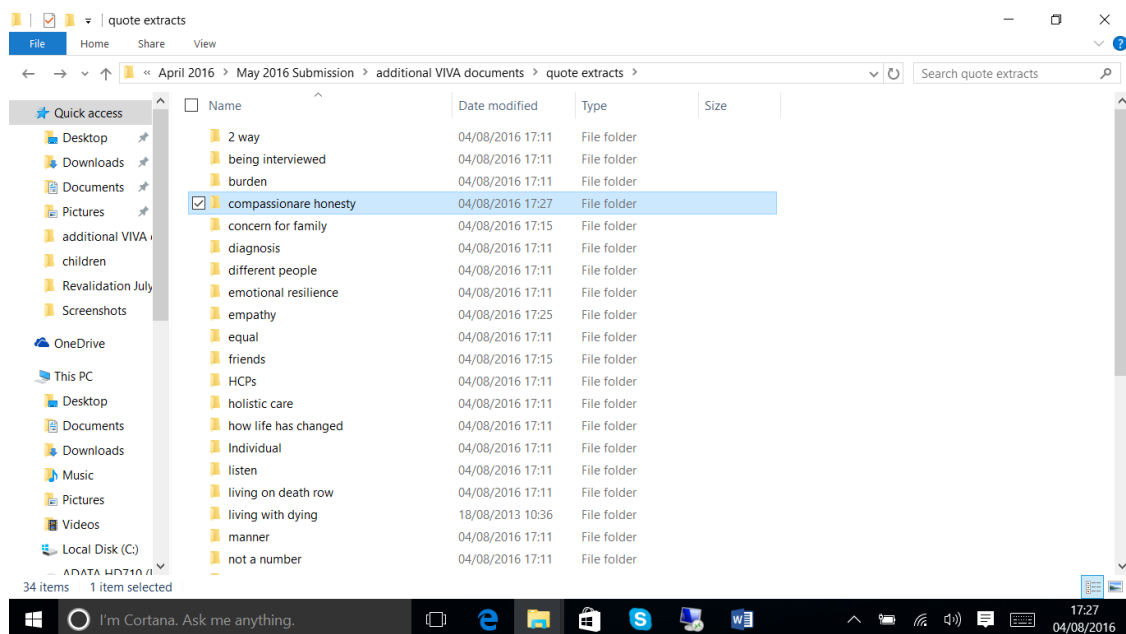
P11:

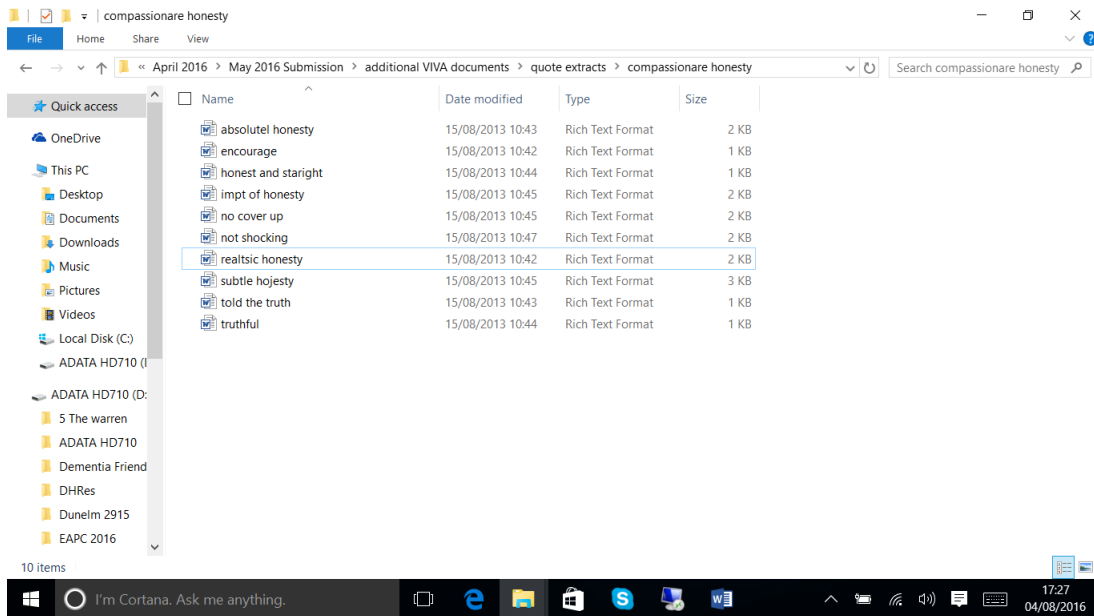
«<1008343>s so how so how do you manage with that what helps you manage
«<1012449>11 its the type of person i am i think ..um..whenever i have problems ...i don't
talk about it ...straightway ..i go through it in my head ..work it out what i can do..how is it
..or all sorts of things ..if theres anything i can't do ..my way accept itso..i mull it all over
...no answer ..i think nothing you can do .but accept itthats the kind of person i am
.....i'm not ...

P19:

and i would say .hat what happened with doctor doctor xx he has no bedside manner ..it
was purely you know ...er do you live on your own ...no..er..well you have prostate cancer
and .its advanced in fact aggressive i think he said and its now in your pelvis that was
it..theres the book ...and your being implants and theres your prescription and it was and in
actual fact for me that was excellent ..being an engineer telling you the steps ...for someone
else may have been ..may have had a more gentle approach

Example of clinician's honesty

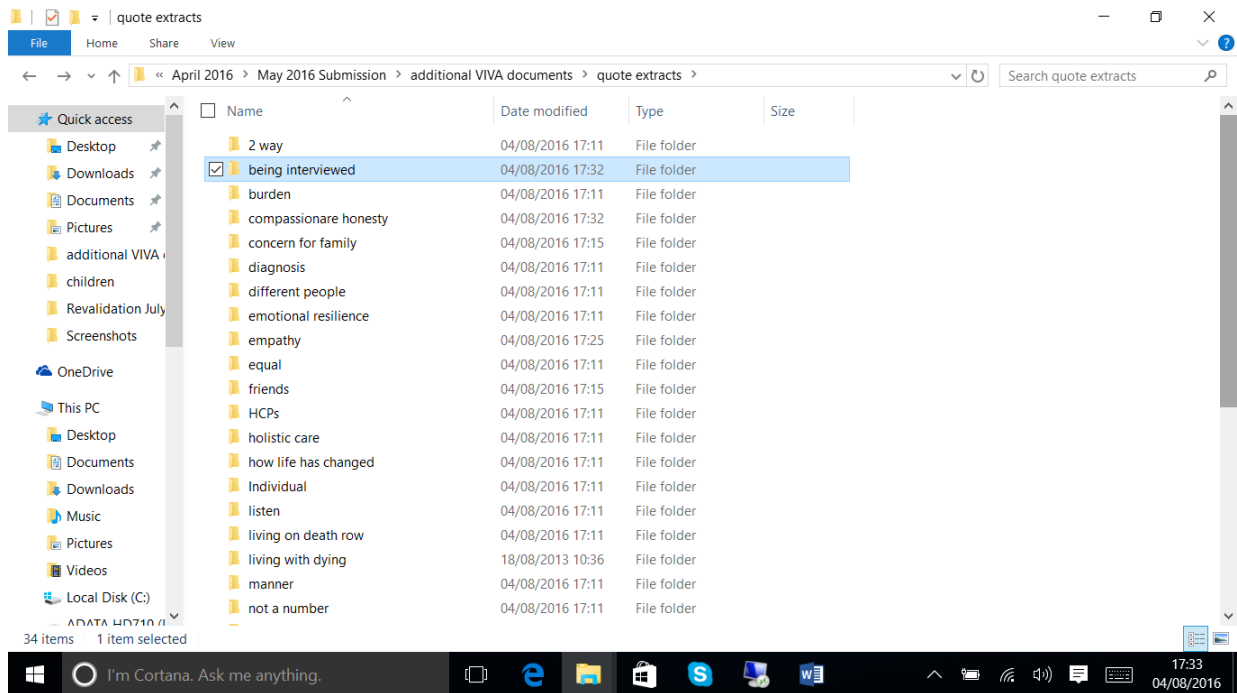


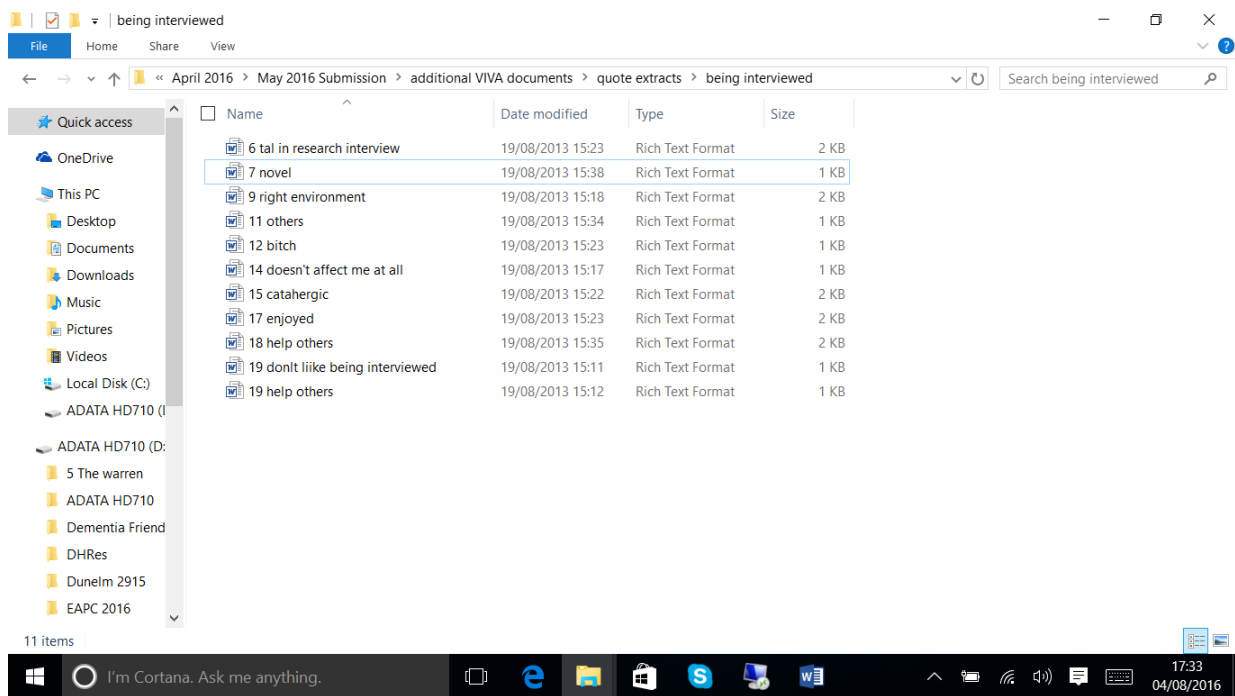


P15:

my surgeon i do trust .. um implicitly because he seems to have been pretty honest down the line when i've asked him .. something. a direct question . he has often been very direct back to me
 \llcorner1566861>S and when you say honest and direct can you just give me an example
 \llcorner1570319>P15 so for example i've given him the same example i gave you which is ..•im not wanting to know for just any old reason im actually wanting to know certain time scales from you because i have fairly important decisions i want to make based on that..• i would go back to work ... possibly.. but not definatley based on the length of time you think it will take for me to have to need treatment again..
 \llcorner1595904>S um

Example of being interviewed





P07:

s how's it been being video interveiwed on this subject

«2111799>07 oh novel (laugh)

«2115094>s is that the video or is that the subject

«2116855>07 oh no it puts you on the back foot ...thats all but you soon get used to it i mean its only tiny interview not for hours (inaudible)

P19:

but as i say if this can be of any help to any other people in the future then fantastic umm thats it you know....er....you know i think the hospoce does great stuff and all hospoces all of the charities that are trying to help people with cancer so you know anything that i can do to help is great...

P19:

«2079785>SR: ok..and today ...hows it been interviewed videointerviewed about this subject? whats it been like for you?

«2088780>19:well its a bit difficult you know...its not really something that iwould choose to do I don;t really like being interviewed anyway...erm....

P12:

«2040347>s; um so i would just like to turn to ..how does it feel ..like to be interviewed and videoed interviewed about this type of ...subject...how has it been for you

«2050884>12; absolutely fine um i don;t feel stressed or difficult its actually quite nice to have the space tpo bitch about the consultant ..who can;t communicate ...um....yeah...i'm really happy to talk about things ..frankly so it feels fine ...

Appendix 8: University of Hertfordshire ethics approval

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE
for
NURSING, MIDWIFERY, SOCIAL WORK, CRIMINAL JUSTICE AND
COUNSELLING

FEEDBACK

Applicant	Sarah Russell
Study	Thinking Ahead – Planning Ahead What would influence you to discuss your preferences and wishes about care at the end of life.
Reference Number:	NMSCC/05/09/14/A
Date of REC	10 June 2009

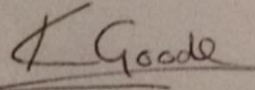
Many thanks for submitting the information requested by the Nursing, Midwifery, Social Work, Criminal Justice and Counselling Ethics Committee. Your study is now approved and on behalf of the Committee may I wish you all the best with your study.

Ethics Committee for NMSCC decision:

Approved	X
Your study is registered with approval number: NMSCC/05/09/14/A	
Minor amendments required - subject to Chair's action	<input type="checkbox"/>
Major amendments required - resubmission to REC	<input type="checkbox"/>
Not approved	<input type="checkbox"/>

Please note that if any significant changes are to be made to the methodology the Committee must be informed.

The enclosed Quality Monitoring Form must be completed and returned to the Secretary to the Committee, Post-graduate Office, 1F264, Wright Building, Hatfield Campus, immediately the study is finished.


Kim Goode
Chair of the Ethics Committee for Nursing, Midwifery, Social Work, Criminal Justice and Counselling

10/06/09

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE

for

NURSING, MIDWIFERY, SOCIAL WORK, CRIMINAL JUSTICE AND COUNSELLING

FEEDBACK

Applicant Sarah Russell

Study Thinking Ahead – Planning Ahead
What would influence you to discuss your preferences and wishes about care at the end of life.

Reference Number: NMSCC/05/09/14

Date of REC 21 May 2009

		Revision
Item	Comments	Major /Minor
1. Title of study	√	
2. Applicant - address e-mail	√	
3. Details applicant 2/3	√	
4. Status applicants	√	
5. Name supervisor	√	
6. Collaborating Inst.	N/A	
7a Literature review	Need to complete as sentence incomplete	Minor
7b. Aim	√	

7c. Methods	Clarification that the researcher is the only one managing the video recorder and that it is unobtrusive. Please confirm that videoing is not compulsory.	Minor
8a	√	
8b. Consent from "vulnerable"	√	
8c	√	
8d	√	
8e	√	
8f	√	
9a. Potential cause of distress	Please would you change the potential distress to 'severe'	Minor
9b. Nature of distress	√	
9c Precautions	√	
9d. Steps if harm is caused	√	
10. Personal Data	√	
10a Justify use of personal data.	√	
10b/c	√	
11 Financial incentives	√	
12 Funding	√	
13 Proposed duration	√	
Declaration by applicant Name Signature	√	
Declaration by supervisor Name Signature	√ √	
Support HoD/Unit/Centre Name Signature	√	

Overall comments.

The Committee had concerns that LREC should be involved as your participants were patients in the hospice however you clarified in your interview that you are the Research Lead at the Hospice and that you will only access patients through the Hospice. The NHS only provides 18% of the funding the rest is provided by the Community. Patients will only be recruited via the use of fliers.

Appendix – Participant Information Sheet.

Please delete sentence which starts with ‘Health Professionals receive...’

Ethics Committee for NMSCC decision:

Approved

Your study is registered with approval number:

Minor amendments required - subject to Chair’s action

Major amendments required - resubmission to REC

Not approved

Please note that if any significant changes are to be made to the methodology the Committee must be informed.

The enclosed Quality Monitoring Form must be completed and returned to the Secretary to the Committee, Post-graduate Office, 1F264, Wright Building, Hatfield Campus, immediately the study is finished.

Kim Goode

Chair of the Ethics Committee for Nursing, Midwifery, Social Work, Criminal Justice and Counselling

Appendix 9: research site ethics approval

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Sarah Russell

[REDACTED]
[REDACTED]
[REDACTED]

23rd April 2009

Dear Sarah,

Re: Research Study:

Thinking Ahead – Planning Ahead: Influences on Advance care Planning Discussions with Hospice Patients and their Informal Carers. (DHRes- University of Hertfordshire)

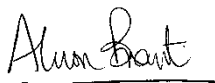
Thank you for submitting your request to the Hospice Clinical Governance Meeting on Thursday 23rd April 2009 for approval to carry out the above research study.

The Committee reviewed your submission and are happy to approve and support your research study at the Hospice, subject to ethics approval from the University of Hertfordshire Ethics Committee. As a condition of the approval we request on completion of your study that you:

1. Report your research findings to the Hospice Clinical Governance Committee (either successful or unsuccessful).
2. Disseminate your results both within and outside of the Hospice.

Good luck with your research study and we look forward to hearing your findings.

Yours sincerely



Alison Briant

Director of Clinical Governance and Development



Dr Ros Taylor

Hospice Director

**Guidance for Hospice Clinical Governance or Senior Management Team for approval of staff
research projects:**

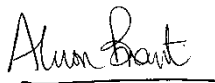
The role of the Clinical Governance meeting or SMT is not to act as an ethics committee. Its role is to be able to confirm that the research project has carried out the following steps and the Hospice is happy to support the applicant in their research study:

- | | | |
|---|------------------------------------|-----------------------------------|
| 1. Has the project been discussed with the Director of Research? | <input type="button" value="Yes"/> | <input type="button" value="No"/> |
| 2. Has the Hospice Research Template been completed? | <input type="button" value="Yes"/> | <input type="button" value="No"/> |
| 3. Is there a research question? | <input type="button" value="Yes"/> | <input type="button" value="No"/> |
| 4. Has the sample group been defined? | <input type="button" value="Yes"/> | <input type="button" value="No"/> |
| 5. Has the research method been defined? | <input type="button" value="Yes"/> | <input type="button" value="No"/> |
| 6. Is there a participant information sheet? | <input type="button" value="Yes"/> | <input type="button" value="No"/> |
| 7. Has ethics approval been obtained or in process of being obtained? | <input type="button" value="Yes"/> | <input type="button" value="No"/> |

If the answer to all of the above is Yes then the project is approved by the Hospice and approval letter will be sent to the applicant.

If the answer to any of the above is No then the applicant will be asked to clarify/resubmit with further details

Signed:



23rd April 2009

Alison Briant – Director of Clinical Governance and Development

Appendix 10: research site research policy

Research, Clinical Audit and Service Evaluation Policy and Procedure	
Approved by:	Dr Ros Taylor
Date approved:	08/08/2012
Source/Author:	Sarah Russell

Audit Standard:

1. All research, audit and service evaluation projects must be approved and registered.
2. There must be evidence of feedback to the appropriate forums of the registered projects

Contents:

Introduction	02
Policy Statement	02
Responsibility	02
Accountability	03
Defining Research, Research Ethics, Audit and Service Evaluation	03
NRES Ethical Approval of Research Projects	04
Hospice Approval of Research, Clinical Audit, Service Evaluation	04
Project Follow Up	05
Appendix One: Project Registration Form	06

1. Introduction

Good quality research, clinical audit and service evaluation across all aspects of end of life and palliative care is vital to improve and sustain knowledge and understanding of end of life care and as part of the ongoing Quality Assurance Framework cycle

People undertaking research, clinical audit or service evaluation in the Hospice of St Francis may be clinicians, those undertaking academic courses and/or members of the multi professional hospice team.

2. Policy Statement

The Hospice [REDACTED] encourages appropriate and properly conducted research, clinical audit and service evaluation projects across all aspects and disciplines of end of life and palliative care. This policy provides an overview of key definitions and procedure necessary to carry out or participate in research, clinical audit or service evaluation projects at the Hospice [REDACTED].

Project proposals are welcomed from all Hospice staff. This includes clinical and non-clinical areas, staff and volunteers.

External staff wishing to access the hospice for their own independent research must register and receive Hospice approval for their project before commencing it. They will be required to provide evidence of ethics committee approval to carry out their research study (appendix 1)

All project proposals must comply with statutory guidelines and requirements and receive relevant ethics committee approval where applicable. All project proposals must be registered and approved before start date of the project : appendix 1.

(DOH (2005) Research Governance for Health and Social Care

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122427.pdf , DOH (April 2012) Governance Arrangements for Research Ethics

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_133993.pdf

3. Responsibilities:

The Director of Education and Research is responsible for:

- the monitoring and implementation of the Hospice Research, clinical audit and service evaluation policy
- the approval of all research projects carried out within or in collaboration with the Hospice
- *In her absence a named clinician with research experience*

The Audit Clinical Nurse Specialist (CNS) is responsible for:

- the approval of all clinical audit and service evaluation projects
- the monitoring and reporting of the research, clinical audit, survey and service evaluation register

4. Accountability

Hospice Registered Manager	Ultimate Responsibility as Registered Manager for ensuring that there is a policy in place and that it is adhered to.
Director of Education and Research	To ensure that all clinical research, clinical audit and service evaluation projects conducted at the Hospice has been planned, approved and executed in line with the hospice policy.
Audit Clinical Nurse Specialist	The approval of all clinical audit and service evaluation projects The monitoring and reporting of the research, clinical audit and service evaluation register

5. Definitions:

Research	Clinical Audit	Service Evaluation
As defined by National Patient Safety Agency: National Research Ethics Service (NRES) www.nres.nhs.uk downloaded May 2012		
The attempt to generalise new knowledge including studies that aim to generate hypotheses as well as studies that aim to test them	Designed and conducted to produce information to inform delivery of best care	Designed and conducted solely to define or judge current care
Quantitative – designed to test a hypothesis Qualitative – identifies/explores themes following established methodology	Designed to answer: Does this service reach a predetermined standard?	Designed to answer: What standard does this service achieve?
Addresses clearly defined questions, aims and objectives	Measures against a standard	Measures current service without reference to a standard
Quantitative - may involve evaluating or comparing interventions, particularly new ones Qualitative – usually involves studying how interventions and relationships are experienced	Involves an intervention in use only. The choice of treatment is that of the clinician and patient per guidance, professional standards and/or patient preference	Involves an intervention in use only. The choice of treatment is that of the clinician and patient per guidance, professional standards and/or patient preference
Usually involves collecting data that are additional to those for routine care but may include data collected routinely. May involve treatments, samples or investigations additional to routine care	Usually involves analysis of existing data but may include administration of simple interview or questionnaire	Usually involves analysis of existing data but may include administration of simple interview or questionnaire

Quantitative – design may involve allocating patients to intervention groups Qualitative – uses clearly defined sampling framework underpinned by conceptual or theoretical justifications	No allocation to intervention: the health professional and patient have chosen intervention before audit	No allocation to intervention: the health professional and patient have chosen intervention before service evaluation
May involve randomisation	No randomisation	No randomisation
Normally requires Research Ethics Committee (REC) review www.nres.npsa.nhs.uk	Does not require ethical review by a Research Ethics Committee Does not require approval from NHS R&D offices May require some other form of approval from the organization(s) undertaking or hosting the project depending on local arrangements.	

PROCEDURE

6. NRES Ethical Approval for Research Projects:

Where a project meets the above criteria as a research project, ethical approval is mandatory. Although the Hospice is a charity, best practice requires us to register our research projects through the NRES system. The NRES provides detailed information about ethical requirements on: <http://www.nres.nhs.uk/applications/approval-requirements/ethical-review-requirements/>.

Please discuss your research project with the Director of Education and Research or her named deputy in order to help you through this process.

All research ethics applications are made through the Integrated Research Application System (IRAS) (<http://www.nres.nhs.uk/applications/integrated-research-application-system/>) which is a single online system for applying for permissions and approvals for health & social care/community research in the UK. It streamlines the process for seeking relevant approvals, as researchers no longer need to enter the details for a single project in separate application forms.

IRAS applications can be accessed at www.myresearchproject.org.uk. There is also a useful e-learning package there about the application process.

Research applications are then considered by the local NHS Research Ethics Committee (REC):
<http://www.nres.nhs.uk/contacts/nres-committee-directory/?entryid27=18603&p=2>
<http://www.nres.nhs.uk/applications/booking-and-submitting-your-application/local-allocation-system/>

All RECs will require the submission of your complete application well in advance of the meeting date (normally 14 days before) and certainly within **four** working days of your application booking being accepted, in order to secure your agenda slot. You will, therefore, be given a submission date for your application when you book your application.

Where studies are carried out as part of a University programme – ethical approval may be acceptable from the University Ethics Committee – but please discuss with the Director of Education and Research or her named deputy.

Where external researchers are asking to access our staff or population for their own research projects they must follow the same procedure for research projects as below

7. Hospice Approval for Research, Clinical Audit and Service Evaluation Projects

All projects must be registered and approved before the start time of the project (appendix 1). Informal discussion with the Audit CNS is necessary for clinical audit and service evaluation projects and with Director of Education and Research for research projects. In her absence discussion with the Audit CNS and on her recommendation named deputy. Copies of the policy can be obtained from the Education and Research team and the Hospice Intranet.

- Research Proposals should be submitted to the Director of Education and Research and Audit CNS
- Clinical audit and service evaluation projects should be submitted to the Audit CNS.
- Approval of the submitted project will be within 5 working days – quicker if you have discussed with them before.

If the proposal is rejected the Director of Education & Research or named deputy will discuss the rationale behind the decision. Advice about re-submission will be discussed.

Research Projects:

Please complete appendix 1 and include copy of your research application and ethics approval from IRAS and copies of all relevant documentation (for example. consent form, invitation to participate form, participant information sheets).

Clinical Audit and Service Evaluation Projects:

Please complete appendix 1 and include sample copies of your audit or evaluation documentation

8. Project follow up

All projects will be registered on the Hospice Research clinical audit and service evaluation register. It is a requirement of approval that you feedback your project results either through the Clinical Care Committee, summary report or academic publications

Appendix One:
CLINICAL AUDIT, SERVICE EVALUATION OR RESEARCH PROJECT REGISTRATION FORM
 After completion, please return to Audit CNS

PART A –Registration – ALL RESEARCH, CLINICAL AUDIT AND SERVICE EVALUATION PROJECTS

A1. Project Title	
A2. Project Team Members	
Project Lead	Contact E Mail & Tel No:
Job Title	Department
Other project members names and emails:	
A3. Audit & Service Evaluation Project discussed with by Clinical Audit Facilitator Yes <input type="checkbox"/> No <input type="checkbox"/>	
Research Projects discussed with Director of Education & Research	Yes <input type="checkbox"/> No <input type="checkbox"/>
Date Discussed:	
A4. Project Details	
Project Question:	
Is the project multi-professional? Yes <input type="checkbox"/> No <input type="checkbox"/>	
Give details:	
Why was the topic selected (please, tick all that apply):	
Academic course <input type="checkbox"/>	High frequency of events <input type="checkbox"/> High cost <input type="checkbox"/> High risk issue <input type="checkbox"/>
Perceived problem area <input type="checkbox"/>	National requirement <input type="checkbox"/> Repeat audit/evaluation <input type="checkbox"/>
Other reason (please state)	
Standard for the audit/service evaluation: (please, tick all that apply)	
NICE Guidance <input type="checkbox"/>	National Guidelines <input type="checkbox"/> Royal College Guidelines <input type="checkbox"/> Hospice Guidelines <input type="checkbox"/>
Specialist professional society guidelines <input type="checkbox"/>	Other standard(s) <input type="checkbox"/> (state which)
Please give references for the standard(s)	
Are patients or carers to be involved in the project? Yes <input type="checkbox"/> No <input type="checkbox"/>	
In the planning stage <input type="checkbox"/>	As a part of the data collection method <input type="checkbox"/>
Other (please state)	

Is ethical approval applicable? Yes No

If yes please provide evidence of approval with this registration form

Expected start date of project:

Expected completion date of project:

A5. Project Lead:

I agree to adhere to Data Protection Act and Caldicott principles during all stages of the project, to submit to the Director of Education and research, on the project completion, project summary in approved format together with data collection form/questionnaire. I also agree that the approved project summary will be included in Hospice reports, published on Hospice Intranet and made available to the public under the Freedom of Information Act.

SIGNATURE.....

DATE.....

Now please complete Part B

PART B – Project Methodology/Methods Details

B.1 –Project methodology

(If you are not sure about the following, Audit or Research Lead will help you decide)

1. Data collection will be:

Prospective Retrospective Serial Other (please state)
(present) (past) (Ongoing)

2. Data will be obtained from:

Case notes Electronic databases Questionnaires
Interviews Focus groups Other (please state)

3. Sample details:

for example. Diagnosis / Condition / Procedure/intervention

Expected sample size in total

B.2 – Project support agreement

Project Lead

I agree:

1. *To adhere to Data Protection Act and Caldicott principles during all stages of clinical audit project.*
2. *To inform Education and Research Dept about any amendments to the project data collection form/questionnaire made during the course of the project.*
3. *To provide a summary report for the Clinical Care Committee, or Education and Clinical Audit Lead*
4. *To inform Education and Research Department about presentation/publication of project results.*
5. *That the final, approved Project Report Summary will be included in Hospice reports, published on Intranet and made available to public under the Freedom of Information Act.*

Signature

Date

Thank you for completing this form.

Please now return to Audit CNS



Office use only

<i>Received:</i>	<i>Placed on register and Project Number:</i>
<i>Audit/Research Lead Approval: Yes/No/Pending subject to changes</i>	
<i>Review date of project progress:</i>	<i>Review completed:</i>
<i>Summary of project received:</i>	

Appendix 11: examples of being an ethical palliative care researcher

Case 1: Ethical Relationship and Informed Consent

Very physically frail potential participant wanting to take part in the research before they died and articulating that they had read and understood the information sheet and consent form. I had concerns that their physical fragility and time span which they had had these documents meant that it was not possible for them to have fully read them. However, the potential participant was insistent in taking part in the interview 'before I die'. The participant asked to sign the consent form saying 'I am sure it will be okay, I trust you'. I sat for 40 minutes with the potential participant and heard their story (thoughts and experiences).

The interview was recorded but not transcribed or analysed. I recorded it because it would have been obvious if I had not. It seemed to me more important to value the effort they were making to tell me their story and possible therapeutic benefit than to advance scientific knowledge through collection of data with an inadequate consent process. At the end of the interview they were thanked for their time. The participant expressed relief at telling their story adding '*I hope it will help someone*'. The participant died 3 hours later.

Reflection note: the participant wanted to control how and when they did the interview. What gave me confidence as an ethical researcher was that I respected their autonomy to control the process and protected their consent gaps in the process. Scientific knowledge should minimize foreseen harm (such as lack of anonymity or understanding of dissemination in this case).

This is an example that some people facing death may wish to participate in research (Kendall et al 2007) with evidence of participant benefit (Pessin et al 2008) as well as an example of respect guiding research design and dissemination (Bold 2012)

Case 2: Ethical Relationship and Participant Agenda

Participant had received information sheet but had also asked for consent form before consent meeting as they felt that would help them understand more what the research was about and involved. The consent form was sent to them, and a venue and time agreed to complete the consent form and then to agree a future interview date.

On arriving at agreed consent meeting they presented me with a signed consent form commenting that they wanted to do the interview now. Following a discussion about the research and consent, the participant remained resolute that they wanted to carry out the interview immediately. This was their preference commenting '*I don't have much time left Sarah and this is how I want to do this*' and they appeared comfortable with the information, consent process and use of words and images. They clearly articulated understanding of these issues.

The video interview was carried out with the understanding that I would contact them in 48 hours to check they were still happy for the interview to have been carried out. 48 hours later they confirmed they were still happy for the interview to have been carried out and they had had no change of mind about their consent.

Reflection note: the participant wanted to control the process. What gave me confidence in being an ethical researcher was that they clearly articulated the purpose and mechanics of how words and images would be used and agreed to a post interview cool over period – so that I felt satisfied

in their understanding and freedom to withdraw and that I respected their autonomy to control the interview timing.

This was an example that retrospective consent could be a solution to enhancing participants control over the interview (Gysels et al 2008).

Case 3: Ethical Relationship and Participant Control

Participant requested information sheet and consent form prior to consent meeting. Both sent to them. At agreed consent meeting, participant wished to add some amendments to the consent form as to how her images could only be subsequently used with her expressed consent. This consent was to be askandrewsed for image by image if I planned to use her images.

The participant was happy for their words to be used in the same way as all other participants but explicitly expressed desire to maintain control of their own public image. They wished to see the consent form early in order to consider how to contribute to the research but also to maintain control of their image. The consent form was added to and signed by the participant with her addition to the words about image by image consent. Within the video interview itself this addition to the consent form was also articulated.

Reflection note: I don't think it is unreasonable to send both information sheet and consent form! I think it can help increase understanding. Adapting the consent form is also reasonable, concerned with them controlling how they share their thoughts and images. In the digital age we can learn from others about wishes and priorities in this matter.

This was an example of the power relationship between researcher and researched (Andrews 2008) as well as that informed consent can't be regarded as a single event (Merrell and Williams 1994).

Case 4: Ethical Relationship and Explicit Contract

Same participant after her death, a family member requested copies of the research video interview for the family personal viewing and memories. Several discussions took place between me, the family member, clinical team involved and research supervisors as to not only what was in the best interests of the deceased participant family but also as to what the participant had believed they had consented to.

The clinical/research interface was challenging because of the competing views (clinical vs research practice) of what was in the best interests of the deceased participant and the remaining bereaved relatives.

The video was not released to family members because the deceased participant in life had wanted to maintain control of her image and had not consented for anyone to see her image without her consent. In her death, her explicit consent, made at the time and in the contexts that we had discussed and agreed in her life were honoured.

Reflection note: Being a researcher in practice is challenging and described by others. If I had not felt so confident about this participant wishes (she was incredibly articulate) and not had doctoral supervision to use as a sounding board I think I would have found this more difficult. The decisions of the participant outweigh others in this case where no for example. safeguarding or emergency

health care issues were present. The time invested in this (with her family and senior members of the team) after her death was extensive.

This was an example of balancing the role of clinician and researcher (Masso et al 2004) as well as an example of respect guiding research design and dissemination (Bold 2012)

Case 5: Ethical Relationship and Honesty

Participant taken through the consent process but after the interview asked to see a copy of the transcript before agreeing 100% for its use in the research. Interview transcribed and sent back to her. However, participant had begun to deteriorate and died before returning the transcript. Partner subsequently returned it with a written note from him saying that they felt the participant would have been happy for its use.

Interview transcript not used as I felt that I was not certain that the participant had read and agreed for its use in the research. However, this interview provided a useful exercise to look at my interviewing skills. Interview transcript not analysed or used for the research, but reflection on interview skills used for researcher reflexivity.

Reflection note: This was my first interview. I had not built in participant review of transcripts into the study design.

This was an example of the challenge of confidentiality (Plummer 2001)

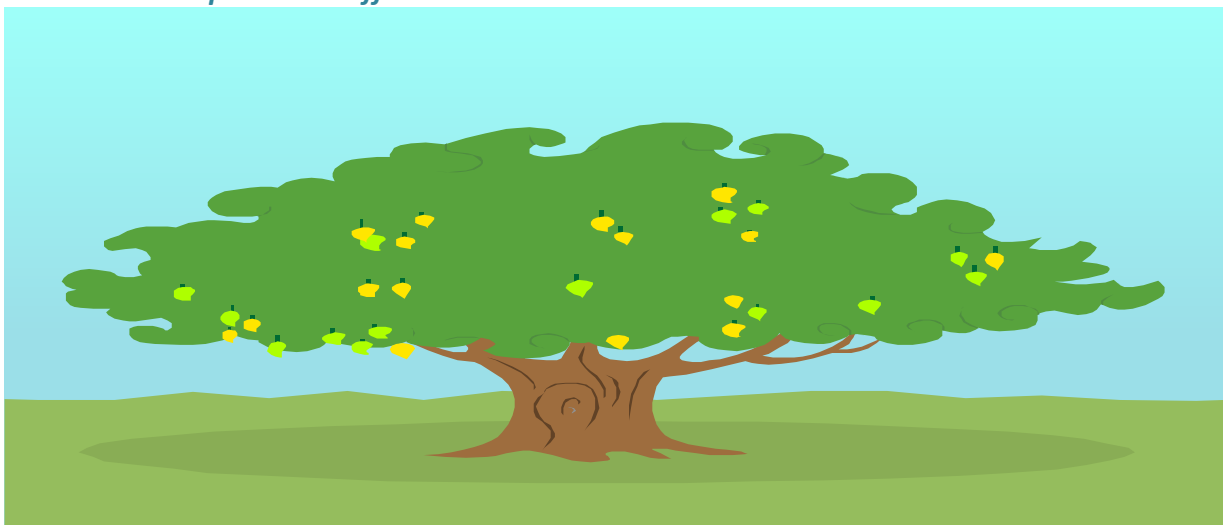
'Thinking Ahead – Planning Ahead'

Would you like to

Take part in a research study?

Share your thoughts and experiences?

Help make a difference to how doctors and nurses are trained?



If you are a patient at the Hospice and are interested in taking part in a video or audio recorded research interview on what would influence you to discuss wishes and preferences for care at the end of life please return the 'I am interested' slip to:

Sarah Russell – Principal Investigator

(Thinking Ahead – Planning Ahead Study)

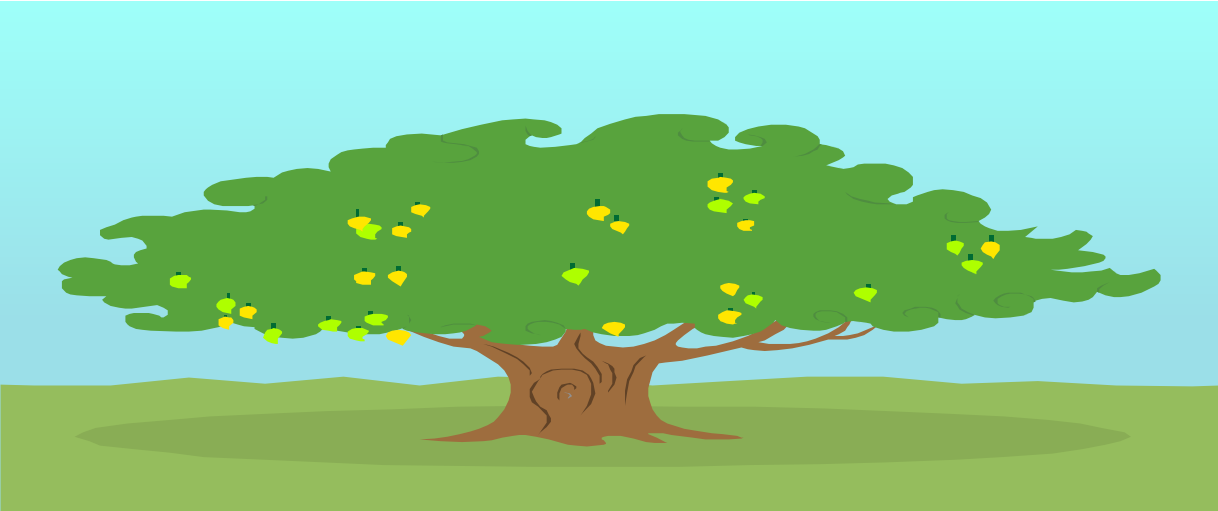
Name and address of Hospice

Contact telephone number and email

Thank you for reading this information.

'Thinking Ahead – Planning Ahead'

I am interested – please contact me!



I would be interested in knowing more about taking part in this research study.

Please contact me:

Name:

Address:

Telephone Number:

E Mail:

Please now return to:

Sarah Russell – Principal Investigator
(Thinking Ahead – Planning Ahead Study)

Name and address of Hospice

Contact telephone number and email

Research Use Only:

Received:

Information Leaflet sent:

T/C 01:

Thinking Ahead – Planning Ahead’ Research Study
‘What would influence you to discuss your preferences
and wishes about care at the end of life’

Research site name and address

XXXXXX

XXXXXXXX

XXXXXXXXXX

Research Phone: xxxxxx

Email: xxxxxx

Principal Investigator:

Sarah Russell – *research site name*

University of Hertfordshire Ethics Reference Number: NMSCC/05/09/14/A

You are invited to take part in a research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and if you wish discuss it with your family, friends or others.

- Part 1 tells you about the purpose of the study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. I would also be very happy to discuss the study with your friends and family if you wish.

Part 1: Purpose of the Study

What is the purpose of the study?

Research suggests that some people would like the opportunity to discuss their preferences and wishes about care at the end of life but that it is difficult for both health professionals and the person themselves to know how, to whom and when to have this conversation. The purpose of the study is to find out what would influence you to discuss your wishes and preferences for care at the end of life and what you think is important when having such discussions. The main findings of this study will be used to design and deliver training for health professionals. The study will take 24 months and will involve you taking part in one video or audio recorded interview.

Why have I been invited to take part?

You have been invited to take part because you are known to the [*name of research site*] team. This may be through the inpatient unit, day hospice, community specialist nurses, hospice doctors or outpatient clinic.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, as well as this information sheet and my details to keep, you will be asked to sign a consent form before the interview.

Can I change my mind about taking part?

Yes of course. If you decide to take part you may change your mind at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive from the hospice team, either now or in the future.

What will happen to me if I take part?

If you decide to take part, you will be interviewed once for about 30 - 60 minutes. You will be asked to tell me your thoughts and experiences about what would influence you to discuss end of life wishes and preferences. I will contact you to arrange a convenient time to come and meet you, to answer any further questions you may have about the study and to sign the consent form and to carry out the video or audio recorded interview. This may be for example. your own home, the Hospice or a place that is convenient to you. I will also look at your hospice records to clarify your medical details.

What are the possible benefits of taking part?

You may not benefit directly from the study; however, I hope that what I find out from the research will be of benefit to others.

What are the possible disadvantages of taking part?

Some people feel tired during or following the interview. As I am asking you to tell me about your thoughts on this subject there is a possibility that you may not want to answer some questions or feel emotional or distressed either during or following the interview. You can stop the interview at any time and not answer any questions that you do not want to answer. You can withdraw from the study at any time. If necessary, I will discuss and agree with you about informing your key hospice staff member about any of your concerns or support that you may wish following the interview.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or possible harm you might suffer will be addressed – the detailed information on this is given in part 2 of this information sheet.

Will my taking part in the study be kept confidential?

Yes – I will follow ethical and legal practice and all information about you will be handled in confidence. The detailed information on this is included in part 2 of this information sheet

This concludes Part 1 of the information sheet.

If this information has interested you and you are considering participation please read the additional information in Part 2 before making a decision about taking part.

Part 2: Detailed Information about the Conduct of the Study

What will happen if I don't want to carry on with the study?

A decision to withdraw at any time or not to take part will not affect your hospice care in any way. If you do decide to take part you are still free to change your mind at any time and withdraw. You do not have to give a reason.

What if there is a problem?

If you are unhappy about how you feel you have been treated during the course of this study, or how any aspect of it was carried out then please contact: Professor Hilary Thomas (details at the end of this form). You can also direct complaints to the Hospice Complaints Procedure (Policy No: D113) which is available from the Director of Clinical Governance and Development at the Hospice on xxxxxxxx

If during your interview you tell me about an incident involving poor patient care, after the interview, I will inform your key hospice team member.

If during the interview you describe feelings of extreme distress, or wish to discuss further your feelings and thoughts, with your permission after the interview I will inform your key hospice staff member.

Will my taking part in the study be kept confidential?

All information collected from you during the course of this study will be confidential. Your name and details will only be known to me. The complete recordings will be stored securely and only I will have access to them. Your recorded interview will not be stored or transported in unsecured areas such as the internet, email or other organisations computers. Information that could identify you will be kept separate from the recordings. All the interview video recording and transcripts will be stored securely in a locked filing cabinet at the Hospice. Digital interview recordings, notes and other related electronic data will be stored on computers that are password protected. All data storage and use will comply with the Data Protection Act (1998) and kept by the Principal Investigator at the Hospice for 7 years, after which all the video recordings and interview transcripts will be destroyed (shredded).

I will inform your key hospice team member of your participation in the research study but not the content of your interview unless you give permission to.

Using your images and words to illustrate the research study findings:

Still or moving images, audio excerpts and quotes will be used to illustrate findings from the research study in my final theses, education lectures, presentations, conferences and journal or book publications. There is a possibility that you may be recognised (where your image and words are used to demonstrate your thoughts). When I present these images and audio excerpts and quotes, I will not reveal your name at any time.

How will the video or audio recorded interview be carried out?

At your interview I will answer any further questions and confirm your consent form. I will then set up the recording equipment and when you are ready to start, turn the equipment on and ask you some general questions about you and why you have been seeing a member of the Hospice team. I will then ask you to tell me your experiences and thoughts about discussing end of life wishes and preferences. During the interview I may ask you to clarify or expand on some of your answers as well as jot down some memos and notes – this is to help me to remember all that you have said. The interviews will be videoed or audio recorded so that I can be sure that I remember and understand correctly all what you say. You may watch or request a copy of the video or audio recording and the transcript if you

wish to do so. You may withdraw your consent to participate in the video or audio recorded interview at any time.

After the interview, I will send you a thank you letter with my contact details – so that you can contact me at any time until the completion of the study.

What will happen to the results of the research study?

When the study ends I will discuss the findings in a workshop of researchers at the University of Hertfordshire and the Hospice. I will also publish and present my findings as previously described in order to help health professionals to understand how to discuss people’s preferences and wishes at the end of life. At the time of your interview I will ask you if and how you would like a summary of the findings.

Who is organising and funding the study?

The study is academically sponsored by the University of Hertfordshire and professionally supported by the Hospice. The study is part self-funded and part by the Hospice. I am an experienced hospice nurse, researcher and educator.

Who has reviewed this study?

This study has been approved by the University of Hertfordshire Ethics Committee (May 2009 Ethics Number: NMSCC/05/09/14/A) and the Hospice Clinical Governance Committee (23rd April 2009). This study is being carried out and supervised as part of my Doctorate in Health Research at the University of Hertfordshire.

Contact for further information:

<p>Contact if you would like further information about the study or to participate:</p> <p>Sarah Russell Principal Investigator <i>Thinking Ahead – Planning Ahead</i> Name and address of hospice Research Phone: xxxxx E-mail xxxxxx</p>	<p>Contact if you have a problem with how the research has been carried out</p> <p>Professor Hilary Thomas Centre for Research in Primary & Community Care University of Hertfordshire Hatfield Campus, College Lane Hertfordshire AL10 9AB Telephone: 01707 284000 E mail: h.a.thomas@herts.ac.uk</p>
---	---

Thank you for reading this information and considering whether to take part. You will be given a copy of this information sheet and a consent form to keep

Health Professional Information Sheet (version 10) *Research site name and address*

'Thinking Ahead – Planning Ahead'

Xxxxxx

Research Study

Xxxxxxx

'What would influence you to discuss your preferences and wishes about care at the end of life'

xxxxxxxxx

Research Phone: xxxxx

Email: xxxxxx

Principal Investigator: Sarah Russell – name of research site
University of Hertfordshire Ethics Reference Number: NMSCC/05/09/14/A

Part 1: Purpose of the Study

What is the purpose of the study?

Research suggests that some people would like the opportunity to discuss their preferences and wishes about care at the end of life but that it is difficult for both health professionals and the person themselves to know how, to whom and when to have this conversation. The purpose of the study is to find out what would influence hospice patients to discuss your wishes and preferences for care at the end of life and what they think is important when having such discussions. The main findings of this study will be used to design and deliver training for health professionals. The study will take 24 months and will involve them taking part in one video or audio recorded interview.

Why have they been invited to take part?

They have been invited to take part because they are known to the Hospice team. This may be through the inpatient unit, day hospice, community specialist nurses, hospice doctors or outpatient clinic.

Do they have to take part?

No, it is up to them to decide whether or not to take part. If they do decide to take part, as well as this information sheet and my details to keep, they will be asked to sign a consent form before the interview.

Can they change their mind about taking part?

Yes of course. If they decide to take part they may change their mind at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care they receive from the hospice team, either now or in the future.

What will happen to them if I take part?

If they decide to take part, they will be interviewed once for about 30 - 60 minutes. They will be asked to tell me their thoughts and experiences about what would influence them to discuss end of life wishes and preferences. I will contact them to arrange a convenient time to come and meet them, to answer any further questions they may have about the study and to sign the consent form and to carry out the video or audio recorded interview. This may be for example. their own home, the Hospice or a place that is convenient to them . I will also look at their hospice records to clarify your medical details.

What are the possible benefits of taking part?

They may not benefit directly from the study; however I hope that what I find out from the research will be of benefit to others.

What are the possible disadvantages of taking part?

Some people feel tired during or following the interview. As I am asking them to tell me about their thoughts on this subject there is a possibility that they may not want to answer some questions or feel emotional or distressed either during or following the interview. They can stop the interview at any time and not answer any questions that they do not want to answer. They can withdraw from the study at any time. If necessary, I will discuss and agree with them about informing their key hospice staff member about any of their concerns or support that they may wish following the interview.

What if there is a problem?

Any complaint about the way they have been dealt with during the study or possible harm they might suffer will be addressed – the detailed information on this is given in part 2 of this information sheet.

Will their taking part in the study be kept confidential?

Yes – I will follow ethical and legal practice and all information about them will be handled in confidence. The detailed information on this is included in part 2 of this information sheet

Part 2: Detailed Information about the Conduct of the Study**What will happen if they don't want to carry on with the study?**

A decision to withdraw at any time or not to take part will not affect their hospice care in any way. If they do decide to take part they are still free to change their mind at any time and withdraw. They do not have to give a reason.

What if there is a problem?

If they are unhappy about how they feel they have been treated during the course of this study, or how any aspect of it was carried out then please contact: Professor Hilary Thomas (details at the end of this form). They can also direct complaints to the Hospice Complaints Procedure (Policy No: D113) which is available from the Director of Clinical Governance and Development at the Hospice on xxxx

If during their interview they tell me about an incident involving poor patient care, after the interview, I will inform their key hospice team member.

If during the interview they describe feelings of extreme distress, or wish to discuss further their feelings and thoughts, with their permission after the interview I will inform their key hospice staff member.

Will taking part in the study be kept confidential?

All information collected from them during the course of this study will be confidential. Their name and details will only be known to me. The complete recordings will be stored securely and only I will have access to them. Their recorded interview will not be stored or transported in unsecured areas such as the internet, email or other organisations computers. Information that could identify them will be kept separate from the recordings. All the interview video recording and transcripts will be stored securely in a locked filing cabinet at the Hospice. Digital interview recordings, notes and other related electronic data will be stored on computers that are password protected. All data storage and use will comply with the Data Protection Act (1998) and kept by the Principal Investigator at the Hospice for 7 years, after which all the video recordings and interview transcripts will be destroyed (shredded).

I will inform their key hospice team member of their participation in the research study but not the content of the interview unless they give permission to.

Using images and words to illustrate the research study findings:

Still or moving images, audio excerpts and quotes will be used to illustrate findings from the research study in my final theses, education lectures, presentations, conferences and journal or book publications. There is a possibility that they may be recognised (where images and words are used to demonstrate their thoughts). When I present these images and audio excerpts and quotes, I will not reveal their name at any time.

How will the video or audio recorded interview be carried out?

At your interview I will answer any further questions and confirm the consent form. I will then set up the recording equipment and when they are ready to start, turn the equipment on and ask them some general questions about them and why they have been seeing a member of the Hospice team. I will then ask them to tell me their experiences and thoughts about discussing end of life wishes and preferences. During the interview I may ask them to clarify or expand on some of their answers as well as jot down some memos and notes – this is to help me to remember all that they have said. The interviews will be videoed or audio recorded so that I can be sure that I remember and understand correctly all what they say. They may watch or request a copy of the video or audio recording and the transcript if they wish to do so. They may withdraw their consent to participate in the video or audio recorded interview at any time. After the interview, I will send them a thank you letter with my contact details – so that they can contact me at any time until the completion of the study.

What will happen to the results of the research study?

When the study ends I will discuss the findings in a workshop of researchers at the University of Hertfordshire and the Hospice. I will also publish and present my findings as previously described in order to help health professionals to understand how to discuss people’s preferences and wishes at the end of life. At the time of their interview I will ask them if and how they would like a summary of the findings.

Who is organising and funding the study?

The study is academically sponsored by the University of Hertfordshire and professionally supported by the Hospice. The study is part self-funded and part by the Hospice. I am an experienced hospice nurse, researcher and educator.

Who has reviewed this study?

This study has been approved by the University of Hertfordshire Ethics Committee (May 2009 Ethics Number: NMSCC/05/09/14/A) and the Hospice Clinical Governance Committee (23rd April 2009). This study is being carried out and supervised as part of my Doctorate in Health Research at the University of Hertfordshire.

Contact for further information:

<p>Contact if you would like further information about the study or to participate: Sarah Russell - Principal Investigator <i>Thinking Ahead – Planning Ahead</i> <i>Name and address of research site</i> <i>Research Phone: xxxx</i> <i>E mail xxxx</i></p>	<p>Contact if you have a problem with how the research has been carried out Professor Hilary Thomas Centre for Research in Primary & Community Care University of Hertfordshire Hatfield Campus, College Lane Hertfordshire AL10 9AB Telephone: 01707 284000 E mail: h.a.thomas@herts.ac.uk</p>
---	---

Appendix 15: consent form one: video and audio

Video and Audio Consent Form (V11)

*Name and address of
research site*

**University of
Hertfordshire**
College Lane, Hatfield
Hertfordshire AL10 9AB

Research Study : *'Thinking Ahead – Planning Ahead'*
Principal Investigator: Sarah Russell
University of Hertfordshire Ethics Reference Number: NMSCC/05/09/14/A

Telephone 01707 284000
Fax 01707 284115
www.herts.ac.uk

Please initial the boxes and sign at the bottom

1. I confirm have been informed of and understand the purposes of the research study as described in the information sheet dated Version 11 for the above study.
2. I confirm that I have asked the questions I want to ask and those questions have been answered to my satisfaction.
3. I understand that my participation is voluntary and that I can withdraw at any time without my hospice care or legal rights affected.
4. I understand that for the purpose of this study my hospice medical records will be examined to clarify my date of birth, diagnosis and treatments.
5. I understand that I will be asked to talk about my thoughts and experiences in *'Thinking Ahead - Planning Ahead'* and that the interview will be video and audio recorded.
6. I understand that the visual and audio recording of my interview will be studied & analysed by Sarah Russell for use in the research study.
7. I understand that my visual still & moving images and audio recording & quotes will be used by Sarah Russell to present the study's findings in scientific and academic publications, education conferences or sessions to interested health professionals or members of the general public.
8. I understand that these images and quotes may be recognised by those that I know.
9. I understand that Sarah Russell will inform my key hospice team member that I am taking part in the study but not the content except for as described below in point 10 and 11
10. I understand that Sarah Russell, will contact my key hospice team member if I tell her about for example poor patient care.
11. I understand that Sarah Russell will with my permission contact my key hospice team member if I wish to discuss more my feelings and thoughts about *'Thinking Ahead - Planning Ahead.'*
12. I agree to take part in the above research study as described *'Thinking Ahead – Planning Ahead'*

Name of Participant:
Signature:

Date:

Name of Principal Investigator:
Signature:

Date:

Sarah Russell – Principal Investigator (Thinking Ahead - Planning Ahead Study) *Hospice address and contact details One copy for participant One copy to Principal Investigator/Research Study Records*

Appendix 16: consent form two: audio only

University of
Hertfordshire
College Lane, Hatfield
Hertfordshire AL10 9AB
Telephone 01707
284000
Fax 01707 284115
www.herts.ac.uk

Audio Consent Form (V11)
Research Study : *'Thinking Ahead – Planning Ahead'*
Principal Investigator: Sarah Russell
University of Hertfordshire Ethics Reference Number: NMSCC/05/09/14/A

Name and address of
research site

Please initial the boxes and sign at the bottom

1. I confirm have been informed of and understand the purposes of the research study as described in the information sheet dated 'Version 11' for the above study.
2. I confirm that I have asked the questions I want to ask and those questions have been answered to my satisfaction.
3. I understand that my participation is voluntary and that I can withdraw at any time without my hospice care or legal rights affected.
4. I understand that for the purpose of this study my hospice medical records will be examined to clarify my date of birth, diagnosis and treatments.
5. I understand that I will be asked to talk about my thoughts and experiences in *'Thinking Ahead - Planning Ahead'* and that the interview will be audio recorded.
6. I understand that the audio recording of my interview will be studied & analysed by Sarah Russell for use in the research study.
7. I understand that my audio recording & quotes will be used by Sarah Russell to present the study's findings in scientific and academic publications, education conferences or sessions to interested health professionals or members of the general public.
8. I understand that these recordings and quotes may be recognised by those that I know.
9. I understand that Sarah Russell will inform my key hospice team member that I am taking part in the study but not the content except for as described below in point 10 and 11
10. I understand that Sarah Russell, will contact my key hospice team member if I tell her about for example poor patient care.
11. I understand that Sarah Russell will with my permission contact my key hospice team member if I wish to discuss more my feelings and thoughts about *'Thinking Ahead - Planning Ahead.'*
12. I agree to take part in the above research study as described *'Thinking Ahead – Planning Ahead'*

Name of Participant:

Date:

Signature:

Name of Principal Investigator:

Date:

Signature:

Sarah Russell – Principal Investigator (Thinking Ahead - Planning Ahead Study) *Hospice address and contact details One copy for participant One copy to Principal Investigator/Research Study Records*

Appendix 17: interview schedule guide/reminder

Thinking Ahead – Planning Ahead Research Study

'What would influence you to discuss your preferences and wishes about care at the end of life'

1. Introductions
2. Thank for participation
3. Show and set up recording equipment
4. Confirm video or audio consent form
5. Check they are physically comfortable/remind can withdraw consent to participate
6. Turn on recording equipment
7. Opening question – *Tell me how you came to know [name of hospice]*
8. Generic questions
 - a. *What would influence you to discuss these type of things [end of life care and advance care planning]*
 - b. *What do you think is important about how doctors and nurses talk to you about these things?*
 - c. *How does it feel to be video interviewed about this topic?*
 - d. *Is there anything else that you would like to say?*
9. At interview conclusion: thank for participation, remind re contact details. Turn off recording equipment.
10. Informal discussion allowing participant to 'debrief' after the interview

REMINDERS:

- Participant can withdraw consent at any time
- If poor clinical practice is discussed obligation to follow up
- If patient is distressed – discussion whether to inform key hospice member

Appendix 18: sample thank you letter

Name and address of research site

Date

Dear

Re: Thinking Ahead Planning Ahead Research Study Interview on:

I am writing to thank you for your time and thoughts at our recent research interview.

I very much appreciated you spending your time with me and was most interested in your thoughts and experiences.

If you should have any further questions or concerns arising from our interview or about the research study please feel welcome to contact me on the above research mobile phone number or at Hospice.

Thank you again for your time and thoughts.

Yours sincerely,

Sarah Russell – Principal Investigator (Thinking Ahead – Planning Ahead Study)

Contact email and telephone number