Northumbria Research Link

Cancer patients' care at the end of life in a critical care environment: perspectives of families, patients and practitioners

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A thesis submitted in partial fulfilment of the requirements of the University of Northumbria at Newcastle for the degree of Doctorate of Nursing Science

School of Health, Community and Education Studies

June 2010

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Acknowledgements

I would like to thank several people for their support and help during my doctorate.

Firstly, I'd like to thank my husband, Kieran, and son, Gabriel (who was born during the write-up and whose birth spurred me on to complete), for their love and support at home which enabled me to finish.

Secondly, I wish to thank my supervision team: Susan Carr, Chris Turnock and Shelley Dolan for their support throughout, their constructive advice, helping me to sharpen my focus, encouraging me to keep going with the write-up and for keeping me contained within the confines of the professional doctoral thesis.

Thirdly, I would like to thank my mum, Ann, and brother, James, whose proof-reading experience elsewhere (and in very different fields!) and comments have been invaluable for my write-up.

Fourthly, I am grateful to Jane Wilcockson and Catherine Exley who both gave me some very useful advice around conducting sensitive research as I was planning the research. I am also grateful to my fellow doctoral students for the discussion and peer support over the years.

Lastly, and most importantly, I would like to wholeheartedly thank the nurses, families, patients and doctors who gave up their time to talk to me, and who were truly honest and frank about their sometimes uncomfortable and sad feelings, and without whom this research would not have been possible. I feel privileged to have been able to have worked with them in this research.

Abstract

Innovations in cancer care requiring intensive support, and improved cancer patient survival in and out of critical care, have led to greater numbers of cancer patients than ever accessing critical care. Of these, however, a fair proportion will die. Current research points to around one in six patients dying in general critical care units and even higher numbers for cancer patients. End-of-life care (EOLC) for critically ill patients is problematic and rarely addressed beyond satisfaction or chart review studies, while palliative care is an established domain in cancer. It is not known whether dying, critically ill cancer patients experience good EOLC. In the context of a cancer critical care unit, this thesis explores the provision of EOLC for cancer patients in a critical care unit. Exploring measures for comfort care and palliative principles of care helped identify what is important for patients and families, and what those measures meant for all participants. The diagnosis of cancer and how it impacts on EOLC provision for critically ill cancer patients was also explored from the perspective of patients, families, doctors and nurses.

A Heideggerian phenomenological interview approach was undertaken, in order to gain personal experiences. Families of those patients who died after decisions to forgo life-sustaining treatment (DFLSTs) were interviewed. Patients who have experienced critical care were also interviewed, since patients' views about EOL care provision are very rarely explored. Doctors and nurses also contribute their vision for, and experiences of, EOL care in a cancer critical care unit. Thirty one interviews with 37 participants were carried out.

Cancer prognosis together with critical illness prognosis contributed to difficulties in deciding to move to, and enact EOLC. The nursing voice in DFLSTs was minimal and their role in EOLC depended on experience and confidence. Achieving a good death was possible through caring activities that made best use of technology to prevent prolonged dying. EOLC was an emotive experience. Decision-making and EOLC could be difficult to separate out which, in turn, affects prospects for EOLC. A continuum of dying in cancer critical illness is presented with different participants' experiences along that continuum. Three main themes included: *Dual Prognostication; The Meaning of Decision-Making;* and *Care Practices at EOL: Choreographing a Good Death* with two organising themes: *Thinking the Unthinkable* and *Involvement in*

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Care. These themes outlined the essence of moving along a continuum toward patients' deaths and the impact that had on opportunities for care and a good death. Nurses could use the care of patients dying in critical care as an opportunity to develop specialist knowledge and lead in care, but this requires mastery and reconciliation of both technology and EOLC.

This work builds on Seymour's (2001) theory of a negotiated and natural death related to achieving a good death in critical care. Trajectories of dying, part of Seymour's (2001) theory, are extrapolated on with reference to Glaser and Strauss (1965) and Lofland (1978)'s theories on dying trajectories. Nursing theory is developed through examination of Falk Rafael's (1996) and Locsin's (1998) theories of empowered caring. Implications and propositions are presented for nursing and wider practice around EOL care for critically ill cancer patients.

Glossary of terms

(terms are described as they are used in the thesis)

- CPAP   - Continuous Positive Airway Pressure (a form of supporting respiration non invasively)
- CCU   - Critical Care Unit
- DFLSTs   - Decisions to Forgo Life-Sustaining Treatment
- DH   - Department of Health
- DM   - Decision-making
- EOL   - End of Life
- EOLC   - End of Life Care
- EOLD   - End of Life Decisions
- ITU   - Intensive Therapy Unit
- ICU   - Intensive Care Unit (used interchangeably with ITU)
- NHS   - National Health Service
- PEEP   - Positive End Expiratory Pressure (Airway pressure is maintained above atmospheric pressure at the end of exhalation)
- Trache   - Tracheostomy tube (used to maintain an airway for ventilation)
- Tube   - Tracheostomy tube
- UK   - United Kingdom
- Ventilation - artificial respiration via a ventilator (also referred to as mechanical ventilation)

Introduction

Timeliness of EOLC is difficult to manage in critical illness and subsequent delays can lead to challenges around quality of dying. High-technology care can seem paradoxical when patients are dying, which leads to uncertain circumstances around when and how to enact EOLC. The added complexity of a cancer diagnosis contributes to difficulties in EOLC practices.

This thesis outlines a research study exploring end-of-life care (EOLC) provision for critically ill cancer patients. As a staff nurse, and later as a critical care nurse researcher and then, research fellow, I had witnessed in practice how cancer added a significant challenge to health care teams considering patients' critical illnesses, by creating additional further uncertainty around prognosis and dying. Having encountered these issues in practice, I found contradictions in care which interested me and led to this study. I wished to enhance my understanding of why ethical intricacies existed in EOLC and decision-making, and also to improve and develop practice. It was clear from my experience that the arena of caring in critical care nursing in this context needed greater consideration and this study explores what caring at EOL means for those involved. In this study I noted how nurses' roles fit into decisions to forgo life-sustaining treatment (DFLSTs) related to moving to EOLC, as well as end-of-life decisions (EOLDs). These EOLDs may be distinct from DFLSTs and take place after DFLSTs to decide how withdrawal should be enacted. I will develop nurses' roles from the study findings in relation to theories of dying in critical care.

No previous studies had explored each key perspective around death in critical care. This study presents a whole picture of care after DFLST are made and outlines subsequent practice implications. Critical care refers to an overall term for intensive and high dependency care (DH, 2000).

This introduction provides the practice background for this study and sets the scene for the thesis, explaining in particular, why EOLC is an issue for critically ill patients, and especially those with cancer. I will outline what the key issues are and how I address these through my research. Policy influences on practicalities around dying in critical care are briefly considered to explain why EOLC is variable, and why there is a

particular risk for poor EOLC in this area. Ethical issues, which frame some professional and moral perspectives throughout the thesis, are briefly introduced. My own background is also given to explain how I became involved in this issue and subsequently carried out research into cancer and critical care practice.

i. EOLC and where patients die: policy background

The following section places the thesis in the policy arenas of critical care and EOLC. I briefly outline palliative care principles and define both palliative care and EOLC. I discuss how government frameworks for critical care provision notably impinge on EOLC by potentially limiting where EOLC can be provided which has implications for policy and practice.

Overall, EOLC has become more prominent in the policy agenda worldwide and is now a priority for care (Great Britain Department of Health [DH], 2008; National Audit Office [NAO], 2008). End–of-life care has been defined nationally as:

> "care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support." (National Audit Office, 2008, p.6)

This definition frames all references to EOLC throughout the thesis. Palliative care is also referred to where there is a distinction to be made between EOLC and palliative care. I will use the World Health Organisation's (WHO) (Sepúlveda *et al*, 2002, pp.94-95) definition (summarised in Box 1).

Box 1. Palliative Care

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Palliative care:

• Provides relief from pain and other distressing symptoms

• Affirms life and regards dying as a normal process

• Intends neither to hasten nor postpone death

• Integrates the psychological and spiritual aspects of patient care

• Offers a support system to help patients live as actively as possible until death

• Offers a support system to help the family cope during the patient's illness and in their own bereavement

• Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated

• Will enhance quality of life, and may also positively influence the course of illness

• Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

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Palliative care and EOLC in cancer has been held up as a beacon of good practice worldwide. However, cancer patients still experience EOLC difficulties (Neergard *et al,* 2008). In critical care, equally, there are more profound shortcomings related to the narrow focus of palliative care in this area. Health professionals focus on alleviating that problem alone, whereas in palliative care the focus is broad, more holistic and centres on quality of life (Randall and Downie, 1996). Associated tensions with cancer care being regarded as synonymous with good palliative care will be discussed further in Section 2.3.

Wider variations in care were noted in palliative care and EOLC in cancer provision across the UK (DH, 2002). Cancer and EOLC was the focus of a review by the National Institute of Clinical Excellence (NICE) (2004) which highlighted how information and support was still lacking. A recent Kings Fund report identified two broad themes that still need addressing in EOLC: communication and advanced care planning, and identification of EOLC needs (Addicott and Ashton, 2010). Research around EOLC predominantly focuses on palliative care initiatives in continuing care and rarely in the acute sector. This is evident in EOLC policy (DH, 2008) and the *National End-of-Life Care Programme* (DH, 2009a), both of which aim to improve EOLC and EOLC access but scarcely address EOLC in critical or acute care settings.

Critical care is an important area for EOLC research, given high mortality rates of 1 in 5 to 6 patients in this area (Wunsch *et al*, 2005; Intensive Care National Audit and Research Centre (ICNARC), 2007; 2009; Rowan, 2009). UK critical care guidance documents also fail to address the trajectory of dying, perhaps because it is uncertain and difficult to predict. *Guidelines on admission to and discharge from Intensive Care and High Dependency Units* (Department of Health (DH), 1996), yet to be superseded,[1] allude to critical care as an inferior place to die. It presupposes that dying in critical care undermines the experience of EOLC for patients and families. 'Transfer to another area' (DH, 1996, p.16) is the only strategy put forward to manage EOLC and achieve dignity in dying, and although reference is made to 'difficulties' (DH, 1996, p.16) it has been reinforced in other policy documents: *Critical to Success* (Audit Commission, 1999) and *Comprehensive Critical Care* (DH, 2000). One interpretation from this is that death and dignity are not compatible with critical care. Seymour (2001) argues that good death and EOLC need not happen only outside critical care, if, as also argued in Pattison (2006b), dignity and humanistic care prevail. If rapport has been established between the critical care team, families and patients, and patients are transferred out of critical care, this may not result in 'good death', argued for as the ultimate goal of dying patients (Neuberger, 1999; Ellershaw and Ward, 2003) and an important thrust of this thesis.

The focus in critical care is on the medical and nursing duty to promote survival (NAO, 2008) although challenges faced by staff when survival fails have been acknowledged elsewhere:

> "staff inevitably focus on trying to ensure that the person survives. The availability of intensive care and organ support may make it harder to accept that the person is dying. In this context it is important that staff are aware of the person's preferences . . . Wherever possible, relatives and carers should be involved in discussions about whether or not to intensify, or to withdraw, life-sustaining treatment and, if the person lacks capacity, then decisions must be made in their best interests and the family must be consulted as part of the process. In this context, death may occur rapidly and it is essential that families are involved in order to gain their acceptance and understanding." (DH, 2008, p.65)

Death as routine occurrence is not recognised despite national figures of 19 to 17.8% (ICNARC, 2007; 2009). Only occasionally, when 'appropriate', should patients be allowed to die in critical care (DH, 1996, p.16). Discharge should be considered when

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[1] These are currently being revised by the Department of Health.

patients no longer benefit from critical care and patients or families wish for transfer elsewhere, where 'palliative care can be provided' (DH, 1996, p.16; Audit Commission, 1999). This implies that palliative care or EOLC cannot be provided in critical care.

Furthermore, DH (1996) recommended following professional body guidelines, alongside appropriate legislation, for information on *where* and *how* to care for these patients. General Medical Council (GMC) (2008) and British Medical Association (BMA) (2007) guidance on DFLSTs notably make no specific mention toward these particular issues. General terms of privacy, dignity and good quality care in comfortable surroundings are emphasised in GMC guidance. Neither the Royal College of Nursing (RCN) nor the Nursing and Midwifery Council (NMC) have produced guidelines on nurses' roles in DFLSTs and subsequent care. *The Nursing Contribution to the Provision of Comprehensive Critical Care for Adults: A Strategic Programme of Action* (DH, 2001), written by expert critical care nurses in response to *Comprehensive Critical Care* (DH, 2000), calls for nurses to provide support at EOL:

> "Nursing supports the patient and their family in making the transition towards the restoration of health, and when it is accepted that survival is not possible, nursing supports the patient and family through the process of dying and the early stages of bereavement."(DH, 2001, p.5)

Practical implications beyond support are not addressed. This thesis highlights nursing practice deficits and emphasises policy gaps in relation to *where* and *how* critical care patients die and access EOLC in critical care. Issues related to cancer patients accessing critical care are introduced next.

ii. Cancer patients accessing critical illness

In this section I introduce how cancer critical illness has particular implications for EOLC and how this shapes the thesis.

Increasingly aggressive and advanced cancer treatments have led to greater numbers of cancer patients accessing critical care, and surviving (Farquhar-Smith and Wigmore, 2008). This represents a fundamental shift in critical care provision for cancer patients over the past decade. Their prognosis has improved immensely,

especially since the advent of new critical care techniques, reaching 40% and beyond (Soares *et al*, 2004; 2005a; Lecuyer *et al*, 2007; Farquhar-Smith and Wigmore, 2008; Thakkar *et al*, 2008). However, many of these patients still die in critical care. This issue is developed further in Section 2.2 and is one of the underpinning rationales for this study.

Cancer survival in general has improved globally and specifically in the UK (Maddams *et al*, 2008; Cancer Research UK, 2009). Cancer has moved towards being considered a chronic and, sometimes, life-limiting condition. While one in three might receive a diagnosis of cancer, only one in four will die from cancer (Office of National Statistics, 2008). Sequelae of treating cancer, increasingly aggressively, can often be critical illness. Furthermore, some patients may present in a poor condition, and, therefore, are critically ill at time of diagnosis.

Prognosis of cancer also needs to be considered when deciding to move patients to critical care and in deciding if, or to what level[2] (DH, 2000), to initiate treatment. This presents new considerations to critical care staff who are increasingly expected to aggressively treat cancer patients in light of the past decade's improved survival (Soares *et al,* 2005a; Thiery *et al,* 2005; Rabbat *et al,* 2005; Thakkar *et al,* 2008; Taccone *et al*, 2009).

There are, consequently, various facets to the issues described in relation to cancer critical illness. First, possible patients' cancer trajectories include: being cured from cancer, living with or dying from cancer. Second, critically ill cancer patients may either receive critical care, be denied critical care or have limitations imposed on the extent of critical care treatment, because of their cancer prognosis. For patients who are not going to survive, there are implications related to cancer diagnosis, prognosis, cancer and critical care treatments that impact on EOL and EOLC. This thesis encompasses and develops these latter aspects in the research findings, including how cancer and critical illness, and prognostication in particular, considered together, affect prospects for EOLC in the context of individual experiences of critical care.

My research, and review of concepts and literature, focuses on care processes at EOL for critically ill cancer patients but acknowledges that care processes and decision-

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[2] Level 0 is the well patient, level 1 the at-risk patient, level 2 the patient with one organ support (but could be cared for on the ward potentially with critical care expertise or in a high dependency unit) and level 3 patients are those who need support for two or more organ failure (DH, 2000).

making are difficult to differentiate between. As I have described in this section, policy expectations around palliative care and EOLC in general settings, as well as in cancer critical illness, provide a background for EOLC in cancer critical illness. Experiences, and relevant related issues, are addressed in this thesis from various perspectives.

iii. An orienting framework; insider perspective

My orienting framework, developed in the reflexivity and conceptual underpinning chapters (Chapters 1 and 5), stems from clinical practice, where I had encountered many dying patients and bereaved families over the years. Axiology, that which is of value (Bahm, 1993; Dombro, 2007), is also determined as examination of one's own values and admitting the study's value-laden nature (Creswell, 2003). This study is part of a practice-based professional doctorate; I work in and influence the research area, so it is important to be candid about this from the outset.

I have chosen to use the first person, where appropriate, in the thesis since this is a professional doctorate, and my role has influenced practice around the research throughout. Furthermore, it is qualitative research, which convention suggests is more amenable to first person use (Hyland, 2001; Lee, 2009). It is easier to convey the impact I have had throughout the doctorate using I, and makes the methodology more accessible.

My background was originally in cancer care; I had worked on various wards, including haemato-oncology. I first became aware of emotional ethical issues associated with EOLC in critical care when working as a junior nurse in critical care in a cancer centre. Despite it being a rewarding environment, I found differences in specifics of EOLC required for critically ill patients and limitations in providing certain aspects of care, in particular around palliation. I happened upon Seymour's (1999) then newly published work which resonated with me, in particular her work around intuition regarding decision-making and subsequent natural death, and I knew I wanted to explore this further.

I saw that a focus on decision-making was at times detrimental to patients', and their families', dying experiences. Literature suggested that my personal experiences were reflective of wider problems fuelling my desire to further explore EOLC for critically ill

patients. Not knowing precisely how nursing and medical EOLC in critical care affects patients, or how nurses could effect good EOLC, despite reflection and discussion, led me to investigate this area. Having cancer, I noted, compounded certain ethical complexities. Dealing with often rapidly changing cancer and critical care prognoses was a challenging part of working in cancer critical care. For example, in patients undergoing rigorous chemotherapy to induce remission, but who subsequently became ill as part of treatment; it was sometimes unknown whether prognosis from cancer was good or bad. These uncertainties were difficult to deal with from a nursing perspective, and our team often spent time after handover discussing and debriefing around these issues.

During the research, I undertook monthly clinical shifts as a critical care outreach sister, enabling me to retain sight of the research within practice and to problematise certain issues. I have described my own experiences and how they form my orienting framework, as Creswell (2003) terms it, and develop this throughout the thesis, namely: that good death can be experienced in critical care for cancer patients and how or why nurses' involvement varies in EOLC and DFLSTs.

iv. Reluctance to move to EOL in critical care

In this section I introduce issues around medical, ethical and legal bases of DFLSTs in discontinuing critical care, associated issues around withdrawing or withholding treatment and how this, alongside futility (i.e. treatment no longer confers any benefit) and prognosis, might lead to professional reluctance to consider timely EOLC.

Withdrawal of active treatment in UK critical care units currently stands at 9.9% (Wunsch *et al*, 2005). Figures for withholding cardio-pulmonary resuscitation are much higher. Withholding, where treatment is purposefully *not* initiated, and withdrawing, where treatment is ceased or de-escalated, are referred to collectively (where appropriate) as DFLSTs. Withdrawal, as opposed to simply withholding, of treatment precipitates death very quickly in critical care (Wunsch *et al*, 2005). With each, underlying processes cause patients to die (Winter and Cohen, 1999; Gedge *et al*, 2007). As acts, rather than omissions, withdrawal can lead to a causality-temporality association (i.e. did my action lead to the patient's death — or would it have happened

anyway?), to fears and feelings of killing patients and a subsequent reticence to undertake DFLSTs and move to EOLC.

For cancer patients, issues around withdrawal are compounded because prognostic models are notably inaccurate in critically ill cancer patients (Blot *et al*, 1997; Guiguet *et al*, 1998; Soares *et al*, 2004; 2005b). Critically ill cancer patients can very quickly deteriorate and the transition from critical illness to the point of futility, and dying, may be difficult to manage.

Prognosis is responsible for some of this difficulty. Prognostication, as it is often termed, forms part of decision-making processes and is very influential in determining futility. Futility may be because of advanced malignancy, impending death (independent of ventilation) or other existing pathophysiologies. Seymour (2001) highlights prognostic indicators as important, iterating the earlier point in Section iii about how accuracy of prognosis affects DFLSTs. With an unclear picture it is more likely that decisions are delayed and for futility to remain undetermined. In uncertainty, there will be reluctance to make DFLSTs, and move to EOL. Consequently this presents a subsequent challenge to timeliness, and quality, of EOLC. This uncertainty about when to move to EOLC often results in prolonged dying that moralistically contravenes ethical principles of beneficence and non-maleficence, upon which nursing and medicine is founded (Bradshaw, 1999; Beauchamp and Childress, 2005). Tschudin (2003), Melia (2004), Davis *et al* (2006) and De Raeve (2006) suggest nursing is founded on virtue ethics. Nurses should examine how we should be and what the 'good person' would do (De Raeve, 2006). This notion of what and how nurses should be is explored in the next chapter.

Modern medicine can now prolong life, even when futile, which raises questions about quality of life considerations. In dying and death, quality is still important (Patrick *et al*, 2001), although the emphasis is on quality of care. This premise of achieving good EOLC underpins my research.

These ethical issues affect processes of withdrawal. DFLSTs are not prescribed in policy and are often negotiated in practice. Moving patients as per policy (DH, 1996), does not acknowledge impracticalities in the case of imminently dying patients and preparation for discharge (e.g. with extubation of endotracheal breathing tubes which could precipitate immediate death (Campbell *et al*, 1999; O'Mahony *et al*, 2003; Marr and Weismann, 2004; Chotirmall *et al*, 2009). A proportion of patients cannot be

transferred out, because they still require ventilation and will therefore require EOLC in critical care (DH, 1996; Wunsch *et al*, 2005). These issues highlight a two-fold problem, dealing with reluctance to move to EOL and once there, providing effective EOLC, which is dealt with in this research. Nurses' complicity in this reluctance and the ability to challenge DFLSTs in EOL made by doctors is an important issue for this thesis. Aspects of power in critical care teams are discussed shortly in Section 1.5 and 1.6.

Moreover, decisions in EOL are contextualised by critical care and technology in critical care. Whether technology is always appropriately used in critical care by both nurses and doctors is debatable (Locsin, 1998; Cook *et al*, 1999; Seymour, 2001); it can prolong life or dying. This notion is developed in Sections 1.5 and 1.6. Yet, technology may be used after the point of futility to allow families and friends time to adjust to the hopelessness of a situation.

v. Summary

This introduction has proposed certain issues for this research: how EOLC is affected by where critically ill patients die and the meaning of certain ethical and practical issues in relation to DFLSTs in this study. I have also introduced my personal background. I have outlined how the influence of cancer on EOLC in critical care is an important factor, not previously described in research, and prognostic influences have been raised. This will be developed further in Chapter 2. Practice and withdrawal implications for EOLC in cancer critical illness set the scene for the thesis. The introduction has raised questions around policy, practical, and ethical issues for cancer patients who are critically ill. Professional guidance, alongside policy, is unclear which may serve to undermine EOL experiences. This prompts me to introduce my research question:

> What are the issues around end−of−life care provision for cancer patients in a critical care unit, as explored through family, practitioner and patient experiences?

I will outline further how this research question was developed in Section 2.1. The conceptual underpinning chapter will now present, as a general concept, caring theory in nursing and then specifically in critical care and cancer care nursing. I will also explore theories around good and bad death and death in critical care.

Chapter 1: Conceptual and Theoretical Underpinning

The following chapter places the study within conceptual and theoretical frameworks, addressing concepts in cancer care and critical care nursing, as well as wider concepts within cancer and critical care. Here I link the need for a conceptual framework with the notion of axiology, actively reporting and reflecting on values and biases. I argue for reflexivity and axiology in Chapter 5, which illuminates personal elements to the conceptual ideals discussed here. Since this is a doctorate in nursing, the conceptual framework centres primarily on nursing, and specifically on critical care and cancer nursing since this thesis spans both disciplines. I begin by outlining theory behind my approach to the research from a professional doctoral practitioner-researcher perspective. Theories of caring in critical care (and caring for unconscious patients in particular), cancer and nursing will be presented to provide conceptual and contextual frameworks for cancer critical care nursing practice. Theories of good death will be explored in Section 1.7, along with corresponding notions of bad death in Sections 1.8. In Section 1.9 I focus on theories of dying in critical care since these underpin the thesis and are developed in the findings.

1.1 A basis for change

In the introduction I outlined the status quo and why I wanted to address this area of practice. I will now preface this chapter by briefly considering what underlies this research within a professional doctorate.

The professional doctorate researcher could be perceived as within the model of 'practitioner as researcher', an agent of the organisation and practitioner, rather than the norm of most health care researchers as external agents to practice (Clarke and Procter, 1999). Practitioner-centred research can be considered beneficial by establishing credence with colleagues but equally can challenge the research by potentially introducing practitioner-centred research bias (Rolfe, 1998). I have striven throughout to make manifest my bias (as I will discuss in the method, reflexivity and discussion chapters: 4, 5 and 7). My ultimate aim was to improve EOLC in critical care, based not only on my experiences as a practitioner, but also verified by the

literature (to be discussed in chapter 2). The discipline of improvement that Clarke *et al* (2004) and Penny (2003; 2009) outline, holds that:

- Work is a process.
- All processes should meet user and carer needs
- All processes can be redesigned and improved
- Everyone should be involved in improving services

This aligns with the flexible philosophy of professional doctoral research that allows for processes to be changed and that has tangible impact 'on the ground', in practice.

It has been suggested that professional doctorates offer the opportunity for transformative practice (Rolfe and Davies, 2009), that is, development and production of knowledge. Being entrenched in practice still meant that practice development, heavily linked with research (Clarke and Proctor, 1999), was also clearly an important part of this process of reflexivity (which will be discussed in Chapter 5) and the professional doctorate model. Reflexive mapping of the impact of my research, both during and after, was an important part of making clear my contributions to nursing practice throughout the process (see Appendix 8). The practice-supervisor, my manager, also held an important role in this regard, encouraging me to become involved in wider issues in practice broadly related to my research. Expert practice developers see opportunity for development in situations less than ideal (Clarke and Wilcockson, 2001), and this research presented challenges in terms of incorporating participants' practical suggestions and LCP introduction for example (see Section 2.7). The role of policy remains important (Clarke and Wilcockson, 2002) and, as I outlined in the introduction, presented significant difficulties, such as lack of guidance on how to deal with EOLC. This study aimed to explore and address these deficits in some way. Being an insider not only provided me with the opportunity to undertake research, but also to ensure practice development and improvement as a result of the research. Underlying my research, therefore, is a desire to change practice, improve the quality of EOLC and also to advance nursing knowledge in a specific area that has struggled to make the contribution of nursing really visible.

1.2 Caring in different contexts

I have chosen a conceptual framework centred on caring in the context of death, dying and nursing and I explore each of these in relation to EOLC and critical care. In my research I wanted to explore *care* at EOL and as such, care needs defining beyond the realm of EOLC as defined in the introduction.

Caring has been regarded as a moral foundation for nursing (Fry, 1989), a participative activity (Noddings, 1984) and the essence or tradition of nursing (Leininger, 1988; Olson, 1993). It can be seen as the profession's special knowledge, under Foucault's (1973) concept of knowledge formations. Care has itself been defined as paradoxical (Fox, 1999), since it is based in intimate human relation, valuing love, giving and concern. It forms part of a 'good nurse' (Gallagher *et al*, 2009). Conversely, it is a set of practices embodied within 'caring professions' that may even be used to wield power and authority. As such, caring can even be used to achieve cure. For instance, caringly convincing a reluctant patient to take antibiotics may result in the cure of their infection. Rationales for such action centre on wanting to achieve cure. One could extrapolate this to the idea of benevolent paternalism that Melia (2004) accuses nurses of. Cure can also be used as a measure of care. This contradiction becomes pertinent when regarding nursing theories that focus on curative paradigms as I discuss next in Sections 1.5 and 1.6. Caring, somewhat dubiously, is deemed synonymous with nursing (Phillips, 1993), and as such both require further exploration.

This brief definition of nursing frames the discussion for focus on cancer and critical care nursing in particular. Attempts to define nursing have been made by the Royal College of Nursing (RCN) (2003), after the United Kingdom Central Council (1999) stated it was too difficult to define. The RCN concluded that nursing is:

> "The use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health, to cope with health problems, and to achieve the best possible quality." (RCN, 2003, p.3)

They list defining characteristics of nursing that suggest, for instance at EOL, nursing's role is to promote best possible quality of life, as well as to empower people and uphold dignity, autonomy and partnership. Within this broad definition of nursing I now

outline two spheres for this thesis: caring within critical care nursing and cancer nursing. This will inform the background of the sample I use for this study: critical care nurses and cancer critical care nurses. I particularly regard art and science (technology) in each, how nurses view themselves in each sub-profession and what that means for EOLC. Defining care also provides a basis for what good care entails (over and above notions of good death that I will explore in Section 1.8), and I will examine this in greater detail in relation to the challenge of caring for unconscious patients in Section 1.4.

1.3 Critical Care Nursing

Critical care nursing skill could be defined by agility in moving between technical and more traditional aspects of care. This research explores some of these tensions in managing that agility, in particular, managing a good death through 'good' quality care. Benner *et al* (1999) cites technological competence as necessary, displaying wisdom in applying knowledge to patients' care, rather than viewing caring as an adjunct to cure. In EOL situations where cure is impossible, this is particularly pertinent because care might be the only measure for quality. Dunlop (1986), Kitson (1993), Darbyshire (1996) and Benner *et al* (1999) argue that art and science of nursing are not mutually exclusive. In unison they lead to excellence in care. Whilst technological proficiency (which could be deemed as science in caring) in critical care nursing is necessary (Cooper, 1993; Barnard, 1999), artful nursing care is still evident in critical care, e.g. ameliorating anxiety. Johnson (1994) in her dialectic of nursing art deemed it nurses' ability to:

- Find meaning in patient (and family/carer) encounters
- Establish meaningful connections with patients
- Provide rationales for appropriate courses of nursing action
- Skilfully perform nursing activities
- Conduct nursing practice morally.

Expert application of empirical and metaphysical knowledge and values characterises art in nursing. It is relationship-centred and involves sensitively, creatively adapting care for individual needs. It promotes beneficent practice, resulting in enhanced patient well-being and professional satisfaction (Finfgeld-Connett, 2008a).

Experienced, 'good' critical care nurses use clinical wisdom or 'comportment', and clinical forethought to provide excellence in care (Benner *et al,* 1999). This, then, is application of care over care versus cure.

Nurses' values and moralities about extraordinary measures used to prolong life in critical care have often been challenged (Kirchhoff *et al*, 2000). I suggest that a contradiction emerges of human feelings about what is right, and what is expected professionally. In the palliative care paradigm, DFLSTs are expected but in critical care these are not always expected and are more ethically complex. Power issues also affect loved ones' contributions towards decisions about transitions in care (Johnson *et al*, 2000; van der Heide *et al*, 2003; Sprung *et al*, 2003), as I discuss in Section 2.4 in relation to literature. Nurses are well placed to advocate for patients and families in resolving inequities in power between families and decision-makers (doctors) (Pattison, 2004). In order to do so, however, it could be argued that nurses need to reconcile where their focus of care lies within the paradigms of nursing and critical care medicine. Caring in critical care nursing therefore needs deeper consideration, since the meaning for those involved in caring at EOL is central to this study. I will now consider this caring issue with particular emphasis on unconscious patients, since this group formed the study sample and focus.

1.4 Caring in nursing: examination of specific concepts for unconscious patients

I outline here notions of caring for unconscious patients because most critical care patients are unconscious and cannot contribute to decision-making and EOLDs. This issue would also relate to unconscious dying patients. How unconsciousness potentially impacts on patient care will be explored in light of caring theory.

Caring has been described, in Finfgeld-Connett's (2008b) metasynthesis of the concept, as an interpersonal process characterized by expert nursing, interpersonal sensitivity and intimate relationships. A need for, and openness to, caring on the recipient's part is noted alongside professional maturity, moral underpinnings, and conducive work environments. Finfgeld-Connett (2008b) also suggests that caring leads to nurses and patients experiencing improved mental well-being, and for

patients, physical improvements. I argue that her notion, interpreted as a form of reciprocity, is difficult to measure in deeply unconscious patients, such as this study's patients. Furthermore, in suggesting that care can effect improvement in physical well-being, it is in danger of reverting to curative notions. For instance, there may be no improvement in trying to manage patients at EOL with intractable cancer pain, but I would argue that a nurse's intention and her presence might characterise care. Swanson's (1991) meta-analysis of caring: knowing, being, doing, enabling and maintaining belief, employs terms also indicative of cure. Maintaining belief is a nursing ability to sustain faith in patients' capacity to get through events or transitions and face a future with meaning. With Swanson's examination of theory, the challenge lies in facing death with unconscious patients and accepting unachievability of enabling the facing of future with meaning.

For me, elements of caring are cognate with Swanson's (1991), Watson's (1979) and Finfgeld-Connett's (2008b) engagement, but are not simply about this. However, application of these theories is difficult where patients, such as in this research, cannot engage. Arguably, a different kind of engagement takes place with unconscious patients. It is engagement with less emphasis on reciprocity, and greater emphasis on empathic ability with families and patients. Caring, therefore, still occurs. Watson (1979; 2006) delineates the explicit moral foundation of a value in the centrality of human caring. In short, nurses attempt to enter and engage with patients' frame of references to be able to connect with their inner life and meaning. This could then potentiate comfort measures, pain control well-being, or even, as Watson (2006) argues, transcendence of suffering. It relates to non-verbal communication, body language, feelings, intuition, thoughts and senses, and requires presencing.

Watson (2006) argues for the notion of presencing and engagement as a nursing and caring fundamental. Notably, Finfgeld-Connett (2006; 2008c) cautions that presencing — an interpersonal process characterised by sensitivity, holism, intimacy, vulnerability and adaptation to unique circumstances — is distinct from caring and should not be muddled. Yet, she presents results for the effect of presencing and caring that are exactly the same. I would, therefore, see presencing as having the same consequence as caring but retain a distinction between the processes. To try and apply presencing (as described above) and caring for critically ill, unconscious patients is somewhat exigent: both would then be regarded as more applicable to family care. I will revisit this theme of caring for families and patients, and differing priorities, throughout the thesis.

Falk-Rafael (1996; 1998; 2001) outlines how critical care nurses align themselves with the dominant medical profession in order to move away from nursing care since it yields little reward. In essence, to progress in nursing, she suggests care is effectively rescinded. Nurses must achieve a certain scientific-technological knowledge base in order to have a voice and credibility in critical care, and yet the traditional art of nursing is devalued by the lack of power it commands. Conflict experienced by nurses trying to balance art in nursing alongside technological-scientific approaches, particularly in critical care settings, might arguably be resolved if humanistic elements are maintained (Kitson, 1993; Cooper, 1993; Dean, 1998). Such conflict may further exacerbate feelings of powerlessness for nurses (Manias and Street, 2001; Coombs and Ersser, 2004). Interweaving art and science of critical care nursing is, as Rushton (2002) asserts, *being* rather than *doing* with patients. The *being* element focuses on patient-centred, quality care and establishing presence. This aspect of critical care nursing, within a cancer context, in particular concomitant emotional consequences, is relevant to this research.

The combination of organisation, physical labour and emotional labour has been described as caring (James, 1992). This would place caring as inextricably linked to emotional labour. Emotional labour, the emotional cost of work (Hochschild, 1983), has been to some extent considered implicit to nursing (James, 1989; 1992; Smith, 1992; Aldridge, 1994; Savage, 1995; Gray, 2009) but less so in medicine (Larson and Yao, 2005). Smith (1992) took this concept further. He describes how emotional work would mean more successful caring. The environmental supportive context and nurse-patient relationships also ensure successful caring. Hochschild's (1983) theory suggests emotions associated with duties of a role and subsequent balancing of actions with genuine feelings against insincere feelings, can be regarded as part of a caring role like nursing. It relates to reconciliation and congruence between action and feeling. Emotional work is regulated by social exchange and human interaction. It centres on managing emotions from demanding work. Hochschild (1979) outlines how supposed social conventions of feelings can either be *evoked* or *suppressed*, which in turn can lead to a commoditisation of feelings: adjusting (or acting) how one should feel according to different situations for social or personal gain. Emotional labour, therefore, implies a way of managing emotions to social advantage, which I suggest in nursing would be to patients' advantage. Here, there is apparent overlap between emotional labour and engagement as empathic ability that I delineated earlier. Emotional labour may be one way of ensuring successful care, but is at risk of being overshadowed by a drive for cure, since that is the basis of the prevailing medical

paradigm. Cribb (2001, p.22) proposes that emotional labour may be one way of making caring sound less 'wishy-washy' and more indicative of skill or expertise. I see this as devaluing the concept of caring even further. I maintain a distinction between emotional labour and caring in nursing for this research.

1.5 Nursing knowledge, exercising power and running with wolves

Locsin (1998) echoes concepts of critical care nurses *being* with patients.[3] Activities associated with technology are often viewed as so arduous that 'true caring' is no longer possible. True caring in this sense would be activities performed *with* patients (eg. hand-holding with deeply unconscious patients during uncomfortable procedures). Computer programmes used to calculate nursing dependency, nurse-patient ratios and funding sadly have limited scope for including *being* activities. The art of nursing is then rendered less visible and emphasis is placed on technical activity. This affirms Sandelowski's (1993; 2000a; 2000b) suggestion that technology can render nurses' roles invisible but equally render it more visible.

Empowered caring, where nurses integrate their technical knowledge and caring knowledge to advance care for patients and thus enhance nursing's status (Locsin, 1998), is one suggested way forward. It is the ability to function at high levels of technological competence but retain traditional caring attributes. As Locsin (1998) stresses, if nurses claim caring is unique to nurses, it is essential to clarify the framework of technological competence as *caring* in critical care nursing. Melia (2004) suggests because doctors take decisions, their technical stereotype is hardened leaving the path open for nurses to claim holistic nursing aspect and advocacy (and perhaps caring). I would suggest it is not as clear-cut as this. Decision-making is increasingly shared these days, as evidenced by Coombs (2003, Coombs and Ersser, 2004; Endacott *et al*, 2008). However, tensions remain around critical care nurses wanting to be technologically competent but remain caring. Technological competence as outlined by Benner *et al* (1999), among others (Ray, 1987; Ashworth, 1990; 1994; Carnevale, 1991; Cooper, 1993; Locsin, 1998; Barnard, 1999; McGrath, 2002),

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[3] This notion of being is also evident in Leininger's (1988) concept of authenticated and intentional presence, which sees this as essential to personal knowing of patients in nursing and a way of engaging with patients to effect cure.

delineates nursing need for technological competence to achieve 'best' practice. Critical care nurses first have to learn to manage complex equipment, understand physiology, apply that knowledge to save patients' lives and then layer or interweave it with artful nursing and caring. Engaging and implementing empowered caring, being cognisant of technology, but still championing art in nursing, is a potential way for nursing (critical care nursing in particular) to present a different challenge to critical care medicine's dominant paradigm. Falk Rafael's (1996) notion of nurses who run with the wolves, presents the dominant paradigm as medicine. Showing empowered caring in behaviours such as personal explanations, anxiety therapy, active listening, hand-holding, whilst undertaking 'technological' procedures provides examples of art and science co-existing to improve patient care and challenge that paradigm.

Benner *et al* (1999)'s *Clinical Wisdom and Interventions in Critical Care,* although not strictly theory (that which can control, explain and predict actions), is based on *Novice to Expert* (Benner, 1984) and provides guidance for structured thinking around critical care issues nurses might encounter. Difficulties in applying many nursing theories to critical care nursing *per se* (particularly around limitations with unconscious patients) might add weight to arguments for explicit critical care nursing theories that would develop each aspect of critical care nursing beyond existing models of critical care nursing, such as the Synergy Model of care (Curley, 1998) which requires nurses to consider: complexity, vulnerability, predictability, resilience, participation in decision-making and in care, and resource availability. While useful, this model of critical care nursing is also not theory. Primary limitations in the nursing caring theories described above do not explain phenomena encountered in this study. These patients are mostly unconscious (addressed in the Synergy Model solely in relation to facilitating family input) and reciprocity is unachievable; there are tensions around at whom care should be aimed and whose needs takes priority. This tension of prioritisation, which informed the sampling and is evident in the thesis findings, will be explored in this study.

Developing previous assumptions about care outlined earlier, critical care nurses apply knowledge of physiology to care for patients holistically. Equally, doctors display caring attributes. Thomasma (1994), a medical phenomenologist, heralds the advent of principled ethics (such as Beauchamp and Childress' (2005) ongoing work) as the precursor to medicine's development into a discipline more sensitive to clinical realities. This is echoed by Pellegrino (2008) who philosophises that phenomenology is useful for considering clinical medical encounters. This signifies how medicine cannot simply be categorised as dualistic, non-humanistic and stemming purely from a

positivistic biomedical stance. Coombs and Ersser (2004) analysed power struggles in critical care, noting a shift towards more dynamic processes between nurses and doctors. This contrasts with Zussman's (1992) theory of intensive care that delineates clearly between nurses and doctors, suggesting a division of labour: nurses do the caring and doctors cure. Despite this shift, critical care nurses may still be complicit in perpetuating the patient as subject somewhat by following a medicalised model of care. The challenge is for critical care nurses to define their success as a sub-profession not by technological proficiency and knowledge, but by how their knowledge can be applied to promote patients' best interests. In the context of EOLC, this research explores some of the tensions in managing knowledge and providing quality care, in nursing and medicine.

Issues around defining nursing and care (a supposed nursing attribute) were outlined previously, but is care what gives the profession its specialty? Taylor (1994) suggests nursing attempts to define itself in terms of roles and responsibilities. Instead, it needs to embrace being and knowing as human concerns (Taylor, 1994). Falk-Rafael (1996; 1998; 2001) scrutinised issues of caring and power. She noted how nurses traditionally align themselves with dominant professions by assuming qualities of that profession, such as increasing medical knowledge and displaying aggressive assertiveness, distancing themselves from caring attributes, to achieve powerful positions. There is an assumption that caring requires no knowledge base (Falk-Rafael, 1996; 1998; 2001). This, therefore, perpetuates the low status of power that caring nurses have. She attempts to resolve this through empowered caring.[4] "Empowered caring is praxis…" (Falk-Rafael, 1996, p.8), that is, practice informed by various knowledge. Such knowledge then conveys power. Falk-Rafael (1996, 1998, 2001) and Locsin (1995; 1998) would seem, therefore, to imply that knowledge is needed to challenge power. This would mean nurses would need to master critical care knowledge, be aware of wider issues in critical care, and apply caring values whilst maintaining this varying knowledge. This theory would seem to hold value in critical care nursing and knowledge and I will develop this later with regard to nurses also needing to apply EOLC and cancer nursing skills in addition to these critical care skills. I will compare this next to skills required in cancer nursing and how cancer nursing defines itself. The complexities of integrating these three knowledge bases: critical care, cancer and EOLC are addressed in the findings.

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[4] This is distinct from Locsin's notion of empowered caring - based in critical care - which enables nurses to care whilst being socially and politically aware, thus acquiring and using knowledge, and creating an opportunity for equality

To summarise, caring critical care nurses have to be able to apply and integrate their knowledge of pathophysiology and technology not only to save patients' lives, but also to ensure presence (even with unconscious patients), empathy, authenticity and caring within interactions involving technology. Critical care is an area in which knowledge is difficult to master, which affects nurses' confidence in caring. Care, then, is related to engagement, an intentional action for someone's well-being beyond simply *doing*, toward as Rushton *et al* (2002) noted, *being*. These principles for care form the basis of the definition for care used in the thesis.

1.6 Cancer nursing and caring

This study is situated in a cancer hospital and, although the focus is on critical care nursing, some participants were also trained cancer nurses. Cancer nurses are renowned for caring and comforting attributes (Bottorff *et al,* 1995; Christopher and Hegedus, 2000; Gambles *et al,* 2003; Radwin *et al,* 2005; Wengström and Ekedahl, 2006). Emphasis on technological competence is less noticeable for both patients and nurses (Kelly, 1998), rendering artful nursing more apparent. However, patient-centred, safe and competent nursing care is paramount for cancer patients (Fawcett-Henesy, 2000; Rchaidia *et al*, 2009), which highlights that technological proficiency (e.g. safe chemotherapy administration) has its place. Cancer patients valued nursing care actions that demonstrated clinical competence as important (Larson, 1984; Mayer, 1987; Rchaidia *et al,* 2009). Gallagher *et al* (2009) and Rchaidia *et al* (2009) noted that cancer patients felt a good nurse displayed certain characteristics (Box 2).

Box 2. Characteristics of a good nurse

Skilful	Appreciating patients as people
Knowledge	Sincere
Person-centric	Respectful
Flexibility	Understanding needs
Helpfulness	Compassionate
Courage	Kindness
Fidelity	Friendliness
Empathy	Patience
Trustworthy	Emotional Support

Cancer nurses cited a desire to care, *caritas*, in choosing cancer nursing as a specialty (Wengström and Ekedahl, 2006). I would argue that care is inherent in the nature of nursing, as embodied in nurses' desire to enter cancer nursing *because* of care, as echoed here:

> "For many nurses, caring competence is perceived to be care that is based on the patients' experiential meaning; that is, the internal environment encompassing desires, values, beliefs, and emotions. To make this possible, a relationship needs to be developed between the nurse and the patient for nurses in cancer care." (Wengström and Ekedahl, 2006, p.26)

Coffey (2006) asserts that cancer nurses enter into a covenant of care with patients, implying reciprocity, a contextually negotiated, binding relationship beyond the technological. Her exploration of patients and nurses' perceptions and the nurse-patient covenant in cancer care reinforces concepts of caring discussed previously. Covenants in nursing are sporadically addressed (Cooper, 1988; Bradshaw, 1999, Melia, 2004) but not for cancer nursing specifically. Coffey (2006) makes no claim that cancer nursing has greater impact on that covenant, but did sample cancer nurses. One nurse in her study described how much of her work would be seen as a failure by those outside cancer care. Dying well, for example, could represent a reframing of success, as to understand how to nurse well and how to see benefits in acute cancer care (Coffey, 2006). Measures of success in cancer care are viewed differently from other areas of practice, e.g cardiac surgery. One in four people will die of cancer (Office of National Statistics, 2008), so cure rates are modest, but cancer nursing is still perceived as 'successful' in care (Radwin *et al,* 2003).

Cancer patients have defined caring in nursing as showing concern, compassion, kindness, responsiveness, individualisation, coordination and proficiency (Radwin *et al,* 2003; Radwin *et al*, 2005). Patients deemed caring as: supportive, comforting, concerned/unconcerned, attentive/inattentive, understanding, sensitive/insensitive, empathetic/unempathetic and helpful, with nurses displaying both positive and negative attributes (Radwin *et al*, 2005). Despite the study setting of a US Comprehensive Cancer Centre, renowned for excellence, nurses did not always display care. Whether pessimistic views of cancer patients' illnesses impact on nursing attributes is unclear. However, nurse-patient relationships would, undoubtedly, be affected by negativity. In caring for cancer patients, nurses have recognised the need to support patients to reach milestones and maintain hope (Kendall, 2006). What happens at EOL, where traditional notions of hope have to be reframed, is not clear.

Indeed, Payne suggests that cancer nurses may need to develop their skills in terms of family communication around death and to consider how to increase carer engagement to facilitate choice in EOLC (Payne and Willard, 2008). This study engages families and patients to explore how caring at EOL in cancer is affected by critical illness and how much influence the impact of cancer has on the potential for EOLC in critical care.

Making assumptions about cancer nurses' caring attributes is questionable (Kelly, 1998), especially with increasingly sophisticated technology in cancer care. There is perceived emotional labour in cancer and cancer nursing (Kelly *et al,* 2000; Magnusson and Robinson, 2000). Emotional labour in bone marrow transplant nursing pertains to daily dealings with death, dying and bereavement (Kelly *et al*, 2000). They highlight how emotional labour should not be avoided in a technical environment which denies palliative care. As in critical care, nurses might deny emotional labour since it requires too much of themselves to engage in it. This echoes the sentiment of engagement raised earlier. Nurses helping cancer patients heading towards death to live a meaningful life are confronted with their own existential issues (Rittman *et al,* 1997; Wengström and Ekedahl, 2006).

As with critical care nursing, Corner (1997) holds that cancer nursing still exists within a culture of biomedicine. It is at risk of developing further into an outcome-driven area of nursing practice by virtue of targets and benchmarks (Donovan and Mercer, 2003). In highly technical cancer nursing, such as haemato-oncology, McGrath (2002) argues that cancer nursing can also be focused on technological competence, and the technological imperative, as much as in critical care. Whereas in critical care survival is the ultimate goal, achieving cure in cancer care is, again, the ultimate goal of the medical cancer paradigm. Cure in cancer can be measured differently by clinicians than by patients. Indeed, clinical measures of cure traditionally remain the focus for reporting cure in cancer (Faithfull, 1994). For patients who achieve cure (albeit in a clinical sense or otherwise) consequences of cancer treatment define whether it can be regarded as 'cure'.[5] Tens of thousands of studies reaffirm how sequelae of cancer treatment strongly impact on people's lives. The subsequent effect and fear, is potentially compounded by critical illnesses, as in this research, which can occur as part of cancer trajectories.

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[5] Success and cure in cancer is most often measured in five years disease-free survival (which means no clinically detectable disease)

Palliative care nursing, historically viewed both as a sub-speciality of cancer nursing and a discipline in its own right, does not have cure as an underlying premise. In palliative care, outcome measures centre on quality care issues (DH, 2009b). Despite this, Field (1994), White (1999), Seymour (1999; 2001), Clark (2002), Corner (2001; 2003), Sandman (2005) and Zimmermann and Wennberg (2006) have all argued that palliative care and death also suffer from aspects of medicalisation. Cook *et al* (2003), Lapum (2003) and Hawker *et al* (2006) suggest polarisation of medicalisation and palliative care is unnecessary and that technology can be used to enhance death. One could draw from this that either nursing in palliative care has not developed sufficiently to challenge this medicalisation or, conversely, it has developed beyond challenging medicalisation. Indeed, there is debate around the potential benefits of the professionalisation and medicalisation of dying (Field and Addington-Hall, 1999; Seale, 2000; Clark, 2002) such as, access to increased knowledge of symptomology, ethics and coping strategies. Corner (2003) holds that palliative nursing is characterised by deep interest in personal and interpersonal aspects of care for dying people. Symptomology is less important and emotional care is prominent. Skilbeck and Payne (2005) suggest that EOLC should be structured around individual needs and that specialist palliative care nurses are ideally placed to create innovative and nurse-led services. Cancer nurses, surveyed by Beckstrand *et al* (2009), were noted to be comfortable in handling EOL issues, and know to involve palliative care, suggesting there is some overlap between cancer and palliative care nursing. While I am not exploring palliative nursing, the idea that cancer nurses might possess palliative care skills by virtue of experiential exposure or training is an interesting point for my research.

Earlier, I defined certain characteristics critical care nurses use to cope and advance in critical care, such as aligning with the technological-medical model. Cancer nurses too, have strategies for managing complexities in their work. In order to cope, Ekedahl and Wengström (2006) found that nurses demonstrate general boundary demarcation, have emotional outlets, caritas oblivion (obliviousness to the desire to care) and periodically changing activity. These strategies can be used in a functional or dysfunctional way. When there was a lack of human support and boundary demarcation, nurses coped dysfunctionally.

Thus, the technical thrust in critical care nursing explored earlier might also pervade throughout cancer nursing. A lack of power issues in the cancer nursing discourse is suggestive of cancer nurses' value in the broader discipline of cancer care. Literature

points to content of cancer nurses' action, rather than professional contexts in which they work. Reasons for this are unclear from the literature, but are likely to be situated in the meso and micro-cultures of cancer care. For this study, this proves an important consideration since it is based in a cancer critical care. The aesthetics in caring for cancer patients lie in recognising the imprecise nature of caring, but trying to define it nonetheless.

1.7 A good death

In this section I outline notions of good death, from differing paradigms (nursing, medical, palliative, acute care and the patient), and discuss how sudden death is viewed in this regard, given the rapid decline of many critical care patients. I explore revivalist notions, autonomy in good death and the subsequent potential for nursing.

The *National End-of-Life Care strategy* (DH, 2008) aims to ensure more people receive what they perceive as a good death. The modern motivation for a good death has ancient Greek roots in *Kalos Thanatos* and *Eu Thanatos,* the achievement of a beautiful and good death (Kellehear, 1990). *Kalos Thanatos,* in particular, is linked to the social meaning of being prepared for death and dying nobly and *Eu Thanatos* relates to the medical quality of end of life (Kellehear, 2001). Ariès (1974, p.5) terms good death a 'tame death'. As with *Kalos Thanatos,* it relates good death to a warrior's death in battle and a prepared death. In contrast, sudden death or *mors repentina* was regarded as shameful and ignominious (Ariès, 1974, p.10). Historically, sudden death was a threat against the social order of the world and was deeply related to belief in, and perceived wrath of, God (Ariès, 1974). This traditional threat to the social order arguably persists today (Seale, 1998; Clark and Seymour, 1999), particularly in sudden death and death in critical care. Yet, peaceful but sudden (which I interpret as swift) death is still a goal of palliative care. In the right part of an expected death trajectory, sudden death might now hold more desirable characteristics than it once did and even be a part of good death (Kellehear, 2001). Indeed, Seymour (1999) examines the process of dying and how that affects the construct of natural death, and how in intensive care units (ITU) technology can become central to managing dignity in sudden, extreme and seemingly 'unnatural' death situations. I shall shortly discuss sudden death in relation to bad death further in Section 1.3.

Staff attitudes towards appropriateness of impending death, and the EOL context, affect the construct of death, its trajectory and whether death is regarded as 'good'. Theories of good death inform notions of what constitutes good death. Good death theories share many similarities and hallmarks of a good death, notably reaching a consensus for valuing the event of death, after death and dying well. Sandman (2005) suggests good death is meaningful and dignified. Indeed, hospice and palliative models of care are based on this and deemed synonymous with good death (Clark and Seymour, 1999; Ellershaw and Ward, 2003). They embrace low-technology, non-interventionist approaches to dying. As I will detail further in Section 2.3, cancer diagnosis does not mean good palliative care will be provided (Neergard *et al*, 2008). Furthermore, McNamara (2001) suggests that palliative care should not be associated necessarily with good death, and that a cancer death is often a feared death. Therefore, I draw a distinction here between cancer and palliative care corroborating the distinction I made regarding cancer nursing in Section 1.6. Jones and Willis (2003) argue that to avoid a paternalistic view, good death should be based on what an individual wants. In critical care, however, individuals are nearly always unable to contribute. This issue proves critical in this study in rationalising the study sample and in relation to the findings in chapter 7.

Ellershaw and Ward's (2003) universal principles of ensuring dignity, preferred place of death and timely diagnosis of dying, are I would suggest, hard to argue against because few would wish to die at variance with this. Neuberger (1999), in contrast to Sandman's (2005) consideration of theories, considered religious, cultural and ritualistic aspects to what might be conceived, and achievable, as good death. Again, individualistic aspects take precedence (Neuberger, 1999; Jones and Willis, 2003; Sandman, 2005). Kellehear (2001, p.120) highlights the palliative care literature on this:

> "Unfortunately, most of the social science and palliative care literature has concentrated on caregivers' realities – the needs of the dying as assessed by family and health care professionals."

Revivalist principles of a good death (Walter, 1994; Clark, 2002; Gott *et al,* 2004) suggest a return toward 'natural' ways of dying, and that death is increasing in prominence in contemporary society, which would seem to correspond with national EOLC strategy (DH, 2008). Clark (2002) outlines features of a revivalist death (Box 3) summarised as:

Box 3. Revivalist death

- Pain-free death
- Acknowledgement of imminent death
- Death at home and with family and friends
- Awareness of death
- A 'resolved' death where conflicts and disputes are dealt with
- Death as per personal preference and reflecting the individual
- Death as personal growth

Despite at first glance seeming at odds with revivalist notions because unaware death takes place in critical care, Seymour's (2000; 2001) theory (see Section 1.9 next) outlines how natural dying and good death could still occur in critical care reflects some of these revivalist principles in relation to resolution and natural order. For natural death to be possible, it requires doctors to make DFLSTs and accept dying as inevitable. Medical concepts of palliative care and good death have been described as encompassing four domains: care, relational and social aspects, preparation and social aspects (Toscani *et al*, 2003). These concepts allow for choice but still presume awareness of dying and disparities between. An alternative, medical notion of a good death, seen in Smith (2000) in Box 4 overleaf, exemplifies health professional influence.

Box 4. Principles of a good death (Smith, 2000, p.129)

- To know when death is coming and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs (at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensure wishes are respected
- To have time to say goodbye and control over other aspects of timing
- To be able to leave when it is time to go and not to have life prolonged pointlessly

I would argue that, *prima facie*, Smith's concept of good death does not allow for sufficient individual choice. He places emphasis on people having access to hospice care ideals when this may not be what a person wishes for, as per the revivalist discourse. In part, according to Walter (1994), revivalism relies on doctors and nurses' invitation, emphasising how health professional contribution to death need not mean medicalised dying. It should be recognised that what health professionals perceive as good death, families and patients may not (Pattison and Lee, 2009). As Voogt *et al* (2005) and Jones and Willis (2003) contend, some patients need to rage against dying if death approaches them suddenly, as with late diagnosis of cancer. Patients may wish for a high-technology death, contrasting with what is felt to be consonant with notions of good death. Equally, however, patients may accept a 'bad death' because they are resolved to have tried all treatment before they die, in a 'last ditch' attempt to stay alive, or to prolong life for a few more days. Patients may wish for chemotherapy, for instance, in the face of newly diagnosed advanced cancer which Bowcock *et al* (2004) argue can be appropriate. Treatment may be either in place of, or alongside, palliative care. If respect for autonomy is applied fully, requests for treatment are hard to decline (Pattison and Lee, 2009). However, striving for autonomy should arguably be tempered by clear truth-telling. Failure of doctors in truth-telling has been outlined as a factor in lack of acceptance about, and coping with, dying (Pellegrino, 1992; Anderlik *et al,* 2000; Jenkins *et al,* 2001; Baile *et al,* 2002). The nursing role in truth-telling has been explored in limited literature (Kendall, 1995; Georges and Grypdonck, 2002; Hyland, 2002; Vivian, 2006) with suggestion that nurses collude with doctors (Kendall, 1995; Vivian, 2006).

Autonomy at EOL, in relation to good death theory, is difficult to apply with patients who lose autonomy through incapacity, such as critically ill patients in drug-induced coma, and dying, delirious patients. Sandman (2005) draws on autonomy as an intrinsic desire; regardless of whether self-determination has final value, here at EOL, it should be respected. This idea, however, seems to stem from the notion that patients can plan for EOLC and are autonomous when they have the potential to know they are dying. He does not discuss how principles of autonomy can apply in unconscious and unexpectedly ill patients, such as in my research. Walters (2004) offers a historical perspective around a good death, suggesting a post-modern death: 'death in my control' and 'death in our control'. Again, his perspective on good death is from the premise of a conscious, controlled demise toward death. Conscious death and dying is unachievable in most critically ill patients, and, too, in some palliative care

patients. Equally, control can be difficult to achieve. This issue of applying a good death, in an ideal situation with an ideal, conscious and capacitous, patient, resonates in much palliative care literature but is at odds with nearly all critically ill patients. The potential for change lies not only with facilitating patient and family autonomy, but also with medical and nursing teams who may need to re-evaluate notions of good death.

Thus, characteristics of good death espoused in literature include a low technology, demedicalised, conscious (at least at the beginning of dying) awareness of dying, and consonant with the hospice model (Bradbury, 1996; Payne *et al,* 1996; Seale, 1998; Walters, 2004). Indeed, even in such models, and as with other dying literature, there is disparity between staff and patient perceptions of what constitutes good death: staff concentrate on spiritual and psychological resolution when many patients, especially older people, desire a quick, unaware death (Payne *et al*, 1996; Catedra, 2004; Gott *et al,* 2008). Payne *et al* (2005) describe further discrepancies with patients wishing to die in sleep, quietly, with dignity and being pain free, where staff talked of adequate symptom control, family involvement, peacefulness and lack of distress.

Exploring further theories of good death led me to consider Johnson *et al* (2000), which I outline below, and Kehl's (2006) concept analysis of a good death (exploring 42 theories and concepts of good death, including theories from research, patient medical and nursing perspectives, acute and non-acute deaths). Kehl (2006) builds a concept analysis from the main precepts: being in control, being comfortable, sense of closure, affirmation/value of dying people recognized, trust in care providers, recognition of impending death, beliefs and values honoured, burden minimised, relationships optimised, appropriateness of death, leaving a legacy, and family care. This concept is echoed in Singer *et al*'s (1999) study with patients outlined shortly. A theory of 'A Peaceful EOL' (Ruland and Moore, 1998), included in Kehl (2006), was one of the few theories based on standards of care in nursing. Nurses, usually key care providers at this stage (Ruland and Moore, 1998; Seymour, 2001), are often still directed by critical care doctors. Notably, this theory excludes doctors who, it could be argued, are key decision-makers. Principles of dignity, privacy, and comfort care in A Peaceful EOL theory do transcend professional boundaries but compartmentalising EOLC to individual professions runs the risk of absolving collective responsibility for good EOLC. Furthermore, Kehl's (2006) composite theory is often not clearly applicable to death in acute care, which echoes sudden death at times and is characterised by uncertainty. I therefore, reject the application of this meta-theory for my study. I have described limitations in applying good death theory based in general

settings to acute settings, which provides a rationale for further exploration of theory based in critical care. I will now explore corresponding notions of bad death to expand notions of good death.

1.8 A bad death

Bad death is the obvious opposite to good death and from the theories above I extrapolate that bad death is characterised by binary contradictions of the factors outlined. In addition, I will explore how sudden death might also be regarded as bad death. Bad death in critical illness-related death, and subsequent EOLC, and potential issues for this study, are also discussed.

Sudden death is, as I outlined previously, historically viewed as bad. It is also perceived as highly consequential in bereavement literature for the bereaved's psychological and physical health (Parkes *et al*, 1969; Kubler Ross, 1981; Parkes, 1986; Wright, 1995; Cook *et al,* 2002; Melhem *et al*, 2008; Soares-Oliveira *et al,* 2008). For those who witness sudden death or experience related bereavement, outcome is worse (Melhem *et al,* 2008). Grief in sudden death is also affected by where death occurred (Wright, 1995). Sudden death also has implications for healthcare professionals, who may find it hard to cope, especially if unsupported (Wright, 1995; Saines, 1997).

For patients, arguably, they would be unaware of how sudden death may or may not impact on good death. When thinking hypothetically, as I outlined in Section 1.7, palliative care patients saw sudden death as sometimes more desirable (Kellehear, 2001; Gott *et al,* 2008). Countering this, palliative care patients, already aware of their dying, would view sudden death differently from those not dying. Inevitably, this is an insurmountable methodological problem. Where death is sudden, in the truest sense of not expecting death at all, there can be no insight into preparation for dying and death by those patients. Those experiencing sudden death are not dying *per se*, in a trajectory sense (i.e. moving towards death), and therefore cannot contribute to this research issue. Sudden death is typified by unawareness of all those involved that death will occur. In Glaser and Strauss' (1965) trajectory toward death, they graphed sudden death as a line that simply and abruptly drops off. There is no 'nothing more to do' phase of dying in sudden death (Glaser and Strauss, 1965, p.204), which might help toward reconciling death and dying for all concerned.

I perceive sudden death, however, as part of a broader continuum that includes unexpected death. Even in critical illness, death may be unexpected. Here, therefore, sudden and unexpected deaths share many similarities and characteristics of bad death.

In unexpected death, no preparation is made for death, which would exemplify bad death. Wright (1995) argues that even where someone has gone through a 'dying' process, death can still be perceived as sudden. Outlining unexpected deaths as cases of probable life, but where death was the outcome, Seymour (2001) sees death as a betrayal of faith in medical technology and 'unnatural'. It is not explicit that sudden, unexpected death equates to bad death but this is intimated through Seymour's typification of good death. As I outlined in Section 1.7, some palliative care patients might wish for sudden death (perhaps to alleviate suffering) which presents a counter to Seymour by placing sudden death as representative of good death and bad death being slow or chronic illness. This also extends to being unprepared for the trajectory of death, so knowing people will die but not at what point. An uncontrolled move toward death was, like sudden death, problematic and disruptive on care (Glaser and Strauss, 1970). This research deals with unexpected death, sometimes viewed as synonymous with sudden death (although I have outlined a distinction above) by participants, but within a context of cancer and critical illness. In this study, compromises had to be made as it would be impossible to interview dying critically ill patients by virtue not only of ethical implications but also because of their unconscious state (see Section 4.4). Therefore, cancer critical illness survivors and families of patients who died provide their perspectives as a proxy for their notions of death: good and bad.

Sudden and unexpected deaths have duality: simultaneously retaining aspects of, and failing in, good death. There is swiftness, but in being unaware of their dying, patients cannot be prepared or in control of death. The paradox of the caring and curing aspect of dying in critical care is introduced next.

In summary, I have argued that good and bad death can sometimes share characteristics, depending on whose perception is being considered. The implications of this dichotomy are explored in this research. Good death often has a set of ascribed principles, but whether all are necessary for good death will be explored in this research (see Section 5.1 for the related research question). The research also

explores a potential oxymoron of implementing palliative care in 'unexpected' (or sudden as I also term it in this context) death. Both unexpected and expected death feature in this research.

1.9 Death in critical care: contemporary theories

In this section, I use theory to describe death in the acute setting of critical care, contemporary theories in death in critical care and what has informed those theories to present a picture of how the phenomenon of death in critical care has been viewed to date.

In an ethnographic study of good death in critical care, Johnson *et al* (2000) explore good death and outline EOL narratives in critical care, demonstrating how withdrawal processes contribute towards perceptions of good death. Withdrawal and withholding are seen as therapeutic acts with technology viewed as the vector through which care is given and death achieved (to which I shall return shortly). Indeterminacy forms a key part of Johnson *et al* (2000)'s good death theory in critical care. The dialogue between families and professionals is initially characterised by uncertainty and not knowing. This indeterminacy then gives way to inevitability that the patient will die. While Johnson *et al* (2000)'s work is clearly applicable to this study, their work is presented as conceptualisation through narratives of withdrawal practices, rather than theory *per se.* I will return to Johnson in my critique of further theories shortly. Seymour (2000; 2001) adds to Johnson *et al* (2000), outlining her theory of good death in critical care, and how that theory differs for patients, families and professionals. Her negotiated death theory centres around an ethnographic study related to DFLSTs, on which her theory was built. She posited intuition as a key factor in making the transition from critical care to EOLC (Seymour, 2000). Seymour (2000; 2001) showed that consultants and registrars frequently and intuitively know, based on experience, when patients in critical care will die. In moving toward a 'natural death', and withdrawal of treatment, this intuition was legitimised. Doctors sought to incorporate nurses and families into decision-making, which further allowed them to 'draw death and dying into the "production"' (Seymour, 2000, p.1245). One could view that seeking to involve nurses and families was to legitimise doctors' own opinions; their reluctance to admit openly patients were dying could be ameliorated. Nurses' pivotal role, not alluded to in Seymour's (1999; 2000) articles, was addressed in her (2001) book, where she stressed how nurses concentrated on bodily care to avoid

emotional work, and the role nurses had in communication between family and health care teams, but their sense of intuition did not arise as an issue. Easen and Wilcockson (1996) discuss how rationalising intuitive thoughts after events is a way of validating intuition. Although doctors in Seymour's study (2000) rationalised decisions as they made them, intuition influenced decision-making to some extent. Therefore, since doctors *know* beforehand who will die and when, DFLSTs could be considered to be predetermined by intuition. Rationality then enters when considering legal obligations in notions of futility and withdrawal of treatment which affects timing on moving to EOLC.

For Seymour (1999; 2000; 2001), good death is about maintaining integrity of a natural order, a negotiated 'natural' death and dying that is as resolved as possible in the minds of all those involved; death, whether expected or not, that ensures personhood for patients and trust between families and staff. Lofland (1978, p.18) on whose work, *The Craft of Dying,* Seymour (2001) builds, suggests the briefest duration of dying and conversely, prolonged dying, with each requiring six interrelated conditions (Box 5):

Box 5. Lofland's (1978, pp.18-27) modern dying trajectories

Briefest duration:

1. A low level of medical technology
2. late detection of disease or fatality-producing conditions
3. a simple definition of death
4. a high incidence of mortality by acute disease
5. a high incidence of fatality-producing injuries
6. customary killing or suicide of, or fatalistic passivity toward the person, once he or she has entered the dying category

Prolongation:

1. a high level of medical technology
2. early detection of disease or fatality-producing conditions
3. a complex definition of death
4. a high incidence of mortality by chronic or degenerative disease
5. a low incidence of fatality-producing injuries
6. customary curative and activist orientation toward the dying with a high value placed on the prolongation of life

One could extract from Lofland (1978) that in order for the trajectory of dying to be quick, it first requires recognition of dying, returning to the earlier issue of prognostication. Add in uncertainty around dying and potential for a good death becomes diminished. Drawing on Glaser and Strauss' (1965) determined patterns of dying — sudden death, lingering, certain to die on time, and a vacillating pattern — their trajectory is of a health status moving toward death. Good death is a perceived entity and there can be no objective reality, regardless of trajectory. Sandman (2005) suggests a temporality aspect too: a good death should be synchronous with the ideal and values held when dying. Developing Lofland (1978), Seymour (1999; 2000; 2001) examines trajectories and durations of dying, in terms of dying critical care patients. This is echoed in Johnson *et al* (2000) in terms of clinical paths or courses relating to illness — the patient's response to clinical intervention — with a smooth, uneventful or rocky directionality. Uncertainty might exist around prognosis or there might be poor communication of prognosis. Those who are on the path are the 'near dead'; that is, machines take over patients' bodily functions (Johnson *et al*, 2000, p.289). Yet, it could be argued that this metaphor covers every patient on life support, regardless of whether dying or not. However, they develop this in relation to how the manner, and timing, of death can be orchestrated by professionals and this is tempered by families 'stepping back', describing reluctance to engage in DFLSTs.

To consider the notion that opportunities for good death *do* arise in intensive care (Seymour, 2001), it is worth considering Seymour's main three principles (Seymour 2001, pp.129-154):

1. Maintenance of the integrity of the natural order
2. Maintenance of the integrity of the dying individual's personhood
3. Maintenance of trust between healthcare staff and patients' companions.

The natural order relates to expectations of survival and success of medical technology. Technology served as a mysterious, miraculous medium through which patients survived, or did not. Technical dying occurred and was confirmed before bodily death took place. Staff assumed predictable roles in this aspect of dying, such as nurses concentrating on nursing care. In expected death, technology was observed as part of achieving the natural 'ideal' order. Interruption of natural order, subversion of natural death, was characterised by unexpected death. Families might have expected patients to die but this threat to natural order was mediated by how technology could protract what otherwise might have been a natural death.

Personhood was threatened by bodily management of dying patients, and even considered as bodily desecration. Bodily management centred on how technology was used to manage the bodily processes that caused death. Ensuring preservation of individuals through bodily care was important, which she related in specific examples of inter-family relationships. In particular, Seymour (2001) cites how families see patients' appearance (in a cosmetic and hygienic way as well as how families viewed bodies as mutilated through critical care interventions) and how this affects their constructs of good death. Melia (2004, p.87), echoes this in her notion of personhood, referring to 'the separation of the physical body from the notion of personhood'. Integrity of trust between family and health care professionals was important for good death (Seymour, 1999; 2000; 2001). Intimacy created by staff attention and personal investment led to faith and trust. This was threatened by contradictory explanations; health service cynicism shaped by previous experiences and having to wait for explanations (Seymour, 2001).

Importantly, Seymour's (2001) concept of personhood is enacted through proxy accounts of families. What seems to be Seymour's constructs of support or threat to personhood appears essentially to be respect for familial interpretations of personhood. Zussman (1992) described threats to personhood in relation to patients being denied personhood by being reduced to medical pathologies. In both these theories, as well as Melia (2004), there is scope for development and exploration of nursing roles in EOLC. There is also opportunity for further development in Seymour (2001) and Lofland (1978) theories around rapidity of the dying trajectory in relation to achieving good death. This is addressed in the findings and in Chapter 7. Lofland's (1978) notions of dying trajectories can be considered because she addresses brevity of dying, which remains a contemporary issue in relation to not prolonging dying (as I discussed in Section *v*).

Seymour (2001) alludes to complexities in managing care between teams in regard to continuity of care, which is important for getting to know patients and their illnesses. For this study, this is a particular issue because there may be a long history with oncology teams. Team working is central to Melia's (2001: 2004) theory of consensus approaches to EOLDs in critical care. In her theory, Melia (2001; 2004) outlines how social processes are important in decision-making with agreement (or tacit agreement to disagree) being how the difficult work in critical care is effected. She develops the work of Zussman (1992) who explored the ethics in working in intensive care and

ensuing confusion around EOLC that result from the division of labour between nurses and doctors. Melia (2001; 2004) seems to follow this thread and in 1.4 I outlined Melia's suggestion that nurses were free to provide holistic nursing because doctors' stereotypes were reinforced by their ownership of DFLSTs and EOLDs. However, as I argued, EOLDs are increasingly shared and nurses might also assume technological qualities to demonstrate their competence. Melia's theory attests to the somewhat limited role that nurses have historically had in DFLSTs and EOLDs and alludes to the potential for (but not actuality of) changing dynamics between critical care nurses and doctors. There is scope here for development in her theory given recent changes (Endacott *et al*, 2008): how the current dynamic might affect EOLC is worthy of further exploration through different professional experiences. Melia (2001; 2004) outlines the role doctors maintain even when (critical care) medicine would theoretically be less important at the point of withdrawal or when awaiting death. Doctors, she suggests, maintain this to ensure smooth functioning of the critical care. However, I would raise the question of whether allowing nurses to have a more prominent role at this point would challenge the smooth functioning or whether it might, conversely, enhance it. I shall be exploring the specific role of nurse in relation to my findings throughout this research.

Johnson *et al* (2000) regard withdrawal as a therapeutic act which builds on the idea that good death is a medical act, a good decision that produces good (optimal care), rather than harm (death) (Johnson *et al*, 2000, p.283). Indeed, they outline the narrative, commonly held in practice, that technology which previously prolonged life becomes technology which prolongs death. Treatment endured evolves to become treatment suffered and technology becomes the villain. They go on to describe natural death as the ideal to be achieved, unhampered and unprolonged by technology (Johnson *et al*, 2000), which resonates with natural death as described by Seymour (2001). Johnson *et al* (2000) raise the metaphor of patients declaring themselves: formal declaration involves doctors formally announcing the patient's status which then determines treatment (or non-treatment). Where there is uncertainty, this is left to patients – allowing the patient to declare himself. They develop the rationale for why natural death would be sought and viewed as the ideal beyond the emotional implications to include judicial reasons, i.e. a neutral death confers no judicial responsibility which in essence exonerates those making decisions. Like both Seymour (2001) and Lofland (1978), the narratives in Johnson *et al* (2000) outline how natural death is about letting nature take its course and technology, therefore, is

'neutral' — it allows this to happen. While remaining mindful that this is only one narrative, I would question whether technology is actually neutral. It can be viewed as a far from innocuous vector through which death is effected even. Simple acts of adjusting technology emphasise the human agency aspect of death in critical care: death can be controlled or influenced by actions.

Importantly, Johnson *et al* (2000) raise the idea that other voices, namely institutions, policy, lobby groups, professional associations and legal systems also shape the construction of EOL narratives. In the introduction, I outlined policy and professional limitations contributing to the need for this study. Recent changes to EOL constructs in the UK (DH, 2008) and the thrust away from EOLC provision in hospitals may even provide less of a rationale for EOL to be considered in acute settings, despite the reality of the numbers that continue to die in critical care as I outlined in Section ii.

Negotiation permeates Slomka's (1992) theory of death in intensive care. For Slomka (1992) negotiating death fulfils a need for doctors, patients and families to reconcile to the limits of technology. As part of this, families (and patients) should be included in EOLDs. She argues that the moral responsibility for the patient's death when treatment is withheld is displaced to the patient. She suggests there is an illusion of choice in medical decision-making, offered by doctors, which begins a negotiation of meanings that allows for shared moral responsibility and acceptance for medical failure by patient, family and doctor alike. The negotiation of death also reflects a growing overall dissatisfaction with medical control over death. In other words, death controlled by doctors does not equate to 'good death'. Power issues are tacit in Slomka's theory since nurses are not mentioned, suggesting they have no place to play in EOLDs and EOLC. However, I have articulated throughout examination of theory in this chapter where nurses' roles are present or lacking, and how the current climate warrants their inclusion.

1.10 Summary

In this chapter I have outlined how this research might contribute to the key theories in good death and critical care deaths. I have explored the concept of good death for these participants against this theory, and what or who might influence the path to good death in critically ill cancer patients. Good death is characterised, principally, by knowing and expecting a trajectory of death. It has been regarded as controlled, allowing for degrees of predictability, negotiated between family (and patients where possible) and professionals, and where all are aware of impending death (Costello, 2000; Seymour, 2001). The achievability of factors suggested by Kehl (2006), Seymour (1999; 2000; 2001), Sandman (2005) and others, and whether all facets are needed for good death, is a core principle of this thesis.

Seymour (2001) develops this aspect of knowing in her theory of negotiated and natural death in the chaotic arena of critical care where achieving good death can be possible, even with technological and temporal constraints of critical care. The teamwork element to EOLDs were raised in Melia (2004). This study's findings will develop Seymour (2001), Lofland (1978), Melia (2004) and Johnson *et al* (2000) in regard to this notion of a trajectory, and the EOLC at the end of the trajectory and specifically expand perspectives on this. General good death theory fails to address the issue encountered almost routinely in critical care: that of an unconscious very rapid demise toward death. For these patients, it is more difficult to reach a concept of good death. Furthermore, good death is also characterised by good quality *care*, which has been hitherto poorly defined in this context.

Boundaries for nurses and doctors are often blurred in critical care (Locsin, 1998; Coombs, 2003; Coombs and Ersser, 2004), where a science model prevails with some strides towards empowered caring. Critical care nurses balance artful nursing with the science of technology (Ashworth, 1990; 1994; McGrath, 2002), which an increasing technological imperative necessitates. Yet at EOL, critical care nurses have to move from this technological imperative and focus almost solely on care. Whether EOLC is technical enough for nurses striving to maintain power through technology use has not been debated in the aforementioned literature and remains to be seen. In EOLC, when curative intent of patient management is removed, critical care nurses are well placed to display those caring attributes discussed earlier (and may even be freed of certain constraints of technological competence because many critical care

interventions are no longer necessary). Critical care nurses can use knowledge and the application of technology to orchestrate comfort measures at EOL. Caring as a core theme throughout both critical care and cancer care both defines, and is defined by, nursing. Yet, different perceptions in what care entails serve to overshadow the essence of nursing, the patient-focused nature of the profession. Furthermore, in order to gain professional power, nurses may relinquish caring attributes and appropriate technical knowledge to advance their own career and subspecialty. A broad brush of dominance and hegemony can clearly no longer be swept over medicine, which has become a far more complex discipline and itself embraces aspects of caring. For nurses, *being* with, alongside *doing* to patients is emphasised as a core facet to caring. Empowered caring presents a challenge to the notion of having to renounce caring qualities but it might require confidence to undertake. Nursing issues around this were explored in light of the findings and Falk-Rafael's (1996; 1998; 2001) and Locsin's (1995; 1998) theories are challenged for how they can be applied in critical care and at EOL respectively.

The technological imperative that contributes to fuzzy boundaries in critical care may also exist within what is traditionally viewed as a caring paradigm, cancer care. Cancer care nursing has a history of focusing on patients more holistically (Haberman *et al,* 1994) and caring attributes of nurses in this field are promoted. Patient-centred care is part of cancer nursing philosophy (McClement *et al,* 2005; Mohan *et al*, 2005). In cancer care, EOLC has become a specialty and knowledge in its own right. This research explores whether there is a place for EOLC as a sub-specialty of critical care, or whether it should be entrenched in everyday, ordinary practice. Furthermore, it explores the uniqueness of critical care and cancer care in a combined paradigm and how they share attributes from each other's paradigm in EOLC.

The literature in EOLC in critical care, cancer care and implications for caring, EOLC and a good death are explored in the next chapter.

Chapter 2. Literature

To date, there has been no research published in the UK around EOLC for cancer patients in critical care. Few of the US studies which are available have included cancer patient data when sampling and none have explored the impact cancer diagnosis has on how EOLC is provided. This chapter provides evidence for the sample, method and topic and outlines some distinctions between US and UK studies. I explore critical care EOLC research in respect to patients, families and professionals, and their respective needs. Cancer critical illness and ensuing prognosis will be discussed to provide a picture of the existing literature and its focus. I describe how the agenda is dominated by retrospective case-note (medical record) review and decision-making literature. Few studies concentrate on EOLC and how it can be provided. Provision of quality EOLC is outlined with regard to nursing. I discuss each issue with particular emphasis on the potential for nursing at EOL in critical care.

2.1 Rationale for the research evidenced by the literature

For the literature review I used a meta-search engine (NORA at Northumbria) including ASSIA, Medline, CINAHL as well as a NeLH search. Although this was a comprehensive review, only that which is pertinent to the research questions are reported because of limited wordage in a professional doctorate thesis. The review provides evidence of command of subject areas, understanding of problems and a rationale for the project (Hart, 1998). Appendix 1 outlines the search strategy and inclusion/exclusion criteria in more detail. I used Hart's (1998) critical appraisal framework to help me explore and refine the qualitative and quantitative research (as can be seen in the literature table categories). I searched for studies pertaining to end-of-life in critical care first, although I later expanded this to include other pertinent research. Key search (MeSH) terms included: critical care; intensive care; death; dying; end-of-life care; end of life; end-of-life decisions; technology; palliative care; terminal care; decision-making; patients; families; nurses; professionals; doctors; cancer. Despite widening my searches, I have retained a focus on the critical care arena including critical care nursing and medicine, because this was the setting for my sample. A detailed description of studies is given in the literature tables (Appendices

2, 3 and 4) which show studies (cited alphabetically) within three main themes: EOL decision-making in critical care and EOLC in other applicable settings and withdrawal practices and EOLC in critical care. I have highlighted implications for my proposed research in the tables. Research predominantly originates in the US. Whilst fundamental issues relating to humanity, like dying with dignity, transcend trans-Atlantic boundaries (Wunsch *et al,* 2009), there are numerous differences in UK critical and cancer care practices, health policies, health infrastructure, professionals and culture that warrant examination of UK EOL practices.

2.1.1. Main themes and overview of literature review

Decision-making at EOL in critical care has been qualitatively researched in both the UK and US (Slomka, 1992; Cook *et al*, 1999; Seymour, 2000; Melia, 2004), but this review's focus is to outline care processes and planning, both during and after decision-making and roles health professionals (nurses in particular), families and patients have. This literature review begins by outlining EOLC in critical care, aspects of decision-making, and more specifically, goals of care in EOL in critical care and cancer, and how each of these contribute to the development of the research questions. Cancer-related critical illness is first explored to provide a context for the area in which the study took place. Early literature was collated with the original research question in mind:

> What are the experiences of end-of-life care of critically ill cancer patients for families, critical care nurses and critical care doctors?

With the doctoral process this was refined, literature searching was expanded and it evolved (as Section 5.1 outlines) to become:

> What are the issues around end−of−life care provision for cancer patients in a critical care unit, as explored through family, practitioner and patient experiences?

These questions provided the backdrop to, and were informed by, the literature explored in this section. Literature is both organised into themes and also considered as areas that nursing can potentially influence (and those it appears it cannot).

2.2 Impact of cancer

This study is focused on cancer patients in critical care; therefore, studies aroud death in critical care for cancer patients are discussed first. The distributive justice principle underpinning equal access for cancer patients to critical care services is increasingly evident. Literature, however, is still slanted toward mortality studies (Groeger *et al,* 1998; 1999; 2003; Staudinger *et al,* 2000; Maschmeyer *et al,* 2003; Soares *et al,* 2005a; Thiery *et al,* 2005; Taccone *et al,* 2009).

For haemato-oncology and bone marrow transplant patients — who comprise a substantial proportion of this study's patients and of overall cancer critical care admissions — in-hospital mortality has dropped from 70-76% (Crawford and Peterson, 1992; Schapira *et al*, 1993; Groeger *et al*, 1999) to 58% over the past ten years (Taccone *et al,* 2009). Sizable estimates of 18-30% of cancer patients utilise critical care services for treatment-induced critical illness (Studnicki *et al,* 1994; Iwashyna *et al,* 2004), but mortality is worse in cancer patients than in the general population (Taccone *et al,* 2009). This international literature reflects smaller single centre UK studies by McGrath *et al* (2010) and Bird *et al* (2010), which have both reported much improved survival in critically ill cancer patients in the UK. Placing the issue of cancer critical illness mortality in a wider context of general critical care, one in six of all patients will die in UK critical care units (ICNARC, 2009), compared to more than one in four deaths for cancer patients in critical care across Europe (Taccone *et al,* 2009).

These figures present the actual problem and extent of dying cancer patients in critical care and introduce how this might needs further exploration. Cancer treatment frequently has a curative intent or is intended to prolong survival by years. However, the aforementioned figures emphasise how, despite recent improvements, cancer-related critical illness raises mortality significantly above that associated with patients' primary cancer diagnosis. These patients are therefore more likely to die in critical care highlighting the need for consideration of EOLC. This provides background for this study but mortality studies are limited for their ability to explain why these patients are dying in critical care.

2.3 EOLC and critically ill cancer patients

Despite preconceptions that cancer patients experience good EOLC, evidence points to the contrary (McNeil, 1997; Benson, 2001, NICE, 2004, Neergaard *et al,* 2008). Reasons for this may relate to setting, resources and patient groups. These issues are explored and critiqued below and have implications for why I chose to explore EOLC in cancer critical illness.

Communication difficulties, encompassing information exchange from professionals to patients and families, empathetic interactions, inter-professional communication are a significant barrier to good EOLC in cancer (Higginson and Costantini, 2002). This was also the case in these US-based studies of EOLC in critical care (SUPPORT Principal Investigators, 1995; Kirchhoff *et al*, 2002). This highlights the role communication has in good EOLC and how the issue permeates both cancer and critical illness. Prognosis, traditionally outside the remit of nursing (Dendaas, 2002; Robichaux, 2002; Robichaux and Clark, 2006), is also significant in EOLC provision in general (Glare *et al*, 2003; Schulman-Green, 2003; Stone *et al*, 2008). But prognostic modelling, on which critical care relies to inform many decisions, is often considered too crude to be used in cancer critical care (Sculier *et al,* 2000; Berghmans *et al,* 2004; Soares *et al,* 2004; 2005a; 2005b; Farquhar-Smith and Wigmore, 2008). For critically ill cancer patients, models such as Simplified Acute Physiology Score (SAPS) and Acute Physiology and Chronic Health Evaluation (APACHEs II and III)[6] underestimate mortality (Sculier *et al,* 2000; Den Boer *et al,* 2005; Soares *et al,* 2005a; 2005b). Prognosis is also highly important in EOLC provision in cancer (Glare *et al*, 2003; Maltoni *et al*, 2005), and this informs how I approached my research question. How much oncologists, for example, accept patients' dying determines whether EOLC can be considered (Glare *et al*, 2003; Maltoni *et al*, 2005), an important issue that supports the need for this to be explored in critical illness situations where time is utmost, and an added pressure for oncologists. Nurses' roles are not discussed in the literature, which proves to be an important issue for my study.

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[6] APACHE II is a severity of disease scoring system that can be used to calculate a risk of death. APACHE III was a revision of the original models by Knaus *et al* (1985) and takes major disease into account which APACHE II does not, however it is not so widely used as it underestimates mortality (Beck *et al,* 1997). Like APACHE, SAPS is calculated from routine physiological measurements during the first 24 hours, including some information on previous health status and certain admission information. It has value in comparing patients with different disease states.

Oncologists and surgeons have been said to maintain covenants of care with patients (McGrath, 2002; Cassell *et al*, 2003; Melia, 2004) and, outside of prognostication, nurses (Bradshaw, 1999; Melia, 2004; Coffey, 2006). These covenants have implications in preventing patients receiving timely EOLC, because in both McGrath (2002) and Cassell *et al* (2003) specialist doctors (haematologists and surgeons respectively) were held to have a special covenantal relationship with the patient, and no nursing role or influence was acknowledged. This emphasises the limited influence nurses have. These patients might also be subject to over-treatment (Gilbar and Cohen, 1995). This would affect prospects for good death, as raised in Section 2.3. Conversely, patients may wish for prolongation of treatment, even in the face of poor prognosis. This is particularly pertinent if cancer was recently diagnosed (Voogt *et al*, 2005). Equally, patients may wish to avoid the full truth of their prognosis and avoid the emotional impact of such prognoses, as well as avoiding decision-making around treatments and supportive care. In not knowing, patients have been said to retain hope (De Haes and Koedoot, 2003). Hagerty *et al*'s (2005) systematic review on prognosis in cancer highlighted how early discussions on prognosis should be had. As Mack *et al* (2006) and Evans *et al* (2009) outline, the upsetting or inaccurate nature of prognostic information does not diminish families' desire for such information, its importance to decision-making, or families' sense of hope. Early discussion on DFLSTs and preferences for dying and death when facing cancer or critical illness is supported by UK, Australian and US literature around patients (Wenrich *et al*, 2001; McGrath, 2002; True *et al*, 2005; Small *et al*, 2009) and families (Mack *et al*, 2006; Evans *et al*, 2009).

The impact of palliative care services on EOLC in the UK is also debated (Addington-Hall *et al*, 1992; Hearn and Higginson, 1998; Higginson *et al*, 2003). Despite literature showing emphasis on cancer in palliative care services, NICE (2004) outlined discrepancies that remain in cancer palliative care (including EOLC), emphasising areas that need to be addressed. These are outlined overleaf in Box 6:

Box 6. Discrepancies in cancer palliative care

- Lack of awareness of existence of services
- professionals not eliciting patients' problems or concerns
- professionals unaware of potential benefits of existing services (therefore not offering them)
- demonstrably beneficial services not universally available
- poor co-ordination among professionals leading to unaddressed needs

The following was suggested as necessary:

- improved assessment of individual needs of people with cancer (including physical, psychological, social and spiritual needs)
- better access to high quality information, including better 'signposting' of statutory, voluntary information and support services
- active promotion of self-help and support groups (recognising their role and patients' own role)
- enhanced provision of supportive and palliative care services to meet current unmet needs and to reduce inequalities in service provision and access
- improved training for health and social care staff in providing supportive and palliative care
- better organisation, co-ordination and integration across Cancer Networks.

(NICE, 2004)

Whether or not palliative care services in cancer care in the UK and US make a difference is contentious (Goodwin *et al,* 2002; Sahlberg-Blom *et al,* 2001), although there is some positive evidence of its impact (Manfredi *et al*, 2000; Higginson *et al,* 2003; Strasser *et al,* 2004). Palliative care, as an established domain in cancer care, still faces shortcomings (Box 6). Accordingly, this research raises some issues around these shortcomings in EOLC and palliative care for cancer patients in critical care. Arguably, nursing contribution could be made or increased in each area that is outlined for improvement by NICE (2004). This study presents a picture of nurses' potential and actual contribution to EOLC. Unmet EOLC needs of patients, and their experiences in particular, are explored next in relation to who contributes to meeting those needs and the current limited nurses' contribution within the professional arena.

2.4 Perceptions of good death and quality EOLC: meeting needs and valuing experience. Who contributes?

This section outlines unmet needs, the value of exploring experiences and provides a rationale for this study's participant groups, particularly nursing. How needs and experiences are assessed is a primary issue in the literature. In particular, how do you gain a rich picture of EOLC with incapacitous patients? These issues are discussed and critiqued for how they informed this study's sample.

Several authors, both UK and US, have indicated there are overarching dilemmas of research with dying patients (De Raeve, 1994; Field *et al*, 2001; Hickman *et al*, 2001). Patients at EOL are frequently unable to participate, due to delirium for instance (Addington-Hall and McPherson, 2001; Hjermstad *et al*, 2004), and in palliative care in the UK, proxy involvement (using family or next of kin perspectives) is often limited for reasons of tokenism, lack of change, dominant professional agendas, time issues and lastly, illness (Seymour *et al*, 2005; Sargeant *et al*, 2008). Aside from illness, the reasons listed above can be influenced by all health professionals, including nurses who Williams (2007) and Preston *et al* (2009) suggest are complicit in failing to address proxy involvement, and along with families, who might gate-keep and over-protect. In critical care, patients are normally unconscious and therefore not 'competent' to give informed consent (Jones and Lyons, 2003; Wright *et al*, 2010). Thus, critical care or dying patients' experiences are rarely researched for these reasons (Campbell, 1996; Sulmasy and McIlvane, 2002). As with palliative care, this particular issue cannot be influenced by nurses. An insurmountable ethical and practical problem presents of needing to elicit in-depth information from unconscious patients.

The literature tables (Appendices 2, 3 and 4) show there are questionnaire studies with dying patients (SUPPORT Principal Investigators, 1995; Hearn and Higginson, 1998; Weeks *et al*, 1998; Emmanuel *et al*, 2001; Sahlberg-Blom *et al*, 2001; Steinhauser *et al*, 2001; Sulmasy *et al*, 2002*;* Heyland *et al*, 2003b; Pincombe *et al*, 2003; Hauser *et al*, 2006), but none of these patients were very critically ill[7], which would mean limited applicability to this group of patients. Few interview studies exist given these justifiable ethical limitations. Instead, data is collected from families, friends or professionals about EOL processes. The groups for whom research could

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[7] 'Very critically ill' is defined in Table 9 and the inclusion and exclusion criteria.

make a difference are increasingly becoming involved in palliative care research, such as the palliative patients in Sargeant *et al* (2008), but in critical care EOLC research this is not so. Sprung *et al* (2007) questionnaired surviving critically ill patients on EOL issues but this had limited scope for how much patients could contribute their own thoughts about EOL. A debate about whether we are caring for families or patients surfaces which presents an ideological problem for this study. When patients cannot contribute, however, should family and professional accounts be the only source of information? While acknowledging limitations of data from patients not actively dying, I would argue that patients who have experienced even *elements* of phenomena will also have highly important views to add. Therefore, wherever possible, these patient accounts (and ways around corresponding ethical issues) should be sought to complement or challenge families' perspectives (outlined shortly in Section 2.4.3).

2.4.1 Unmet Needs in patients' voices

There is evidence of unmet needs voiced by patients in various palliative care studies (Singer *et al,* 1999; Steinhauser *et al*, 2000; Curtis *et al*, 2002a; Farber *et al*, 2003; Toscani *et al*, 2003; Harstäde and Andershed, 2004; Cotterell, 2008; Sargeant *et al*, 2008; Shah *et al,* 2008; Spichiger, 2009). Patient preferences for quality EOLC included wanting safety, participation in care planning and trust, receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones (Nelson *et al,* 2001; Harstäde and Andershed, 2004). Preparing for death, expert support and a 'soft atmosphere' were core elements for good death in Toscani *et al* (2003). Receiving information also proved important in Steinhauser *et al* (2000). Acknowledging imminence of dying was additionally important in Gott *et al* (2008). Furthermore, like the aforementioned studies, patients in those studies also were not at EOL. Arguably, some patients sampled had what might now be considered chronic, not palliative illnesses, because life can be significantly prolonged, even by decades. And yet, in choosing those patients, researchers are more likely to sample participants who have considered death in greater depth *because* they have that life-limiting illness. Indeed, in this study it could be countered that cancer patients might have considered death, contrary to my earlier point in Section 2.4. This challenge will be discussed in the findings.

Moreover, in certain studies the focus was on doctors' skills (communication or medical) rather than patients' experiences or needs, such as in Curtis *et al* (2002a),

Wenrich *et al* (2001) and Steinhauser *et al* (2000). In addition, as discussed shortly, it is often through families' experiences and needs that issues around death and dying are constructed. Limitations of nursing are flagged, for there are areas outside of nursing control, which may also be related to limited foci of certain studies. These studies were for palliative patients, not actually at EOL, which has implications for extent of applicability to EOLC. These studies' patients had time to consider or plan their dying and death. While patients in my research had cancer, the sudden onset of critical illness, and their subsequent swift demise, means they did not have time to plan death and dying. This provides a rationale for inclusion of patients in the study, in order to answer the research question in Section 2.1.1.

Farber *et al* (2003) studied professionals', patients' and families' feelings regarding EOL issues, and like Steinhauser *et al* (2000), found that patients highlighted awareness of impending death, managing ongoing treatment, relationships and personal experiences associated with facing EOL as important. These US studies, however, were solely concerned with doctors' skills, limiting applicability to nursing. Normative expectations of good death, where caregivers' responsiveness (or lack of) to how patients deal with death, were flagged in a study of palliative care patients (Goldsteen *et al,* 2006). Unlike previous studies, Goldsteen *et al*'s (2006) notion can be applied to nursing; suggesting that all health care professionals have a duty in this regard. Ease, and importance, of patient involvement is stressed by Sargeant *et al*'s (2008) study where benefits to palliative care patients were stressed as important, although limitations with patients too unwell to contribute were noted. Again, this reiterates the issue of critically ill patients' contribution in this study. Forewarning in knowing what to expect, having a surrogate named, financial affairs in order, treatment preferences in writing, and knowing clinicians were comfortable talking about death and dying were all important in Farber *et al* (2003) and Steinhauser *et al* (2000). All except Sargeant *et al* (2008) were US-based studies, and there are issues around naming surrogates (who have legal responsibility in proxy decision-making in the US) and written treatment preferences (such as advance directives, which are more popular in the US), that are more pertinent to the US than the UK. However, other aspects from the themes listed above can be applied worldwide. These studies' foci tended toward what patients who were not critically ill, wanted from their doctors as opposed to what patients wanted for themselves and the wider context of dying. Moreover, across the world measures of patients' satisfaction with EOLC rely on patient questionnaires (Kristjanson, 1993; Hearn and Higginson, 1999; Patrick *et al,* 2001; Morita *et al,* 2002; Sulmasy *et al*, 2002; Steinhauser *et al,* 2004) or family

questionnaires (Addington-Hall *et al,* 1998; Hickman *et al,* 2001; Teno *et al,* 2001a; 2001b; Morita *et al,* 2004; Lévy *et al,* 2005; Mularski *et al,* 2005; Curtis *et al,* 2002b; 2008). In critical care, assessment of satisfaction relies on family accounts of processes of dying (see Appendices 2, 3 and 4) (Heyland *et al,* 2001; 2002; Wall *et al,* 2007; Gries *et al,* 2008). Again, these are all US studies, where patients may have named family as surrogates, which might affect their perceptions of satisfaction. Moreover, satisfaction questionnaires have significant limitations, since they focus on areas researchers dictate and have no scope for in-depth answers. Mayland *et al* (2008), having evaluated all except Family Satisfaction in Intensive Care Unit (FS-ICU), iterate this view, suggesting these questionnaires all have limitations and miss important factors as outcome measures of families' evaluation of EOLC. The first FS-ICU study (Heyland *et al,* 2002), however, did highlight greatest satisfaction with nursing skill, compassion and competence, which echoes some of the issues raised in Chapter 1 and the value of nursing for families in critical care, which emphasises how this perspective is important to explore further, providing rationale for nurses' inclusion from another viewpoint. Importantly, with all these measures, care is not clearly defined, with the exception of Teno *et al* (2001b) who define care but purely as *medical* care. This has implications for nursing, and again stresses where nursing can make a difference and where it is limited. If care, as in nursing, underpins palliative care intent, as discussed in Chapter 1, then clearly defined terms are needed to 'measure' against or explore. As Chapter 1 underlined, care is a nebulous concept for nurses, which adds to the complexity of exploring notions of care at EOL. This informed my desire to explore what EOLC means for those involved (see Section 5.1).

I have delineated further areas from each of these studies in relation to this study in Tables 1, 2, and 3 (see Appendices 2, 3 and 4). The most common EOLC research in critical care is US-based, case-note (medical record) analysis (most commonly retrospective) to assess how critical care DFLSTs are made, and time and resources spent, or to quantify EOL symptoms or treatments: Goodlin *et al* (1998), Prendergast *et al* (1998), Campbell and Guzman (2003), Kirchhoff *et al* (2004), Rocker *et al,* (2004). These are even further removed from patients than proxy sources but have value in underlining questionable EOL practices. These practices include: poor communication, paternalistic decision-making, poor withdrawal practices and limited evidence of EOLC planning and preparation. Each of these contribute to an incomplete picture of EOLC issues in critical care.

2.4.2 Families' perspectives

This section draws on the literature on behaviours, conflict and communication around families. Arguably, data from families are subject to bias, particularly in sensitive areas like dying (Addington-Hall and McPherson, 2001; Casarett *et al*, 2003) and this can manifest as family needs potentially taking precedence over patient needs, or, has been suggested, even over-estimations of preferences for continued treatment (Lynn *et al*, 1997), or symptoms (Hauser *et al,* 2006). Indeed, Wahlin *et al* (2009), although not related to EOLC, compared family, professional and patient needs in critical care and noted disparities with levels of actual or potential involvement of patients, even with families. In fact, Tilden *et al* (1995) found that families would prefer more comfort care at EOL, as opposed to the 'doing everything possible' philosophy resonant in other studies (Swigart *et al*, 1996; Lynn *et al,* 1997; Sulmasy *et al,* 2002), which contrasted with patients' wishes to move away from aggressive treatment. This literature suggests that in the absence of patients' views, families may provide a valuable proxy assessment. In the presence of patients' views, family views might complement or challenge, as Swigart *et al* (1996), Lynn *et al* (1997), Sulmasy *et al* (2002) and Hauser *et al,* (2006) found. As such, this also has particular importance for studies focusing on professional perspectives because they too lack that contrasting or complementary user perspective. This informed participant choice in this study. Value was highlighted in different areas: comfort care; not delaying withdrawal after DFLSTs (Tilden *et al*, 1995); encouraging patients to participate in discussion early on in illness; adequate pain control (Jacob, 1998); unpressurised DFLSTs (Abbott *et al*, 2001); facilitating expression of wishes and clear communication (Counsell and Guin, 2002) with no collective overlap among studies. The importance of patient involvement, and the ease with which they can be involved, as raised in the previous section (2.4.1) is a significant facet when considering family perspectives. Family views around EOL differ from patients noted in Section 2.4.1: safety, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones, forewarning about expectations, naming surrogates, financial affairs in order, written treatment preferences and having clinicians comfortable talking about death and dying (Steinhauser *et al,* 2000; Farber *et al,* 2003; Sargeant *et al,* 2008). There was overlap only in a few areas, namely: participation in care planning and trust, pain control and symptom management (Nelson et al 2001; Harstade and Andershed, 2004).

Further distinction between families and patients can be seen in the behaviours that families in several studies identified in health professionals and strategies as helpful and unhelpful during the process of shifting care goals in critical care (Tilden *et al*, 1995; Swigart, 1996; Jacob, 1998; Abbott *et al*, 2001; Counsell and Guin, 2002; Kirchhoff *et al*, 2002; Carline *et al*, 2003). Communication with families at EOL is identified as highly important (Levy, 2001; Kirchhoff and Beckstrand, 2000). Levy (2001) pinpoints being able to communicate in a clear, straightforward and compassionate manner, echoing that in Section 2.4.1. for patients, to the relatives as an essential part of good EOLC in critical care. Similarly, families perceived conflict in discussions about EOL in critical care, often as a result of miscommunication and seemingly unprofessional staff behaviour (Abbott *et al*, 2001). Conflict related to perceptions of care. When comfort has not been made a priority, focusing ensuing care around decision-making and communication of DFLSTs means that issues such as pain management — earlier highlighted as important by care-givers and families (Tilden *et al,* 1995; Jacob, 1998; Abbott *et al*, 2001; Truog *et al,* 2001; Counsell and Guin, 2002; Kirchhoff *et al*, 2002) — are likely to be disregarded. This may be as much about failure to 'let go' and make decisions as about conflict (Tilden *et al,* 1995; Swigart *et al,* 2002). Families even remarked they felt pressurised to hasten DFLSTs, leading to death, in order to ease resource burden (Abbott *et al*, 2001). It is clear from what families and professionals perceive as important (see Appendices 2, 3 and 4 for further description), that unmet and disparate needs exist. What can be done in practice about these negative experiences, and how we can meet those unmet needs, from both nursing and wider perspectives, was a primary driver for this research.

2.4.3 Professional studies

Conflict, behaviour and communication issues at EOL are iterated in professional studies. In this section, developing on family and professional needs, I make explicit where nurses, in particular, can make visible their care. Qualitative exploration of EOLC in critical care focuses either on doctors (Tilden *et al*, 1995; Pettila *et al,* 2002; Svantensson *et al*, 2003) or on nurses (McClement and Degner, 1995; Kirchhoff and Beckstrand, 2000; Kirchhoff *et al*, 2000; Curtis *et al*, 2001; Melia, 2001; Puntillo *et al,* 2001; Trovo de Araujo and Paes de Silva, 2004; Badger, 2005; Robichaux and Clark, 2006; McMillen, 2008; Fridh *et al,* 2009). Rarely are team members (Nordgren and Olsson, 2004) or families considered together (Johnson *et al,* 2000; Norton and

Talerico, 2000; Seymour, 2000; Cassell *et al*, 2003). There are even fewer studies that also include the patient perspective, beyond ethnographic studies of Johnson *et al* (2000), Cassell *et al* (2003) and Seymour (2000), all of which did not directly seek patients' views (since they were unconscious) but observed them as part of the process of decision-making in EOL. Studies tend towards decision-making (Kennard *et al*, 1996; Cook *et al*, 1999; Jezuit, 2000; Johnson *et al*, 2000; Kirchhoff *et al*, 2000; Seymour, 2000; Robichaux and Clark, 2006; McMillen, 2008; Bach *et al,* 2009*;* Popejoy *et al,* 2009), and withdrawal (Melia, 2001; Cassell *et al*, 2003; Kirchhoff *et al,* 2003; Halcomb *et al*, 2004), with few concentrating on EOLC (McClement and Degner, 1995; Yang and McIlfatrick, 2001; Badger, 2005). For all these studies, maintaining comfort and dignity, alongside ensuring patients were as pain-free as possible, were features of good EOLC (see Appendices 2, 3 and 4). One study noted how when patients were unaccompanied these left a lesser impression on those nurses caring at EOL (Fridh *et al*, 2009). This might suggest family interaction is important to nurses in making EOLC visible and satisfying, however, this was not explicitly identified. Poor communication, disagreement among family or surrogates and uncertainty about prognoses all complicated EOL scenarios for clinicians providing care. These findings reflect those identified in family studies outlined previously and suggest that communication, uncertainty and disagreement are important themes in EOLC. Of note is the number of nursing studies that explore nursing in isolation in EOLC, which points to two possible issues: first, nursing needs in caring for EOL patients are unmet and, second, nurses want to explore how best to care for EOL patients and consider their role in this respect as remote from other influences. In addition, EOLC (as opposed to palliative care) is under-researched in critical care and there is potential scope for nurses to develop this aspect of care. Helpful nursing behaviours in providing EOLC have included: improving communication, staffing, education and support, along with involving family in the care of patients, responding after death has occurred and recognising importance for information from doctors, not just nurses (McClement and Degner, 1995; Kirchhoff and Beckstrand, 2000; Popejoy *et al*, 2009). It is, however, debatable whether perceived experts' views of best practice 'mean' anything to the patients they care for especially where professional agendas can overshadow those of patients (Sargeant *et al*, 2008). This study considers the nursing experience and notions of good EOLC within the wider context of the team, and families' and professionals' experiences, with descriptions around behaviours and meanings. This will highlight whether there are transferable meanings across groups. The next section develops this section about

nursing and professional behaviours and delineates nursing roles in EOLC and the extent of nursing contribution.

2.5 Decision-making regarding end-of-life care goals: nursing issues within the team

This section delineates where nurses' and doctors' roles diverge and converge. Professional roles should centre on patients, in EOLC particularly, adding weight for exploring the sphere of influence nurses have in EOLC alongside patients, doctors and families. Differences raised in previous sections between families and patients, and doctors and patients, can be regarded as outwith nursing practice. Doctors have a legal obligation to decide if certain treatment is useful, or not, in EOLC (BMA, 2007). Nurses, as those closest to patients, are supposed to be part of that consultation (BMA, 2007). While nurses make important contributions to EOLDs (Curtis *et al*, 2001; McMillen, 2008), this is by no means routine practice (Latour *et al*, 2009). In their European nursing survey (Latour *et al,* 2009) emphasised that while the majority of nurses (73.4%) are actively involved in DFLSTs, they are not necessarily invited into discussions routinely, despite 91.8% of these nurses being actively involved in EOLC. This highlights continued disenfranchisement of nurses in EOLDs. Furthermore, Hamric and Blackhall (2007) noted that nurses in ICU reported more distress and lower collaboration than doctors. Bach *et al* (2009) outlined the nursing role in DFLSTs as being supportive to families and patients. While family support is extremely important in the nursing role, these findings emphasise an area of limited scope for nurses. Nurses have less of a perceived, or actual, role in decisions than they might desire, which affects their feelings about EOLC. Diminished nursing voices in discussions about DFLSTs in critical care (Robichaux and Clark, 2006) and lack of nursing confidence to contribute to DFLSTs resonate in palliative care (Barthow *et al,* 2008), suggesting this issue is not restricted to critical care.

Decision-making can be difficult for nurses but particularly doctors, who bear ultimate responsibility. Nurses have to deal with consequences of DFLSTs, on which they may have little bearing, and which can be emotionally laborious (Stayt, 2009). Some of these difficulties will be addressed in Section 2.5.2 with regard to conflict. In critical care, ethical concerns related to withdrawal of treatment can lead to conflict among teams making decisions (Cassell *et al*, 2003; Ferrand *et al*, 2003; Frick *et al,* 2003;

Keenan *et al*, 2003; Hamric and Blackhall, 2007; Azoulay *et al*, 2009), leading to unsatisfactory outcomes for patients and families who bear the brunt of these conflicts and the resultant delay in moving to EOL. This study aims to explore further what this delay means for those involved, since some of these studies intimate there can be a delay, but not the effect of that on families and patients. Critical care nurses felt excluded from much decision-making with perceived lack of input and cohesion a major obstacle to timely discussions about DFLSTs and notably, EOLC provision (SUPPORT Principle Investigators, 1995; Faber-Langendoen, 1996; Vincent, 1999; Kirchhoff and Beckstrand, 2000; Fetters *et al*, 2001; Kyba, 2002; Prendergast and Puntillo, 2002; Ferrand *et al*, 2003; Beckstrand *et al*, 2006; Latour *et al*, 2009). Whilst nurses express dissatisfaction with decision-making processes (Ferrand *et al* 2003; Keenan *et al* 2003), and lack of nurses' autonomy in EOL decision-making is implicit in Badger's (2005) study, in hypothetical scenarios nurses also found decision-making processes difficult, tending towards more aggressive care (Walters *et al,* 1998; Frick *et al*, 2003). This tendency could be perceived at odds with caring values espoused by the profession, as Leininger (1988), Fry (1989) and Olson (1993) describe, and emphasise the complex nature of nurses' feelings and limited roles in EOLC in critical care. Whether nurses who were more involved and autonomous would be as aggressive in treatment decisions is not clear from the literature.

Japanese nurses had difficulties respecting dying critical care patients' wishes, because of pressure from families and doctors (Kinoshita, 2007; Miyashita *et al*, 2007), which further highlights the importance of autonomy when nursing vulnerable critically ill patients. Where, or how, nursing could contribute was not clear in any of these studies. This study aims to highlight not only nursing implications for contribution, but also wider implications for teams, families and patients.

Despite recommendations to include families, patients, nurses and other healthcare professionals in medical care decisions, the language used in *Comprehensive Critical Care* (DH, 2000) confers power explicitly on doctors, deeming them responsible for the 'overall plan of patient clinical care' (DH, 2000, p.20), thus reinforcing power debates and serving to further diminish patients, relatives and nurses' power over issues such as EOLC practices. However, when legal responsibility for decisions rests with one group it is somewhat inevitable that their voice will be loudest since responsibility is not shared (Pattison, 2006a; 2006b). While doctors have legal responsibility, it could be argued that the overall plan for care is a collective responsibility. Slomka's (1992) notion of negotiation in critical care highlights a paradox in relation to policy: there is little or no negotiation of power when power rests

with a dominant group, such as doctors. Nursing is supposed to support patients and families through dying (DH, 2001), but, as Coombs (2003) suggests, many nurses still lack adequate power to make decisions about EOLC practices. Moreover, as Chapter 1 introduced, *how* nurses should do this when they lack the requisite power to allow patients to die in critical care after DFLSTs have been made. The nursing role is not clear, from literature nor policy. This study, in sampling nurses, provides a nursing perspective, in a context of all key perspectives, and issues around power, as described in Chapter 1 become evident in the findings.

Furthermore, outside of critical care, conflict in decision-making around withdrawal also exists in palliative care. Continuation of antibiotics or intravenous hydration may be questioned among the team for its value at EOL (Teno *et al*, 2001a). Fins *et al* (1999) looked at decision-making processes and care for hospitalised dying patients, including those in critical care, and found that fewer than half had comfort care plans, once DFLSTs had been made. Nursing involvement in palliative care DFLSTs, as with critical care, also depends on nursing confidence and experience (Barthow *et al*, 2008).

In cancer nursing, there are some similar issues with nursing contribution to EOLC. Beckstrand *et al* (2009) surveying cancer nurses found they were comfortable with EOLC; however, they experienced difficulties in managing angry families, concurrent workloads of non-palliative patients and with family rejection of prognosis. Experience was a notable issue in Lange *et al* (2008)'s cancer nursing EOL survey with lack of experience related to poorer attitude. Junior cancer nurses needed exposure, support and education to help them care for palliative patients (Lange *et al,* 2008).

Further to issues around decisions and prognostication noted in Sections 2.2 and 2.3, palliative care input in critical care is limited and there can be conflict between oncologists and critical care specialists (Melia, 2001; McGrath, 2002). Formalised palliative care in critical care is rare, even in the US where the Society of Critical Care Medicine has suggested how EOLC in critical care should be implemented (Danis *et al*, 1999; Nelson *et al*, 2001; Truog *et al*, 2001; 2008). A need for acute palliative care has been highlighted (Levy and Carlett, 2001; Nelson and Danis, 2001; Rushton *et al*, 2002) and this is discussed in relation to doctoral outputs later in section 4.4. No research literature to date was identified that explores, in-depth, formalised palliative care expertise in critical care, and the influence of cancer on this, providing evidence for this area to be explored in this study.

2.5.1 Critical care nurses and EOLC as specialist practice

In-depth literature on EOLC in critical care tends to focus on nurses and the majority of these studies sample only nurses. Reasons for this are unclear. There are allusions to the emotional toll suffered by nurses (Yang and McIlfatrick 2001; Badger 2005; Robichaux and Clark, 2006; Fridh *et al*, 2009; Stayt, 2009) but this is not extended to any description of those around the nurses, doctors and families, whose own responses shape and influence nurses' reactions to the stresses of caring for patients at EOL. Seymour (2000), however, did note both doctors' and nurses' emotional responses. How this affected the nursing role was less clear. Themes from the literature centre on nurses' feelings rather than practical implications of EOLC and withdrawal practices. Melia (2001) identified how nurses are left with care after EOLDs, but alluded to a negotiation of a division of labour between nursing and medicine at EOL with nurses taking EOLC. Education is a predominant theme, suggesting existing critical care post-registration programmes do not meet nurses' needs in this respect. One study noted how previous palliative care experience would not help in ICU, which has implications for this study given the cancer element and the nursing sample, some of whom had such experience. The focus of these nursing-based studies remains around implications of EOLDs and distinct roles for nurses are unclear, other than nurses are there to provide 'care' (with no articulation of what this represents).

2.5.2 Families and effects of decisions

A core theme arises for this study of the difference between treating families versus patients in critical care, which has been hitherto unaddressed in the aforementioned research. This section outlines how families involved in DFLSTs face limitations. ETHICUS and Ethicatt studies (Sprung *et al,* 2003; 2007) investigating EOL withdrawal practices in critical care, along with the SUPPORT study (SUPPORT Principal Investigators, 1995) reiterated diminished family and patient voices in medical EOL decision-making. However all of these US studies were questionnaire-based allowing little scope for further exploration of reasons why these voices were diminished.

Benner *et al* (1999) outline expert nursing care in critical care that focuses greatly on families. It is implied that patients are of lesser focus. Johnson *et al*'s (2000) research highlights how EOL narratives of clinicians and families may conflict, with families

vulnerable to unequal power relationships. Cook *et al* (1999) and Johnson *et al* (2000), writing about the same study, explore how doctors socially negotiate EOL decisions to synchronise understanding and expectations between families and clinicians. *How* a good death could be enacted is not addressed. Seymour (2001) addresses issues of 'nursing care only', an edict issued by medics after DFLSTs and reinforced by nurses. Practicalities of dying processes after ventilator withdrawal, for example, are explored but nurses' roles in deciding courses of care, or care-planning, at EOL, after DLFSTs, are not clear. What has not been raised in the literature is how nurses could potentially use this area of practice to their advantage creating specialist knowledge in this area of EOLC.

Poor decision-making in critical care was frequently observed by Ferrand *et al* (2003) in relation to inconsistency, insufficient information and poor discussions around family responsibility. Patients, families and professionals have been left dissatisfied, excluded or confused by DFLSTs (Kyba, 2002; Prendergast and Puntillo, 2002; Kirchhoff and Beckstrand, 2000; Faber-Langendoen, 1996). Decisions can be subject to individual doctor control, rather than being dependent on patients' 'best interests' (McGrath *et al*, 2002; Cassell *et al,* 2003). Families may perceive conflict in EOL discussions, as in Abbott *et al*'s (2001) study, through poor communication and professional behaviour. Box 7 (Pattison, 2006b) summarises the effects of conflict that EOLDs can have.

Box 7. The Effect of Conflicts

- **Fragmentation** - disagreement between disciplines, leading to disjointed care for the patient and families

- **Feelings of exclusion** - lack of consideration of opinions of the key people involved in the patient's care

- **Patient care suffering** - as a result of above fragmentation

- **Dissonance (personal)** - care givers' own values being challenged

- **Dissonance (professional)** - care givers' having to provide care inconsistent with their own values, and being tempted to deviate from prescribed care to assuage this dissonance

- **Confusion and distress** - conflicting opinions leading to families, and care-givers, not knowing where care is proceeding to

- **Delay** - decision-making delay because of conflict

- **Poor communication** - may result from the conflict

Furthermore, conflict between medical teams may arise with differences between prognoses: prognosis from cancer and prognosis from critical illness. This presents an issue not explored before in the literature which, in turn, affects prospects for good death in this situation.

2.6 Integrated Care Pathways: The Liverpool Care Pathway Experience

Palliative care has seen the advent of the Liverpool Care Pathway (LCP) initiative (Ellershaw and Ward, 2003), established to improve EOLC in many settings, irrespective of diagnosis. It aimed to transfer models of excellence for EOLC from hospices into other healthcare settings. I outline LCP use here because this initiative was extended in 2007 to critical care (Liverpool Care Pathway for Intensive Care Units: LCP-ICU), part way through the study[8]. At the Royal Marsden, one of the research sites, I became clinical lead of LCP-ICU, which we adapted in line with early study findings and practice experience. This shift to embrace palliative care across the UK, as a result of the LCP, has meant movements to implement it in critical care are extremely pertinent to this research. Once dying has been diagnosed, LCP-ICU can be implemented. It provides key prompts for withdrawing treatment, for care, along with some prescription of treatment around palliation interventions such as analgesia.

However, these prescriptions are not always context-appropriate (indeed, we changed ours with expert input from a pain consultant). Limitations around LCP-ICU use centre on the fact that it is merely a guide. It does not offer information on *how to* do aspects of EOLC in critical care, which is what many clinicians struggle with (Rocker *et al*, 2010). It also requires agreement from all teams on whether patients are dying before it can be implemented, highlighting a specific issue around entanglement of decision-making and EOLC. The comprehensive nature of LCP-ICU did not address these issues. Moreover, filling in this large document in the two to four hours it takes from decision-making to death in critical care can be problematic for clinicians wishing to concentrate on care provision at this time.

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[8] We introduced the LCP-ICU after data collection was complete.

Evaluative evidence for LCP use is scarce and limited to certain settings (Jack *et al*, 2004; Watson *et al*, 2006; Lhussier *et al*, 2007), with no research[9] to date regarding LCP-ICU (see Appendix 5 for our pre and post audit findings). Lastly, evidence points only to improvements in documentation, not quality of death and dying. Primarily, it is a prompt tool. Despite this, the *End-of-Life Care Strategy* (DH, 2008) and NICE (2004) expect all trusts to use LCP, and increasingly LCP-ICU. Specific issues around this will be considered in the discussion and conclusion chapters.

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[9] Ellershaw and Perkins are undertaking a multi-centre research study funded by the National Institute for Health Research (SDO Project - 08/1813/256) which began in 2010 and is due to complete 2012.

2.7 Summary of key points from the literature: Tables 4 and 5

Table 4. Interpersonal interactions and effects on treatment and decision-making

Interpersonal interactions and effects on treatment and decision-making	Literature
- **Critical care nurses experience dissatisfaction with the level of input in decision-making in critical care at the EOL.**	Baggs and Schmitt, 1995; Jezuit, 2000; Kirchhoff and Beckstrand, 2000; Kirchhoff *et al*, 2000; Melia, 2001; Ferrand *et al*, 2003; Keenan *et al*, 2003; Robichaux and Clark, 2006; Latour *et al*, 2009; Popejoy *et al*, 2009
- **Critical care nurses have some or limited influence on doctors' DFLSTs.**	SUPPORT Principle Investigators, 1995; Jezuit, 2000; Abbott *et al*, 2001; Melia, 2001; Puntillo *et al,* 2001*;* Ahrens *et al*, 2003; Keenan *et al*, 2003; Carlet *et al,* 2004; Latour *et al*, 2009
- **Need for nurses to act as patient advocates for critically ill patients is apparent.**	Beland and Froman, 1995; McClement and Degner, 1995; Kennard *et al*, 1996; Cartwright *et al*, 1997; Counsell and Guin, 2002; Robichaux and Clark, 2006; Kinoshita, 2007; Fridh *et al*, 2009
- **Critically ill and dying patients are difficult to sample due to incapacity to consent issues.**	Lynn *et al*, 1997; Seymour, 2001; Johnson *et al*, 2000; Ferrand *et al*, 2001; Sulmasy and McIlvane, 2002
- **Lack of communication between families, patients and clinicians (nurses and doctors) prevails and leads to feelings of frustration and dissatisfaction for patients and families.**	Kirchhoff *et al*, 2002; Cassell *et al,* 2003; Ferrand *et al*, 2003; Beckstrand *et al*, 2006; Latour *et al*, 2009; Popejoy *et al*, 2009
- **Presumptions about patients' care preferences persist on behalf of the doctors, nurses and even families.**	SUPPORT Principle Investigators, 1995; Phillips *et al*, 1996; Walter *et al*, 1998; Weeks *et al*, 1998; Kirchhoff and Beckstrand, 2000; Teno *et al*, 2000; Pochard *et al, 2001; Tilden et al*, 2001;Cassell *et al, 2003;* Cook *et al,* 2003; Sprung *et al*, 2003; Van der Heide *et al*, 2003; Beckstrand *et al* 2006; Hauser *et al,* 2006; Sprung *et al* 2007
- **Conflict (between doctor groups; between families and professionals; between nurses and doctors) inhibits DFLSTs and initiating EOLC.**	Kirchhoff *et al* 2000; Abbott *et al* 2001; Cassell *et al*, 2003*;* Ferrand *et al, 2003;* Latour *et al*, 2009

Table 5: Withdrawal and care processes

Withdrawal and Care Processes	Literature
- **A wide variation in practices of withdrawal of treatment and EOLC practices exists, in part due to wide variation in individual patients.**	Christakis and Asch, 1993; Campbell, 1996; Prendergast *et al*, 1998; Sprung *et al*, 2003; Wunsch *et al*, 2005
- **Technology can be used to shape the course of a patient's death.**	Slomka, 1992; Hall and Rocker, 2000; Johnson *et al*, 2000; Seymour, 2001; Cook *et al*, 2003; Halcomb *et al*, 2004
- **Quality of dying associated with less intervention and clear plans and goals.**	Hall and Rocker, 2000; Kirchhoff *et al*, 2002; Campbell and Guzman, 2003; Fins *et al*, 2003; Halcomb *et al*, 2004; Hodde *et al*, 2004; Nordgren and Olsson, 2004
- **Symptom management at EOL in critical care is often inadequate and difficult to manage due to concerns about 'killing' patients.**	Hawryluck *et al*, 2002; Carlet *et al*, 2004; Treece *et al*, 2004
- **Meeting comfort needs is seen as a supportive measure for patients and families.**	Lynn *et al*, 1997; Desbiens *et al*, 1998; Lilly *et al*, 2000; Nelson *et al*, 2001; Nordgren and Olsson, 2004; Rocker *et al*, 2004; Badger 2005a, 2005b; Beckstrand *et al*, 2006
- **EOLC is not planned by nurses, and tends to be prescribed as part of the withdrawal process determined by doctors.**	Kirchhoff *et al*, 2000; Teno *et al* 2000; Cook *et al*, 2003; Sprung *et al*, 2003; Van der Heide *et al*, 2003; Trovo de Araujo and Paes de Silva, 2004; Robichaux and Clark, 2006
- **Time to death after withdrawal of treatment in critically ill patients is short.**	Dowdy, 1998; Manara *et al*, 1998; Sprung *et al*, 2003; Wunsch *et al*, 2005
- **Death need not be a wholly negative experience in critical care.**	Tilden et al, 1995; Seymour, 2001; Melia, 2004; Badger 2005a, 2005b; Teno *et al*, 2005
- **A good death for patients (not necessarily in critical care) is about having awareness of dying, open discussion of dying, forewarning of trajectory of dying, and preferences expressed and facilitated.**	Singer *et al*, 1999; Steinhauser *et al*, 2000; Curtis *et al* 2002b; Farber *et al* 2003
- **Providing EOLC, as well as making DFLSTs, can be emotionally laborious.**	Seymour, 2000; Badger 2005a; Beckstrand et al, 2006; 2009; Robichaux and Clark, 2006; Fridh *et al* 2009; Stayt, 2009

2.8 Conclusion

Epistemologically, in EOLC in critical care, we have seen emphasis on outcomes research, alongside family and professional notions of decision-making, good death and EOLC, rather than research with patients. There still exists a dilemma about how to measure dying critical care patients' perceptions of whether certain care practices are useful. There is an important difference between the concepts of treating families versus treating unconscious patients, not previously addressed in critical care research, and only rarely in palliative care research. This is an important premise and area to explore in this research study. Care as a measure is rarely defined but often employed. Emphasis is on medical interaction and care, rather than the whole patient experience. This was raised earlier as an insuperable methodological issue when patients are at the very EOL but for patients with life-limiting illnesses, an important and different perspective to professionals and family opinions is offered. By correlating family and health professional perceptions of helps and hindrances in EOL in cancer critical care, with perceptions from patients with a life-limiting illness, which the literature identified has been done only very rarely in this area, this study will help identify disparate needs. No published studies in EOL in critical care sample patients, families, doctors and nurses as this study does. What can be done about these disparate experiences and needs is a primary driver in my research that also aims to change practice.

Conflict, as a phenomenon, is seen in EOL literature but measures for resolving conflict have not been explored in depth. Nurses appear to have a small voice in the context of DFLST, despite their large number and role in EOLC. This study samples nurses' perspectives to give them a greater voice in EOLC and enable them to attribute meaning to their actions. Descriptive or interventional methodology, which current research in EOLC tends to favour, would not answer *why* there are problems in EOLC. A qualitative approach, using a collaboration or comparison of proxy assessments of the process of dying in critical care, lends weight to the argument of enhancing understanding of EOLC in critical care, and how it is represented by nurses, doctors, patients and families. Literature would suggest that critical care nurses are ideally placed as advocates or facilitators for good EOLC decisions *and* practices after DFLSTs, as well as having the advantage, through one-to-one care, of being able to be patient-focused. Yet critical care nurses struggle with transitions to EOLC (Melia, 2001; 2004; Badger, 2005a, 2005b; Robichaux and Clark, 2006; Popejoy *et al*, 2009; Stayt, 2009). This study explores difficulties nurses face caring for

critically ill cancer patients at EOL and will, unlike existing literature, explore nurses' experiences in the context of all key perspectives. This will contribute to the literature on critical care at EOL by providing a broad and rich picture of EOLC, beyond simply nursing. It acknowledges nursing exists within a wider environment where there are many key players interacting to provide EOLC.

There are no published studies in palliative or critical care that encompass critically ill cancer patients moving to EOL and EOLC. Principles of palliative care and EOLC in critical care are clouded by cancer, the intent of treatment and curative goals of critical illness in cancer. This research explores how cancer diagnosis might impact on EOL in critical care. Increasing cancer-related critical illness survival lends weight to a moral argument of increasing access to critical care interventions, which means more patients will die in a critical care, curative paradigm where high technology is omnipresent. Individuals responsible for care can overly influence processes of moving to, or choosing not to move to, EOLC but recent initiatives, such as the LCP, aim to challenge and address this. When critical care interventions 'fail', however, variability in care and organisations mean EOLC and a good death is not guaranteed. How we enact good death in the face of these cancer and critical care challenges is examined in this research. This provides a fresh perspective by acknowledging the interplay of chronic or acute illness, such as cancer, and critical illness where patients' potential outcomes are not clear cut.

The next chapter outlines the chosen qualitative methodology, phenomenology, evidenced by the literature and conceptual underpinning chapters and used in this study.

Chapter 3: Philosophical Perspective and Methodology

First, this chapter addresses why a qualitative, phenomenological interview approach was chosen, how it was informed by literature, and charts aspects of the journey to reach that decision. Second, it outlines the implications for using phenomenology and philosophical underpinnings of the methodology, specifically: hermeneutics and *Dasein*. I discuss appropriate methodology in this regard. I then outline why it is appropriate for nursing, discussing interpretive nursing study and potential implications for nursing experience. Lastly, I outline the rationale for phenomenology as applied to this study. Phenomenology, regarded as the study of experiences, explores the structure of consciousness from a first-person perspective (Smith, 2008).

3.1 Rationale for Qualitative Method and Phenomenology

This section outlines why in this context of research into experiences, phenomenology was appropriate. The conceptual underpinning underlined how the root of the division between the two disciplines of critical care and palliative care may relate to how the patient is viewed and Chapter 2 demonstrated how this division extends to research methodology; EOL research predominantly employs questionnaire surveys or case-note review. Few studies use qualitative approaches, even when this may be more appropriate in certain circumstances, such as bereavement (Stroebe *et al*, 2003). A need for qualitative research in EOLC in critical care has been articulated (Baggs and Schmitt, 2000; Rubenfeld and Curtis, 2001; Rusinovà *et al*, 2009). Despite qualitative research in EOL generally (see Appendix 2), in cancer, there is none that pertains to critically ill cancer patients and EOL.

Here, I discuss considerations in undertaking qualitative research, having presented a rationale for this in Chapter 2. Studying the meanings behind nursing and medical actions in EOLC may, for example, yield rich data about why certain practices exist. Furthermore, exploring experiences and needs is best achieved through qualitative method (Denzin and Lincoln, 2003). In order to investigate meanings behind knowledge, beliefs and ethical concerns around cancer patients dying in critical care, qualitative research methods are appropriate. Ostensibly, the current palliative care

paradigm embraces qualitative research, but Corner (2001) charges it with being dominated by quantitative issues of service evaluation and symptom identification. This is also true of EOLC in critical care, but instead of symptom quantification, EOLC is dominated by outcome measures of satisfaction with EOLC, alongside service and resource evaluation (as I discussed in Chapters 1 and 2 and outline in Appendices 2, 3 and 4). In light of this, qualitative method best answered my research question:

> What are the issues around end−of−life care provision for cancer patients in a critical care unit, as explored through family, practitioner and patient experiences?

What was required from my methodology can be considered in relation to the research question. It was a question of best fit in answering questions about experiences. I required an underpinning that allowed deep exploration of experiences, since this is what I wanted to explore. It needed to also allow me to investigate the literature, bring along my own assumptions from literature and practice, enable me to acknowledge existing theory, reach understanding about the experiences, and would provide a rich picture of all the perspectives, without compromising my position as a researcher-practitioner.

Phenomenology met these requirements because assumptions associated with phenomenology — being-in–the world (*Dasein*) (which I discuss shortly in Section 3.2.3) — suited my conceptual ideals of *being* with patients (see Section 1.6 in the context of nurses' caring); enabling hidden experiences to emerge through joint interpretation. Phenomenology is aligned with my personal philosophy in this sense: one co-constructs phenomena together, since it is notoriously difficult to vicariously study experiences (Yegdich, 2000). Therefore, the research has to become a joint venture, but with clear researcher-participant boundaries. In this research study, this is important because examining experiences underpins future changes in practices. Without exploring issues and illuminating what is hidden for families, patients and professionals concerned, change takes place in the 'dark'. This co-creation was achieved through questioning and achievement of points of 'fusion' during interviews (exemplified in Section 4.6 and 4.8). Furthermore, as Section 5.3 outlines, I needed a method that could accommodate changes since the research was taking place in a rapidly changing-environment, and phenomenology seemed to fit with these premises.

Phenomenology aims to reveal previously unknown phenomena (Munhall, 1994). In revealing the hidden, this approach to the research could uncover previously undiscovered areas, not yet reported in the literature. This is even more pertinent given that a significant part of the research area, EOLC in cancer critical care (after DFLSTs have been made), has not previously been addressed. Moreover, the whole research area has not been addressed from the perspectives of *all* those involved in one research study in critical care (and to only a very limited extent in cancer).

As discussed in Chapter 2, it became clear that experiential aspects of EOLC have been rarely addressed, particularly in the context of patients' perspectives and experiences. Nurses' experiences have been explored in a handful of studies but these were explorations of nurses' experiences, apparently occurring in a vacuum. The interrelatedness of how each nurse's experience might affect another person's (doctor, patient, family) was not explored. Essentially, data collection strategies, as well as gaps in the literature, dictate chosen methods and provide rationales for philosophy (Wimpenny and Gass, 2000). As I outline in this chapter, phenomenological methodology explores underlying meaning of experiences and emphasises the intentionality of consciousness where, as Creswell (2003) outlines, experiences comprise outward experiences and inward reflections based on memory, image, and meaning. In other words, a person's experiences of reality are inextricably related to their consciousness of it. This can be pre-reflective, where those experiences were already present and held meaning (Gallagher and Zahavi, 2008). Pre-reflective self-awareness suggests that experiences have a subjective 'feel' to them, a quality of 'what it is like' or what it 'feels' like to have them (Gallagher and Zahavi, 2006). In other words, self and consciousness permeate all our interpretations (Heidegger, 1927). These relate to the ontological concept that there are multiple truths. This research acknowledges that people work to different models of practice, and experience different truths. Reflecting on one's lived experiences to find the truth is an authentic way for discovering the real knowledge for each person. Phenomenology as a method for doing this will be discussed next.

3.2 Phenomenology: a philosophical underpinning

This part of this chapter firstly deals with hermeneutical phenomenology as a philosophy and methodology. It then goes on to explore specific aspects of phenomenology as applied to the research question. This includes a brief explanation of Heidegger's (1927) concepts of *Dasein* and affectivity (*Befindlichkeit*) since these relate most readily to the research questions. The value of phenomenology as a method and in nursing research is highlighted. The chapter will finally link to the method undertaken in the research study, providing further rationale for my application of phenomenology.

3.2.1 Phenomenology as philosophy

Phenomenology emerged within a context where Husserl was studying human phenomena: thoughts, feelings and emotions (Husserl, 1913; Speigelberg, 1969). Phenomenology is further rooted within existentialism: understanding people by how they exist in the world and understanding their choices and freedom within the world. Heidegger found through Husserl's phenomenology movement a method which would lay open the processes in human existence in such a way that *being*, and not simply one's own ideology, might become apparent (Palmer, 1969).

Phenomenology is one way, which Leonard (1989) outlines, of searching for different possibilities in the quest to both make sense of human life and to do justice to unfixed notions of much of human experience. Heidegger, exploring Husserl's notion of transcendental subjectivity, saw that within subjectivity there was a vital element of one's being-in-the-world, both a historical and temporal concept. He felt that phenomenology would allow things to become manifest as they are without forcing our own categories on them. Things show themselves to us (Heidegger, 1927). It implies that interpretation is not grounded in human consciousness and human categories but in the manifestness of the thing encountered, the reality that comes to meet us.

In *Sein und Zeit* (Being and Time)[10], Heidegger (1927) establishes understanding in the fact that one has with their existence, along *with* it; a certain understanding of what

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[10] I chose *Sein and Zeit* as this work is the most comprehensive of all his work for accessing concepts of *Dasein* and affectivity which are not addressed in his subsequent works including *What is called thinking?* (Heidegger,1954) and the *Zollikon Lectures* (Heidegger, 1959-69) which I also explored in relation to methodology

fullness of being is. It is not a fixed understanding but historically formed, accumulated in the very experience of encountering phenomena. Phenomenology is letting 'that which shows itself be seen from itself, in the very way in which is shows itself from itself' (Heidegger, 1927, p.58). In other words, it renders visible the invisible structure of being-in-the-world, or, reveals the hidden.

Heideggerian philosophy enables us to understand human agency (Leonard, 1994). An understanding of human agency underpins this study, as described in Chapter 1 in relation to Seymour's (2001) theory and later in Chapters 6 and 7. Furthermore, revelation of experiences is a central tenet to the research question. Existing research, outlined in Chapter 2, demonstrated a lack of studies delineating experiences in EOLC. Using phenomenology to understand experiences and interpret human meaning and agency provides evidence in this area. Furthermore, each participant group's experience is presented within a whole picture of EOLC in cancer critical care. This goes beyond one group's experiences to contextualise it from various relevant perspectives and shows how each experience might be affected by, or affect, another person's.

3.2.2 Hermeneutics

Heidegger became the architect of a major shift in phenomenology: hermeneutical phenomenology. Hermeneutics grew as an effort to describe 'historical' and 'humanistic' modes of understanding (Annells, 1996). Some researchers term hermeneutics as interpretive phenomenology (Benner, 1994; Maggs-Rapport, 2001). Heidegger (1927) considered understanding and interpreting phenomena rather than description alone. Hermeneutics is described in greater detail than the act of interpretation by Heidegger (1927). He explicitly links hermeneutics with Hermes. For Heidegger, philosophy is interpretive; it is:

- To say aloud (to listen to experiences)
- To express (in participants' interview dialogue)
- To interpret (in reaching points of fusion and clarification).

For Palmer (1969), understanding under Heideggerian philosophy is temporal, intentional and historical: it is disclosing what is real for a person. In relation to this research study, for example, a person's interpretation of the reality of confronting

death (either a person's own death, a loved one's death or a patient's death), is fundamental to understanding their experience.

It is assumed in hermeneutics, given common background meanings in culture and language, that the researcher has some understanding of the world to be explored and studied (Leonard, 1994). Interpretation involves the presence of outside factors; in bringing up those outside factors, the text becomes meaningful. Meaning is a matter of context; the explanatory procedure provides an arena for understanding. In a specific context an event is meaningful. However, as I argue in 3.3.1, some degree of transferability is possible. This is important because my sample includes different groups of participants who are placed together, and have to work together, in EOL situations for the good of patients. In hermeneutics, this area of assumed understanding is termed pre-understanding (Heidegger, 1927). For instance, listening to families and patients, describing their experiences and reaching interpretations from those, I must possess a degree of understanding about the context. Interpreting is therefore an extension of pre-understanding, and is never 'presuppositionless' according to Heidegger (1927, p.191). The essence of hermeneutics for Heidegger is ontological power of understanding and interpretation, which renders possible the disclosure of being of things and ultimately of the potentialities of *Dasein's* own being (Heidegger, 1927).

3.2.3 *Dasein*

In this section, I outline Heidegger's concepts of *Dasein* and, briefly, associated affectivity in his philosophy and as applied to this study. *Dasein*, a central tenet to hermeneutical phenomenology, is the notion of being-there. This is arguably a simplistic translation of a difficult to translate term (Reed, 1994; Wrathall, 2005). It seems to refer to the concept of the situated meaning of a human in the world: human everyday existence, the taken-for-granted. *Dasein* can refer to a single person or a way of being. For Heidegger, person and world are 'co-constituted' (Heidegger, 1927, pp.26-27). Put simply, *Dasein*, or existence and 'being there', to which Heidegger refers, is the human being, the locus where Being manifests itself, rather than the human subject (Crotty, 1996). How we interpret the world shapes our being. In relation to this study's methodology, participants are therefore not subjects but co-creators, giving accounts of their *Dasein* and experiences. Heidegger's being-in-the-world was his evidence that when humans share things or practices we give meaning to them. It is about everyday, taken-for-granted, existences and how we make sense of the world

through those existences. As researcher, my role is to allow participants a voice, to draw out the issues and experiences, and to reach meaning that can be understood by many. As Sandelowski and Darbyshire (1997) outline, researcher skill comes in applying existing literature and concepts to those voices and creating an interpretation. Yet, participants' own interpretation of meaning informs our interpretation of meaning that we might reach from the study findings.

Affectivity is one way in which meaning can be reached. Heidegger (1927) describes his notion of affectivity, the modification of one's existence in the world, and in one's own world, having realised the context of meaningful relations established by the purposeful activity of people around oneself. We understand our own affectivity by having and experiencing the *feeling* in question. For example, in the context of this research, families understand their experience of witnessing EOLC and frame it through reflection, anxiety, despair, and concern. These characteristics Heidegger viewed as attunements to the world (Heidegger, 1927). Affectivity may be the everyday feelings, taken-for-granted, or ordinariness (for instance, ordinariness in nursing practices as Taylor [1994] describes), or even the extraordinariness in the feelings health professionals encounter in our experiences of a phenomenon. In this research, caring for a patient at EOL is not an everyday occurrence but it can be *ordinary* in the grand scheme of intensive care where many patients die. For experienced senior doctors and nurses used to dealing with death in intensive care, not all deaths will be reflected on as extraordinary, yet for more junior nurses, relatives and patients it is highly likely be an extraordinary experience. I have discussed how capturing this aspect to affectivity, specifically surfacing the taken-for granted, is key to phenomenology and important in the research study presented here. For senior staff, I wanted to gain perspectives and experiences about deaths that are not normally reflected on, not just unusual deaths that might be remembered for a long time, but the 'everyday' deaths to gain a sense of the ordinary. In Section 3.3 next I outline how phenomenology can be regarded as a research methodology, beyond philosophy, and in particular as a nursing research methodology.

3.3 Phenomenology as method

The Heideggerian-based work of van Manen (1990) stems from the Dutch (Utrecht) school of philosophy which believes in applied practical rather than professional philosophy. He delineates how hermeneutical phenomenology can be viewed as interplay between six research activities:

1. turning to phenomena which interest us and commit us to the world
2. investigating experience as we live it rather than as we think about or conceptualise it
3. reflecting on essential themes which characterise the phenomena
4. describing the phenomena through the art of writing and re-writing
5. maintaining a strong, oriented pedagogical relation to the phenomena
6. balancing the research context by considering parts and the whole

Revealing a deep understanding of a description, and interpreting human meaning from that description, is achieved by bringing the researcher into closer contact with those who have experienced the phenomena. Researchers and participants together reframe the experience, through questioning the everyday experience. van Manen's (1990; 1997; 2002) way of analysing phenomenological texts was most appropriate because his practical approach to analysis also emphasises how phenomenology can be applied to practice.

The hermeneutic circle is essential to the process of analysis in hermeneutic phenomenology: interpreting, analysing and critiquing (Darbyshire *et al*, 1999). It is the moving back and forth between parts and the whole, between the initial forestructure and what is being revealed (Leonard, 1994). Furthermore, the hermeneutic circle fosters a skill in listening to the participants, encouraging them to distil their ideas about the concepts and the issues discussed and to find meaning in the context of the expressed language. Reeder (1985) describes it as a metaphor for moving between parts of the text and the whole of the data and Annells (1996) as 'the art of understanding', but this is perhaps to undermine its value somewhat. The researcher should enter the hermeneutic circle by immersing in the whole of the text and considering lines and sections of it against its whole interpreted meaning. This is where the researcher's role and need for reflexivity becomes clear. In order to truly understand the data, a process of self-discovery and reflection is necessary as the whole and parts of the text are considered in order for the phenomenon to emerge.

Leonard (1994) also asserts that in order to engage phenomenologically and enter into the hermeneutic circle, researchers also need a fundamental understanding of the phenomena themselves.

3.3.1 Value of phenomenology in nursing research

The benefits to nursing are described in this section and provide a backdrop for why phenomenology proved suitable for this study from a research and humanistic perspective to find meaning around practices. A phenomenological approach generates an exhaustive description, and interpretation, of a phenomenon and helps achieve an understanding of its essential structure. Darbyshire *et al* (1999, p.23) expressed the benefits to phenomenology in nursing:

> "interpretive scholarship works to point to possibilities in order to enrich human existence through increasing understanding of the everydayness of being human. Interpretive phenomenology realizes the limitations of reducing existence to transcendental ideals or mechanistic atomisms. Humans are an integral part of the tradition in which they are immersed. It is in the context of everydayness that shared practices and common meanings contribute to the interplay of meanings and understandings."

Its value should not be disregarded because of examples of appropriation of phenomenology into a nursing phenomenology, such as Diekelmann (1992; 1993) and Benner (1994), where nurse researchers are criticised for misinterpreting phenomenology (Crotty, 1998; Paley, 1996; 2002) (see Appendix 6 for further exploration and critique of phenomenology). Munhall (1994; 2007) and Darbyshire (1994; 1997; Darbyshire *et al*, 1999) are strong advocates of the use of phenomenology in nursing research. Both consider phenomenology as a research methodology important to the practice of nursing, and view seeking understanding about phenomena and reflecting upon meaning as essential in the health-care system. For Munhall (2007), phenomenology is a quest for what it is, and means, to be human, while for Darbyshire (1997), phenomenology is a means for nursing to advance research inquiry.

In relation to nursing, phenomenology raises benefits not obvious when first examining Heidegger's work. Reeder (1985) expresses these certain benefits as:

- fostering the skill of listening to the research participant
- listening to the context and meaning of expressed language
- lived experience being seen to precede understanding
- the ability to illuminate nursing questions
- seeing the multiple perspective
- universality of language in giving and receiving care
- deepening and broadening of understanding through the fusion of past, present and future of persons in different situations.

The notion of shared meaning underpins how phenomenology can give nurses something to learn from. Practice can be revealed in ways not previously considered. That which is taken for granted and concealed is disclosed. Hermeneutic phenomenology elicits hidden meaning within words and help develop understanding through language (Maggs-Rapport, 2001). In essence, nursing can learn from phenomenological inquiry since nurses frequently witness extraordinary and ordinary events that humans experience (Taylor, 1994; Madjar and Walton, 1999). Examining these can facilitate understanding of human experience and potentially improve such experiences through practice. Little (1999) argues for the possibility that unique human experience might also be shared human experience, which reinforces notions of transferability and what Williams (2000) terms *moderatum* generalisations in qualitative research.

Ways of knowing in nursing, such as that espoused by Carper (1978) can be enhanced by phenomenology (Van der Zalm and Bergum, 2000), because nurses can find meaning in and understand everyday situations and change their practice as a result of findings. Having discussed nursing rationales for phenomenology in practice, the following section now highlights specific issues in relation to this study.

3.3.2 Rationale for phenomenology applied to this study

Chapter 1 raised the notion of valuing individuals and recognising the need to care for the patient as a whole, which lends itself to phenomenology. I now link here the conceptual framework and phenomenology, and develop the rationale for the study. I discuss the assumptions that I had to meet and how I used phenomenology in developing my aims.

Phenomenology and caring fit together as philosophical and conceptual frameworks since, as we saw in Chapter 1, caring is notoriously difficult to articulate and the meanings behind caring are often concealed. Furthermore, there are many hidden issues in EOLC that are rarely articulated in everyday practice and I wanted to explore and make these manifest. Alongside philosophical and conceptual relationships between nursing and phenomenology lies the methodological relationship. Spiegelberg (1965) sees hermeneutic phenomenology, employed in this study, as an interpretation to unveil otherwise concealed meanings in the phenomena. Interviewing and phenomenology can be allied together since the aim is to explore meanings together with another person until fusion is reached.

My chosen approach using hermeneutic phenomenology attempts to:

- determine the nature or meaning of an everyday experience - in this case, the process and experience of dying, and those caring for, and witnessing the dying
- try to describe and interpret experience without letting previous assumptions influence the objective reality of those experiences.
- presuppositions will be not be suspended but examined, explored and made explicit
- understand the experience (in this case EOLC provision).

I wanted to explore notions of what families experience in witnessing the processes of dying, and notions of 'good death', in comparison to patients', nurses' and doctors' perceptions. From a phenomenological stance, exploring the nature of human experience is what defines phenomenology as a methodology (Van der Zalm and Bergum, 2000). For patients, a phenomenological approach makes sense of what it is like living with cancer, often a severe, chronic and life-limiting illness. For patients, describing and interpreting the processes of dying and the concept of good death may help us to better understand and improve practice around EOLC because their voice is rarely heard in this context. Benner (1985) conceptualises phenomenology as a method that can provide understanding of experience, realities and one that values individuals. This philosophy could underpin nursing and medical practice, but it risks being lost in the medicalised lifeworld (*Lebenswelt*) of critical care (Benner *et al*, 1992). Phenomenology may help to reveal the unique and common meanings that underpin reactions and experiences of families or, indeed, patients at EOL.

Trustworthiness of phenomenological data is context-specific argues Streubert-Speziale and Carpenter (2006), yet van Manen (1990) discusses how phenomenological research is about applying essences of lived experience to theory and concepts. These could be used to develop practice, the ultimate aim of this research. This suggests that from contextual experiences practice implications can still be drawn. Van der Zalm and Bergum (2000) label this 'prescriptive theory', theory that has implications for practice.

Exploring patients', families' or clinicians' experiences and subjectivity may provide inquiry that counteracts dehumanising tendencies (Playle, 1995, Yegdich, 2000, Polit and Beck, 2004) and the focus on symptoms and professionals noted in Chapter 2. Reflecting on practice (or lived experiences) raises questions about knowledge, increases knowledge or understanding, which in turn enlightens practice.

3.4 Summary

In this chapter, I have outlined phenomenology and in particular interpretive Hermeneutic phenomenology, where it is placed in a philosophical context and have briefly drawn upon some of Heidegger's central tenets as they relate to the research. In laying open consciousness, true meaning and being can be seen. Briefly, to recapitulate: *Dasein* was explored in how it pertains to phenomenology as a means to revealing the true meaning of being, this being key to the research: revealing truth and meaning together with partipants. The hermeneutic circle, moving between the parts and the whole, is presented in the context of using phenomenology as a research method. If phenomenology is applied carefully, the value in exploring meaning in nursing research becomes clear. Phenomenology allows individual's experiences, and meanings held from those experiences to be accessed and explored in depth through, and with, researchers. How I undertook the study is outlined next in Chapter 4.

Chapter 4. Method

This chapter outlines in turn the research questions, aims, method, sample (including alterations), methodological ethical issues and the analytical framework.

4.1 Research Question

The aim of this research was to gain a picture of experiences for those whom EOLC affects. Witnessing, providing, deciding and experiencing care when critically ill provided the four key dimensions to exploring these processes. The primary research question in 3.1.1 evolved following further methodological, theory and literature exploration into:

> **What are the issues around end−of−life care provision for cancer patients in a critical care unit, as explored through family, practitioner and patient experiences?**

Secondary aims included:

> 1) **To describe, and explore, what is happening around end-of-life care provision in a cancer critical care unit.**

> 2) **To explore what it is like for families, patients and practitioners who experience or provide end-of-life care in critical care**.

> 3) **To explore what end-of-life care in a cancer critical care unit means for patients, families and practitioners working in critical care.**

> 4) **To examine what, if any, impact a diagnosis of cancer has on patients', families' and practitioners' perceptions and experiences of end-of-life care provision in critical care.**

> 5) **To assess the experience of timeliness of moving to end-of-life care, once end-of-life decisions have been made**

6) To explore what issues around end of life mean for cancer critical care nursing and where nursing can contribute to improving care

The aims of this study reflect my ontological and epistemological standpoint that I have detailed in the introduction and Chapters 2 and 3, and will discuss in Chapter 5.

4.2 In-depth interviewing method

In this section, I outline the rationales for the phenomenological interview approach used; in particular I discuss how these shaped interviews and refer to the achievement of the essence or *Wesen*.

In-depth interviewing, the most appropriate approach in phenomenology (van Manen, 1990; Munhall, 1994), is characterised by allowing interviewees to express in their own words what they feel is relevant and pertinent on a particular topic (Pontin, 2000). Phenomenological interviewing relies on the interviewer and interviewee co-creating truths together. The interviewer reflects on what the interviewee has talked about and reaches a point of fusion, where both parties understand what each other means about the phenomena (See Section 3.8). This co-creation can also be regarded as an early stage of analysis. I tried to seek meaning as I was gaining these experiential accounts (as seen in distinctions between inferential (interpreted) and descriptive coding in Section 4.8.3), although interpretation also took place after interview. I structured interviews loosely to additionally offer the individual the opportunity, having shared their experiences, to think about how practices could be changed. This was also to present a possibility for nursing and medical issues to be challenged, and for contributions to practice to emerge. Interview schedules were peer-reviewed to ensure the logic of cues and consequently, credibility and reliability.

Phenomenological interviewing establishes the context of participants' experiences, constructs experiences and, finally, enables reflection on the meanings these hold (Wimpenny and Gass, 2000). Gentle probing is a characteristic of phenomenological research. Typical phenomenological questioning aims to capture the experience. 'How' questions are more appropriate to 'why' (Benner, 1994; Wimpenny and Gass,

2000). This approach contributes to this construction and co-creation of meaning discussed in Sections 3.1. and 3.2.3.

The achievement of 'Essence': *Wesenschau* or *Wesen*, is the ultimate aim of phenomenological method. *Wesen* denotes how phenomena appear or come-to-be, and remains as they are (Heidegger, 1927). Phenomena to be revealed are seen or heard by anyone who choose to see or hear them. For the purposes of phenomenological investigation this is an important notion: essences of phenomena can be revealed by researcher and researched in alliance through researcher questioning, reframing and reconsideration of the essence and meaning with the person being researched. In this sense, the phenomenological fusion that I raised earlier, and in Section 3.1, can be reached.

I undertook in-depth, unstructured,[11] tape-recorded interviews with participants. I carried out interviews at place of choice for patients and families, with all but three in the home setting. This was participant choice. Interviews can be considered a cathartic or therapeutic process for some participants (Cook and Bosley, 1995; Rosenblatt, 1995; Sque, 2001; Emanuel *et al*, 2004), and distressing for others (Lee, 1993; Cook and Bosley, 1995; Parkes, 1995; Seamark *et al*, 2000). Interviews could raise intensely personal issues. I reiterated that participants retain control of subject area and they were encouraged to talk about areas they felt comfortable with. All interviews, except one at the express wish of the participant (which was instead annotated throughout), were audio or digitally taped. I used cues at interviews where appropriate.

4.3 Sample, setting and access

The setting for the research was a critical care unit within a large cancer hospital, spanning two sites, in the UK. A single hospital was used since, during the research, there was only one cancer critical care unit in the UK that provided level three[12] care and comparison was not the aim.

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[11] Loose cues were used rather than interview schedules e.g. experiences/wishes around EOLC.

[12] This denotes patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure (Department of Health, 2000).

I predominately used purposive sampling to gain perspectives across a variety of patients' cancers, nurses' grades and consultant doctors. This ensured inclusion of the missing voices outlined in the literature (Chapter 2) and conceptual underpinning (Section 1.2). Table 6 outlines inclusion and exclusion criteria. Morse (1991) also suggests that both typical and atypical descriptions of the phenomenon should be sampled so a whole range of experiences can be seen. It is difficult to surmise at the outset which of the phenomena will be atypical in the sampling frame. Atypical might be, for example, a very different or surprising meaning or interpretation. However, I used whole sampling where the sample was small (for example, consultant intensivists and anaesthetists, and palliative care consultants). For families, the need for whole sampling reflected my limited data collection period and the relatively small numbers from which to draw related to tight eligibility criteria. I sought a heterogenous sample of patients to reflect a range of experiences across different types of cancers. I chose patients who had been very critically ill and where odds of survival were around 50%[13] (as seen by highest APACHE scores) in order to gain an idea of the experience of being nearly as critically ill as dying patients (and to gain an idea of the sorts of interventions a very critically ill dying patient might undergo and what that meant to them). How the sampling evolved will be outlined in Section 4.4.

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[13] Patients with an APACHE >25 had a survival prediction of 0.55.

Table 6. Sample Inclusion/Exclusion criteria (additional changes in bold, with rationale in Section 4.4)

Inclusion:
- Adults (>18 years of age)   - Level 3 cancer patients with either admitting APACHE II scores >25 (meaning a probability of death of 0.55); patients who had cardiopulmonary resuscitation (CPR) during admission; patients ventilated >7 days **(and spouse or family member if wished by patient)**   - Families of cancer patients who died in critical care in the three-nine months prior to recruitment following stays over 24 hours, not-for–resuscitation, withdrawal or withholding treatment orders (a decision to forgo life sustaining treatment (DFLST)   - Consultant intensivists and anaesthetists (*who regularly cover critical care on rota 1 in 7)   - Permanent or regular bank nurses (all grades) working in critical care   - Nurses who have experience of caring for critically ill patients at the EOL
Exclusion:
- Families of patients who died when no DFLSTs were initiated and who received full critical care interventions, including CPR, until death.   - Patients who are *not* now at the EOL or palliative stage (since it may be too distressing) (this was ascertained from discussion with follow-up nurse. Patients who are no longer eligible for treatment and at EOL were excluded)   - Patients who experienced critical care more than three months ago   - Patients who spent more than three days in critical care (in order to gain rich data)   - Speakers of languages other than English (less than <1% of admissions)   - Nurses with no experience of caring for critical care patients at end of life   - Temporary staff   **Oncology consultants with recent experience (within 6 months) of shared care of dying critically ill cancer patients**   **Palliative care consultants with recent experience (within 6 months) of shared care of dying critically ill cancer patients**

4.3.1 Approvals and Approaching Participants

Local Research Ethics Commitee (REC) and Committee for Clinical Research (CCR) approvals for the study were obtained in June 2006 and amendments in October 2006. Confidentiality was assured (see Appendix 7 for all study documentation). The process of approaching participants is summarised below (Figures 1, 2 and 3):

Figure 1. Access: families

Eligibility - Families of patients who died in critical care
- Families of patients who had DFLST and who subsequently died in the CCU
- Families whose family member has died within the past three to six months in the unit

Phone call to families (by nurse responsible for bereavement follow–up) asking if they would be prepared to receive a letter re: a study at the hospital - made two weeks after unit bereavement card (routinely sent out by unit to all bereaved families).

Contact about study was also sometimes made by third parties e.g. Nurse Consultant; CNSs or doctors who often remain in contact with families and offer opportunity for discussion about patients' care.

If family member stated they were not interested – no further contact

If yes: letter of invitation to study was sent out. Letter also asks families to consider nominating another family member if that is more appropriate. This letter required participants to **opt-in** via a reply slip to receive further information, ensuring family member were not bothered by unnecessary literature.

If family member stated they were not interested – no further contact

If family member was interested and returned reply slip or contacted me, I offered the opportunity to visit and discuss study with family, ensuring information sheet and consent were explained further. Alternatively, I posted this information and discussed the study on the telephone as would-be participants preferred.

If family member was not interested (i.e. no reply slip received) – no further contact

Family member was given time to think about participation, at least 24 hours, ideally a week.

If family member was not interested – no further contact

Opportunity for further discussion at home/ hospital wherever convenient

If family member was not interested – no further contact

If family member is interested – and has fully understood/ is happy with information sheet, informed written consent taken and interview arranged

Final step: Processual consent – consent after interview

Figure 2. Access: Patients


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┌──────────────────────────────────────────────────────────────┐
│                    Eligibility (see table 9)                   │
│               - Adults in critical care >72 hours              │
│           - Highest APACHE >25 during admission                │
│    -Follow-up nurse identified as not at high risk of distress │
└──────────────────────────────────────────────────────────────┘
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Follow-up nurse identifies patient – outlined study to patient (who had access to info sheet/letter if he/she wanted it as this point)
Alternative option of follow-up nurse posting invite letter to patient with opt-in slip

If patient was interested I discussed study with patient and ensured information sheet and consent were explained (either at that first clinic, second clinic appointment or at their preferred place e.g. home, or on telephone)

If patient was not interested – no further contact

Patient was given time to think about participation, at least 24 hours, ideally a week.

Opportunity for further discussion at home/ hospital wherever convenient

If patient was not interested – no further contact

If patient was interested – and had fully understood/was happy with information sheet, informed written consent was taken and patient interview arranged

If family member or spouse wished to be present, with patient participant's consent. Separate written consent also obtained from them.

Final Step: Processual consent - consent after interview

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Figure 3. Access - staff

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┌──────────────────────────────────────────────────────────────────────────┐
│                               Eligibility                                  │
│  -  Critical care nurses (purposeful sample D-H (5-8a) with experience in   │
│                              EOLC in CCU                                     │
│      -  Consultant anaesthetists/intensivists covering ICU (total sample)   │
│                    -  Consultant oncologist/palliative care                 │
│                      -  Permanent/regular bank contract                      │
└──────────────────────────────────────────────────────────────────────────┘
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        ┌──────────────────────────────────────────────────────┐
        │  Study raised/outlined at Critical Care MDT and open and │
        │                staff meetings for nurses                 │
        └──────────────────────────────────────────────────────┘
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        ┌──────────────────────────────────────────────────────┐
        │  Consultants and nurses approached in person informally   │
        │   to discuss study (with information sheet for discussion) │
        │             and potential participation                    │
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                                    ▼
              ┌────────────────────────────────────────┐
              │     Formal letters of invite and         │
              │       information sheets given            │
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                                    │
                                    ▼
              ┌────────────────────────────────────────┐
              │  Opportunity for discussion given and time │
              │  for consideration of participation at     │
              │       least 24 hours, ideally a week.      │
              └────────────────────────────────────────┘
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                                    ▼
        ┌──────────────────────────────────┐      ┌─────────────────────┐
        │ If staff member is interested –   │ ───▶ │ If not interested –  │
        │ and has fully understood/is happy │      │ no further contact   │
        │ with information sheet, informed  │      └─────────────────────┘
        │ written consent taken and         │
        │ interview arranged                │
        └──────────────────────────────────┘
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                                    ▼
        ┌──────────────────────────────────────────────────────┐
        │ Final Step: Processual consent - consent after interview │
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In discussion with REC, I interviewed patients around two months after discharge, to allow for time to readjust to life at home, and families around 3-6 months after bereavement, to allow for initial deep grieving to abate.

4.4 Changes to sample: the changing dynamics of professional doctoral research

After some preliminary analysis it became apparent that two substantial strands to the research needed inclusion. This led to the following four alterations which were approved by the CCR and REC as a substantial amendment.

First, I additionally decided to interview two or three oncologists to get their perspectives on caring for these patients. A shift in the administrative management model in CCU to greater shared care (between oncologists and critical care doctors), alongside emerging data from families and other doctors suggested that oncologists had more impact than I anticipated. There were strong emotional associations with prognosis and diagnosis of cancer, alongside many references to oncologists as part of the whole process for families and patients.

Second, I found during interviews that sometimes family members suggested contacting them again in two or more months' time (rather than three months after bereavement). I made adjustments to allow for this.

Third, many patients wished for partners or family members to be present during the interview. I obtained written consent from them at the time of the interview. Certain aspects of the responses could be only analysed as relating to the patient's experience, which I had to be aware of.

Lastly, I decided to interview two consultants in palliative medicine who had since become more formally involved with EOLC planning in the CCU. This was quite a new development and was not established practice in CCU when I first planned the research study. This progress arose partly as a result of me sharing my vision for good practice in critical care EOLC, based on US literature explored for the doctorate. The nurse consultant (my practice advisor) subsequently invited the palliative care

team into the critical care unit multi-disciplinary team (MDT) meetings as a result of those discussions. This reflected the dynamic nature of practitioner-based research.

4.5 Interview Questions

Interviews lasted from 32 minutes up to 103 minutes. I allowed time either side of the interview to introduce the subject, debrief and discuss any issues. Interviews were shorter with medical staff (average 47 minutes). As I outlined in Section 4.2, I used cues based on the study aims, not set questions. Examples of interview questions can be seen in Box 8 below. I opened interviews with questions such as: "Tell me about your experience of when [patient's name] was in critical care?" The ease of undertaking the interviews varied depending on individual cases, such as the manner and resolved (or unresolved) nature of the patient's death, but my confidence increased after the first few interviews.

Box 8. Examples of questions

Patients
- *What did you feel was important to you when you were critically ill?*
- *If it is not too difficult to think about, what might you think a good death in critical care might mean to you/might entail?*

Families
- *What did you feel was important to you when your loved one was critically ill?*
- *How did it feel when that happened?*
- *With hindsight, what was important to you about your loved one's care at the very end of their life?*

Clinicians
- *How do you normally experience the withdrawal process when caring for these patients?*
- *What does end-of-life care in critical care mean to you?*
- *What does end-of-life care mean to you working in a cancer critical care unit?*

4.6 Rigour in the process

I added analytical notes immediately after the interviews and during transcription (or reading of transcription. I undertook half of the transcriptions and used a service for the remainder). A red-thread or decisional audit trail, as Lincoln and Guba (1985) describe it, was maintained. I referred the questions I had asked during interviews back to interview cues and compared across interviews to ensure further dependability. Phenomenological enquiry deems that questions should not be exactly replicated across interviews, but reflecting on previous interviews helped enhance the reproduction of, and justified adherence to (or not), themes set out in interview cues. In using cues, however, my inherent researcher bias has to be acknowledged because I risked guiding questioning too much. To increase rigour, I examined my assumptions at the outset, outlined earlier as: EOLC experiences could be improved and a good death could be had in critical care. I maintained a reflective diary throughout to enhance awareness of bias, and annotated immediately after interview. These measures, along with the analytical processes that will be described in Section 4.8, help towards confirmability (the quality and reflexivity in the approach), which is developed through further measures around reflection and reflexivity in Sections 5.1 and 5.5. I have addressed certain issues of credibility and dependability in phenomenological analysis to ensure transparency. I chose not to return transcripts (or derived concepts) to participants for reasons that will be discussed below. Furthermore, van Manen (1990), whose analytical framework I used, does not advocate returning transcripts. While this can be a marker for credibility, it is not the sole criterion.

First, the researcher constantly reframes and interprets as the interview progresses, checking and re-checking that the experience reflects the participant's meaning, exploring concepts at that time.

Second, phenomenological research is, by its very nature, temporal. What was felt at that time may well be interpreted or felt differently in another time. Ashworth (1993; 2003) questions whether participant validity is the key to phenomenological validity and concurs that those findings emerge in a specific context. Interviews undertaken at another time might reveal different phenomena. Denzin's (2001) perspective of the interview as an active text, where meaning is created and performed means that participant checks would be meaningless since the interview itself is a construction. Munhall (1994) and van Manen (1990) raise the issue that co-constructing together in

the interview is a member-check in itself. Indeed, it could be deemed a more valid member check since the researcher clarifies what was meant by that statement at that exact moment, rather than several weeks or months later.

Lastly, and importantly, there was an ethical issue around returning the transcripts in this research study. The texts contained many very difficult ethical issues. To require people to re-read a lengthy transcript and again address many very difficult feelings, without any support package in place, is ethically dubious.

Transferability, in relation to the findings, will become evident in Chapter 7 and finally in Section 8.5. Internal validity and credibility in phenomenology rests on the richness of the data (Stephenson and Corben, 1997). Finlay (2006) argues that credibility replaces internal validity and dependability replaces reliability. Indeed, validity in phenomenological texts is sparsely addressed for these reasons. The very nature and uniqueness of exploring individual experience, for example, means it cannot be generalised from. However some degree of *moderatum* generalisation and transferability from the findings' essences can be applied. Therefore, here I apply general principles of qualitative validity to ensure my choices and influences remain clear. Denzin and Lincoln (2003) define validity as relating to the description of an explanation and whether or not the explanation fits the description. How I demonstrate authenticity in my research is evident in Section 5.2. I strived to maintain validity and reliability as described in Boxes 9 and 10 overleaf:

Box 9. Credibility and validity trail

- In-depth and prolonged engagement with the data (Lincoln and Guba, 1985; Ashworth, 1997)
- Exploring and making explicit bias and assumptions through reflexivity (Lincoln and Guba, 1985; Streubert and Carpenter, 2003)
- Peer review of concepts (and debriefing (Lincoln and Guba, 1995; Robson, 2002) to enhance credibility
- Additional peer review of transcripts and reflective accounts (Janesick, 1998)
- Exemplifying concepts with verbatim quotes (Johnson, 1997)
- Reframing the meanings with informant at the time of interview to ensure what was interpreted reflected the true meaning (van Manen, 1990)

Box 10. Reliability and consistency trail

- Audit and decision trails (Lincoln and Guba, 1985; Koch, 1994), reflective research diaries (maintained in this study as described above and in Chapter 5)
- Making explicit assumptions (Lincoln and Guba, 1985) (as outlined in this chapter and in Chapter 1)
- Using verbatim quotes to ground interpretations (Johnson, 1997) (as exemplified in Chapter 6)
- Peer review of transcripts to check for technical accuracy (Peräkylä, 1997), questioning and concepts (using supervisory support as discussed)
- Iterative engagement with the data and interpretation (Stiles, 1993; Priest, 2002) (as detailed in 4.7)
- Transparency in all processes to enhance neutrality (Beck, 1994a)

Analysis proceeded from preliminary thoughts to explicit understanding, emerging as data interpretation could be explained (Streubert-Speziale and Carpenter, 2006). This essentially formed the hermeneutic circle of examining and re-examining the data, whilst reflecting upon emerging phenomena. I have attempted to ensure that I adhered to these principles throughout the study. I outline the process of analysis in depth next to exemplify transparency in coding and analysis.

4.7 Process of Analysis

Consideration of the structure, and context, of the text helps in eliciting a phenomenological reverberation when interpreting phenomenology. Heidegger (2001, p229) refers to this as the 'aha experience' when we encounter something again and finally describe what is the essence. The interpreter tries to make sense of disparate or ambiguous meanings. Analysis must preserve the uniqueness of the person's lived experience whilst permitting an understanding of the phenomenon (Streubert-Speziale and Carpenter, 2006). Heidegger provides no analytical or coding frame, since he was primarily a philosopher. I chose van Manen's (1990; 1997) loose coding frame and data synthesis techniques for undertaking Heideggerian inquiry. van Manen's phenomenological analysis clearly describes the 'how to' element in Heideggerian phenomenology. I chose an eclectic, pragmatic approach to analysis in order to manage and arrange the volume of data generated (and themes in particular). I additionally employed Attride-Stirling's (2001) thematic network analysis, for use with phenomenology. Attride-Stirling's (2001) approach is not novel. It is a pragmatic approach to organising a thematic analysis of data and seeks to aid in depicting themes, and representations of meanings, at different levels. This added a level to my analysis framework to make analysis easier and is described in Section 4.8.

All recorded data was transcribed. I re-listened to audiotapes and files, and re-read transcripts, in order to engage with the data as a whole (Priest, 2002). I read interview data as a whole to gain a sense of the data and capture overall meanings but also focused on lines and segments of text to look for areas that seem essential to the participants' experience. van Manen's (1990; 1997) iterative processes (see Figure 4 and Sections 4.8 [Stages 1-6]) were undertaken to allow an essential structure of phenomena to appear. Each stage is outlined next in Section 4.8 with examples of process stages.

Figure 4. Process of analysis as a flow diagram

1. Establishment of codes
(several matrices are essential to undertake this, given the volume of data)

2. Testing the reliability of the codes, moving between the parts and the whole

3. Summarising data and establishing themes

4. Applying template of coding, taking into account any new or additional codes

5. Interlinking the codes and identifying themes (distinguishing between BOTs and organising)

6. Corroboration of themes, including expert analysis of themes

7. Final stage, Attride-Stirling's (2001): Development of thematic structure

4.8 Seven stages of analysis

Analysis: example of process

An example of the process of analysis follows to show how I worked through transcripts to reach themes. The analytical frameworks centre on the phenomenological framework of van Manen (1990) (seen in the first six stages described next and later in Figure 5) with additional thematic development using Attride-Stirling's thematic networks (2001) (stage 7). The aspect of analysis presented here relates to a basic order theme of *personal dissonance* and an organising theme of *Emotions of EOL work*.

Whilst suspension of personal beliefs is not so defined in the hermeneutic phenomenology of Heidegger (as discussed in Section 3.3.3), the acknowledgement of the influence of any beliefs is paramount. My analytical diary and interview notes helped me recall potential influences and also acknowledge any personal beliefs related to sententious statements. I was also wary of developing themes too early on and looking for confirmation of these as interviewing went on. Chapter 5 also addresses this aspect of reflexivity in analysis and process.

4.8.1 Stage 1

Verbatim transcriptions were read through to gain a feeling of the interview again. I also re-listened to each audiofile, reading through the text to check for accuracy of transcription and to gain a sense of the text as a whole. Shorthand in transcription included the use of:

.. to indicate a pause

. . . to indicate broken text

[ ] to indicate clarification of word or concept in context.

Names are replaced with descriptors in square brackets. Where I include my questioning these are prefaced with NP: and italicised. I made secondary reflections if it prompted recollections about issues from the interview at that point. Notes from the interview were also re-read to gain any additional information.

4.8.2 Stage 2

I explored each transcript individually, one at a time, moving between the parts (selective) and the whole text (holistic), line by line, as is common practice in hermeneutic phenomenology. van Manen (2002) suggests that expressing the fundamental or overall meaning of a text, is an interpretive act. Whilst different researchers may glean different thematic meanings, no single interpretation is ever necessarily more "true" than another. van Manen (1990, p.93) asks: "What sententious phrase may capture the fundamental meaning or main significance of the text as a whole?" The first process was to explore all of those sententious phrases.

I additionally summarised questions and responses including salient responses and quotations, in particular noting and reflecting on my questioning. Significant, or sententious, statements were taken from each transcript; from a line or paragraph. Spiegelberg (1975) refers to this initial process as *intuiting*, where the researcher opens their eyes to the phenomenon and significant statements. An example of this can be seen below:

Nurse 05: "I think what is very hard is when you're coming on a shift and you really don't know the family at all so it's, I find that, it's, it, it's, it's quite..I feel then you could..be a bit of an impostor and I think often what I feel as a, even as a nurse and I think it's you know moving quite nicely and help-- and we're being very helpful, it's a bit, as a nurse you..I feel that we're an addition that um is in the way because I think you know dying is such a sort of private process that	No rapport, feeling like an impostor. Intruding on their grief
	Sententious: Feeling an impostor
	Being a nurse does not negate feelings of being an impostor
	In the way; Dying as a private process

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I feel sometimes we bear witness to pr--, ~~sort of very private,~~ personal moments."

Significant statements I drew from can be seen in the comments boxes alongside the text above, with some preliminary thoughts also noted in the blue comment boxes.

After significant statements had been noted, the next stage involved noting points of fusion. Fusion is the 'co-creation of meaning together' interview moment (described in Section 3.1). In areas where clarification was needed at the time of interviewing, this was checked by reflecting/reframing with the participant. Reframing and achieving agreement can be seen in points of fusion related to *personal dissonance*, which evolved to become a basic order theme, in the first of two transcript excerpts:

Nurse 03: If there is mistakes by the surgeon, the doctor or the staff the family is informed in England. In [my home country] we hide that from the family and I'm not sure if it's written in the folder. It's just hidden sometimes. I think it's better to don't hide [*sic*] because just be honest, just be honest. To be honest is better because if it was us we realise that people in front of us be honest, so it's better to be honest with the family and just don't hide things and tell the truth.

NP: And *how do you feel when people are dishonest about things like that*?

Sentential statement

Reframing feelings, fusion – recognising dishonesty as key and the personal dissonance related to that

The second excerpt, with initial intuiting in comments boxes, shows not only a point of fusion with directing dying but also clarification:

Nurse 02: I think most of the time it [monitor] should be turned off ~~actually.~~ If the decision has been made to pull out, as soon as that decision's been made, fair enough, don't stop the treatment, but I think the monitoring, whatever happens we not going to act on it. Because that is why we don't take these observations on the ward, it's because we're not going to act on them. So the difference between other dying [ward] patients aren't looked after, is er it's easier to say to relatives of patients, we don't know when it's going to happen. Whereas here sometimes we can actually say at least we can say it's soon, meaning the next hour or two or three. Whereas on the ward you can't say that, and I think sometimes it's a bit… [pause, trails] you feel like you're playing God. You can tell them almost by the minute, again it's actually horrible.

NP: So how do you manage that process.. that process of almost what seems to be directing the dying?

Wanting to turn off monitors

Monitors impacting on ability to provide ~~EOLC~~

Why bother? Not acting on consequences of what is seen in monitoring. Who has control of monitors?

Difference between ward and critical care

Feel like you're playing God

Feelings associated with perception of playing God

Reaching fusion, seeking clarification

4.8.3 Stage 3

Early codes were applied, relating to meanings from the text. Most of these codes were initially put into NVIVO N7, the qualitative data management software tool, to aid numbering and retrieval. Each significant statement was coded at node level (basic of code) level and certain recurring or related themes were coded at tree level, a higher level of coding where interrelated codes that logically lie together are placed under a tree node. Tree nodes were developed to become basic order themes (BOT). Descriptive codes were denoted by a D before the code number and inferential codes, where some interpretation of the statement has taken place, is denoted by the prefix I to the code number. The numbering was done sequentially as I analysed each transcript for each group so if a code arose in an early transcript I used it for subsequent transcripts. A suffix of N for nurse, D for doctor, F for family, P for patients was added to help identification across participant groups. An example of this can be seen below related to the basic order theme (BOT) (see stage 4) *personal dissonance*. The preliminary or basic codes are, at this stage, undeveloped and intuitive based on the interview. The tree level node requires consideration of the basic codes and a 'formulated meaning' (i.e. a decision to ascribe the code as descriptive or interpretive) to reach the next level of coding, basic order themes. Tree nodes can be a way of organising codes into categories to reach basic themes. The excerpts above, from Nurse 03 and 02, which demonstrated where the interviewer and interviewee reached fusion, are considered again here to demonstrate a picture of coding at a basic level:

Nurse 03 ". . .both the family and patient are informed about what's going on. You don't hide anything from the patient and the family. And I think it's a good point because they are not prepared, because we are never prepared for this kind of thing. But they are just informed and…awake and very conscious about what's going on and they are not surprised at the end. Mm you are very close to the family.. just see the family for 24 hours. The family can stay. You can speak with them or .. even the nurses we can take time to speak with the family. We are all the time with the family and I think that's good; that's good. It's different because in [my home country] you hide a lot of things from the family.

Code D33N Informing patient and family; Code D12N Communication with patient and family

Code D12N Communication with patient and family; Code D79N Maintaining honesty

Code I15N Preparing the family; Code I77N Positive aspects to not preparing the family

Code I78N Team unprepared for death; Code I27N Knowing when patients will die

Code D33N Informing patient and family; Code D28N Awareness/ consciousness of the situation; Code I19N Realisation of reaching EOL

Code D68N Establishing rapport with the family; Code D22N Facilitating presence

Code I19N Realisation of reaching EOL

Code I37N Benefit of being with the family; Code I14N Positive side of nursing at EOL/honesty

Code I79N Negative -Hiding things from family; Code D69N dishonesty family; Code I14N Positive side of nursing at EOL/honesty

Nurse 02: I think most of the time it [monitor] should be turned off actually. If the decision has been made to pull out, as soon as that decision's been made, fair enough, don't stop the treatment, but I think the monitoring, whatever happens we not going to act on it. Because that is why we don't take these observations on the ward, it's because we're not going to act on them. So the difference between other dying [ward] patients aren't looked after, is er it's easier to say to relatives of patients, we don't know when it's going to happen. Whereas here sometimes we can actually say at least we can say it's soon, meaning the next hour or two or three. Whereas on the ward you can't say that, and I think sometimes it's a bit.. [pause, trails] you feel like you're playing God. You can tell them almost by the minute, again it's actually horrible.

Code I42N Monitoring exposing dying
Code I43N Monitoring inhibiting good EOLC
Code D39N Examining rationale for monitoring
I44N Reliance of Life on Technology and Drugs
D40N *Playing God* - predicting time of death
I45N Predicting when death happens I20N controlling death and dying
I46N Nurses role: breaking bad news

The comments boxes alongside display line-by-line, statement by statement coding, and also show how closely related some of the codes are at this basic level. After the first transcript analysis, each new transcript was considered against that initial transcript and then against subsequent transcripts.

4.8.4 Stage 4

Since there were many codes for each transcript, each transcript was in turn revisited, to check for over-repetition of closely related codes. This helped address code reliability. As I progressed with coding I became more familiar with the codes I had assigned. The accuracy of linkages of codes to statements was checked again against the context of the statement in the interview, and the whole interview. Progressing through the excerpts above, following the numbered codes, helps show how some of the codes now additionally have tree level nodes assigned (Table 7). Overlap can be seen in the new coding, such as Tree code 05 which had various associations and was formed with D67N, D22N, I37N. Basic order themes (developed from tree nodes) are formulated meanings that are achieved with, as van Manen (2002) puts it, thoughtful attentiveness of reduction. Reduction is not abbreviation; it pertains to producing textual representations that reflect the kinds of meanings found in pre-reflective experience (pre-understanding).

Table 7. Coding through excerpts in Stage 3 to reach tree codes

D33N Informing patient and family	Tree Code 04: Family communication
D12N Communication with patient and family	Tree Code 04: Family communication
D12N Communication with patient and family	Tree Code 04: Family communication
D76N Maintaining honesty	Tree Code 19: Importance of honesty
I15N Preparing the family	Tree Code 03: Forewarning the family
I77N Positive aspects to not preparing the family	Tree Code 03: Forewarning the family
I78N Team unprepared for death	Tree Code 18: Recognising the dying patient in the team
I27N Knowing when patients will die	Tree Code 18: Recognising the dying patient in the team
D33N Informing patient and family	Tree Code 04: Family communication
D28N Awareness/ consciousness of the situation	Tree Code 09: Patient/family awareness of/at EOL
I19N Realisation of reaching EOL	Tree Code 09: Patient/ family awareness of/at EOL
I19N Realisation of reaching EOL	Tree Code 09: Patient/ family awareness of/at EOL
D67N Establishing rapport with the family	Tree Code 05: Nursing role with family
D22N Facilitating presence	Tree Code 05: Nursing role with family
D12N Communication with patient and family	Tree Code 04: Family communication
I37N Benefit of being with the family I14N Positive side of nursing at EOL	Tree Code: 05 Nursing role with family* (NB Code I14 Positive side of nursing at EOL not coded in tree code, left at basic level)
I79N Negative - Hiding things from family	Tree Code 19: Importance of honesty
D69N Dishonesty	Tree Code 19: Importance of honesty
I42N Monitoring exposing dying	Tree Code 61: Technology in diagnosing dying Tree Code 05: Nursing role with family Tree Code 19: Importance of honesty
I43N Monitoring inhibiting good EOLC	Tree Code 09: Patient/ family awareness of/at EOL
D39N Examining rationale for monitoring	Tree Code 04: Family communication
I44N Reliance of Life on Technology and Drugs	Tree Code 62: Technology's influence on dying
I45N Predicting when death happens	Tree Code 63: Prognostication of death (nurses)
I20N Controlling death and dying	Tree Code 62: Technology's influence on dying
I46N Nurse's role: breaking bad news	Tree Code: 05 Nursing role with family Tree Code: 64 Role within team

As I progressed through the transcripts, more codes would be added to the coding template. In coding there is a risk of missing important, or sententious or salient statements since they might not relate to the primary formulated meaning. Ensuring coding and reduction reflects the original meaning requires miscellaneous codes to be addressed. By selecting sententious statements that reflect the overall sentiment, this issue can be addressed. For example, in the following excerpt, the statement: "I can't get too emotionally involved" reflects the overall sentiment.

4.8.5 Stage 5

Having outlined excerpts from text to exemplify some of the coding processes, the next part of my example shows moving from tree level coding to basic order themes and working across transcripts and groups. To develop tree codes into basic order themes was again partly an intuitive process. Prominent and recurrent tree codes became basic order themes (see Section 6.2 for list of all basic order themes). I recognise my questioning might have impacted on thematic development since there was a risk that I would sometimes direct the interview, especially where I wanted to get at feelings, which is fundamental in phenomenology. In this section I describe the process for how I reached BOTs across transcripts for each participant group (beyond individual coding) and across groups below with *Clinical engagement vs detachment* and *Emotional cost of work*. Codes and BOTs that contributed to the organising theme of *Emotions of EOL work* are shown with associated inferential and descriptive coding, and fusion in meaning in comments boxes alongside the quotes.

Nurse 02: You go into autopilot. You do what you're obliged to do professionally. And that is the only way that I think I managed to deal with it at the time. Whether it is a good death, or a bad death, you know.. in terms of, what.. it doesn't matter. I go into this mode of: this is how you do it. This is how you do it. This is how I'll talk to family. And although I'll be caring with it, I think, I can't get too emotionally involved. Because…[pause, trails]	Code I50N Professional actions versus personal feelings
	Code I51N Detachment as coping
	Code I53N Emotional cost of work
	Code I52N Clinical engagement vs detachment
	Code D54N Emotional involvement
NP: So it's retaining a bit of detachment do you think, or..?	Fusion of meaning - detachment Seeking clarification
Nurse 02: Yeah, yeah, definitely. Because otherwise I would be in bits. I would because when I didn't... that's why I left [previous place of work]. Because I didn't learn the detachment very early on. And I'd take it home too often. And that's really… you know, I wasn't sleeping at night with it. Wasn't resting, wasn't…you know, yeah. And you used talk about it and now I don't talk about it much at home, at all. Which isn't good because when I do I get all upset, so I just..[trails].	Code I51N Detachment as coping
	I53N Emotional cost of work
Palliative care consultant 02: " . .because the oncologists take these patients on when they're fit and well, they've known them for many years and everything they've done has kept them alive and so to change that and say goodbye to them is very tough, very, very tough. And also to have that discussion with them is emotionally completely draining because they know these patients very, very well."	I303D Recognising emotion in others
	I304D Emotions as rationale for actions or inactions
	I53D Emotional cost of work
Critical Care consultant 04 "I still think it's part of the job, it drains you, um, and you call upon all your sort of deep seated powers to cope. But I can't think of a time where I've come out of it feeling… I mean drained, yes, emotionally involved, yes, part of the whole	I127D Emotional reserve; I53D Emotional cost of work
	D54D Emotional involvement; Code I52D Clinical engagement vs detachment

process, yes. <mark>Not remotely objective about it any longer,</mark> but still, um… but still in a way satisfied that you've done everything you can and ultimately that other forces have intervened."

Using excerpts across participant groups I looked for codes to corroborate or disprove codes found in a group, in context of the emerging theme. This showed both positive and negative experiences in EOLC and presented variant cases. For example, in exploring *Emotions of EOL work* I looked for instances where emotions were denied or embraced (see Section 7.3).

"<mark>I don't tend to let it [decision-making] make me feel anything personally</mark>" (Critical Consultant 03)

Table 8 shows some of the codes that led to the BOTs (next to each code) for each participant group for *Emotions of EOL work*. The BOTs for this organising theme comprise: *Personal dissonance; Moral pain of prognosis; Establishing presence; Engagement versus detachment; Emotional exhaustion; Emotional cost of work* led to the organising theme of *Emotions of EOL work*. There was greater significance attributed to this by nurses and doctors. Mapping BOTs helped me reach organising themes. Table 10 and Figure 8 in Chapter 6 demonstrate interrelationships between themes and show it was too simplistic to group BOT themes purely to lead to organising themes without considering overlap. Overlap between contributing BOTs and organising themes can be seen in the thematic development. Furthermore, I was conscious when labelling themes of what that might represent to readers; I wanted to retain the original meaning of phenomena as participants identified them but also place them in a practice and literature context.

Table 8. Codes contributing to Emotions of EOL work

Doctors	Families	Patients	Nurses
I52D Clinical engagement vs detachment: *BOT Engagement versus detachment*	D68F Family on an emotional level; doctors medical *BOT Personal dissonance; BOT Emotional cost of work*	D11P Nursing kindness: *BOT Engagement versus detachment*	I13N Emotional cost of work: *BOT Emotional cost of work*
D54D Emotional involvement: *BOT Emotional costs of work*	I74F Doctors' empathy; *BOT Emotional cost of work; BOT Engagement versus detachment*	I23P Importance of nursing and medical empathy: *BOT Engagement versus detachment; BOT Emotional cost of work*	I50N Professional actions versus personal feelings: *BOT Personal dissonance*
52D Clinical engagement vs detachment: *BOT Engagement versus detachment*	D113F Forcing emotions: *BOT establishing presence*	D27P CCU nurses' attitude to work: *BOT Engagement versus detachment*	I51N Retaining detachment as coping: *BOT Engagement versus detachment*
I127D Emotional reserve; *BOT Emotional exhaustion*	D22F Family presence; *BOT establishing presence*	I23P Importance of nursing and medical empathy: *BOT Emotional cost of work; BOT Engagement versus detachment*	I52N Clinical engagement vs detachment: *BOT Engagement versus detachment*
I53D Emotional costs: *BOT Emotional costs of work*	I141F 'Clinical' nurse versus nurse 'giving something': *BOT establishing presence; BOT Engagement versus detachment*	I31P Nurses disengaging: *BOT Engagement versus detachment*	D54N Emotional involvement –costs: *BOT Emotional cost of work*
I53D Emotional costs: *BOT Emotional costs of work*	D149F Not wanting to see: *BOT Personal dissonance*	I44P Nurses being involved and involving patients: *BOT Engagement versus detachment; BOT Establishing presence*	I67N individual nursing commitment: *BOT establishing presence; BOT Engagement versus detachment*
I304D Emotions as rationale for actions or inactions: *BOT Engagement versus detachment*	D212F Family vigil: *BOT Emotional exhaustion*	D58P CCU nurses as technicians over carers: *BOT Engagement versus detachment*	I70N Knowing the patient: *BOT Personal dissonance: BOT Engagement versus detachment*
I63D Able to separate personal morality and beliefs from withdrawal decisions: *BOT Engagement versus detachment*	D225F Boxing around the subject- avoidance: *BOT moral pain of prognosis; BOT factors in reaching futility*	D88P Value of seeing professional emotions: *BOT Emotional cost of work; BOT Engagement versus detachment*	D88N Personalising minutiae of care: *BOTEngagement versus detachment*
D67D Not the right thing to do: *BOT Personal dissonance*	I239F Doctors' contactability, emotional availability: *BOT Establishing presence*	D121P Professionals maintaining emotional distance for self: *BOT Emotional cost of work; BOT Emotional exhaustion*	D90N Emphasizing 'if it were my mum': *BOT Emotional cost of work*
D83D Knowing in your soul: *BOT Engagement versus detachment; BOT Moral pain of prognosis*	I271F Staff commitment: family and patients: *BOT Engagement versus detachment*	D132P Emotional engagement as supportive: *BOT Engagement versus detachment*	D101N All the time managing conflict (everydayness): *BOT Personal dissonance*
I120D Undermining by colleagues: *BOT Personal dissonance*	I346F Differences between family members coping strategies: *BOT Personal dissonance*	I167P Nurses as emotional support: *BOT Engagement versus detachment; BOT Establishing presence*	I124N Moral and professional difficulties: *BOT Personal dissonance; BOT Moral pain of prognosis*
I196D Questioning yourself: *BOT Personal dissonance*	I349F Caring for families: *BOT Emotional cost of work: BOT Personal dissonance*	D201P Nurses showing emotional involvement: *BOT Engagement versus detachment*	I129N Recognising the value of self as a nurse: *BOT Engagement versus detachment; BOT Emotional cost of work*
D202D Knowing the moral point to withdraw versus the legal point: *BOT Moral pain of prognosis*	D363F Nurses talking about memories; *BOT Engagement versus detachment*	I211P Consultant support, beyond duty: *BOT Emotional cost of work*	D135N Patients/families suffering and personal anguish: *BOT Personal dissonance; BOT Moral pain of prognosis*
D220D Wear heart on sleeve: *BOT Establishing presence*	D371F Nurse awareness: presence: *BOT Establishing presence; BOT Engagement versus detachment*	I277P Professional explanations - ameliorating emotions: *BOT Emotional cost of work*	D142N Good nursing as knowing how to care emotionally: *BOT Emotional cost of work*
D224D Brings tears to eyes: *BOT Emotional costs of work*	I375F Nurses providing relief from burdens: *BOT Emotional exhaustion*	I331P Cost to family of emotional involvement: *BOT Personal dissonance; BOT Emotional exhaustion*	I153N Moving beyond superficiality: *BOT Engagement versus detachment*
D239D Revisiting feelings: *BOT Emotional costs of work: BOT Engagement versus detachment*	D386F Nurses do all work: *BOT Emotional exhaustion: BOT Engagement versus detachment*	I348P Emotional engagement by staff as caring: *BOT Engagement versus detachment: BOT establishing presence*	I164N Depth of nursing: *BOT Emotional cost of work; BOT Engagement versus detachment*
I249D Personal responsibility: *BOT Personal dissonance; BOT Moral pain of prognosis;*	I388F Consultants lower level of engagement: *BOT Engagement versus detachment; BOT Emotional cost of work*	I354P Ongoing care: person not patient: *BOT Engagement versus detachment*	D166N Emotional care: *BOT Emotional exhaustion*
D272D Feelings of irritation: *BOT Personal dissonance*	D398F Staff fantastic: level of care/understanding: *BOT Establishing presence*	D379P Helping emotionally: *BOT Engagement versus detachment*	D208N Legacy of difficult deaths, still traumatic years on: *BOT Emotional exhaustion; BOT Emotional cost of work*
D275D Putting work in for nothing; futility: *BOT Factors in reaching futility*	D401F Level of care tremendous: never-ending: *BOT Engagement versus detachment*		D211N Putting on a front/Importance of collegiate support: *BOT Personal dissonance; BOT Emotional cost of work*
*this list continues but only first few codings given			*this list continues but only first few codings given

4.8.6 Stage 6

Additional analysis across groups brought to light issues not evident in their participant 'parts'. Looking outside natural groups of consultants, patients, nurses and families and themes within those groups, to illuminate contradictory cases, showed how certain themes were common to all, and vice versa.

As described above, establishment of tree-level codes, BOTs, organising themes and global order themes eventually resulted in matrix development, where I mapped BOTs and emerging organising themes (OTs) because the volume of data and codes meant it was too unwieldy to manage purely with tree-level codes. This next stage involved moving beyond the coding and initial themes. Once I had interlinked codes and identified themes (distinguishing between tree codes, BOTs and OTs), I then planned the hierarchy of themes and which of the BOTs fitted into which of the organising themes. I also undertook corroboration of themes, including expert analysis of themes (supervisory team used as experts) in stages 4, 5, 6 and 7. This helped me deal with a crisis of representation, to which Mason (2002) refers, in managing and representing the essence from initial interview data. Academic supervisors' unfamiliarity to the research setting challenged me to reconsider certain areas of analysis. In this chapter, I have used examples to show the process of coding, analysing and development of thematic structures. This will be discussed further in relation to provisional thematic structures in Section 6.1.

I then refined identified and abstracted themes from coded text segments. Reflection of the categories against the situated context, all the transcripts and the literature were then undertaken. This can be summarised as:

- Gleaning thematic descriptions from additional sources (e.g. literature)
- Preparing an exhaustive description
- Identification of categories, and thematic structure that form the basis of the study
- An exhaustive description is outlined and an essential structure reached.

The next step was development of a thematic structure (based on Attride-Stirling (2001).

4.8.7 Stage 7

Supervision helped thematic development and refining hierarchy of themes, which was based on my research questions (see Section 4.1). I left out themes not essential to the essence of the findings (see Chapter 6 for discussion on this). Attride-Stirling (2001) suggests organising themes as shown below in Figure 5:

Figure 5: Proposed organisation of themes
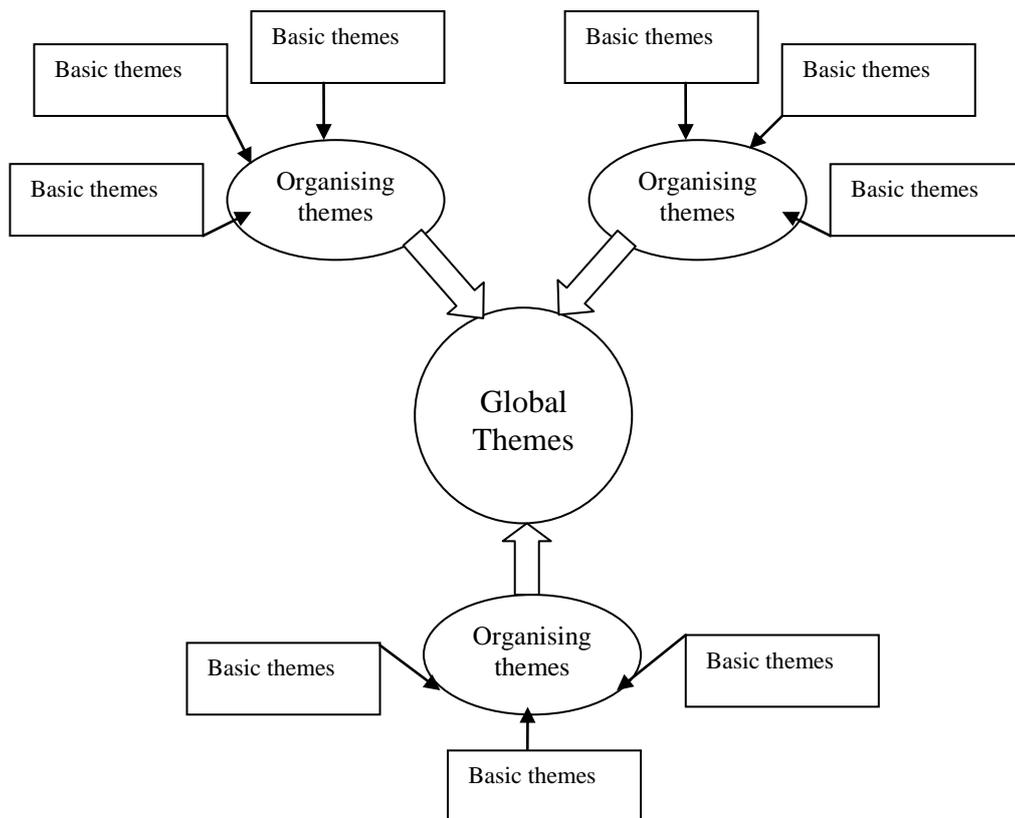
The emerging thematic network was then further honed. Four groups were studied here: patients, nurses, doctors and families, and there is overlap of phenomena. Using principles of network analysis (Attride-Stirling, 2001), alongside van Manen's (1990) primary coding frame in stages one to six, helped me manage the large volume of data generated from this phenomenological study, exploring meaning from various angles in a more comprehensive manner. This can be seen in Figure 5 in Section 6.2. Further issues of rigour are discussed next and preface the following reflexivity chapter.

4.9 Rigour in analysis: additional issues

The stages above exemplify rigour in analysis. In addition to validity principles outlined in Section 4.6, such as using supervisory support in developing themes, categories and codes, construct validity was sought by constant reflection with existing theory literature in the field and with the institutional context (Peräkylä, 2004). This helped ensure undue weight was not placed on any one category without consideration of organisational contexts, ensuring acknowledgement of, but not overshadowing by, *a priori* knowledge. While suspension of personal beliefs is not a feature in hermeneutic phenomenology, acknowledgement of the influence of any beliefs is paramount. A reflective diary, alongside analytical and interview notes, helped me to recall potential influences and also acknowledge any personal beliefs related to sententious statements.

4.10 Summary

In this chapter I have outlined the approaches to method used in this study, and provided a rationale for such approaches. I have discussed phenomenological interviewing and substantiated the rationale for phenomenology as methodology that I described in the previous chapter.

I outlined the rationale for the original sample alongside subsequent revisions. Altering the sample has led to a more robust, inclusive picture, which describes the whole experience of providing EOLC in critical care, from all key perspectives, corroborated by the literature and conceptual underpinning in chapters 1 and 2. My process for accessing the samples, and associated ethical issues, has been outlined. Reflexivity as a necessary part of method and analysis has been briefly introduced and I discuss this in greater detail in Chapter 5.

I have articulated processes of analysis and given choices for what may at, at first, appear an eclectic choice of using thematic network analysis alongside van Manen's (1990) coding frame. This chapter has provided a rationale for such an approach. The large volume of data generated, from four distinct sources, needed to be managed in a systematic and structured manner. Moreover, it adds to rigour, the red-thread or audit trail, of analysis. Ensuring systematic management and analysis of data reduces

the risk of forcing logic, and addresses potential gaps in the data, and facilitates development of themes. While this does not lead to what can be deemed generalisable data, which is not the aim in phenomenology, concepts still have wider applicability. Phenomenological research should lead to illuminating essences that may describe and provide common meanings and experiences. This, then, is transferable data. Interpretation of meaning can then be applied across groups and experiences. My resultant findings from this research study will outline themes and meanings emerging in areas previously undeveloped in existing research, which prove challenging and exciting in the contexts of critical care, EOL, EOLC and cancer research. The next chapter will outline reflexivity in method, my role, analysis and constructing truths and conclusions I came to about the research process.

Chapter 5. Reflexivity: the researcher voice

Methodological rigour in qualitative research requires researchers to examine their own assumptions, and this is also particularly important in hermeneutic phenomenology, as described in the previous chapter. Reflexivity is the examination, consideration, reflection of the objective relationship with the subjective (Ratner, 2002). Professional doctoral learning has been noted for providing opportunities for reflexivity. It is characterized by the experience of epistemological uncertainties and of remaining reflexively self-aware of these (Forbes, 2008). In this chapter I first outline what characterises reflexivity and research, then discuss the need for personal and epistemological reflexivity. I then discuss this 'in action', mapping certain issues proceeding through the research process, the interviews and analysis. I describe some of the researcher-practitioner tensions I encountered and outline how reflexivity has a place in this research.

5.1 Reflexivity as a core tenet

Since this thesis is based on my interpretations of participants' meanings, I have a duty to expose my own forethoughts and develop how my biases might have influenced research questions, the study and processes. In laying open my own beliefs, my ontology and axiology, I hope to create a greater transparency in the research and the conclusions I draw. I have introduced reflexivity throughout the thesis so far in the conceptual and theoretical underpinning (see Chapter 1), exposing my own presumptions that good death and EOLC is possible in critical care. I have reflected on sampling, interview and methodological issues. I am aware that my own experiences of decision-making and EOLC (and my belief that things could be improved) framed the study background and influenced how it progressed. From a phenomenological stance, reflexivity is embodied through the notion of intentionality. This is the inseparable connection to the world, the act of researching, questioning and theorising, as an intentional act of attaching ourselves, or becoming the world (van Manen, 1990).

I filled eight A5 notebooks and diaries with thoughts about my research questions, theory, analysis, interviews and literature as well as epistemological and supervisory questions which all contributed to charting the journey and informed each process of the study.

5.2. Background to research reflexivity

Reflexivity can be characterised by *personal* and *epistemological* reflexivity: how the researcher's actions and thoughts might influence research and how examination of the approach and question might reveal limitations to the study and outcomes. Exploring each of these respectively I have become aware of my impact on the research beyond simple introspective reflexivity. This expanded view debunks some of the criticism levelled at reflexivity as a wallowing exercise (Finlay, 2002).

Ensuring awareness of insider issues within the research, particularly with respect to the phenomenological method and the nature of my own presumptions, is something to be consciously maintained. A hermeneutical approach allows exploration of assumptions, making these explicit (van Manen, 1990). Reflexive validity, the attempt by the researcher to constantly examine biases, suppositions and presuppositions (Streubert-Speziale and Carpenter, 2006) can be achieved through constant reflection of personal views. How this shaped a reflexive approach becomes clearer in Section 5.4, my influence on sampling and interviewing. I was first challenged by my practice advisor, prior to commencing the doctorate, to think about my own assumptions for the research based on my experiences. Schon (1991) summarises how, for some, reflexive questioning might become an 'ethic for inquiry', as it did for me as a practitioner undertaking research in my area. Brechin (2000) asserts that one of the central tenets of a reflexive researcher-practitioner is to be aware, whilst in the process of establishing a perceived need, of one's own position or assumptions.

Seymour's (1999; 2000; 2001) work revisited the medicalisation of death and dying in intensive care (critical care) and the negotiation of a natural death in critical care. First reading her work was a revelatory moment since I had not really thought about doctors having conflicting inner turmoils around intuition and rationality. I wanted to develop what I saw as missing aspects to her work: patients' voices, EOLC itself and the nursing aspect to this in particular. I also knew from literature and, at times, personal experience that nurses had a limited voice in these discussions, but was

unclear as to how this affected actual EOLC. End-of-life care in critical care seemed to be an area nurses could carve out their own niche for, but again from experience and the literature, this appeared to be haphazard. My passion for cancer care, and treating critically ill cancer patients who might have otherwise been declined treatment in other units at that time, also informed my assumptions that it was morally and ethically right to treat critically ill cancer patients (with appropriate caveats) and other critical care patients equitably. My research was based in practice and I wanted it to inform practice as it went along. Reflexivity proved a useful tool in managing researcher-practitioner tensions for the research in the following respects: I maintained sensitivity around research-practitioner tensions, I remained aware of my role and self and how that might influence interviews with people who knew me, I reflected on how I influenced the interviews and my interpretations of analysis and I was able to think critically about the impact this research could have on my area of practice.

5.3 Epistemological and personal reflexivity

Chapter 3 outlined the rationale for phenomenology in this study. This also stemmed from doctoral assignments which helped me establish need for a qualitative methodology and hermeneutic phenomenology as an approach that would best fit and answer my questions (as described in Section 3.2). Inherent in the process of Heideggerian phenomenology is the notion of reflection or *Reflexion*, which I associate with personal reflexivity.

 Heidegger (1927, p.48) suggests that reflexion is part of being:

> "A person is in any case given as a performer of intentional acts which are bound together by the unity of a meaning".

Interpretation and self is inextricably tied up with reflexivity. As part of Being-in-the-world we cannot deny our pre-existing knowledge (Heidegger, 1927). By extension, nor can we deny assumptions. Being-in-the-world, the phenomenological term for what others refer to as: living-in-the-world (Sandywell, 1996), essentially reflects conscious tuning into experiences, defined by one's own life experiences. For a practice-based doctorate this has resonance because my assumptions were, and are, grounded in where I both worked and undertook research. For example, when interviewing participants, my responses and questions were partially shaped by how I

remembered my own experiences of the phenomena, particularly when I knew dying patients or families.

Phenomenological reflexivity is temporal transcendence, as Sandywell (1996) sees it. This refers to the reflexive self as someone who engages in self-reflexive interpretation, acknowledgement of self-hood and reflective deliberation, while being alert, attentively curious and semantically inquisitive (Sandywell, 1996). *Hervorbringen* or *bringing-forth*, as Heidegger (1927, p.53) terms it, in this reflexive context, I regard as poiesis: the emerging concept becomes apparent and reveals its (possibly hidden) meaning. This is done via the researcher (me) bound up as part of that process.

Epistemological reflexivity was required in data collection, particularly with reference to undertaking one-off interviews, as described in Sections 4.1. I was not interested in exploring the changes of perceptions of experiences over time; I wished to gain a rich in-depth snapshot, but was aware of the pitfalls of doing so. I decided I would at least offer all participants the option of being interviewed again, but none actually took up this offer. This suggests one interview was either enough, and contributed to closure or that participants did not feel the need or desire for re-interview.

In relation to reflexive sampling, I reflected part-way through the research that I was missing important voices from survivors' families, oncology consultants and palliative care consultants (as described in Sections 4.3 and 4.4). This was an example of epistemological reflexivity emerging as the research got underway. I had also hoped to include very junior nurses' voices (lower band 5) but was not able to because they had not encountered the phenomena.

5.4 Personal and epistemological reflexivity in action: the interviews

I used supervision, and my practice advisor, as a way of challenging the direction of my interviewing and to reflect on difficult issues. I was very conscious of achieving rapport since I knew this to be important in interviewing (Streubert-Speziale and Carpenter, 2006) and reflected on this after every interview. I found Boeree's (1998) prompts for aiding reflexivity constructive when thinking about my phenomenological

interaction after an interview. These prompts included, but are not limited to, those in Box 11 below:

Box 11. Boeree's (1998) prompts

- Was I fully present, phenomenologically? (Or did I sink into a routine, a sort of semiconscious scribbling?)
- If I was fully present, did I nevertheless take care to not allow my own ideas, desires, interests, needs to distort the interview process?
- How was my aesthetic sense? Did I see the pattern or essences? Did I communicate them to the reader as the interviewee would have wanted to me to?
- Did I check my intuitions with the person by reflection or simply by asking?
- Did I capture the person, as well as the topic?
- Did I capture the conversation, the flow of words and ideas between two real people in a real setting?

I also used van Manen's (1990) reflective tool for undertaking phenomenology, both during analysis and the interviewing process, which served as a reminder for gaining the *eidos*, or essence, of what was meant in the interview. Supervision was an integral part of the process of reflecting on interview skills. We discussed issues I had noted in my research diaries and met frequently to discuss these issues. Early in the process, I forwarded anonymised transcripts to my supervisors for them to assess my interviewing skills. An example of managing the interview can be seen below:

> "*I worried initially that I had let her go off at too many tangents, but on reflection these are difficult topics to discuss and to be able to also talk about more trivial things, like shopping the day before her loved one died, allowed her to pace the interview which already clearly had brought back some sad memories.*" (field notes F01, 26.10.2006)

I gained incredibly rich data from bereaved relatives, and although a fair proportion of it related to after-death care, an aside from my research questions, I was able to use this in other work, such as articles and practice guideline development (see Appendix 8).

5.5 Managing conflicting role as practitioner-researcher in professional doctorate

The transaction between workplace and doctoral research is critical in practice-based research for developing personal reflexivity. There were times in the interview that I was seen as nurse and not as researcher. An example of this is given shortly. Negating my assumptions and *a priori* knowledge would deny the realities of research, and of Heideggerian phenomenological inquiry that demands pre-understanding as part of pre-reflection, and could lead to a depersonalised, mechanical qualitative approach that might even result in power imbalances in interviews (Daly, 1992; 1997). Being familiar with terminology and the area enabled easy rapport and access. Participants were forthcoming with information and I generally found the interview a natural, informal process. I was deeply interested in the accounts given to me. This in itself is likely to have enhanced the interview process (Patton, 2002). Yet, being first and foremost a nurse then researcher created recurrent tensions which I had to manage, and I described how I did this in my field notes.

> "*The patient I met today clearly had some concerns related to a clinical issue that, as a nurse, I could tell he wanted some advice on; it was a small issue that he returned to a couple of times during the interview. I suggested that I talk to him about that issue after the interview. This seemed to me to be a way where I could ameliorate my own desire to 'help' but also let us get back 'on track'.*" (field notes, P07, 8.1.2007)

5.6 Reaching meaning during interviews

Reaching epistemological reflexivity can also be seen in reaching meaning. van Manen (1990) also proved useful as an aide memoire about techniques for extraction of meaning (e.g. did I extract meaning over that point?). I also used it as a preparatory tool regarding how I could best extract meaning and reach 'fusion' in my questioning. Consonant with the phenomenological process, I verbalised any intuitions as we were talking to try and achieve fusion (van Manen, 1990) as I described in Section 4.8.2. I later reflected on which questions furthered my own interest and which served to clarify meaning.

I had to acknowledge my own thoughts about participant responses, especially responses at variance with my own and with the literature, and also tried to ensure we had reached shared meaning:

> *"I noted my own surprise, internally, at one of the responses but put it to one side. I tried to reframe things with her to reassess whether I had reached the essence of what she'd meant."* (field notes, N07, 15.3.2007)

By documenting emotional responses to respondents (and social location), the researcher becomes aware of how their interpretations of respondent accounts can be shaped (Mauthner and Doucet, 2003). I had to revisit initial biases: my belief that doctors might not feel the level of emotion was quickly quashed after two consultant interviews when I saw the personal toll decision-making bore on them. I had also anticipated decision-making taking a 'back-seat' to the central issue of EOLC, but quickly realised they were inextricably bound together, since decision-making and DFLSTs can lead to a very quick death, thus affecting EOLC and a potential for good death. This led me to be conscious of not moving off decision-making too quickly.

5.7 Reflexivity in analysis

During analysis I used structured reflection with practice or academic supervisors, as Parkes (1995) advocates with bereavement research in particular. Ongoing reflexivity shaped my analysis, with two specific issues.

First, I derived the analysis and interpretation from the interviews. Reflexivity in analysis sometimes blended in with data collection, as Section 4.8 highlights. Achieving fusion in the interview means that a shared meaning is reached at the encounter, further analysis on that is limited, other than to code it and place it within a thematic context, since to do so would be to move away from the original intended meaning. One interprets experience through contextually mediated experiences (van Manen, 1990), that is, we analyse based on the situation and our own experiences. Sword (1999, p.277) notes that:

> "Although myself was an inherent influence on the interpretive process, the meaning I brought to the data was supported by the text".

Second, there was reflexivity in analysis of transcripts during coding and thematicising of data. I remained conscious not to make my research 'fit' into what I wanted it to be

in relation to the literature and my assumptions. Transparency in coding, as part of this, is exemplified in Section 4.8. I discussed themes at length with my supervisory team, as principles of validity, credibility, rigour and worthiness dictate. Ensuring data from each sample group were presented in a cohesive manner that still accurately represented meaning seemed to flow quite naturally because common themes pervaded each group (see Sections 4.8.5 to 4.8.7).

Reflexive analysis may help researchers manage tensions around interpreting meanings (Finlay, 2003; 2005). Adhering to phenomenological analysis and moving between parts and the whole in what Finlay (2008, p.6) terms 'a kind of dialectic between experience and awareness', ensured reflexive analysis and methodological rigour. Beyond coding and themes, van Manen (1990, p.132) outlines how writing is a 'reflexive activity'. In committing words down, researchers will re-read and re-write as a process of refinement that is essentially a reflexive activity. I remain aware of content, form and the context in which the research exists, which I raised in my conceptual underpinning and background chapters. Terminology in coding retained initial meanings but also reflected the influence of theory and literature (e.g. prognostication: *Dual prognostication*).

Since this was professional doctoral research I made practice changes before final findings were produced (these can be seen in my doctoral outputs in Appendix 8). For example, I incorporated offering families a lock of hair from patients who had died into bereavement guidelines that I was encouraged to write during the research, I obtained a television for the relatives' room, and adjusted my EOL teaching activity. Being embedded in the field meant I could deal with these issues and transact with practice but rigorously incorporate findings to improve practice. This could be viewed as practice development or research in real-time, as discussed in Section 1.1).

5.8 Summary

This chapter demonstrates issues around personal and epistemological reflexivity in professional doctoral research embedded in the real world of clinical practice. I am cognisant of the ever-looming critique of over-reflection, which could even compromise research knowledge and creativity (Pels, 2000; Cutcliffe, 2003). I cannot completely account for my actions, nor become neutral by being reflexive but this is

not the intention. Instead, the intention is to be transparent and describe my potential influences. Furthermore, Cutcliffe (2003) suggests reflexivity is the base for explaining judgment calls made. Supervisory discussions were integral to each stage of the doctoral process and study. I was reflexive on a lower level in my diaries and personal reflections, but taken to a higher level of reflexivity when probed by my supervisors, both in practice and at university, to think about things in different ways. I have outlined in this chapter how, if carried out with care (and without adversely affecting creativity in research and practice), epistemological and personal reflexivity can prove useful as part of an ever-shifting research arena. Being reflexive can help illuminate and challenge some of the realities that surround professional doctoral research. Legacies of the research evolve as the research itself evolves, and since it is such a potential quagmire, the need for reflexivity becomes evident.

The findings chapter will next outline the main themes (alongside decisions I took to reach those) and the subsequent essence of the research.

Chapter 6. Findings

This chapter outlines themes and the overall phenomenological essence reached. Three global order themes (GOTs) and two essential organising themes (OTs) give meaning to the overall research question (Box 12) and the findings. The themes presented are:

- Dual Prognostication;
- The Meaning of Decision-Making;
- Thinking the Unthinkable;
- Involvement in Care
- Care Practices at EOL: Choreographing a Good Death.

These themes are presented to represent the essence: a continuum of moving to EOLC and, ultimately, death for cancer patients who have been critically ill (see Figure 8).

Theme order also signifies the chronology of that continuum to make it clear how each area impacts on another and eventually leads to EOLC. Participant meanings are drawn on and analysed throughout each sub-section, comprised of basic order themes (BOTs) and OTs. First, I outline participant characteristics, then how themes developed using an exemplar, the thematic network and, then, finally describe each of the five themes.

6.1 Responders/non-responders

I interviewed thirty-seven participants. Response rates, with an overall response of 88% (37/42), are seen overleaf in table 9:

Table 9. Participant Characteristics

	Grade/Specialty/ Disease	Ethnicity	Gender	Invited	Number	Percentage participating
Critical care consultants	Intensivists $n=2$ Anaesthetists $n=5$	1 asian / other 6 white british /other	7 male	7	7	100%
Critical care nurses	D grade $n=1$ (band 5) E grade $n=2$ (band 5/6) F grade $n=2$ (band 6) G grade $n=1$ (band 7) H grade $n=1$ (band 8)	2 asian british /other 4 white british/ other	1 male 6 female	7	7	100%
Oncologists	Surgical consultant $n=1$ Medical consultant $n=1$	2 white british/ other	2 male doctors	2	2	100%
Palliative care consultants	n/a	2 white british /other	1 male/ 1 female	2	2	100%
Patients	Acute leukaemia $n=1$ Non-hodgkins lymphoma $n=1$ Cancer of naso-pharynx $n=1$ Cancer of esophagus $n=1$ Renal cell carcinoma $n=1$ Upper GI $n=1$ Sarcoma $n=1$	7 white british/ other	6 male/ 1 female	7	7	85.7%
Patients' spouses	n/a	5 white british/ other	2 male/ 4 female	6	6	100%
Bereaved Families	(Cancer of Patient who died) Acute leukaemia $n=3$ Lymphoma $n=2$ Myeloma $n=1$	1 asian british 5 white british/ other	5 female / 1 male	12*	6	50%
Total				42	37	88%

* Letters of invitation were sent out by third party to 12 family members. Despite initial interest and one returning the opt-in slip, four declined to proceed to interview. Eight of these agreed to take part. Two agreed in principle and did not subsequently complete interview.

6.1.1 Introduction to themes

I reached the final global order themes and essence of the findings in an iterative process of moving between parts and the whole as detailed in Section 4.8). I found 51 BOTs (grouped according to organising themes in Table 10). This provisional thematic structure list contributed to nine OTs and three GOTs. These emerged from 1693 codes, distilled into 203 tree level codes, which I originally identified. Interrelationships between themes can be seen in Figure 7 and are represented by colours:

Table 10. Basic order themes: provisional thematic structure

Family versus Patient needs	OT 1	OT 1 Family vs patients: split loyalties
Patient and Family Connection	OT 1	
Advocacy	OT 1	
Timing and mechanics of withdrawal	OT 2	OT 2 A Good Death
Active vs passive withdrawal	OT 2	
Controlling the dying	OT 2	
Dignity and Privacy	OT 2	
Priorities of care at EOL	OT 2	
Limitations of care and medicine	OT 2	
Cues to manage EOLC (Learning the monitor)	OT 2	
Body disaggregation versus Whole person	OT 2	
Defining care	OT 2, OT 3*	
Engagement versus detachment	OT 2, OT 4*, OT 9*	
Establishing presence	OT 2	
Specifics of EOLC	OT 2	
Travelling their journey	OT 2, OT 3*	
Timeliness of moving to EOL	OT 2	
Rapidity of transition to dying	OT 2	
Death as failure; death as respite	OT 2	
Team contributions to EOLC	OT 2, OT 3*	
Directing withdrawal and EOLC	OT 2, OT 3*	
Equitable communication	OT 3	OT 3 Involvement in Care
Treatment Preferences	OT 3	
Dynamics of Communication	OT 3	
Reaching understanding	OT 3	
Confidence to Challenge	OT 3, OT 4*	OT 4 Personal Dissonance
Empowerment	OT 4	
Displacing responsibility	OT 4	
Managing/dealing with conflict	OT 4	
Differentiation in roles	OT 4, OT 9*	
Emerging insight into futility	OT 5, OT 6*	OT 5 Reaching and defining futility
Knowing in Futility	OT 5	
Pragmatism	OT 5	
Personal definitions	OT 5	
Realisation of possibility of death	OT 6	OT 6 Thinking the unthinkable
Life Support to extend life	OT 6	
Uncertainty	OT 6, OT 7*	
Survivorship and confrontation of death	OT 6, OT 8*	
Moral pain of prognosis	OT 7, OT 9*	OT 7 Domains of knowledge
Weighing up the issues/realms of knowledge	OT 7	
Validity/Invalidity of tacit knowledge	OT 7	
Impact of cancer	OT 7, OT 8*	
Destiny and fate: existential coping	OT 7, OT 8*	
Clinical histories	OT 6, OT 7*, OT 8*	OT 8 Story of cancer and critical illness
Waning positivity	OT 8	
Hope against hope	OT 8	
Transference to self	OT 9, OT 1*	OT 9 Emotions of EOL work
Distress of prolonging treatment	OT 9, OT 4*, OT 1*	
Supporting each other	OT 9	
Emotional cost of work	OT 9	
Emotional exhaustion	OT 9	

*these OTs overlap with other themes but are classified under main aspect of theme

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As I described in Section 4.8, I coded transcripts within each group and then compared across transcripts and groups, which altered the balance of themes.

The following example of GOT *Care Practices at EOL: Choreographing a Good Death* demonstrates the contribution of themes. Organising theme 2 (*A good death*) had many thematic components, as described in table 11. It comprised a significant element to the development of the GOT. As an OT, what good death meant as a description and interpretation was presented, but this did not represent the whole situation around good death. How that care was provided and good death subsequently achieved was better embodied as a GOT, given the significance placed on this by each participant, and the frequency it arose. The interplay from other themes is also represented in this GOT and can be seen in the following concept map (Figure 6).

Figure 6. Example of a phenomenological concept map for GOT *Care Practices at end of life* using thematic network analysis

Family versus patient needs	Family vs patients: split loyalties	OT 1			
Patient and family connection		OT 1			
Advocacy		OT 1		Managing practicalities of care	(Nursing roles; Communication; Dilemmas in treating families over patients; Involving families, key players and patients; Caring demeanours; Prolongation of dying – practitioner responses; Timing and practicalities of withdrawal)
Timing and mechanics of withdrawal		OT 2			
Active vs passive withdrawal		OT 2			
Controlling the dying		OT 2			
Dignity and Privacy		OT 2			
Priorities of care at EOL		OT 2			
Limitations of care and medicine		OT 2			
Cues to manage EOLC (Learning the monitor)		OT 2			
Body disaggregation versus Whole person	A good death	OT 2			
Establishing presence		OT 2			
Specifics of EOLC		OT 2			
Timeliness of moving to EOL		OT 2			
Rapidity of transition to dying		OT 2			
Death as failure; death as respite		OT 2			
Travelling their journey		OT 2, 3			
Team contributions to EOLC		OT 2, 3			
Directing withdrawal and EOLC		OT 2, 3		Roles, legacies and being involved in EOLC	
Defining care		OT 2, 3			
Engagement versus detachment		OT 2, 4, 9			
Equitable communication	Involvement in care	OT 3			
Treatment Preferences		OT 3			
Dynamics of Communication		OT 3			
Equitable communication		OT 3			
Reaching understanding		OT 3			

Care Practices at end of life: choreographing a good death

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This theme also includes OT 3: *Involvement in care.* I will expand on this OT further (in Section 6.3), beyond that described as part of the GOT in 6.6, to frame how each participant group contributes to EOLC. This was particularly important to do given the strong relation to the research questions and overall aim of gaining different participant group experiences (Box 14). Inclusion of this OT and OT 6: *Thinking the unthinkable (*which warranted discussion in the findings as it framed the move to EOL and EOLC, the crux of the research), provided articulation in a previously hidden area. The example in Figure 6 presented another crisis of representation which I resolved through rationalising the role of OT 3 within the overall findings and aims.

Furthermore, the blurring of thematic boundaries (as seen in Figure 7 and Table 10) was difficult to manage. I settled this by working through each theme again and taking the prominent aspect of the theme and categorising it under that prominent aspect. I present the overlap so that my thinking is evident.

Figure 7 below, based on Attride-Stirling's (2001) model of thematic networks, outlines the construct of the themes and how the basic order themes (BOTs) have been adapted to show visually which findings apply to which aspect of the research objectives. The complexity of the data is evident in Figure 7 and colours represent each theme to make it easier to visualise thematic structures. A mix of colours represents thematic overlap (also described in Table 10). Arrows point to GOTs from their contributing OTs. I initially developed the themes and, from this, the continuum developed as an overall concept or essence.

Key for Figure 7. Colours represent themes as follows:

| OT 1: Family vs patients: split loyalties |
| OT 2: A Good Death |
| OT 3: Involvement in Care |
| OT 4: Personal Dissonance |
| OT 5: Reaching and defining futility |
| OT 6: Thinking the unthinkable |
| OT 7: Domains of knowledge |
| OT 8: Story of cancer and critical illness |
| OT 9: Emotions of EOL work |

Figure 7. Themes and Thematic Network

1: Family versus Patient needs

1: Patient & Family Connection

8: Hope against hope

8: Waning positivity

8: Destiny existential | and fate: coping

1: Advocacy

1, 9: Transference to self

9 : Emotional cost of work

9: Supporting each other

9: Emotional exhaustion

4,6,9: Distress of prolonging treatment

4: Differentiation in roles

4: Displacing responsibility

4: Managing / dealing with conflict

4: Empowerment

3,4: Confidence to challenge

3: Equitable communication

3: Treatment Preferences

3: Reaching understanding

3: Dynamics of Communication

7, 8: Travelling their journey

6, 7, 8 Clinical histories

7: Weighing up the issues / realms of knowledge

7, 9: Moral pain of prognosis

7: Validity/Invalidity of tacit knowledge

7, 6: Uncertainty

6, 8: Survivorship and confrontation of death

6: Realisation of possibility of death

6: Life support to extend life

2: Specifics of EOLC

2:Timing and mechanics of withdrawal

2: Active vs passive withdrawal

2: Controlling the dying

2: Establishing presence

2: Dignity and Privacy

OT 1 Family vs patients: split loyalties

OT 9 Emotions of EOL work

OT 8 Story of cancer and critical illness

OT 6 Thinking the unthinkable

GOT 1 Dual Prognostication

OT 7 Domains of knowledge

GOT 3 Care Practices at end of life: choreographing a good death

Essence: Continuum of moving to EOL in cancer critical illness

GOT 2 The Meaning of decision making

OT 4 Personal Dissonance

OT 5 Reaching and defining futility

5: Pragmatism

5, 6: Emerging insight into futility

5: Knowing in Futility

5: Personal definitions

2: Body disaggregation versus whole person

2, 4, 9: engagement versus detachment

OT3 Involvement in Care

2, 3: Directing withdrawal and EOLC

2, 3, Team contributions to EOLC

2, 3: Defining care

2, 3: Travelling their journey

OT 2 A Good Death

2: Timeliness of moving to EOL

2: Rapidity of transition to dying

3: Dynamics of Communication

2: Death as failure; death as respite

2: Cues to manage EOLC (Learning the monitor)

2: Limitations of care and medicine

2: Priorities of care at EOL

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Only findings absolutely relevant to research questions are presented (Figure 7, in bold). Additional findings, important nonetheless (such as *reaching and defining futility*), are dealt with outside of this thesis, in practice developments and other academic work (see Appendix 8). The development of these organising themes and the essence from Figure 7. into the continuum, which is described later on in this chapter (Figure 9.), can be seen summarised in Figure 8. below.

Figure 8. Thematic development into a continuum
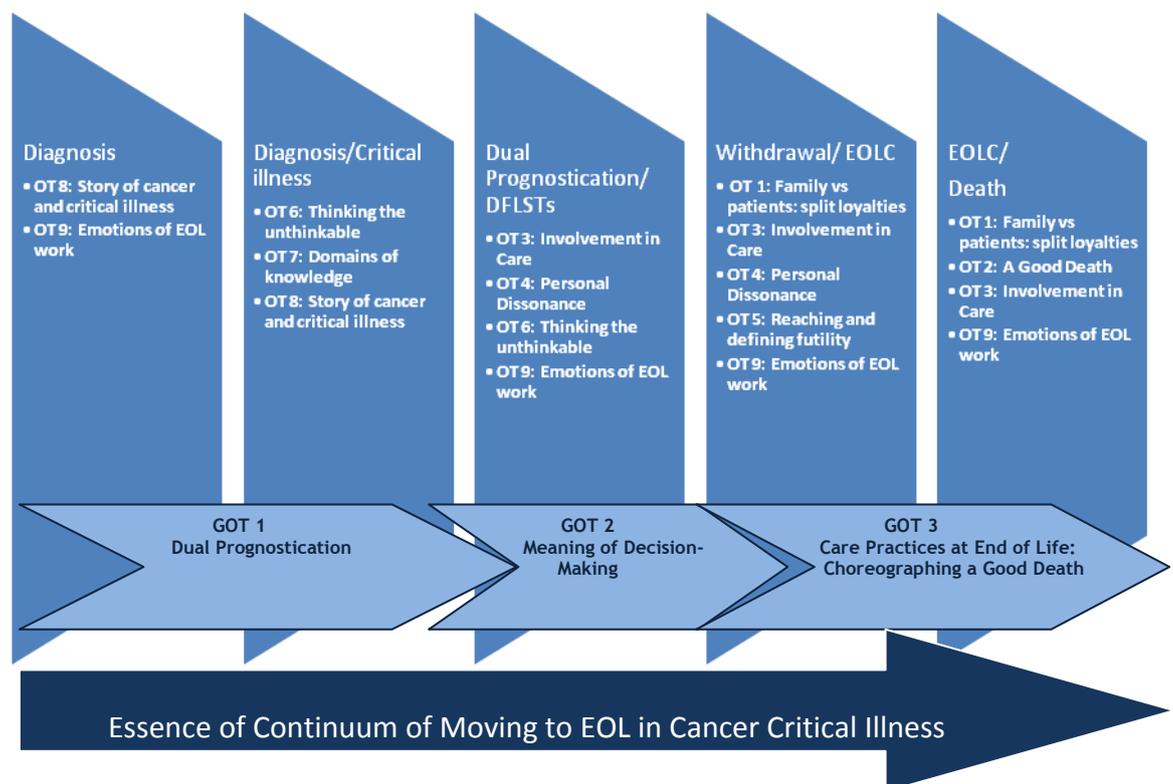
In this figure, the influence of OTs and the subsequent development of GOTs into the concept of a continuum, the essence of the findings are represented. For the purposes of explaining a trajectory along cancer critical illness, phases are presented that encompass issues, and themes, around diagnosis, critical illness, prognostication, decision-making, withdrawal and EOLC practices. The intersection of GOTs in these stages can be seen in the light blue arrows underneath the grouping of OTs. Some of the OTs can be considered across themes and phases and this is discussed in the findings, which are presented next. The final development of the continuum is presented at the end of the findings in Figure 8.

Research questions that frame the study and the findings are recapped below in Box 12.

Box 12. The research questions

Primary:
• **What are the issues around end-of-life care provision for cancer patients in a critical care unit, as explored through family, clinician and patient experiences?**
Secondary:
• To describe and explore what is happening around end-of-life care provision in a cancer critical care unit.
• To explore what it is like for families, patients and practitioners who experience or provide end-of-life care in critical care.
• To explore what end-of-life care in a cancer critical care unit means for patients, families and staff working in critical care.
• To examine what, if any, impact a diagnosis of cancer has on patients', families' and practitioners' perceptions and experiences of end-of-life care provision in critical care.
• To assess the experience of timeliness of moving to end-of-life care, once end−of−life decisions have been made.
• To explore what end of life issues mean for cancer critical care nursing and where nursing can contribute to improving care

6.2 GOT 1: Beginning of a continuum: Dual prognostication

Dual prognostication is informed by OTs 5, 6, 7 and 8 and sets the scene for the findings chapter. Prognostication proves a major issue in the context of team decision-making and EOLC in a cancer critical care unit. For families and patients, it frames the move to EOLC. Doctors are the main people involved in prognostication. However, families' stories of how patients came to be in critical care are important for setting scenes. Prognosis relates primarily to how cancer contextualises these experiences.

This theme raises several issues in relation to prognostication and relates not only to survivorship issues, complicated by cancer, but also to an ongoing need to face mortality, and the speed of cancer or critical illness progression. Prognosis affects nearly all treatment decisions. Superimposition of both prognoses, issues around uncertainty and patients' and families' roles will be discussed. Furthermore, accuracy, the dynamic nature and complexity of prognosis, for both cancer and critical care, was difficult to communicate and the nursing role in this was limited by confidence in specialist knowledge. However, this theme introduces how nurses have a role in communicating prognostication around dying.

6.2.1 Cancer in the context of a critical illness: facing prognoses and mortality

Patients' perception of care during critical illness was generally positive, perhaps because they had survived. The absolute nature of death means families' stories are recurrently replayed by those who witnessed death. For some patients, cancer was (sometimes simultaneously) both extraneous and integral to perceptions of the critical care episode. This was influenced by the admission circumstances and stage of cancer.

After initial elation at surviving having nearly died, this patient now felt critical illness had challenged his positivity about cancer prognosis, despite oncologist reassurance. This was represented by the BOT 'waning positivity' and overlapped with aspects of *thinking the unthinkable*:

> "Erm but I think I had been positive, I don't know whether I have been as positive since, that is the only thing that.. Whereas I had a very positive attitude that I was going to beat it sort of thing and it sort of has changed that little bit I think, I don't feel quite so confident about.. as I did I don't think. Erm because I didn't think that anything could go wrong sort of thing and then suddenly it did. . ." (Patient 02)

He had faced his own mortality in critical care and realised that he could die, whereas before, dying of cancer had not really penetrated his thoughts.

A cancer diagnosis is enough for this nurse to consider mortality and death, since that is her experience with families.

> ". . .sometimes from a relative's point of view they do associate cancer a lot with death which I think brings that into their minds even at the point of diagnosis, which with other illnesses people take longer to come to terms with. But I mean still we have a lot of people pass away where the relatives still haven't completely come to that point." (Nurse 07)

Reaching that point meant accepting death as a possibility. Cancer and critical illness can be seen as separate, and no patient talked about cancer leading to their critical illness.

Conversely, families of patients who had died made clear links between the trajectory and prognosis of cancer to critical illness, even in cases where diagnosis was just a few days before death. Families experienced a concrete outcome of death to make those links undeniable. Patients, on the other hand, talked of how they feared their cancer more now after experiencing critical illness.

6.2.2 Shared contributions to prognostication

Care is shared between oncology and critical care teams, which is perhaps where waters can be muddy. These domains of knowledge, respect for different specialities' knowledge and team elements to prognostication resonated in consultants' accounts.

> ". . .we would be very much involved because we would know about the biology of the disease and [had] an idea about prognosis. Also from, presumably from my patient, from a surgical point of view, about what we believed the outcome was like. But then we'd need to hear the outcome perspective from the palliative care team as well. And from the critical care team" (Oncologist 02)

For all but one family, hope through active treatment represented care, since hope for survival was sustained through critical care interventions. Yet one family member felt maintaining hope was inappropriate. To her, honesty was important in demonstrating care.

The speed of the trajectory for either cancer or the critical illness had an impact on how families and patients felt too. This rapidity in relation to receiving both prognoses is exemplified here:

> ". . .we went through the experience from literally a Wednesday in [home town] when I thought they'll find out what [wife's name]'s fever is, she'll have strong antibiotic, and we'll still go on holiday on the Friday to suddenly being told by the doctor no that's not going to happen and in fact your wife's got leukaemia. It takes.. It almost doesn't sink in. . . . You know, your life goes through a huge switch and I remember thinking 'golly we'll actually have to cancel our hotel, this is really serious', but you don't know how serious. And on the Sunday afternoon my daughter and I decided that [wife's name] might not pull through." (Family member 05)

Stories, as a BOT, held importance here. Participants relaying events again underlined their vividness and importance. For some there was an obvious replaying of events in their minds and reasoning through decisions again. For one family member revisiting the story meant more opportunity for regret which was extremely painful. It had not occurred to her that her partner's prognosis could change and that he could die *because* he was in remission:

> "I just thought 'he is just being dramatic', you know? And by the time I got in there. . . he was struggling to breathe and they were just taking him into the intensive care unit" (Family member 03)

She likened it to a slow motion car crash that she could not get her head around. Once she had realised the seriousness of the situation, she needed to be with him continually. Timeliness for EOLC went out of the window because she was not reconciled to the fact he could die and could not countenance that prospect. He was in remission from his cancer but died from his critical illness. Patients' cancer stage meant families were not always ready to consider death as a possibility. I raise nurses', and doctors', potential roles in relation to introducing this possibility to families in Section 6.3.3. Recognising that patients' cancer trajectory had reached a point where death was a potential reality also caused conflict for some professionals. This critical care doctor accuses oncologists of not being able do this:

> ". . .the oncologists want to look at the prognostic indicators for the disease that the patient has, and they tend to miss the point that the whole of the ITU type state has even bigger implications for prognosis. So they'll say: 'yes, but his or her disease is in remission'. Well actually they are in multiorgan failure and they've got.. and they'll say: but they were walking round three weeks ago. Yes, but that was before they had multiorgan failure." (Critical Care Consultant 03)

Nurses' voices in this theme were not as strong. Four nurses raised the issue of both cancer and critical illness prognoses as impacting on the potential for moving to EOL and EOLC. They lacked confidence and knowledge to contribute to patients' clinical histories and, to some extent, DFLSTs since only two were cancer trained. Both senior and junior nurses were unclear about ethical issues. This deficit could be partially ameliorated by knowing the patient, and learning about their clinical history. Knowledge limitations and nurses' positions, however, were acknowledged for lack of nursing input in this regard. A junior nurse summarised how she felt she cannot contribute to either cancer or critical illness discussions. Yet, as seen in *Dual Prognostication*, acceptance of death as a possibility was made harder by medical uncertainty.

6.2.3 Superimposing and seeing past prognoses

Complexities arose when prognostication differed on different aspects of care or domains of knowledge. There is potential uncertainty in both aspects of prognostication, which compounds what it means for patients when combined in relation to DFLSTs. This was also alluded to by four nurses and all but one consultant drew this out when explaining prognostics. Horrendous critical illness prognosis, despite cancer prognosis, made DFLSTs clear and easy for critical care doctors.

Conversely, one consultant uses cancer prognosis as a starting guide for deciding to initiate or forgo treatment. Furthermore, this consultant also outlines his perception and presumption about oncologists:

> "prognostication for the cancer to me is a guide as to how hard we should drive from the beginning. . .if they're dying from their critical illness they're dying from their critical illness, it doesn't matter what that prognosis re: cancer is. Sometimes I think that is difficult for the oncologists to understand, that's why you have to bring them to the bedside, because no matter what you tell the prognosis of the cancer is, it's now irrelevant, the patient's dying from their associated complications . . ." (Critical Care Consultant 05)

By bringing the oncologist to the bedside this consultant means he wants the oncologist to see past the prognosis to the patient, and that they are dying. One nurse expressed anger, moral distress and sadness, and her sentiment that oncologists couldn't see past cancer. To her, their focus on cure meant patients' situations (and their critical illness prognosis) were ignored and it caused her much distress. Indeed, the emotive nature of interviews led to four nurses crying, stressing the BOT *Emotions of EOL work*. Anger was not a united belief, however. Nurses also recognised the difficulties their colleagues encountered in prognostication and subsequent decision-making, especially noting oncologists, who had established relationships and emotional connections with patients. Views of oncologists' realism is developed more by this nurse:

> "I think they [oncologists] are realistic, but I think they have as much hope, or if not more hope than we do, thinking: yeah they'll sort them out in ITU. They're realistic and they'll .. you know if the disease is progressive I think they all hope that we'll manage to get the patient out of ITU. I think that oncologists have a lot of faith in intensivists in that, you know, they'll, that we will get them out of ITU and maybe on to [the palliative care] ward. I think that it's really upsetting and disappointing for the oncologists. That's probably why you don't see them very much towards the end either." (Nurse 02)

Her acknowledgment of their moral pain legitimised her sentiment of oncologists retreating from the unit at EOL. Prognosis, therefore, could be used to allow time for processing or delaying EOLC, which has differing potential consequences on EOLC; allowing families time to adjust to the idea of death and say goodbye; allowing teams to feel they have done everything; or it could impede the amount of time left to enact EOLC for patients and prolong dying. Oncologists reinforce this in later themes.

6.2.4 Honesty, uncertainty and reluctance in prognostication

Diplomacy in managing conflicting interpretations of prognoses was important, alongside direct contact within different specialities. Practicalities of managing different knowledge domains impact on patients' situations. Direct, unimpeded contact with oncologists was paramount. In this consultant's mind, dying patients, iatrogenically ill from cancer trials, would be treated harder, emphasising oncologists' reluctance to accept patient's dying and move to EOLC. However, he understood this reluctance:

> "And sometimes you have to ask: what have we been doing here? ..Luckily it usually can be resolved, but there are some who feel the push to keep someone alive or active too hard. . .One recent patient. . .with advanced lymphoma. . .was ventilated and had a trache[14] and had quite a problem with bleeding from the rectum, requiring multiple transfusions and factor VII.[15] It had settled over the past few days but it was realised at that stage that with her lymphoma she was not capable of having any more treatment. The family were a little surprised, partly because some of the words that were used to them: partial response.[16] They took that to be positive when of course the reality is that it often isn't. . . With all of the events it became obvious she wouldn't have survived." (Critical Care Consultant 06)

Ultimately, this doctor wanted to prepare the family for death and felt the potential for EOLC was compromised by cancer treatment imperative. Here, the implication is that oncologists can find it hard to be upfront and clear about prognosis. The limited opportunities nurses have and use to challenge oncologists will be discussed in Section 6.2.2 and drawn on later in Section 6.5.4 in relation to possible reasons why they might not challenge.

Dual prognostication was closely influenced by the BOT *personal dissonance* because it created feelings of dissonance for nearly all in addressing and resolving these ethical and moral issues. The sadness and frustration one doctor experienced with incorrect cancer prognosis shaped his belief that uncertainty in prognostication is immensely aggravating and if in any way avoidable then it becomes absolutely unacceptable. Another critical care doctor and nurse even accused oncologists of "cherry-picking" the best bits of patients' cancer in prognostication, implying they might at times withhold necessary information from critical care doctors when making decisions, skewing directions of care. Yet, this was tempered by recognition that it was hard to let go where a relationship had been established. This represents different approaches and perceptions of responsibility for maintaining knowledge in relation to prognostication. It also raises issues of advocacy, to which I shall return.

One oncologist outlines challenges faced in making decisions about care in either direction toward cure or EOL, and the importance of oncologists' involvement, relating

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[14] A trache or tracheostomy is a hole made in the trachea (windpipe) to enable a tube to be passed for breathing. Patients have these sited to enable weaning from the ventilator, or for other physiological reasons.

[15] Factor VII is a clotting factor.

[16] Partial response (PR) is part of a classification of response to cancer treatment. PR means that the cancer is progressing despite treatment.

it to painful processes of being honest in prognostication and estimations of quality of life.

> ". . .when you actually bring it up with the family, you know, they say 'Yes, look we've had this discussion'. . .the prospect of being on prolonged ventilation, you know, they would have thought of that as not being a great quality of life and would have wanted the thing just to stop there. Other people haven't had those discussions because it clearly.. you know, they're hard discussions to have. . I see that as a challenge, as I say, being able to have those discussions.. as I say the [oncologist] being involved and kind of taking some.. some responsibility in having those discussions." (Oncologist 01)

Another nurse and doctor used the terms 'torture' and 'torture chamber' around the implication of imprecise prognostication: patients will suffer. This implies taboo, unethical practice and conveys strength of feeling in their work. There is also an element of communicating prognosis: inadequate communication by oncologists effectively stifles opportunity for critical care and potential for EOLC. Patients and families, however, can often be key players in requesting treatment.

6.2.5 Patients' and families' role in prognostication

Acknowledging that, for some patients, a need to attempt critical care measures, as opposed to move to palliative care, was understandable for some. Patients might deny their impending death as one consultant describes. As drivers for treatment, patients add pressure to implement and sustain critical care measures, even in advanced cancer. Assessing quality of life after critical illness to inform that aspect of prognostication, was mentioned by only one consultant.

Nurses' role as advocates in these situations was not strong, whereas patients felt it could be stronger and saw nurses as having an advocacy responsibility toward patients. Again, nurses' reluctance to advocate may be related to their own feelings about their knowledge. This issue is returned to in *Meaning of Decision-making*. There is also the issue of nurses wanting to support medical colleagues and feeling split in their advocacy as outlined here:

> ". . .I might say you know, if, you know, the doctors have said you know the next 24 hours are critical etc. I'll say the same… although…[pause]
>
> *NP [seeking clarification]: So, is it that you're saying the same thing so that you are backing up your colleagues, or so you don't confuse the relative?*
>
> To support what my colleagues are saying. And I suppose that helps the relative because they don't want to hear two different pictures. Er but I think it's going to be imminent I will say: my colleague said it was this, however er[pause] things

change from the minute, you know, to minute. I suppose that's one way. Or I'll actually say that you know I've noticed a change in the your... in your relative's breathing." (Nurse 02)

Being part of, and loyal to, the team is therefore important, and either relates to nurses' lack of confidence in their own knowledge and their ability to advocate, or to their belief in unified team communication. Yet, this nurse also appears to manipulate subtly how patients' situations are conveyed to deal with this conflict of loyalty. Here, predicting prognosis of death and dying is apparent too, as is the role nurses can play. This is drawn on in later themes as death becomes imminent.

Ongoing sequelae of critical illness and protracted recoveries took surviving patients and families by surprise. Where cancer had, to a degree, impacted on patients' lives before, the impact now was much greater as a consequence of critical illness. Peripheral neuropathies, temperature changes, mobility issues, fatigue and a loss of independence, alongside psychological issues, such as stress, periodic confusion and memory problems were described as a result of critical illness. These additional health implications were on top of cancer-related symptoms and prognosis, now sometimes worsened because of the critical illness episode, acting as an additional reminder of critical care. Furthermore, symptoms served as an ongoing reminder to patients of their mortality, as the following family member discusses. Related unmet information needs, by nurses or the team, are described:

> "I'd like to know more about what's happening as regards the cancer now. You know, whether they did … Did they cut it all out, did they get rid of every bit? You know, this leg, he couldn't walk on it, he couldn't even lift it off the ground. [Surgical Consultant] said I'm not surprised it's to do with the circulation and the lymph nodes. So I said but did you take some of the lymph nodes? He said oh, yeah. Well, they didn't tell us that you see." (Patient 07's family member)

Families may also display a need to understand prognostication to help process why patients were dying (linking to *Reaching and Defining futility*). Understanding cancer and critical care prognoses forms a basis for exploring and rationalising the meaning that events held.

> "…One of the doctors here in describing [my wife's] chances for the chemotherapy to work he said you need to understand [wife's name] starts with a big overdraft, which brought it home." (Family member 05)

Two consultants brought up the notion of addressing cancer prognosis issues much earlier, at initiation of cancer treatment, alongside complications and prognosis of critical care conditions. Clearly though, prognostication is very dynamic and addressing it at one point in time is rarely sufficient, even if only considering cancer prognosis. Prognosis in critical care, for example, could change hourly. However, there was a feeling that forewarning might make it easier to address dual prognoses for patients.

6.2.6 Summary of key issues

A cancer prognosis adds a different dimension to critical illness survival and death. Prognostication and decision-making are inextricably interwoven with EOLC provision; without accurate prognosis it is difficult to make decisions to move to EOL, and shift the focus of care. Making tangible unthinkable thoughts about prognosis is developed in the next section. In summary, as Box 13 shows, there are several factors here that would affect EOLC:

Box 13 Facets of dual prognostication

- Separating cancer and critical illness was frequently encountered in patients who survived

- Survivorship from cancer was tainted by critical care leading to waning positivity

- Facing mortality from cancer and critical illness led to consideration of EOL issues

- Intervention meant care and maintenance of hope, but equally honesty represented care

- Speed of trajectory of cancer diagnosis and demise significantly impacted on ability to move to EOL

- Preparation for critical illness and death as a possibility from cancer and treatment would help in EOL planning

- Cancer prognosis relates to oncologists' accuracy in determining patients' cancer prognosis

- Critical care prognosis relates to critical care doctors' accuracy in determining critical care prognosis

- Both specialities have to communicate prognoses, which is where difficulties arise

- Nurses have a role in predicting the timing of death: prognosis of dying (this is addressed in Sections 6.3.3 and 6.6)

- For accurate dual prognostication, collaborative prognostication amongst teams is necessary

- Nursing ability to advocate for patients is limited by team loyalty and lack of confidence in their perceived limited cancer knowledge

- Super-imposing prognoses: dual prognostication is difficult to quantify and estimate, and therefore rests uncomfortably with many doctors

- The dynamic nature of prognostication: having to reframe it frequently or at the point of EOL (links to reaching and defining futility)

- The uncertain nature of prognostication affects confidence in prognostication

- Treatment decisions are inextricably affected by prognostication

6.3 OT 6: Thinking the unthinkable

As patients' clinical situations and prognoses worsened, several family respondents talked about recognising the possibility of no recovery. One respondent termed this: "to think the unthinkable" which fits with meanings ascribed to this phenomenon by other respondents.

This organising theme highlights how hope holds meaning, but that gradual acceptance of a bleak situation is reached through effective staff communication, watching patients decline and learning clinical cues. This OT is presented because it represents an inexorable move towards confronting death as a possibility and, for some, reality. Patients who survived reflect on nearly dying and this links in with the previous theme of facing mortality.

6.3.1 Survivorship versus Confrontation of Death

Only some patients who survived were able to give meaning to being near death. For others, it seemed hard to look back and contemplate that they were quite so ill. They *had* survived. Families of patient survivors, however, tempered survivorship with real memories of confronting death. The possibility of not recovering was presented to all families. For patients, who were not party to those consultations due to critical illness, it was difficult to comprehend how sick they actually were, stressing a role for nurses to ascertain what has been communicated and understood by families.

> "For me [it was] terrifying..Obviously you think the worst when you get that call. [The doctor] was trying to explain things that they were doing and it.. either both [son] and I were in a very low state and it just washed over our heads, or he just spoke over our heads." (Patient 06 spouse)

There was a difference between families being told of the high possibility of patients dying and understanding this, to actually accepting it emotionally, internalising and thinking about it. Hope for recovery was integral to this.

> "I knew that things were really bad but I didn't ever allow myself to think that they were. I mean I think you know how you can intellectually know something and just not really accept it emotionally and it wasn't until I think when [doctor's name] told us much later that his, um, the oxygen saturation was the lowest that he'd ever seen in anybody but that's when it kind of hit me because I kind of knew how bad it was." (Patient 03 spouse)

Patients' spouses indicated they were more frightened than patients, but maintaining positivity or disallowing themselves to feel scared was a common feature. Disengaging from certain fears, feelings and emotions seemed to be a way of coping at the critical stage.

For patients during initial stages of critical illness, usually when most ill, it had not occurred to them that they could die. Realisation came later on reflection. One patient could not remember much past having difficulty breathing (consonant with issues in *Lack of recall* not discussed here). He had not felt it was something to worry about, despite rapidly deteriorating and needing intubation that night.

Patients' experiences of nearly dying prompted existential reflection, sometimes during interview. They considered their religious and spiritual self, and needs. Pastoral support and the ability to talk about existential issues was useful for one patient to deal with issues after that dawning realisation.

> "I quite strongly believe in God and I believe that there is a power beyond us that controls our destiny somewhat." (Patient 01)

Patient 07 puts this simply: "You realise how lucky you were" (Patient 07).

6.3.2 Confronting a reality: emerging insight

For families of patients who died, not only was the possibility of death confronted; it became reality. This reality would inherently skew their interpretation of what was unthinkable. Thinking the unthinkable meant confronting the possibility that this respondent's wife might not survive her critical illness episode, or her cancer; the possibility of death became tangible:

"…after a bit, when the doctors.. because you look on the outside of all the reports, oh well this is looking better, this is looking better, but we don't like the look of this. At some point you began to think, do you know what I don't think that [patient] would ever be able to live with the consequences of her hair coming out, perhaps continued ill health for many years. And I began to sort of think the sort of unthinkable that she might not recover. And the day that I drove to Sussex and, erm, opened her letter [of last wishes].. And I'm glad I did because she did die that night." (Family member 05)

For other respondents the theme also encompassed dawning realisation, where the shock of critical care admission had not initially led them to think that their loved one could, or would, die:

". . .as far as I was concerned, it was just a bad case of flu, you know, or a chest infection, whatever. . . it didn't occur to me that that was the last time I was ever going to speak to him. And nobody I suppose could have warned me, erm. . . and I really had no idea that things were as bad as they were. Whether anybody knew and didn't tell me or whether people just didn't know, I don't know. If they had known, I would have liked to have known because I went happily off. . . And I got a telephone call at four o'clock in the morning saying, "come in, things are critical". And I was going "what do they mean? What do they mean?" because it had not crossed my mind for a second that he would die. Not for a millisecond." (Family member 03)

Indeed, she had not countenanced thoughts of the unthinkable until her partner was almost dead because of his remission; his heart rate was dropping and he was imminently at death.

". . . this was different, it was sudden. He was in remission. I wanted the physical presence of him still I wanted to keep going. With every fibre of my being I wanted to keep him alive. He was my absolute soulmate. . . I wanted him kept awake as long as possible. . ." (Family member 03)

This demonstrates perceptions around EOL and how timing of moving to EOL can be meaningless if information about patients' conditions has not been made clear and processed, emphasising the previous theme *dual prognostication*. She still wanted him awake, even when dying.

6.3.3 Reframing thoughts from saving to dying

Notions of 'thinking the unthinkable' were transformed into concrete understanding when situations were communicated by medical teams as being futile; there was no longer any hope. *Hope* and *Reaching and defining futility*, not addressed in depth here, are poignant in that once the unthinkable has been thought, there has to be a reframing of hope. This is made harder with conflicting messages about hope.

"In this little meeting the consultant said that there er wasn't any hope, you know, this wasn't news. And the..one of the registrars had actually apologised because there was one day when..she phoned me when I was at [patient name]'s [house] first thing in the morning, after she had been ventilated in the night and said, you know, she has deteriorated during the night. . . then er..er.. I think it was the next day she said: she's very slightly better but from a very bad place, or something like that. And then the day after she apologised..sort of saying that because you know, death was virtually inevitable anyway.." (Family member 01)

A very rapid adjustment takes place from hope for cure, or reversal, of immediate critical illness to a realisation that death is inevitable. One family member felt she was viewing the horrific events unfold before her, as opposed to participating in the situation. Some families learnt to read clinical cues that health professionals might use to draw their own conclusions about patients' condition, contributing to this theme.

"There was a period when they, they reduced it and he was sort of.. seemed to be a little bit more aware of what was going on. Um.. That was nice, I mean it was, it was nice to sort of see him, you know, occasionally sort of open his eyes and.. you know, if you sort of spoke to him and, and, yeah, so that was nice. But then, you know, and there were decisions made about whether to reduce the amount of ventilation he, you know, amount of oxygen. Um, I did realise that things weren't going too well when the level of oxygen had been reduced." (Family member 06)

These experiences outline the fragility of life in that families had not fully considered that patients could die, sometimes a while into their stay. This represented a move along a continuum towards death and reaching realisation at differing points. Emerging awareness happened over days, rapidly over hours or, in the case above, very late at withdrawal.

The health professional role in this theme again extends to advocacy and communication. Expanding the divided loyalties between families and colleagues this nurse felt in Section 6.3.4, the nursing advocacy role is complex here:

"[family] don't want to hear two different pictures. Er but if I think it's going to be imminent I will say: my colleague said it was this, however er[pause] things change from the minute, you know, to minute. I suppose that's one way. Or I'll actually say that you know I've noticed a change in the your, in your relative's breathing. Obvious things that are, from experience, that I've picked up. I won't say it's because I know. It's from experience, it is detecting different patterns of breathing, or whether it's that they feel colder. Sometimes you just have this feeling, that you, you know, that things are going to be a bit more imminent than, than its. . .[trails]

NP:. And what do you think informs that feeling? Where does that come from? [pause] Is it an intuitive thing?

I used to believe, when other people used to say it to me I used to believe it was intuitive, but and now I.. [pause] it's not, I think it's experience. And you know, because, I know when my first two or three years when I was in palliative care, I used to think: it's gonna to happen now, it's gonna to happen, no it's not going to happen type of thing. Er. It is experience I think." (Nurse 02)

She did not wish to contradict the doctor's view on the trajectory of dying, but knew from experience, and notably *not* intuition, that it would be quicker. The nursing role in timeliness becomes clear: in telling the family her prediction for death she would contradict colleagues, creating personal dissonance and potential family confusion. She talked of detecting subtle changes and, therefore, she had a clear idea of patients' dying trajectory. So, she carefully mediates by introducing families to breathing pattern or appearance changes. In this way, she reconciles her wish to be loyal to the team but also to families. Verbalising experiential knowing and the confidence to do so becomes especially important in the final theme.

Precipitating *thinking the unthinkable* were often conversations with health professionals about decision-making and withdrawal.[17] This theme is also closely linked with BOT: *reaching and defining futility;*[18] where nurses and doctors used futility in guiding their beliefs. Organising theme 6 *Thinking the unthinkable* leads to themes of GOT 2: *Decision-Making* and GOT: 3 *Care Practices: Choreographing a Good Death* and is influenced by another theme: GOT 1: *dual prognostication*.

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[17] Non-escalation and withholding are often considered together in the literature, but I make a distinction here based on interviewee responses

[18] Futility has not been presented here due to lower theme priority and limited confines of professional doctoral thesis. However, an article outlining professional discussions of futility has been prepared for publication.

6.3.4 Summary of key issues

This theme had several key facets to it and reflected issues related to GOT 1, but in a subtly different context. Survivorship and confrontation of death still featured for survivors but it took on a different hue and could be translated across to feelings of families of patients who did not survive as the box (Box 14) below summarises.

Box 14. Facets of Thinking the Unthinkable

- Hope for recovery was important and held meaning for both survivors and non-survivors

- Gradual acceptance of a situation was generally achieved and facilitated by staff explanations as well as visual comprehension of patients' situation

- An emerging, or dawning, awareness characterised this theme

- Disengagement was used as a coping strategy and Illness trajectories were displaced to patients, rather than medicine *per se*.

- Existential reflections on what might have been were often made by survivors

- Families moved along a continuum towards realising death as a possibility to a reality at differing points

- Families reframed thoughts from saving and recovery to dying. This led to a reframing of hope

- Clinical cues held meaning that families quickly learnt to interpret as positive or negative

- Nurses and doctors have responsibility to ensure that all communications are understood

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6.4 GOT 2: Meaning of Decision-Making

Meaning of decision-making evolved into quite an expansive theme across all groups. As outlined in Chapter 1, decision-making and EOLC cannot easily be separated. This theme therefore overlaps with other themes around care-giving. Decisions about moving to end of life are also dynamic, with timings of decisions ever-changing with patients' conditions.

The theme has different facets: rationales and understanding rationales for treatment decisions, emotional burdens and coping, to the inextricable link with EOLC. Heuristics as a mechanism for making decisions is noted with some doctors. Involvement will be discussed in relation to burdens of involvement in DFLST and will be discussed in greater depth in 6.5. Varying approaches framed DFLSTs from collaborative, facilitative and rationalistic to paternalistic. These approaches consequently had meaning for those around those primary decision-makers (doctors) and especially for nurses. However, doctors also keenly feel the consequences of decisions for all participants, which add to these burdens. I first discuss burdens and dissonances, personal involvement and subsequent collaborative element. I then discuss how doctors, families and nurses employed different strategies around engagement, displacement and collaboration as part of their management and coping mechanisms. Displacing decisions to patients and making non-decisions affected prospects for moving to EOLC. Specialty conflict emerges as an issue, but this was seen as somewhat inevitable and part of medical decision-making. This theme draws strongly on dual prognostication because how DFLSTs are informed was not always tangible.

6.4.1 Personal responsibilities in DM

There were perceptions that families should make decisions on EOLC and some recognition of nurses' influence. There were also families who did not wish to be involved or who did not perceive to have been invited into any decision-making process. Doctors could either facilitate or take responsibility for involvement, usually depending on what families wanted.

> "I make it clear to the family that it's not their decision, but it's my decision, because somebody has to take responsibility for the decision. But you always

hope.. you actually get them to the point where they can see that it's the obvious way to go. Again, if anybody in the family were to disagree, then I wouldn't do it, wouldn't withdraw without, although I'm aware that legally you can." (Critical Care Consultant 05)

Some family members wished to relinquish any involvement completely, since burdens of decision-making were too great. One family member outlined how she felt about doctors' surprise, and their subsequent pressure, about the family choosing not to participate in decision-making. Another participant, who did not indicate any burden associated with decision-making, clearly felt that the doctors had let her decide on whether her husband should be admitted to critical care, intubated and resuscitated. Realisation emerges that this was not simply another complication of his cancer or treatment, as previous admissions had been, and was actually becoming more serious. It can be seen here that OT 6: *Thinking the unthinkable* overlaps with GOT 2: *Meaning of decision-making*.

> "..it was a sort of emergency situation . . .They decided to move him to Critical Care, with my permission, and it sort of.. after some more discussion up in that ward, they decided that he was not.. they asked me if it would be appro-[priate] if I wanted him to be put onto a life-support machine. But the doctor advised me that if that was the case that I did want him to be put onto a life-support machine, because eventually he was going to stop breathing by himself. . . But I would have to then decide to switch off the machine in two days which would be more difficult than letting him die naturally. So in many.. I think that I can't criticise any of the advice I was given or the amounts of time.. they didn't rush me, they left it entirely up to me to decide, but they did point these things out, which is quite good. Because I think a lot of people wouldn't have considered that, they would've just immediately said 'of course put him on a life-support machine', it's an emergency, you know." (Family member 02)

This situation was slightly different from other patients' scenarios. There were questions around his admission to critical care because he had received cancer treatment for fifteen years. However, these were complicated by his critical illness being unrelated to any progression of cancer, iterating the importance of *dual prognostication*, explored earlier. This family member saw it would be futile and harm her husband should she have decided to institute full life-support and therefore 'chose' that her husband just receive CPAP support.[19]

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[19] CPAP (Continuous Positive Airway Pressure) is a tight mask or helmet to deliver oxygen under positive pressure (rather than usual breathing, which is under negative pressure) and supports breathing in patients with respiratory distress. It is often used until intubation is required or the carbon dioxide levels climb too high, and the respiratory drive suppressed, to such an extent that respiratory arrest and death will ensue. CPAP is usually carried out in critical care units and can be used where a DFLST has been made not to intubate.

6.4.2 Burdens and dissonance

Dissonance at not being involved in decision-making or, if involved, dissonance at the moral choices in the decision, was a significant issue for nurses. For instance, one nurse's response in the theme of personal dissonance referred to the discord she felt because she did not make decisions:

> "it's not [up to] us to take the decision. The doctor takes the decision to stop or to continue, with the family, sure, but the nurses are only here to give the care and accept" (Nurse 03)

Another nurse raised the impact of decision-making and I probed about this in relation to her role. In the interview, she realised she had a greater role in DFLSTs in relation to controlling dying than she had thought, emphasising a revelatory capacity of interviews, reaching meaning and my influence as researcher.

> *NP: How much would you be involved in directing that decision and what's that like?*

> "I think the ultimate decision is the consultant's, of what is going to be done. But I think when is it going to be done, I feel just as involved as anyone else i.e. the doctors and the family. The last.. the time before this patient, I had just discussed the.. We knew we were going to reduce the PEEP[20] and the pressure support. And I said.. We spoke to the family etc. etc. and they asked me: when is a good time? Well, there is no good or bad time. Blahdy blah. I feel I was..I ultimately controlled that. If the doctor was happy for me to decide when things were done, obviously within reason. You know, you know, they wanted a time: six o'clock. But I said: if you want.. If your family still has to come in and it's seven o'clock then it doesn't matter. Yeah, we do control it. More than I've ever thought about actually." (Nurse 02)

The supportive role of other specialists was clear to some doctors. Conflict, though rare, related to issues between oncologists, families and critical care doctors, all approaching decision-making from differing perspectives. As oncologist 02 outlines, it was most difficult when critical illness was unexpected. He felt it was important to ensure consistent and clear lines of communication, echoing Section 6.3.3.

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[20] Positive End Expiratory Pressure: a pressure exerted at the end of each ventilatory breath to ensure maximum gaseous exchange and felt as resistance to the patient.

". . .The most difficult situation is there's been, as I say, unexpected events, unexpected complications, number one. And number two, where the family dynamics become a most difficult issue to deal with. . .the lines of communication have to be consistent, and where there's mixed messages, with the best will in the world, mixed messages are often given to different members, if they're given to different members of the family, then that can cause some dissatisfaction. . ." (Oncologist 02)

Strategies for managing that burden included ensuring personal clarity of mind, either through consultation with colleagues or rationalising decisions, considering consequences of their actions and applying personal frames of reference. There was recognition of doctors' power in DFLSTs, but this was related to the burden of responsibility, which could not be legally shared. Being unemotionally involved, at the point of decision-making, was a prerequisite to rationality for one doctor. Yet, this was tempered against an apparent contradiction of applying a personal frame of reference in order to humanise the process. Personal frames of reference for the basis of decision-making repeatedly arose for nurses, consultants, both oncologist and critical care doctors, using the 'Mother test' and even the personal test about what they might want in that situation. By internalising the events that were unfolding before them and then applying a personal perspective – imagining it were their mother, father, or self – allowed them to introduce an 'irrational' element to decision-making legitimately and, for nurses in particular, to decisions about EOLC. Nebulous and subtle differences between the meaning of moral and legal points for decision-making (and subsequent withdrawal) are considered below. Some of the consultants acknowledged one's personal morality, responsibility to the patient and subsequent impact on moving to EOLC.

"Even before you get to thinking about withdrawal you know this.. the moral side kicks in and you realize.. that it's erm.. er.. what…er you know in your own mind you've probably reached the point of futility. And that carrying on is itself is probably an inappropriate thing to do.. not a right thing to do. . .It's er kind of a gap in between the few days of the moral point and the legal point. But I am, as I say I am very pragmatic about it. . .Once you've reached the moral point you say: my duty is to the patient and I don't want to do anything wrong so I won't withdraw." (Critical Care Consultant 01)

Legal responsibility[21] is impacted by a sense of morality and, for some, was deep-seated and part of who these doctors are as people. For others, they held no strong personal beliefs about withdrawal. Nurses uniformly held strong beliefs about moving to EOLC, with a feeling that it was sometimes delayed inappropriately, particularly with regard to decision-making. They saw the continuum toward death as unnecessarily protracted at the end by prevarication over decisions. For these nurses, it was clear-cut: witnessing patients' demise more closely at the bedside for whole shifts contributed to a sense of patients' suffering. Where there was suffering and perceived futility, from cancer and, or, critical illness, it was felt DFLSTs should be made.

Doctors articulate personal burdens of DFLSTs. These burdens add to the humanistic element to decision-making.

> "It is a very great responsibility to make the decision to withdraw. Whoever does it, they have to live with their decisions and the way the patient is." (Critical care consultant 06)

Living with the consequences of decisions added to the burden of decision-making. It was also about the legacy of that decision. Recognising the limitations of personal morality within the confines of decision-making was also raised; applying personal moral beliefs inflexibly in critical care would not work. These internal struggles of applying morality and logic in a rational way, but also knowing and anticipating what the end result of interventions (i.e. death) would be, could cause consternation and characterised complexities in DFLSTs. Yet, for the following consultant, he was at peace with his decision-making: he accepted that death was part of the continuum of care.

> "I'm not the moral arbiter of everything. But it just seems to be, the moral argument follows on from the logical argument: if you are gonna do no more treatment, then do no more treatment. Instead of some halfway house where you think well why are we doing this? Are we doing this for us or are we doing it for the patient? [pause] . . . for somebody who is extremely unwell in multi-organ failure that you felt the point before you stopped treatment that you'd done everything possible and that treatment was in the end futile, that as long as I'm happy that that decision has been made then I'm quite happy.. well not happy, but it's an acceptable thing to then do palliation of symptoms on the intensive care unit." (Critical Care Consultant 03)

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[21] Legal responsibility for DFLSTs rests with the consultant in charge who may be the oncologist or the critical care consultant doctor and this depends on the administrative model of critical care (i.e. do critical care doctors assume overall responsibility on CCU admission or is it shared care?). Our unit subscribes to a shared care philosophy but unilateral decisions are sometimes still felt to be appropriate.

6.4.3 Involvement and collaboration in Decision-Making

Involvement and collaboration on DFLSTs is presented here to be distinct from the next theme in Section 6.5 *Involvement in care.* This is in order to outline their impact on decision-making, as opposed to care planning. Although one doctor would not let the burden of decision-making make him feel anything, tackling the process using a team approach, involving oncologists, nurses and families (and when appropriate patients), dissipated consultants' burdens in decision-making. Yet, it was clear that whilst some doctors talked about involvement, philosophies of owning decision-making were evident in language used ('my decision'), suggesting mere lip service to the concept of involvement. Nursing involvement was not significant in either doctors or nurses' accounts, but did arise in decisions on *how* to stop treatment, discussed in Sections 6.5 and 6.6 in greater depth. Legal responsibility may rest with consultant doctors, often the critical care doctor, yet all the consultants talked of decision-making as a collaborative process, particularly so between oncologists and intensivists. Conflict was, as oncologist 02 puts it, "part and parcel" of medicine. For him, conflict was not threatening, it was part of medical decision-making. Another oncologist talked of sometimes needing the critical care team's objective persuasion to move to EOL, especially when he had grown close to the patient over the course of their disease. Critical care doctors and nurses (and, at admission, critical care outreach nurses) provided not only distinct knowledge, but also emotional distance, to help him make decisions to move to EOLC. In this context, OT 9: *Emotions of EOL work* can be seen. What nurses bring specifically is difficult to determine here as he describes critical care as a team (itself an important perception). Whilst collaboration was noted by each consultant as key in decision-making, one palliative care consultant talked of frustration at not being able to implement good EOLC in cancer because of oncologists' untimely decision-making. According to this palliative care consultant, nurses who felt EOLC was obstructed by oncologists would seek palliative care input to sidestep potential conflict and manage patients' symptoms. Some nurses felt the potential for nurses to be involved in DFLSTs should be encouraged because of time spent with patients.

> "I think it's better even for us if we can stick and make the decision together because we are with the patient. I understand the patient." (Nurse 03)

Doctors were aware that cooperation was the key to good practice and good EOLC. Furthermore, one doctor recognised that they, along with patients, were often guided by nurses, suggesting that nurses have more influence than they themselves

discernibly felt. Despite this, as outlined earlier, nurses sometimes felt disenfranchised from decision-making processes, compounding feelings of personal dissonance.

One doctor was adamant that he would not make unilateral decisions, contrasting with other doctors who saw it as 'their decision':

> ". . .if I'm doing it [withdrawing treatment] it will have been discussed amongst members of the team for quite a long time before we actually make the final decision to withdraw care and I would never withdraw care if anybody in the team decided that it wasn't appropriate." (Critical Care Consultant 05)

In this context, withdrawing care refers to withdrawing treatment. Nurses, from both cancer and critical care backgrounds, often talked about complicating factors of both cancer and critical illness in prognostication and decision-making. *Domains of knowledge* (OT 7) was important here (linking in with GOT 1: *Dual prognostication*) for many of the nurses to feel confident in contributing to decision-making:

> "I guess because I'm not a cancer nurse erm some of the things they are out of my realm, kind of thing . . .I don't have a lot of confidence I guess to make a decision, or to input on that, that's part of it. . ." (Nurse 01)

Furthermore, general confidence and experience was notable. Furthermore, in contrast with confidence issues, two nurses felt it was not necessarily their role to contribute to DFLSTs, to raise concerns or challenge DFLSTs and timing. These nurses' perceptions were that nurses should focus on EOLC, not on when, or if, to move to EOL. Patient perceptions of nurses' roles in decision-making, despite aspirations of collaboration intimated and expressed by some consultants, suggest that nurses are seen as having a limited role.

"I mean the consultants would come in and say, 'Right,' you know, 'we might do this and we might do that,' and the nurses wouldn't, you know they wouldn't be making those decisions. They might be able to help explain what the doctors want but the consultants would explain that as well and I think the nurses would be dealing sort of a bit more with the daily care and the hour by hour care, you know, and seeing to the physical comfort more than the, um, er, more than the medical decisions about what was being done. . .I didn't get to the point where I felt that the consultants were not.. were ignoring me and I needed to get the nurses involved to help protect me and that just didn't come up because I thought, you know, the consultants were being perfectly responsive. . .and you could ask them more questions, um, and the nurses were, you know were there, and certainly you know I mean I certainly never got the feeling that the nurses were apart, you know, or separated from the regular, um, you know, not so much the decisions that if it was the consultants that were taking the decisions but the nurses were part of it and so they weren't just coming in cold without understanding it." (Patient 03)

Although he did not need advocacy because his wife fulfilled that role, he saw nurses as patient advocates, drawing a contrast with divided loyalties the nurse felt in Section 6.3.4. Best collaboration, for oncologists, meant a united front presented by all and a transparent process for families. Not only did this include multi-disciplinary members, but also families and patients.

6.4.4 Displacing decision-making to dying patients

At times decisions were seen as out of consultants' or teams' hands and this had consequences for the potential for moving to EOLC. Unconscious dying patients would 'decide' when to move to EOL and die, meaning the responsibility for decision-making no longer rests with doctors. This consultant sees ultimately that he has no impact on decision-making and it is a higher order, or the patient, that chooses to move to EOL. This then becomes a non-decision. It is so clear that the patient is dying that there is no decision to make. The situation has evolved to a point of futility where the patient will die imminently in spite of non-decisions and one doctor talked of DFLSTs being 'taken out of their hands' (oncologist 01).

This correlates with critical care doctors and nurses' experiences below. In displacing decisions, the burden articulated in the previous section for the doctor is lessened. The opportunity for timely EOLC, however, is at greater risk. Displacing decision-making to either the referring (oncology) team or both teams (as in the oncologist's excerpt

above), to patients' conditions might also be regarded as a coping strategy for that burden.

> "The patient has already taken the path, we don't have to decide. We aren't deciding, the patient is declaring himself or herself. And then we'll say: yes, no further treatment, other than we [sic] deciding." (Critical Care Consultant 02)

> "Often you sort of find that when you want to make a decision like that for patients they want to make their own decision for you." (Nurse 06)

This family member reinforces this notion of displacing to the patient in his account of decision-making together with the doctors. He felt it was up to his wife whether she pulled through, not critical care support.

> "I had a very open conversation with the two doctors and I had said 'are we going to have to make the very difficult decision vis a vis removal of the support?' And we'd been boxing round the subject for two or three days because he couldn't answer it any more than I could, but at least he could advise. And the doctor I met that day said to me if tomorrow the chemotherapy hasn't worked then we are going to have to face a difficult decision, but he said I think nature may take its course tonight." (Family member 05)

In circumventing the subject of decision-making, nurses and doctors were abdicating responsibility for decision-making to patients' conditions and letting nature run its course. Rather than imposed by consequences of decisions, this is reaching a 'natural' death.

6.4.5 Summary of key issues

The theme of decision-making has raised some of the complexities in making and contributing to decisions for all participant groups. Decisions are based upon many factors and are influenced by personal, family, patient, clinical and other less tangible factors, such as heuristics and considering the consequences of decisions. The complexities of decision-making for these participants are summarised in Box 15.

Box 15. Meaning of Decision-Making

- Heuristics influence decisions and a case-by-case approach is often taken by decision-makers

- It can be unclear to families how much involvement they should have in decisions to move to EOLC (as seen by feelings of burdens and feelings of exclusion)

- Burdens of decision-making are eased by collaboration for some consultants

- There is a widely-felt personal burden to decision-making for doctors and families. Living with the consequences of decisions for all participants was articulated and this added to the burden of decision-making.

- Doctors vary in their approach of facilitating inclusive decision-making, either facilitating or assuming responsibility for decision-making.

- Relinquishing involvement might be a coping strategy to avoid burdens of decision-making

- There was an apparent contradiction for doctors of trying to maintain rationality and applying the Mother test in order to humanise the process

- Internalising and personalising events allowed doctors to introduce an 'irrational' element to decision-making legitimately

- Recognising the limitations of personal morality within the confines of decision-making was also raised.

- Conflict between oncology and critical care was not necessarily threatening; it was part of medical decision-making.

- Best collaboration, for the oncologists, meant a united front presented by all and a transparent process for families.

- Ethical principles can provide a framework for decision-making, but difficult issues of morality and logic can also make decision-making harder

- Decisions are based on clinical indices, yet are also informed by less tangible 'knowing'

- Displacing decision-making to patients' conditions was a strategy for avoiding decisions and reducing burden. It is seen as the patient that chooses to move to EOL.

- Displacement facilitates non-decisions: it becomes obvious that the patient is dying and there is no decision to make. 'Nature' is seen to take its course.

- Displacement limits opportunity for timely EOLC.

6.5 OT 3: Involvement in Care

I considered involvement beyond GOT 2, where obvious thematic blurring occurs with Sections 6.4.3 and 6.6 (in being able to convey needs and wishes, and feeling included in care planning), and this led to the presentation of OT 3: *Involvement in care* as a distinct theme. As an OT it influenced overlapping themes and contributed to the GOT *Care Practices at end of life: choreographing a good death* (as I described at the beginning of this chapter) and was so important in answering the research questions that it warranted separate presentation as a theme.

The theme, firstly, raises care as a notion alongside family and patient involvement in care and, secondly, how professionals feel about facilitating involvement (as well as reflections on their own and colleagues' involvement). It has specific implications for nurses and why they choose to engage or not in DFLSTs and EOLC, developing burdens outlined in previous sections. Nurses' roles become more prominent in EOLC and are also discussed in Section 6.6. Personality, perceptions, confidence and communication all affect the level to which doctors and nurses facilitate involvement for each other, and for families and patients. Nursing advocacy is important in this theme. Taking part in care, planning and decisions helps families' acceptance of moving to and subsequent care processes, but nurses remain sensitive to needs around this. Disenfranchisement and disengagement are, at times, problematic but when practitioners engage in EOLC there is a sense of fulfilment and purpose. Balanced involvement is essential for all participant groups.

6.5.1 Characteristics of involvement and care

Some patients and families felt more comfortable in becoming involved in care than others. Actively engaging in being involved by asking questions was, it seemed, related to personality differences. Personal confidence was an important facet. In more than one case, confidence in having built up a relationship with oncologists and the hospital prior to critical care admission, in turn, gave confidence to challenge in critical care, emphasising how confidence has implications around the effect of developing relationships with specialist doctors and nurses. A patient earlier talked about his perception of nurses' involvement and described how nurses were not active participants in care planning regarding medical decisions, seemingly more focused on comfort and care issues and acting as mediators or advocates (see Section 6.4.3). This perceived role for nurses becomes particularly important at EOL; family perceptions of

nursing roles around care practices at EOL have particular significance and are dealt with later in Section 6.6.

The experience of challenging doctors was helped by both family members and nurses advocating for patients. Despite some patients outlining their involvement in care planning, others entrusted their care to doctors and nurses, and were happy to let them decide. Notably, these patients were elderly, which might possibly have had a bearing on that interaction. Confidence to challenge extended to families. It was important that care was done with the patient; she felt both she and her husband were involved in care, "it wasn't just something being done to you" (Patient 03 wife).

Being part of the process and interaction represented care. It is important to define care in terms of participants' responses. Caring was universally regarded as ensuring comfort, privacy and dignity. This will be discussed in the final theme. As discussed above, care was raised by family participants as being about maintaining hope (even if that was reframed to hope for a good death) and, in one case, care meant honesty. Care is also talked of in terms of families' experiencing presence (see Section 6.6). Caring was, therefore, about being concerned with patients' and families' wellbeing and doing everything possible to uphold or enhance this by showing interest in patients and families as people. Taking time to ensure involvement also represented care. A rift between caring for families and patients opens here yet again. This patient suggested tangible care was needed and that there was a fine balance to be had in maintaining a distance from patients while supporting them:

> "I mean not that I think I didn't already receive, you know, which is, you know care from you know the staff from everyone, from the nurses, from the consultants, that was caring. I think that's quite hard because I think even for, you know, it's a caring profession but you're also dealing with people who are sick all the time and so as a nurse or as a consultant or as any staff, and I assume. . .just for your own survival you need to put a little bit of distance between yourself and the patient but on the other hand you're there in order to help the patient. . .sometimes it's a difficult bridge to gap" (Patient 03)

Emotional connection enhanced feelings of being cared for with families but emotional distance did not necessarily impinge on caring.

6.5.2 Communication and involvement in care planning

There were practical aspects which were really important to patients, such as ensuring their involvement in care planning. Simple things such as lipreading skills, which seemingly only experienced nurses possessed, were important to over half of patients. One patient could not convey his distress at interventions because he could not communicate with the nurses nor contribute to his treatment plans at the morning ward round due to sleep disturbances.

> "I was still asleep so I didn't know what was really going on then. You know they had obviously discussed what they were going to do that day and I had missed out on it. [*wife interrrupts*…'And you wanted me there at eight o'clock in the morning because he couldn't talk, couldn't get it across, how he was feeling, what.. when they were asking the questions. So I made sure I was there at eight o'clock in the morning']" (Patient 02; Patient's wife 02)

From the perspective of patients who had survived, it was an essential part of the process for families to be involved. In knowing the family was there, patients felt their loved one would be involved in care planning.

> ". . .they did involve you with those [ideas], you know. They really didn't make you feel like an outsider or anything like that." (Patient 07 spouse)

Being unable to communicate (a BOT), because of delirium, inability or incapacity (and the subsequent impact that had on involvement in care) was a source of deep aggravation for all patients. One patient saw nurses as preoccupied with machines and observations over facilitating communication, thereby limiting involvement. Being included – an insider in care-giving – gave a sense of wellbeing for families and patients. This was an important area for nursing care.

How nurses allowed or invited families to participate in minutiae of care both for patients who survived, and those at EOL, shaped families' feelings of being involved. One family member was asked to help out with teeth cleaning and massaging the patient's swollen feet, which she found pleasing.

> ". . .the nursing staff got you involved and they told you what they were doing all the time. Erm, I liked it when they.. they cleaned him and washed him down and that was really nice and then we'd help" (Family member 05)

> "Nurses allowing, but not pressurising, families to take part in administering comfort care helped facilitate a sense of doing something, of 'being 100% involved' " (Family member 03)

On a practical level, being involved also extended to interacting with nurses which helped break the monotony of being in critical care. Generally, practitioners as a whole, were sensitive to how much families wished to be involved, sensing when they wanted to be involved in EOLC planning.

> "I would emphasise care and comfort um so I think, I think it's really important for them to be very much involved with what you're doing and why you're doing it" (Nurse 05)

Nurses could also involved families in timing of withdrawal of treatment. They were flexible about reducing life-support with timing that suited the family 'within reason', implying that prolonging suffering would be unacceptable. Involvement not only related to what nurses could do to involve families but also how to involve palliative care to facilitate EOLC (see Section 6.6).

6.5.3 Emotional costs: engagement versus detachment

This sub-theme was particularly notable for nurses. An emotional toll led to differing coping mechanisms between nurses and doctors. The emotional nature of nurses' interviews corroborated this. Potential consequences of engagement and detachment are also discussed.

One junior nurse even outlined how she felt she shouldn't cry in front of families because it might mean she wasn't professional, despite feeling emotionally exhausted from supporting and getting to know families at such an intimate time. Yet, on further probing she reached a realisation it would not be unprofessional to cry. Another nurse talked of not disclosing the emotional cost of work for fear of being seen as weak and unprofessional.

> "You go into autopilot. You do what you're obliged to do professionally. And that is the only way that I think I managed to deal with it at the time. Whether it is a good death, or a bad death, you know.. in terms of, what.. it doesn't matter. I go into this mode of: this is how you do it. This is how you do it. This is how I'll talk to family. And although I'll be caring with it, I think, I can't get too emotionally involved. Because.. [pause, trails]

NP:.   *So it's retaining a bit of detachment do you think, or..-?*

Yeah, yeah, definitely. Because otherwise I would be in bits. . . Because I didn't learn the detachment very early on. And I'd take it home too often. And that's really.. you know, I wasn't sleeping at night with it. Wasn't resting, wasn't.. you know, yeah. And you used talk about it and now I don't talk about it much at home, at all. Which isn't good because when I do I get all upset, so I just. . .I suppose I only talk about it when I have to. If I think, if the pot's boiling over and you just think this is too much to handle. And then I will talk about it. So I don't know if it is good or bad actually, 'cause if you were, it's good 'cause you don't want to be.. it's because it helps me do my job, at the time. . . surprised as I am at this, but it's true: everyone seems to put on a front. I used to think that nobody.. Do they not care? Do they not think about patients? But they do, but they..we're not very good I don't think, at sharing what we feel and think. So and so has passed away: oh right, okay. And that's where it finishes. (Nurse 02)

The nurse above also alludes to the fact that others put on a front of detachment, which signified lesser caring. Yet being involved in care, particularly at EOL, was about caring. This nurse perceived nursing to mean care.

"I mean nursing is for me, um, it's care, to be honest. It's care, you know. We care about everything. It's no matter like, er, [that] this is not my speciality, I don't know this one.. but this is, it's.. it's in everything you know. We.. we get, you know, the full picture, everything we just make sure that we have to do everything yeah, everything, this is nursing. So at this time, we need to make sure that we are really, really nursing" (Nurse 04)

One junior nurse also felt disengaged from involvement in decision-making, but passed no judgment on that; it was simply a fact, rather than it being an important oversight and was not a cause for conflict in this situation. For her, only sometimes were nurses involved in decisions regarding palliation of symptoms with sedation and analgesia, which seemed an obvious thing for nurses to do.

"Um, I've never really been involved oh I mean it's not your decision. . . I know they do sometimes ask the nurses who have been looking after the patient in terms of sedation or in terms of pain care what's needed or whatever. Which is good because quite often the nurse is a lot more aware of that, spending more time with the patient." (Nurse 07)

Her perception of lack of involvement might also have been related to her junior status. Another experienced nurse recognised that decisions were ultimately down to the doctors but felt very involved in EOLC planning. Equally, though, another senior nurse articulated that only certain doctors included them, emphasising how variation in doctors' personality had an impact on their level of involvement. Critical care doctors

and oncologists all mentioned involving families in processes of care, but two neglected to cite nurses in their planning and decision-making. This may have been because it was presumed, however, rather than a conscious omission.

Once palliative care had become involved, this nurse noted a carte blanche for some nursing staff to step back: 'Whoop, over to them' (Nurse 05) and not engage in care around death and dying. The emotional cost to them becoming so involved in care of dying patients was perhaps why some resisted. This builds on patient 03's perspective in Section 6.5.1 that maintaining distance could be a protective mechanism. He recognised high emotional costs to critical care and EOLC.

Empowering patients and families to participate in care planning and decision-making was important to the following doctor who recognises how not all families want to be involved. He wanted some indication of treatment preferences from families as a tipping point for making decisions either way. He was conscious not to add to family burden by overdoing empowerment; he might live with the decision, but the family lived its consequences.

> "You know, yes you might have to live with the decision, um, but you're not the one having to necessarily, er, sort of enact and, er, kind of live through the whole experience. So I can't.. I can't see any other way than discussing, um, both with relatives, so involving them in the discussion with the relatives and also on a one-to-one basis take them. Sometimes it's like you get a look and you're sort of please just make a decision, I can't make a decision, please just give me something, tell me what to do and I'm happy with that. So I perhaps overcook the, um, empowerment thing a bit sometimes." (Critical care consultant 04)

This family member recognised that overemphasising involvement could lead to problems, and even conflict, in families. She also raised finite resources as an issue, suggesting some families are aware of the 'bigger picture' and might be able to see beyond their own tragic situation.

> "I think if you give too much responsibility to the family it can lead to, especially if there are lots of people, I was by myself so I had nobody talk to, but you can imagine rows breaking out, people arguing. And then decisions being made which are not practical. . ." (Family member 02)

In spite of these emotional implications, all but one nurse and some doctors talked of the satisfaction gained when dealing with patients who were dying. It was sad work but held a sense of purpose. For nurses, it was because they could focus almost

completely on patients and families, and concentrate less on machines (aside from using machinery to orchestrate dying as discussed in Section 6.6).

Involvement of critical care doctors appeared to be in an explanatory role, which they chose to assume. For the two oncologists, who might form close relationships with their patients, involvement was sometimes emotional. Whilst the excerpt below pertains more to decision-making, it also outlines the personal challenge felt in dealing with involvement and a covenant towards both patient and family. This consultant candidly talked of needing to be guided. He knew his own ability would be clouded by his emotional involvement with patients and families.

> ". . .this is the time we should be thinking about pulling out, that's the most appropriate thing to do, or reduce the level of support, can be quite hard. . . you know, they're hard discussions to have and they can be pretty painful and upsetting for all those involved, and others are very much of the opinion they want everything to be done to the last possible moment. . .you know, we definitely needed to be guided by you [critical care team] as well, er, because you're in a more sort of objective position to look at these things as well. Especially for us having looked after the patients, you know, at certain times it can be quite hard and you think oh, you know, it's a young person, you must just keep going.. there's everything to go for here, but, you know, realistically, you know, they're.. the writing's on the wall." (Oncologist 01)

It was beyond wanting to achieve treatment success, and encompassed his own emotions at having known that patient and wanting to do something for them to keep them alive, even if that meant the potential to move to EOLC in a timely manner might be compromised. Delaying decision-making means chances for enacting a good death are diminished. This is a key tenet to this theme and highlights overlap with *Meaning of Decision-making* (discussed in Section 6.4). In recognising he needed to step back from his involvement he facilitated moving to EOLC.

Team support was important for achieving a greater voice for critical care or oncology consultants to which to listen to. One palliative care doctor relayed how nurses sometimes sought specialist palliative care advice when decisions were not forthcoming in order to strengthen their position and corroborate arguments for moving to EOLC. Nurses' involvement in care also increased as time progressed. Once DFLSTs had been made, nurses became more prominent in the level of involvement in care, while some chose how to enact EOLC (as discussed in the next and final theme) others increased involvement with families.

6.5.5 Summary of key issues

Involvement in care builds on the issue raised in Meaning of Decision-making and highlights associated facilitative and inhibitory factors for ensuring smooth timely moves to EOLC and the role that different participants play (Box 16 below).

Box 16. Involvement in Care

- Personality differences, confidence to challenge and relationships with staff affect levels of involvement in care

- Perceptions of involvement varied, even in the same clinical case, from clinicians to families to patients

- 'Doing' care together was seen as involvement by families and patients, and was important in feeling useful, valued and part of the process

- Patient communication was very important and if not facilitated, by nurses in particular, led to feelings of disenfranchisement

- Nurses had a clearly perceived role as advocates

- Nurses were seen as careful not to pressurise involvement

- When palliative care became involved, there was a perception among nurses that they might disengage from EOLC because they did not possess specialist knowledge

- Nurses felt a sense of purpose could be gained from being involved in EOLC as the patient and family were the focus, not machines

- Empowerment was acknowledged but could be over-emphasised potentially leading to conflict for families

- Emotional involvement from oncologists could cloud decisions and stepping back facilitated palliative care involvement and moving to EOLC

- Balanced involvement was key

6.6 GOT 3: Care practices at EOL: Choreographing a good death

The final theme draws together previous themes that have contributed to an overall chronology, or continuum, of moving to EOL. The culmination of those themes is portrayed here in the final stage: actual care at EOL. Withdrawal practices and who should decide and enact those are presented first. Confusion still exists among disciplines for who should determine this aspect of care and who should enact it. Timing issues and how to aspects are discussed. How decisions are made will influence, to varying degrees, the mechanics of a good death, which is presented as the final part of this theme. It encompasses practicalities of care, and further notions of what care constitutes, developing Section 6.5. Whether there should be guidance in care practices is outlined here as an underlying dialogue from professional perspectives.

Nurses' roles are clearest and most prominent here for all participants and specialist roles are discussed. Emotional implications of diagnosing dying and trying to ensure good EOLC abound. There is a dilemma in treating patients or families evident throughout previous themes, but it surfaces here as a particularly important issue for professionals to resolve. This difficulty, along with issues around prognostication and DFLSTs, sometimes results in prolongation of dying that compounds emotional suffering for all. Furthermore, the rapidity of dying is pronounced, with adverse effects on EOLC possibilities. Differing approaches to EOLC and withdrawal contribute to a haphazard provision of EOLC but good death is possible. Choreographing EOLC is described as one way of achieving this. Caring demeanours are important at EOL, more than at any time and care can be represented in the 'small things' and ensuring dignity.

6.6.1 Which to withdraw, when to withdraw, who to withdraw, how to withdraw?

Where EOLC had been agreed on, for oncologists, the experience as a whole was of greater importance than order of withdrawal: that patients had perceptibly died with dignity and patients' death had been as good as possible. Achieving good death was partly due to perceived specialist critical care knowledge about how, what and when to withdraw.

Much planning was given to this aspect of dying and preparing for dying by critical care doctors and nurses.[22] Intensivists, as opposed to anaesthetic doctors who cover critical care but are not critical care specialists, spoke more about mechanics. This doctor carried out the final act of withdrawal himself, rather than delegating or allowing other team members to undertake that.

> ". . .I'll give them the option to wait to bring people over from wherever. I'm quite happy to just keep going for a couple of days if necessary. Erm, we might also be in a situation where actually we want to get the palliative care team involved, if that was the case then I'd get them involved early on. . .I'll make suggestions about how have done it in the past and whether they wanted to be present and whether they wanted to be absent and how many people they wanted around, making clear if it's on the unit then we withdraw all our visiting restrictions, as many people as want come . . .If we're doing it in the unit and it's active withdrawal and we're actually going to turn something off, then again I give them the option to be there at the moment of turning off, or to come back. I usually make sure that I'm the person to do the turning off." (Critical Care Consultant 05)

His undertaking withdrawal ensures that he achieves closure and is seen to support patients and families along the whole critical care trajectory to death. He retains ownership since he had made the decision and wanted to deal with its consequences, but it could also be seen from a team perspective; he did not feel he could delegate withdrawal. Notably, he would delay withdrawal and thus prolong dying to meet family needs. Importantly, he also emphasises palliative care input into EOLC in critical care.

Some, as described above, preferred to do it themselves; others were happy to let experienced nurses do it. The following nurse discussed how, as an experienced nurse she felt comfortable carrying out practicalities of withdrawal, such as weaning inotropes, herself. She infers that she can adjust the timing of death through withdrawal practices. This also evident in many critical care doctors' accounts. Yet, she is comfortable in herself that adjusting mechanics can alter the trajectory of death and dying.

> "You don't want to be prolonging something that, you know.. you can tell if they are really for it, if the family are really for it. If it's not something that is well-planned or well talked about, or the patient has only been given a short time, as well I think, if the patient has been given a long time you haven't.. you get a better feel for how they are.. in their emotional, sort of, state . . . you know going back to capping[23] inotropes, and things like that, I never, ever think that that's final. Like, I know like I can always, you know, change that.. or if the

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[22] As later evidenced in local implementation of the LCP-ICU and subsequent audits.

[23] Capping inotropic, ventilatory or other organ support was referred to under ceilings. This is the limitation of treatment at a maximum level e.g. 80% oxygen for ventilation or 0.9mcg/kg/min for inotropic support.

families not ready, or if they're not ready.. or you know, [if] I don't think that we're ready to cap inotropes, then I'll try and do it slowly." (Nurse 01)

In this situation a family member recounted how the nurse, with whom she developed a strong rapport, directed withdrawal of treatment.

". . .And I asked what, um, what exactly would happen, um. So, she sort of explained. She switched off all the [crying, sniffs], all the beeping of the machine and turned, and also turned it away, so I just sort of sat there just sort of talking to [him]. And she also left me, um, left me alone with him for quite a, you know, for a few hours.. .. and I was just sort of, you know, just talking to him about, you know, things we'd done together, um, anyway, she was brilliant. . . She was obviously aware that, you know, it was going to be very soon, so she came back in and sat with me. . .that was very good, she was tremendous." (Family member 06)

This nurse was able to anticipate when the patient was imminently dying and could appropriately support this family. However, some nurses expressed reluctance to deal with practicalities of treatment withdrawal and undertake withdrawal. Lack of confidence and experience openly contributed to reluctance. One junior nurse's sentiment was that it was tantamount to her feeling like she would be killing patients to do this practical aspect of care. This issue in particular highlights the extraordinary task that EOLC can mean for nurses and doctors: life or death as a consequence of a normal (in non-EOL contexts), ordinary nursing action of weaning inotropes. However, consequences of patients dying, and her feeling that turning off could precipitate early death, for that nurse, prohibit her from doing so at EOL, emphasising ethical knowledge deficits.

This doctor recognised how the experience of undertaking that extraordinary action could make nursing staff feel, as the nurse above suggested.

". . . you don't know what the, um..for instance, the experience of the nursing staff at the.. at the bedside. If you march in and say "Right, futile - this is EOL, ventilate him, air, remove inotropes, and palliate", it's not.. it's something that I don't do because it can be very distressing for the people actually who are, if you like, feel like they're pulling the plug." (Critical Care Consultant 04)

'Pulling the plug' has the greatest consequence: death, and he feels he should be careful in asking nurses that could lead to feelings of letting someone die. As one nurse puts it, it is like 'playing God' (Nurse 02). But some nurses appreciated how

undertaking EOLC could be satisfying if used to achieve a good death. However, timing of withdrawal could be controlled. Effectively, therefore, dying could be controlled. Managing timeliness contributed towards feelings of a good death for families and many staff.

6.6.2 Managing timing of withdrawal

One nurse talked about timing of reducing ventilatory, and then inotropic, support until the patient was on minimal support in preparation for the active dying phase.[24] Underlying this, she knew the patient was dying and needed palliation. The inference is that motions had to be gone through.

A commonality existed in all professional accounts around timing. A good death was also deemed to be of a certain length: not too long and not too quick. This nurse felt death was quick because of visibility via critical care monitors. Monitoring inhibited dying because temptation could be there to act on adverse observations.

> "I think it is very quick because we can see it on the monitor. You can see the heart rate or you can see the blood pressure drop, the minute. i.e. the noradrenaline, the plan was the noradrenaline would run out, and we were not to renew it. That kind of thing. So we didn't make a decision, and then withdraw. It was.. we told the family and then rather than them being told: within 10 minutes we are going to be stopping everything, it was when things ran out and if they were very dependent on that drug, it is incredibly fast. . . you can see it, it's so closely monitored. . . I think most of the time it [monitor] should be turned off actually. If the decision has been made to pull out, as soon as that decision's been made, fair enough, don't stop the treatment, but I think the monitoring, whatever happens we're not going to act on it. Because that is why we don't take these observations on the ward, it's because we're not going to act on them." (Nurse 02)

Nurses' roles in managing aspects of dying: controlling drug administration and monitors, and their subsequent impact on families are raised here. Two nurses and two doctors raised how families fixate and concentrate on monitors rather than patients at EOL. Nurses saw it as their role to draw families back to patients by stopping monitoring. Prolonging death was seen as unnecessary suffering not only for patients

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[24] Active dying is defined as where a patient is expected to die imminently and is showing signs of dying: e.g. agonal breathing if not on ventilator; mottled skin pallor; irreversible delirium; advanced cachexia; unmanageable pulmonary congestion that cannot be suctioned or cleared; irreversible organ failure (Rocker *et al*, 2010). This is distinct from the notion of 'assisted dying' or euthanasia, where patients are helped to die prematurely, at present, illegally.

but also for families. Gradual withdrawal was seen as an easy option, especially to appease families, but potentially wrong in that it could prolong dying and prevent good death:

> ". . . I'm quite happy to, or reasonably happy to, go down the path of doing sort of gradual, easy sort of slow withdrawal of treatment which we could argue, you know, is the wrong thing to do. But I think all the considerations and sort of, constraints as a setup is, you know at the moment, it's fair enough to do that." (Critical Care Consultant 03)

This consultant rationalised much of his decision-making and for him this dilemma could be addressed through processing his thoughts. For others, enacting EOLC was harder and more emotive; wishing to give families a chance to deal with situations might risk protracting patients' dying. Two consultants reflected on talking about EOLC after interview. A realisation emerged that they might have drawn out withdrawal and expressed gratitude to me for the opportunity to self-reflect on areas of practice. The impact of cancer on prolonged dying was evident with several nurses, who had experience outside cancer critical care, alluding to how these patients would be treated for longer in this unit. Emotional costs of protracting withdrawal also caused personal pain for a number of the nurses. They were deeply sad, even crying at interview about it.

Equally, very rapid death could be hard to deal with emotionally since nurses feel unable to provide the care, or support families, as they would have wished. Some nurses outlined variability in practices according to doctors and unit bed pressures, which led to frustration at inconsistency. Yet, two nurses recognised how uniform approaches would be equally inappropriate.

One palliative care consultant outlined her stage-management of withdrawal processes as a way of promoting a rewarding, good death. She talked of holding families and patients' hands at each step, guiding not controlling and moving away from critical care constraints.

> ". . .you carry them through each stage. The minute they think that you are dumping them, the whole thing goes pear shaped. But if they feel every.. it's almost choreographing an event. You take them from one stage and you move them to the next act. . . and, um, if it's well managed and well choreographed and everybody feels comfortable, and everybody's achieved their goals and has resolution.. everyone needs resolution and if you complete the circles of each individual involved in that act the satisfaction is enormous." (Palliative Care Consultant 01)

The short amount of time from withdrawal to death significantly impacts on the ability to choreograph good deaths. One of the critical care doctors outlined how, in critical care, death is not usually expected. Unexpected death can mirror sudden death, making EOLC almost impossible (iterating points made in Section 6.4.2). Two nurses contradicted this, believing that patients because with cancer should, to a degree, expect death. Neither families nor patients raised this. Stage-managing the little time to death, and preparing to commence EOLC, however, may help ease potential discomforts.

6.6.3 How to withdraw: Mechanics, de-escalation, ceilings and implications on timeliness

Doctors were reluctant to withdraw life-sustaining support they had not initiated and found it easier to withdraw treatments that had been initiated later.

Oncologists were clear that the mechanics of withdrawal were the domain of critical care doctors. Ceilings were often applied to limit the level to which support is allowed to go. Ceilings were seen as a way of allowing patients a window of opportunity to improve and if they did not, then further decisions to move to EOL could be enacted. A doctor may decide to set a ceiling on treatment first and then move to active withdrawal,[25] but practices varied. Tensions existed for doctors about setting those levels.

Reducing ventilatory support included turning down oxygen, reducing PEEP and changing from complex to more simple ventilation modes. Certain doctors preferred to use a T-piece[26] and others to simply turn the oxygen requirements down to 21% (or room air as it was often referred to as, giving it a somewhat innocuous association). Others favoured extubation[27] but acknowledged that this was a contentious issue because it potentially risks airway obstruction, leading to immediate, and potentially

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[25] Active withdrawal (meaning active withdrawal of treatment such as extubation) is where treatment that actively being administered to treatment is withdrawn (stopped or weaned).

[26] Using a T-piece is a ventilatory measure that means the endotracheal tube is still in place, yet no ventilatory support via a ventilator is given. It is a popular method of withdrawal internationally and is referred to as t-piecing. Extubation is where the endotracheal tube is taken out altogether.

[27] Extubation is inserted as a yes/no option on the Liverpool Care Pathway for ICU.

distressing, death. Yet, this was often felt to be less distressing for families since their loved one appears more 'normal'.

Here tensions arise again of prioritising families' needs over patients'. It was very clear to some professionals that the tension existed and yet, for others, there was no obvious issue creating strain, or they held patients' needs as priority foremost and disregarded tension. These strands of dissonance rose periodically through various themes, highlighting the complexity of minutiae of even seemingly small matters around EOLC, as well as characterising larger issues in decision-making.

With reference again to timing, this was an important area of control where nurses or doctors could, effectively, choose the point at which patients died. Some doctors devolved responsibility to nurses to decide timing, perhaps because they were deemed to understand family dynamics more closely and would know what would be important for that family.

While some doctors were clear-cut about their actions, others prevaricated and contradicted themselves more: initially saying they placed ceilings while contradicting this later on. This suggests again there are complexities in making choices about actions with withdrawal causing inner turmoil to the point of contradiction, which links to the conflict theme. Nurses often talked of conflict where decision-making seemed incongruous and, if these doctors are not clear about what, when or how to withdraw, that inevitably creates conflict. Palliative care doctors wanted control of palliation and wondered why death would need to be in critical care at all. This difference underpinned their philosophy of a good death. Oncologists underlined the importance of palliative care involvement. Practicalities of shared care between palliative care, oncology and critical care doctors occasionally proved problematic, particularly for nurses.

> "I personally would rather look after them on my own um, rather than sharing the care because the trouble then is you know if something goes wrong who does the nurse call? . . . if you can persuade the oncologists to um, be less intensive, then they usually are reasonably happy for you to take over their care. . . So you know if continuing with CPAP or whatever is the best treatment for their breathlessness, that's fine I have no problems with that, um, but um, if whatever has been done helps great that's fine um, but everybody needs to know that the focus has changed, the family need to know that." (Palliative Care Consultant 02)

For palliative care specialists, the specific implications of withdrawal practices were less important. Achieving withdrawal without suffering was a united goal, but palliative care specialists would strive further to encourage family and patient to communicate and resolve unfinished business, as well as to die in peace and quiet, a potentially unachievable goal in critical care deaths. Indeed, noise was an issue for some families. The issue here seems to be frustration that palliation is not carried out to the degree which palliative care specialists feel it should be.

6.6.4 Moving onto a good death

How withdrawal practices shape the beginnings of a good death have been outlined. Good death here relates to processes around, not just during, withdrawal. Patients take a few hours to die, or rarely, even days following withdrawal. Care given at this stage influenced good death. As outlined in Section 6.5.1, care manifested itself in different ways to families and patients. Displaying a caring demeanour through ensuring patients' dignity was seen as important. Having a caring nurse was felt to be important by all nursing participants. Someone who would not simply give 'just their twelve hours in a shift' (Nurse 02), but who would engage with patients and families. Engagement, developing on that raised in Section 6.5.3, was noted as nurses who could show 'presence', and were not just present. This implies giving something extra of oneself rather than just carrying out nursing tasks, but actively being part of the process with families and patients. It was about being emotionally alongside them in their grief, as well as physically present. 'Presencing' also came up in OT 3 and GOT 2 but here it takes on a different mantle because it also relates to witnessing the pivotal, private moment of death.

> "I think sometimes I enjoy giving end of life care um and when I mean enjoy it's because you actually know the patient really quite well, you know the family very well, and have been through the journey with them. I think what is very hard is when you're coming on a shift and you really don't know the family at all. . .I feel then you could… a bit of an impostor. . .because I think you know dying is such a sort of private process that I feel sometimes we bear witness to sort of very private, personal moments." (Nurse 05)

The Mother test tree code also arose again here. Not only was it applied to personalise and humanise prognostication and decision-making, but also to ensure that care given to dying patients passed that test. Every one of the professional respondents talked how much comfort meant as a feature of a good death. Comfort in critical care doctors'

terms pertained to ensuring a pain-free, anxiety-free and sedated (unaware) death for all but one, who outlined how one could have a comfortable death awake, in certain rare situations. Comfort, privacy and dignity were considered universally paramount.

For families, good death meant not only addressing physical care issues, but extended to letting them participate in care, or contribute to care planning (such as suggesting what patient's usual skin care was, for instance). Here overlap with *Involvement in care* can be seen. It was also important to remember small personal, comfort issues such as applying patients' favourite lipbalm; using the right moisturiser; using patients' own pillows, nighties and blankets; playing patients' music, as well as more usual aspects of comfort associated with nursing. Usual aspects meant: positioning; ensuring pressure-relieving devices were used; ensuring warmth; regular mouth, eye and skincare; ensuring hygiene needs were met. Personalising care, and as one nurse put it 'patient aesthetics' (nurse 06) were important to maintain at EOL. One family member talked of being aware that families could think that comfort and hygiene care might be painful for their loved one and distressing to watch.

This patient's wife knew that, at EOL, patients took priority, but felt this was okay. She talked of the support encountered from nursing staff and their palpable, reassuring presence.

> "They changed his bedding frequently which was nice. And I remember one nurse really cleaning his face really well, erm, and brushing his hair. Just little things." (Family member 04)

Maintaining sensitivity to families' need for presence or privacy was an important skill and fell predominantly to nurses. Privacy was high on both families and staff list of needs for a good death. Despite not all deaths occurring in single rooms, families generally felt privacy was facilitated. The one exception was a teenage son who was never able to spend private time alone with his dying father since there was too much going on at that point. Furthermore, the 'dreaded 7pm' (Family member 04) visiting hour, meant laughter and witnessing other happier families, which caused anguish for two families. Both palliative care consultants saw simply having another patient present nearby when patients were dying was also seen as an infringement of privacy. Their notion of good death was, aside from adequate sedation and analgesia, centred on low-technology, private death.

Physical environment played an important part. Perceiving themselves as 'in the way', in cramped bed spaces in critical care was a concern voiced by two family members (Family members 02 and 04). Unrestricted access to patients was important. Patients did not identify privacy, or single rooms, as an issue. Continuity of care was important for nurses, but no families mentioned this. Offering family control over small issues as well as involving them in care (as raised in Section 6.5.2), was one way of promoting good death.

It was also about nurses allowing families to deviate from expected norms of behaviour and grief, allowing them to climb into bed with loved ones, to have champagne if they wished, but this took confidence. One nurse suggested that EOLC was no different from normal care, but this was a solitary view. For others, it was an extraordinary event that brought mixed emotions and feelings:

> "it's never going to be one of your favourite jobs but for some patients you do feel sometimes um, that it's um, it's a relief, it's a you know um, it's the end of all that suffering and you know in that way it can be positive and when you get relatives coming back and saying how we dealt with things so well or how they're coming to terms then that really helps and that makes it more positive as well." (Nurse 07)

Of all practitioners, only one nurse discussed how patients could express their discomfort via grimacing. This nurse talked of asking unconscious patients if they were in pain to assess non-verbal signs, demonstrating her belief in continuing communication with dying unconscious patients. Checking comfort with patients was perhaps otherwise presumed and inferred by references to ensuring sedated, comfortable patients.

The pre-bereavement aspect to caring for families whose loved one was about to die, could be difficult for nurses used to getting feedback. Not only might families be unable to engage when their grief is too raw, especially in unexpected death, but also nurses could not meet their own desire to ameliorate in some way.

> "I think sometimes you don't know if you're really doing… you know, if you're really doing the right thing. You say and you try to be supportive but at the end of the day you know what do you say, somebody is losing a loved one and nothing you say is really going to make that alright, but you know you do what you can. You try and reassure them that the person is comfortable and um, you know but that there wasn't anything more that could have been done or whatever you know you need to." (Nurse 05)

Most patients were able to express how they felt priorities in critical care would shift if there was no hope of recovery. Whereas for nurses, priorities focused on comfort measures, for most, but not all, patients having family present, people to talk to, and putting affairs in order took priority over comfort measures. Patients who could discuss notions of good death felt that a comfortable environment was important, but this did not preclude death in critical care, thus implying that you could die comfortably in critical care. None expressed a wish to die outside a critical care environment. The positivity towards medical and nursing care may be a key factor in this, in that they felt fundamentally cared for. From this it could be drawn that humanity displayed in care approaches from doctors and nurses humanised the high technology critical care environment.

Patients who found it difficult to talk about EOL (as discussed in Section 7.4.1) were able to talk about what others might want, a way of distancing them from their recent situation; a form of hypothetical extrapolation of their own wishes and experiences.

> ". . .you don't realise that you're that ill. Perhaps if you are dying, if you really are going to, you do realise, but [if somebody had told you], that your family's there obviously. And that you were comfortable, I can't really see what else you can do. The nursing's superb, you do the best you can." (Patient 06)

The importance of talking to patients was raised, especially at EOL where patients might still hear, iterating the earlier point. Having one's affairs in order was a recurrent code. When probed about what this patient would want if critically ill again with little hope for recovery, he too talked about this, as well as having the opportunity to say goodbye:

> "I suppose putting all my affairs in order is one thing. Mind you before I went in, I left [patient's son's name] a note with all important things on and which I did have to tell him where it was so it was destroyed. No that would be one …and saying goodbye to the wife, obviously." (Patient 04)

The importance of being near loved ones was also echoed by this spouse of a patient who survived:

> "…the fact that [patient's name] was so near death, I had to be there for as much as I could." (Patient 06 spouse)

Practical issues around comfort for patients were also a reflection on what they had actually experienced. These centred on seemingly minor nursing issues: sliding down the bed; ensuring no pain; being free from diarrhoea; having minimal suction.

One nurse found out from family that music comforted the patient. She then played personalised music to add a sense of comfort and care, as well as a sense of the patient's personality so that the patient remained very much a presence and a person even when dying. This exemplifies nurses going 'the extra mile', as one family member (06) describes. Perceptions of comfort also extended to after-death care.[28] Certain families saw comfort as relevant at all stages of dying and death. Ensuring comfort, in this sense, is synonymous with ensuring dignity at all stages.

For all respondents, good death included families' feelings, those who witnessed sadness unfolding before them. This aspect of dying returns to the BOT *family vs patient: split loyalties*. One family talked of the importance of recognising 'how hard it is to witness the death' of a loved one (Family member 02) and that it can be 'very visually shocking' (Family member 05).

For families, seeing that staff became emotional about achieving good decisions and reaching a good death contributed to the overall perception of a good death. Care became all the more tangible when staff emotions were expressed. One family member was clear that she 'forced her emotions onto all the staff and they responded right back amazingly' (Family member 03), iterating engagement noted in Section 6.5.3. Another talked of seeing the nurses in tears at the death of his wife and how that positively impacted on his experience. Simple gestures such as smiling after 12 hours on duty and doctors sitting at family level, rather than standing, were very important to families.

Oncologists rarely became involved in EOLC practicalities or mechanics, seeing their role as supportive at that point. Their clinical expertise lay elsewhere outside critical care or palliative care, unless palliative oncology procedures were necessary, such as palliative surgery or chemotherapy.

> ". . . often our visits are perfunctory, where it becomes social, and sometimes it is the chance for us to say the word goodbye to the patient and their family. So our role will move from active medical care to much more on the psychological

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[28] After-death care is not discussed here but related works are outlined in Appendix 8.

level, just letting the family and the patient know that we're still there" (Oncologist 02)

Families could not always offer perspectives on whether patients were comfortable or not, highlighting how care practices are undertaken which contribute to what is thought to make patients comfortable, but in reality it is not known if these help when patients are unconscious, emphasising potential tensions between family and patient care.

> "I don't think he was conscious though, it was probably immaterial in many ways, but the nurses were trying to do everything to make him comfortable, like turning him and covering him up because he felt cold and putting extra socks on him, and I don't know just. . .But [patient's name]'s died in the way that he would've wanted to die, which was very quickly and no pain. For some reason he wasn't in pain and he just fell asleep which I think most people would want to do that." (Family member 02)

This family member was aware of this tension between conflicting patient and family wishes:

> "I don't think in the end he worried about the fact that he wasn't at home, which would've been his choice. But it wouldn't have been my choice. . . I think there's always this dilemma between the patient's wishes and the families'. The practicalities you know, I just don't really like the idea of someone dying in my house, in many ways. I don't care who it is, I don't want anybody to die in my house. And also because of the children, you didn't want to have ambulances arriving and the neighbours all coming out and all this sort of stuff, and general..so I think it all happened..and the nursing staff were absolutely excellent, I can't..I have no criticism at all of anything that happened in fact. I have ticked all the boxes about 100% perfect really." (Family member 02)

For this family, it was a good death, since he died in hospital away from the neighbours and free from the shackles of critical care equipment, and even the face mask was taken away, but we cannot know what he, the patient, would have felt as he was dying.

6.6.5 Summary of key findings

This theme is highly significant since it is the precursor to the final event of death along a continuum. It outlines what it is like to experience and witness EOLC. What it means, and the timeliness factor, assumes greater importance, because it emphasises how death can effectively be controlled by practitioner action or inaction. A number of key points were raised (Box 17):

Box 17. Care practices at EOL: Choreographing a Good death

- Delegation for who should enact withdrawal varied according to nursing confidence, doctors' sense of ownership and collegiate protectiveness

- Mechanics of withdrawal/withholding were delineated by critical care doctors. Some gave more experienced nurses parameters in which to work. Oncologists and palliative care consultants were not involved in mechanics of withdrawal/withholding.

- Responsibility for withdrawal is great with concomitant emotional costs for nurses and some doctors.

- Prolonging death was synonymous with suffering. Treating patients versus families dynamic at EOL created dissonant feelings here. Death and dying was sometimes prolonged to allow families to come to terms with death.

- Different styles of withdrawal/withholding practices and EOLC were noted, with some more humanistic than others. Variation allowed individualism in families and patients.

- A caring demeanour in doctors and nurses was noted as important, and apparent, by all families.

- The rapidity to death following withdrawal/withholding made it hard to enact good EOLC.

- Stage-managing death can reportedly lead to a more rewarding experience of death.

- Philosophies of a good death differed between specialties. Palliative care doctors felt a low-technology private death was paramount. Critical care staff felt it was important to be pain-free and treated with dignity. Comfort prevailed in all specialties.

- 'Little things' were deemed important in personalising care, such as specific hygiene and comfort care actions and represented care.

- Patients and families were both regarded as priority at EOL by different clinicians. Some families saw patient as priority after DM. Palliative care doctors were more likely to place patients' perceived needs as paramount.

- Nurses sometimes disengaged from EOLC as it was not seen as their specialty, but when they did engage they gained a great sense of purpose in their nursing as the patients, not machines, were the focus.

- Patients who survived did not raise minutiae of comfort and EOLC. General principles were discussed such as comfort, family presence, and having their affairs in order.

- Dignity and caring was evident in small gestures, such as smiling at the end of a shift.

- Nursing and medical response to family emotions was consonant with what families wanted and demonstrated their sensitivity.

- Dying at home was not always seen as desirable for families and no patients expressed this desire.

6.7 Summary of all findings and the essence

This findings chapter has outlined unique experiences of witnessing, experiencing, moving toward and providing EOLC to dying patients in a cancer critical care unit. It has outlined five aspects of the journey to death, primary issues affecting EOLC provision, and represents the essence of the findings: the trajectory of dying along a cancer critical illness continuum toward death and beyond. This continuum is represented in Figure 8 overleaf.

Cancer affected the trajectory in unexpected ways. The trajectory could be very quick, especially in unexpected death and some newly diagnosed cancers. Even in the face of a life-limiting and serious disease like cancer, death could be unexpected. The rapidity of trajectory related to cancer diagnosis, prognosis, withdrawal and patient demise significantly impacted on the potential for, and timing of, EOLC. A sentiment of moving on from historical practices around critical care for cancer patients, and related poor prognoses, was overwhelmingly agreed on, but important caveats in cancer prognostication remain. Prognosis and decision-making were shared activities beyond oncologists and critical care doctors, and included nurses, patients and families. Differing perspectives on cancer and critical illness prognoses and superimposing prognoses affected the move to EOL. Reaching a point of futility was a defining factor in making DFLSTs and moving along the continuum. Decisions to forgo life-sustaining treatment and mechanics of withdrawal practices (sometimes based on heuristics and 'knowing', rather than clear fact) might alter the rapidity of death, but did not alter the course and inevitability of death. Patients were almost always unable to contribute at EOL, emphasising how preparation for critical illness and death as a possibility early on in the cancer continuum would help planning for EOLC.

What is happening in a critical care unit can be seen in accounts throughout the findings, represented by stages towards dying and the roles that different participant groups played along that continuum. Families travelled the journey with patients along their continuum from diagnosis through critical illness prognosis and revised cancer prognoses. Oncologists had a role not only in prognostication and decision-making but also in supporting patients all along the continuum. They were around for explanations if needed but their involvement in care is minimal and they were less evident at the very EOL. Critical care doctors' and nurses' roles became evident toward the end of the continuum and EOL and they would only meet patients and families at the critical illness stage. Nurses predominate in EOLC, although some of these doctors also took

part in EOLC. All of the nurses travel through each stage after critical illness to death. The level of engagement at each stage was highly variable and individual, and emotional implications were one reason why some professionals declined to engage or become involved at the different stages, particularly toward the end. Families needed support along the continuum because, while patients travelled the whole journey, they were unaware at the very EOL and this highlighted the issue of patients versus families. In unexpected death — and this continuum of life, cancer and death in critical care — the role of critical care doctors and nurses was more pronounced. Surviving patients had stepped onto the continuum but their trajectory toward death had slowed and they had stepped off after critical illness before DFLSTs were needed. Palliative care input with these patients was an even smaller slice of the trajectory; where they were involved it was limited to the very EOL, and not necessarily the actual care. The continuum and trajectory along it toward dying highlight the significance of timeliness of decisions, impact of cancer, EOL withdrawal practices and care, especially with regard to how it can or cannot be controlled and the impact this has on the potential for a good death. The level of involvement by participants with less prominent voices, such as patients, families and nurses, could positively affect the trajectory and EOLC. Yet, facilitating involvement had to be carefully balanced against family and patient wishes. How and why different participant groups travelled along the continuum in the way they did related to a number of factors that are briefly summarised here and discussed overleaf in Figure 9.
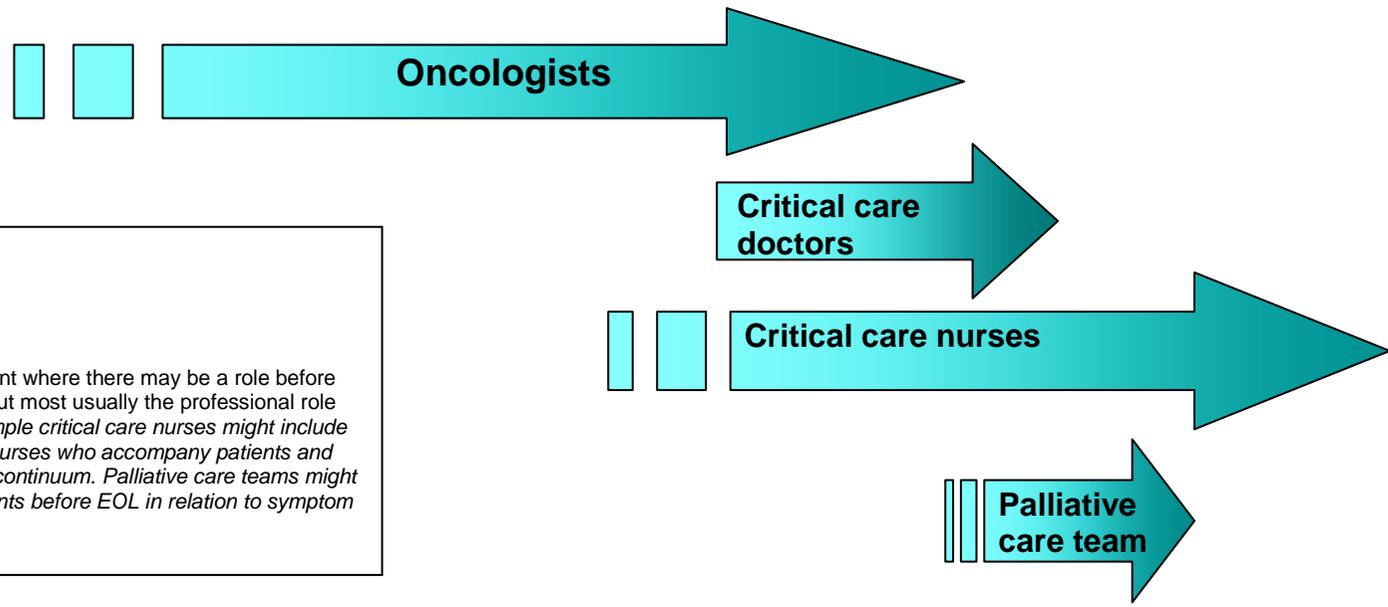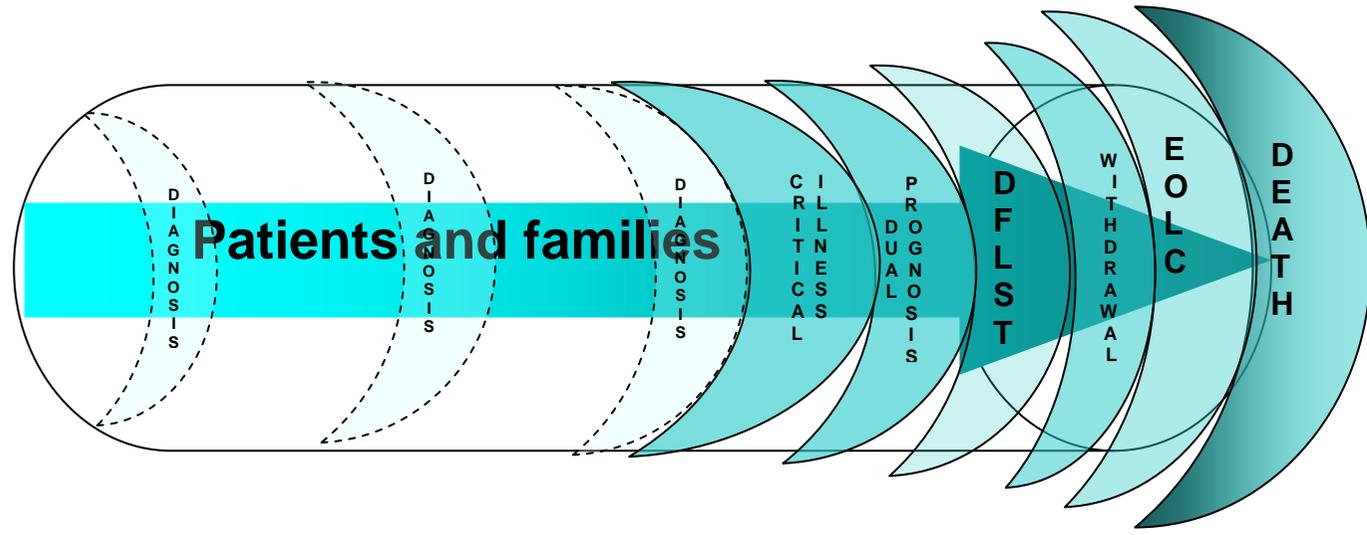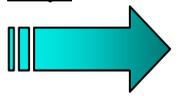
Figure 9. Continuum of a cancer critical illness towards death

Surviving patients still on the continuum were living with cancer but had considered EOL issues outlining the importance and meaning of family, dignity and comfort at EOL. There was waning positivity about their cancer prognosis and greater consideration of death having faced death and critical illness.

An important and original aspect of this research was the dilemma of treating patients over families. This caused personal dissonance and had associated emotional costs. Burdens in EOLC and decision-making existed for not only families and nurses but also for doctors. The meaning EOLC held for participants varied, emphasising the individual nature of EOLC. Shared principles of care such as good communication, honesty and involvement in care and decisions characterised each aspect. Nurses' involvement varied according to their confidence, experiences and emotional costs to what they were doing. Engagement and detachment were noted in both doctors and nurses. There were opportunities for nurses to be pro-active in EOLC, but these were not always seized for a number of reasons, including a lack of confidence in cancer care and ethical knowledge, and wishing to disengage. Medical voices were strongest because of the overall responsibility conferred but families felt they had an important voice and could contribute to EOLC plans. Patients' wishes were not discussed to the degree families' were. By implication, families seemingly took priority at EOL. Few participants, including patients, talked about patient needs beyond universal notions of comfort and dignity. Yet, paradoxically, inherent in every professional account were the central issues of patient comfort at EOL.

Care figured in many guises throughout as part of the principles and wording of EOLC, as nursing, and as family bereavement support. Some participants held care to mean the care given at EOL. Others held care as representing nursing, and for families care was about the demeanour held by doctors and nurses at EOL. This demonstrates how caring was not unique to nursing. Nurses and doctors preoccupation with technology could threaten notions of care but displaying sensitivity and facilitating family inclusion, even when managing technology, was part of showing care. Engagement was not seen as necessary in caring, but some nurses felt it was important to be fully present with families in order to give good EOLC and to be fulfilled in their nursing. However, this came with considerable emotional cost.

End-of-life care was inextricably linked with decision-making, prognosis, withdrawal practices and good death. A good death was the ultimate goal of the end of the trajectory, the final part of EOLC. The quality of the last part of the continuum was a

major issue for this study and the thesis findings. Achieving this was affected by many deeds or inactions, beyond those outlined above. Common practical principles were outlined, but core tenets included comfort, less visible technology, privacy and dignity. Place of death was not raised as an issue by any family or patient participants, only by professionals, suggesting that they see the potential for (or witnessed actual) good death in critical care with cancer.

The next chapter draws together the findings from this chapter; in particular the essence from all of the findings presented in Figure 8, and develops them in light of theory and the conceptual underpinning discussed in Chapters 1 and 2.

Chapter 7. Discussion

This chapter ties together findings, context, conceptual and theoretical underpinning and literature. It provides further explanation for the essence: the continuum (Figure 9), the overall metaphor given to the description of experiences, introduced in Section 6.7. This continuum is the trajectory of moving along a cancer continuum, via critical illness, and then to dying and death. The findings are developed for what they reveal, how they contribute to and develop theory, in particular theories of dying in critical care, raised in Chapter 1. My influence, as researcher, method chosen and research findings outcomes are discussed in varying depth.

This study has shown what it was like witnessing EOL, as well as providing EOLC. Timeliness, as well as what good EOLC meant, were particularly notable in the final theme. What distinguishes this study from other EOL research is that it aims to capture a 360 degree perspective of EOL in critical care by researching all those immediately affected as witnesses, providers or patients who have experienced near-death and might have some insight into EOL in cancer critical care. This study noted the influence of different specialities, and their subsequent interplay at EOL.

Having described in Figure 8. how I reached the continuum via the themes, I now outline and discuss a continuum (Figure 9.) that represents the essence of moving to EOLC in cancer critical illness in three broad stages: stepping onto the continuum, the impact of human agency, which outlines DFLSTs and effect of moving to EOL, and finally reaching the end of the continuum, EOLC. The continuum commences with critical illness, taking this preceding factor into account for EOL, and can even include cancer diagnosis. Themes that shaped and influenced the description of these stages is discussed at each stage. This continuum encompasses research questions of *what is happening at EOL, what it is like, what it means, the impact of cancer and the timeliness moving to EOL*. Each of these is considered throughout the continuum as ongoing, intrinsic issues, rather than separate, entities.

7.1 Stepping onto the continuum

Critical illness in cancer could be deemed the beginning of the continuum of moving to EOLC through an acute phase of a chronic or acute illness. For most participants the continuum of moving to EOL started with critical illness. Families and patients travelled its journey, accompanied at different points by professionals, who might also be considered to be on a journey (and one that is repeatedly undertaken in cancer critical care). Occasionally, formal diagnosis with cancer in critical care meant the critical illness coincided with cancer diagnosis, rather than a decline toward acute critical illness. Participants outlined their journey to reaching critical illness as part of the theme of *dual prognostication* (GOT 1)*;* stories for how patients came to be in critical care with cancer (OT 8), and their subsequent prognoses, had a great effect on possibilities for EOL and EOLC, as presented in Figure 9. Families facing concrete realities of death linked the trajectory of cancer to critical illness. Critical illness and patients' subsequent demise was therefore inextricably related to cancer for families. Yet, two patients regarded them as separate entities. This important distinction shows a compartmentalisation of feelings for some patients and demonstrates reluctance to face the possibility of death, as represented by OT 6: Thinking the unthinkable. In turn, this can have implications for positioning along the continuum. If patients are not ready to consider death as a possibility they will be unreceptive to planning for EOL. For others, previous positivity toward cancer recovery was overturned by a new critical illness, affecting rehabilitation and made death a real possibility. In essence, diagnosis, critical illness and thinking the unthinkable (see Figure 8.) comprise the main facets of this stage, which are now discussed in depth.

7.1.1 Prognostication and rapidity

Prognostication proved a key issue throughout, and hence it became a global order theme (GOT 1) and an important stage for the continuum in Figure 9. Without being able to predict which patients will die, and when, doctors may be reticent to institute withdrawal or comfort measures, as I discussed in Chapter 1. Reasons for this were related to reluctance in prognostication and complex, superimposed prognoses. In Sections 6.2.1 and 6.2.3 I outlined how having to contend with both cancer and critical illness prognosis, a dual prognosis, added a level of complexity unseen in previous studies. As we saw, if doctors have a clear idea of prognosis, undertaking DFLSTs is easier. Prognostication in Section 2.3 was deemed outside nursing's remit. However,

nurses, too, might be able to prognosticate for death, which affects how they carry out EOLC and potential for increasing prominence in this area. This will be explored further in Sections 7.1.3 and 7.3 regarding practical issues. If both critical and cancer care prognoses were poor and aligned — depending on doctors' confidence and assuredness in prognostics — patients would move further along the continuum, and faster, toward EOL and EOLC. A nursing role in prognostics therefore relates to dying and predicting and controlling timing of death through care at withdrawal and beyond.

Speed of the trajectory (Section 6.2.2) affected how participants moved along the continuum, the development of which was introduced as the essence of the findings in Figures 7. and 8, and finally represented in Figure 9.. For patients, speed could be influenced by various things: age, type, stage of cancer, co-morbidities and actual critical illness. Section 6.2.1 outlined how a nurse suggested 'cancer' means you know you are dying. The notion that having cancer raises death as a possibility, along with critical illness, can be considered against Seymour's (2000; 2001) notion of natural order of dying and Lofland's (1978) dying trajectory. I have presented a continuum that reflects experiences of both expected and unexpected death, which relates to natural order and subversion of natural order. Seymour (1999; 2000; 2001), whose theory of negotiated dying underpins this study, discusses moving toward a natural death with unconscious critically ill patients. In relation to the rapidity I have described in Sections 6.2.2 and 6.6, I particularly want to contribute to Seymour's and Lofland's theories. I will now explore theories outlined in Section 1.9 in light of my findings.

Lofland (1978) (Box 5.) holds that six interrelated conditions are necessary for a brief death. My findings concur with stages 3, 4, 5 and 6 outlined in Box 5 in Section 1.9, however, the low level of technology she deems necessary for a brief death requires signs of death to be taken as definitive which, as I described throughout the findings, is difficult. As I will describe in this section, and later in Section 7.3, patients with a high level of technology could have their dying accelerated along the continuum presented in Figure 9. Through management of withdrawal of technology death and dying can be also speeded up rather than prolonged as Lofland (1978) suggests. However, this does not suggest that sometimes dying was not prolonged in my research (as we saw in the accounts of emotional consequences of prolongation and which I will discuss in Section 7.2.4), but rather that prolongation was more related to human agency and DFLSTs, and less on technology. I shall develop human agency in relation to Seymour's (1999; 2000; 2001) theory shortly in Section 7.2. Moreover, cancer adds a new dimension to Lofland's (1978) notion of late detection and fatal conditions as a pre-requisite for brief

death. Late detection was a potential issue, and indeed could produce a fatal condition (Lofland, 1978). However, my research showed how some cancers challenge the necessity of late detection for brief dying (or conversely the early detection of disease of fatality-producing conditions in prolonged dying). Patients can present early with highly proliferative disease, such as certain haematological cancers that patients experienced in my research, and their decline and dying is not related to late detection necessarily, but more to severity of disease that is unforeseeable, which echoes her 'fatality-producing' condition (Lofland, 1978, p.18). In this sense, the issue of sudden decline and subsequent death present a challenge to natural order which I shall discuss next.

In relation to Seymour's (2000; 2001) first principle: *maintenance of the integrity of the natural order*, this natural order might logically be perceived to be death, given these patients had cancer *and* critical illness. Yet, this was evidently not the case in many accounts. Patients and families' accounts in *dual prognostication* (GOT 1) and *thinking the unthinkable* (OT 6) contend a perception that cancer means awareness of dying. In this study, cancer mortality first encountered at diagnosis was revisited with critical illness prognosis and, in some cases, a revised cancer prognosis, which compounded mortality issues. Superimposed on these critical illness issues is an additional mortality tag of cancer (Pattison *et al*, 2007). This represents one aspect of the impact of cancer. When becoming critically ill patients were forced to address mortality again, having previously confronted it at diagnosis. This highlights for patient and families a potential threat to the natural order outlined by Seymour (2000; 2001). Many patients and families in this research chose to avoid this 'foreknowledge' of dying that Lofland (1978) argues we possess. Death was, often, still unexpected despite a diagnosis of cancer, especially in highly proliferative disease where patients presented critically ill. These participants might not be ready to consider EOL, or might even be cured, and as such do not see themselves as on a continuum toward EOL. High proportions of curative and substantially life-prolonging cancer treatments (DH, 2009c) might allay thoughts of death. Cancer might force someone to face mortality but I would maintain this as distinct from knowing they are dying. This was also evident in OT 1: *Story of cancer and critical Illness.* For survivors, in Section 6.2.1, there was a peculiarity between cure from cancer — which may or may not have been achieved — as opposed to cure from critical illness, which *had* been achieved. Having to face mortality challenged positivity about cancer and introduced the possibility of dying. There were also additional issues of legacies from cancer and critical illness. Some patients' existential and spiritual reflections on what it was to have cancer, and discussion about

fortune and fate enabled these patients to extricate from a sense of ownership of survival, putting it instead down to destiny (which may be religious or not), rather than anything they could control. Here, patients referred to destiny in terms of dying, not surviving. A sanguine approach to survivorship seemed also to lie in patients' personalities and could not be explained by their disease situation. *A posse ad esse,* death from possibility to reality, was related to destiny. In knowing nothing could be done and the situation was futile, there began to acceptance of a situation.

An additional feature to cancer patient survivorship, critical illness, has not previously been raised in research as a specific affective factor in cancer. Physical symptoms, even small twinges, which could be a legacy of critical care, not cancer, led them to *think the unthinkable* (OT 6): recurrence of cancer and potential death. Here, the threat of moving along that continuum faster presents itself. This may have been why some chose not to think the unthinkable, again as a protective measure. Whatever the personal outlook, as Chapter 1 raised, patients *would* be more likely to die from two perspectives: as a critical care survivor with cancer and the long-term mortality associated with cancer. Patients may have undergone critical illness, had a diagnosis of cancer, and be elderly, but interestingly some maintained an expectation of longevity. Expectations of how the continuum, represented in Figure 9., *should* progress, and managing those expectations (particularly around prognosis), become evident.

7.1.2 Expectations

Three practice issues around expectations arise here and are discussed in relation to the theory outlined in Chapter 1. Expectations also related to what it means for those experiencing, witnessing or providing DFLSTs, EOLDs and EOLC.

First, professionals' respect for patients' wishes not to talk about EOL issues. Respecting this reluctance to talk about EOL relates to Seymour's (2001) second principle: *maintenance of the integrity of the dying person's personhood*. Here patient voices are a paradox. Respecting patients' choices to engage with EOL, as a possibility, could signify preserving personhood. The degree to which participants accepted dying, either their own as a potentiality or (for families, doctors and nurses), patients' dying, differed. How much patients felt able to discuss death, dying and EOLC was an indicator of how much they had conceived, or could conceive their own death.

Death denial can be applied to both patients and families. Some patients found it hard to, did not wish, or arguably need to, confront the fact they could die (emphasising again the influence of OT 6), which means we do not know *what* would be important in preserving their personhood at EOL, other than it was not raised as an issue nor intimated.

Some of these patients, therefore, accepted they were on a continuum toward EOL and some did not, perhaps perceiving the continuum to be suspended through the phenomenon of surviving critical illness. Families might find it hard to accept the inevitability of death but have to be reconciled to it when death becomes an actuality (as we saw in OT 6: *Thinking the unthinkable).* Families might also push for more treatment, as the findings suggested with the theme of Family versus patients: split loyalties (OT 1), because they are not ready to accept death. In this sense they can be regarded as avoiding or denying the fact that their loved one is dying, and that futility is nearing or has been reached (OT 5). This raises the issue of whether there should be greater preparation around the possibility of dying and death for patients and their families. If so, at what point should this preparation take place? By whom should that preparation be done and is it an iterative process? Findings around prognostication and EOLC develop these questions further and are discussed shortly.

Second, as we saw, doctors and nurses described sequelae of poor prognostication as unnecessary prolongation of dying, 'torture' and limited, or no, opportunity for good EOLC and death. Here, it becomes plain how uncertainty pervades prognostication; the ability to predict timings of death. Doctors and nurses making or contributing to DFLSTs are plagued by uncertainty, reflecting OT 7: Domains of knowledge. Managing uncertainty in prognostication represents a facet of human agency, which is developed in Section 7.2 next. Individual judgment about moving to EOL, rather than death taking its 'natural course' or being 'neutral' (Johnson *et al*, 2000), and the Meaning of Decision-Making (GOT 2) ascribed by those making judgments, will evidently affect the trajectory along the continuum toward EOL. Doctors might also struggle with giving bad news and poor prognoses to patients for reasons of emotional costs, as described and represented in OT 4: Personal dissonance, alongside uncertainty. It might be easier to avoid poor prognostication and offer more treatment.

For families, rapid dying as a result of poor prognostication means less preparation for death and dying which in turn has implications for EOLC. There is, then, no opportunity for change in treatment focus and patients may be denied symptom control, comfort

and palliative care principles. The opportunity for nursing advocacy arises here. Many patients saw this as nurses' role, with regard to facilitating communication in particular, and although not explicit, advocacy was implied in some nursing accounts where they talked about increasing involvement in care planning. Some nurses didn't seem to have a strategy for dealing with delay in prognostication although more confident (and particularly those experienced in cancer care) nurses would challenge doctors. The nurses have a role in prompting doctors to address prognostication, even if they are reluctant to do it themselves, as the helpful nursing behaviours outlined in Section 2.4.3.

Lastly, how to address expectations in relation to this, prognostication in Section 6.2.4 relates to nursing and medical communication and respective roles in truth-telling, uncertainty and where patients and families drive treatment. Again, this raises issues around how practitioners individually manage their feelings and communicate, as represented in OT 4: Personal dissonance. Importantly for practice, we saw care can be disrupted when expectations for death trajectories do not meet realities. This was particularly the case in unexpected death. Developing the notion outlined in Section 1.7, a duality to sudden and unexpected deaths. Here, sudden death was historically seen as bad, but a swift death in a patient expected to die was seen as good. The implication for the continuum presented here is that death in critical care, despite cancer, can be expected or unexpected. To return to Seymour's (2001) first principle (integrity of natural order) she argues that there is subversion of the natural order through unexpected death and this challenges the opportunity for a good death. Johnson *et al* (2000) also conceptualised how natural death was threatened by prognostic uncertainty which creates a rocky path to death. There is scope for development around the issue of rapidity of dying and deterioration, which surfaced as an issue in this study, in both of these theories. Unexpected death also challenged the opportunity for moving along the continuum in a timely manner. I will develop these notions throughout the discussion chapter.

In Sections 6.4.3 and 6.6.2, a role arose for realigning expectations to meet realities through honesty. The doctor's and nurses' positions here become clear; honesty and truth-telling, as Section 1.7 outlined, need to balance against maintaining hope. As families highlighted, maintenance of hope represented care in all but one case. Confidence to provide prognosis in this study relied on good information about all aspects of patients' clinical situations, both cancer and critical illness related. This relied on Domains of knowledge (OT 7), Dual Prognostication (GOT 1) and, as

mentioned previously, OT 4: Personal Dissonance. Some doctors find it hard to accept that a patient is moving toward EOL and truth-telling can then be difficult. This relates to Seymour's (2001) third part of her theory: *maintenance of trust between health care staff and patient companions.* If *dual prognostication* (GOT 1) is difficult to achieve, and a conflicting picture presented to families or patients, there will be a threat to trust which will adversely affect the potential for moving along the continuum toward EOL and EOLC. Patients and families demonstrated the need to believe there were no other options before moving to EOL but, as described earlier, inevitable medical uncertainty in both cancer and critical care prognosis clouds this issue. Families in this study needed to understand why patients were dying from cancer and, or, critical illness. This helped them make sense of the situation both at the time *and* in hindsight. Participants could think about what held meaning, and was important at the time and what was important, and held meaning, now.

In giving information about prognoses, addressing *thinking the unthinkable* (OT 6) and early discussion of options, patients' journeys along this continuum might be appropriately speeded up toward EOL, where there is risk of protracted DFLSTs and death. Although early discussion does not address rapidity of decline, the impact that had on rapidly changing prognoses and evolving prognoses that my research raised, it does highlight how some information might be better than none for helping families and patients deal with death and dying, especially while they are adjusting to increasing speed along the continuum toward EOL. Many nurses, as we saw, lacked confidence in information giving, which also raises issues around collusion as seen in Sections 1.7 and in 6.3.3, and highlights a further issue around Domains of knowledge (OT 7) with nurses being reticent because they are not confident in their knowledge. However, experienced nurses clarified information and subtly managed expectations, centring on patient and family advocacy (drawn on later in Section 7.2.2). This was alluded to by one nurse who talked of sensitively manipulating information to families to give an honest picture of dying timeframes, noting challenges to loyalty to doctors, who created different expectations of dying timeframes amongst families. The degree to which doctors complement nursing is underlined along the continuum and in relation to differing roles noted in the findings, particularly in EOLC. This also highlights a subtle undercurrent around nurses' management of interprofessional tensions. Nurses wish to present a united front to patients, and lack confidence to challenge for reasons given in Section 7.2.2. As I discussed in Section 1.9, Melia (2001; 2004) in her theory of consensus working, outlined how nursing roles were distinct from medicine at EOL. Yet, this study has highlighted overlap (this is particularly evident at EOL and will be

discussed in Section 7.3) between some aspects of roles; specifically, nursing ability to assume ownership for enacting, controlling and timing EOLC. This is represented by the theme Involvement in care (OT 3), where levels of involvement differed according to emotional engagement (related to OT 9), confidence in knowledge (OT 7), personal dissonance felt (OT 4), and personal approaches. The level of involvement for nurses (and families) increased as the continuum progressed (see Figure 8. for thematic contributions to stages). The importance of nursing and medical teamwork is central to her theory, and my research has outlined some tensions, especially around EOLDs. Collusion might have been evident to promote Melia's (2001; 2004) consensus in team-working and this, in turn, creates personal dissonance (OT 4) for these nurses. I shall return to this in relation to heuristics, and the theme Meaning of Decision Making (GOT 2) described next.

7.1.3 Heuristics

Developing these three facets: honesty, prognostication and managing expectations, it is worth briefly reflecting on prognostication (GOT 1) and decision-making (GOT 2). In this study, both appeared at times to be led by heuristics: experience and common sense, rather than hard evidence and prognostic indices. This notion of heuristics offers expansion to the theories outlined in Chapter 1. Heuristics has been termed a way of making probability judgments, a strategy used to make inferences and make choices. In clinical situations, heuristics can inform intuitive decision-making (Cioffi, 1997). Heuristics *may* be based on logic but tends to be based on past experience[29]. In Sections 6.2.4 and 6.4 critical care doctors accused oncologists in general of basing decisions on similar past successes. Heuristics and rationality seem, therefore, to be at odds in this situation. Yet, in critical care, decision-making could equally be partly based upon heuristics rather than purely on hard evidence. Experiences and common sense influenced the weighting of factors in each particular case, especially where evidence was lacking. Heuristics was also applicable to nurses' experiential knowing in relation to prognostication around dying, discussed at the end of this chapter,

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[29] Representative heuristics are quick decisions based upon odds: e.g. what are the odds of this septic cancer patient dying now that they have three organ failure? Doctors (and the team) compare and consider the case in front of them with cases or concepts that are least similar and work out how it might alter or deviate. Availability heuristics assesses what the probability of an event occurring is based upon it springing to mind. This type of heuristics, often used, demonstrates how easily bias influences decisions, since recent cases will affect case consideration. Each of the consultants used a case to exemplify their decision-making.

predicting when it would happen. Nurses not only tended to disengage from prognostication but also, at times, from decision-making. This was because of lack of knowledge or confidence in their knowledge about cancer, reflecting Domains of knowledge (OT 7). Where some nurses did prognosticate was around death. These nurses voiced that nurses at patients' bedsides witnessed patients' demise over a twelve hour shift, giving them different insights into predicting death and this created personal dissonance and conflict around loyalties. These two issues of wanting to support colleagues and lack of knowledge to prognosticate about cancer can be regarded in relation to nursing knowledge in critical care and will be discussed further in Section 7.2.2.

Entry to the continuum can either be at critical illness, when prognosis for critical illness and cancer are deemed significant enough for entry, part of the way along a cancer journey, or even at diagnosis, when patients present as critically ill (as OT 8, Story of cancer and critical illness, testified to). To summarise, there are two strands to this part of the continuum. First, there are surviving patients who enter the continuum at diagnosis and travel through critical illness but whose trajectory slows with either cancer cure, maintenance of cancer or, even, denial of dying. Second, there are patients for whom critical illness means death becoming reality (OT 5: Reaching and defining futility) and the continuum's end is reached. They enter at critical illness and progress at varying speeds to death. How nurses and doctors facilitate and deal with this affects potential for death, timing and end of the continuum: EOLC and EOL.

7.2 Travelling along the continuum: the impact of human agency.

This aspect of the continuum describes the influence of DFLSTs on participants, using agency as a way of explaining this, the related influence of nurses and a subsequent caring paradox. It also encompasses how people are involved, what it was like, and the human legacy of making decisions (GOT 2), including emotional labour (OT 9). It captures how moving along the continuum toward death is heavily reliant on decisions.

7.2.1 Decisions and agency

Human agency is important for this aspect of the continuum. Agency is described in Benner *et al (*1999, p.14) as the "ability to act upon or influence a situation". Seymour (2001) used agency to delineate impact of people's decision-making to move to EOL in her theory of a negotiated death. In my research, patients' deaths were prevented by critical care intervention, prolonged or apparently hastened through doctors' and nurses' actions. End-of-life and EOLC was speeded up or slowed by human action or inaction. Actions were affected not only by processes of prognostication but by decision-making (GOT 2), which were, in many accounts, influenced by emotional issues (OT 9).

Domains of knowledge in decision-making as part of human agency are also an area of distinction for this study. Each discipline's prognostication and decision-making directly affects the other's plans for care and outcomes. As I outlined in Sections 6.2 and 6.4 these were not relayed as competing domains of knowledge and there was evidently respect for knowledge (OT 7) but there were tacit expectations that knowledge presented should be correct and accurate as far as possible. Nurses, families and patients also contributed to doctors' feelings of confidence about decision-making (GOT 2).

As outlined in Section 6.4, most doctors rationalised decisions as they made them; two participants' talked of knowing in their soul that certain patients would die, giving meaning to the decisions they made (GOT 2) even before the point of futility (OT 5). This develops the heuristics raised in Section 7.1.2; decisions are often based on experiential knowing. This develops Seymour's (2000; 2001) work which suggested that doctors based DFLSTs on experiential knowledge; patients with more than three organ failure were likely to be deemed futile and 'natural' death was likely anyway. It also develops Johnson *et al*'s (2000) notion of indeterminacy in critical care: my research has shown how the consequences of uncertainty extend beyond poor-decision-making to mean limited opportunity for EOLC. Johnson *et al* (2000) suggested 'good' decisions and the act of withdrawal equate to optimal care, which I shall explore further in Section 7.3 because withdrawal processes can still be carried out in a way that undermines good or 'optimal' care.

The impact of human agency is clear here; uncertainty not only affects entry but can affect also the possibility for moving along the continuum to EOL. While nurses did not necessarily articulate a contribution, their accounts suggested heuristics were also responsible for their feelings about DFLSTs. They used past experiences, some clinical, some rational and some emotional (reflecting themes OT 7, OT 9 and, to some extent, OT 4 in the dissonance felt when making and rationalising decisions) to inform what they would like done for patients to avoid future suffering.

Nurses input into decision-making varied and this was not always consonant with grade, suggesting it is too simplistic to imply that experience in decision-making was needed for nurses to participate. As Sections 6.4.3 and 7.1 outlined, for nurses in this study it was more about possessing certain knowledge (OT 7) to feel confident to participate and be involved in decisions of care (representing one aspect of OT 3: Involvement in care related to decision-making).

7.2.2 Nursing caring and advocacy paradoxes in DFLSTs

Critical care nurses were identified in Section 1.5 as running with wolves (Falk Rafael 1998); aligning themselves with medical colleagues and renouncing caring attributes in order to move ahead in nursing. For this aspect of human agency, the findings would suggest it is not as simple as this. As I discussed in Sections 6.3.3 and 7.1, collusion instead was related to wishing to protect families from contradiction. For some nurses, and in one patient's view, focus on technology took precedence over caring (albeit less so as the journey along the continuum progressed, see Figure 9.). Exceptions to this were where technology was used to manage dying both by doctors and nurses (as described in Sections 6.6.1, 6.6.2 and 7.3). Locsin (1998) suggests that technological competence in caring is realised through technological expertise. This would seem to suggest that knowledge and competence with technology is needed before caring can take place. Nurses in this study did not describe competence issues but implicit was the assumption that you needed critical care experience to manage moving to EOL and EOLC, aside from the contribution to DFLSTs raised above. This phenomenon was also evident in the sampling difficulties I encountered with junior nurses. They were deemed too inexperienced to be allocated EOL patients. It might be then, that seemingly uncaring nurses were striving to reach technological proficiency, as Locsin (1995) terms it, and had not yet reached the level of competence to be able to interweave with core caring attributes. This would resonate with the aspects of the

findings represented by OT 7: Domains of knowledge. Nurses need specialist knowledge, demonstrated by proficiency, to confidently become involved in care and decisions (OT 3). However, dying patients in this study were arguably not growing, nor reaching healing which, according to Locsin (1998), also characterises technological competence in caring. This is a significant limitation to this theory. My findings would suggest that caring and technology can be achieved in EOLC. Caring facets were not exclusive to nurses but there was a clear sense that nurses provided the necessary, in-depth emotional support to families; as one nurse termed it 'travelling their journey'. Locsin (1998) suggests nurses should claim caring as a unique facet to their profession. This will be further developed in the final stage (GOT 3: Practices at EOL: Choreographing a good death). Caring remained important to this study's nurses, one of whom saw this as synonymous with nursing. Families and patients talked of both medical and nursing caring. Caring, therefore, was not unique to nurses in this study, emphasising a team element to care and a prompt for nurses to think hard about securing an area they regard as their domain (OT 7). This concept of caring challenges Zussman's (1992) and Melia's (2001; 2004) notion of doctors' curing and nurses' caring, outlined in Section 1.9. Caring, in Section 7.5.1, was about being concerned with, and trying to do everything possible to uphold or enhance wellbeing, showing interest in patients and families as people and about being emotionally available and showing presence, facilitating inclusion, privacy and dignity. It was important to outline what participants' saw as caring because as Section 2.4 showed, care is used ubiquitously and what that entails is rarely described. This corresponds to Locsin's (1998, p.54) notion of intentionality in caring: accepting patients as caring people.

Nurses here had the potential to exert significant influence over EOLC, even controlling dying. These two points show how nurses could (and some did) develop their potential in withdrawal practices controlling timeliness of dying, and create an areas of specialist EOL practice, as well as demonstrates how doctors might assimilate seemingly traditional nursing qualities of caring dispositions to improve experiences of EOLC. This shows how nurses involvement in care (OT 3) is beginning to become more prominent as the continuum progresses. This research also supports the challenge I mounted in Section 1.4 to the notion that nurses need reciprocity to demonstrate caring, engagement and presence (Watson, 2006; Finfgeld-Connett, 2006; 2008c). Furthermore, it challenges nurses to consider if the qualities, such as care, can be considered unique to nursing (Gallagher *et al*, 2009; Rchaidia *et al*, 2009). For nursing to excel in EOLC, this needs to be examined in relation to power dialectics between nurses, doctors, patients and families.

In Section 6.4.3 I outlined how nurses needed cancer, ethical and critical care knowledge (reflecting the ever-present issue around Domains of Knowledge in OT 7) to become more involved in prognostication and decision-making. These critical care nurses had to manage and master varying knowledge, and demonstrate agility in these skills, which corroborates Locsin's (1995; 1998) theory of empowered caring. Improving communication and education comprised some of the helpful nursing behaviours outlined in Section 2.4.3. Basics of nursing care in this study were not problematic. Nevertheless, interweaving cancer, critical care (including technical) and ethical knowledge sometimes proved difficult. Despite nurses' experiences suggesting areas of deficit, families did not note any deficiencies in nursing care and talked of nurses who were skilful in managing those different areas of practice. In addition, nurses who had confidence in skills in these domains would be more likely to use technology to manage dying as described in Section 7.3, or make decisions to dispense with technology.

Empowered caring (Locsin, 1995; 1998; Falk Rafael, 1996; 1998; 2001) was implicit in many nursing accounts: displaying caring behaviours with patients and families while managing technology. To reach this empowered caring (discussed in Section 1.5), pathophysiology knowledge should be interwoven with caring, which then presents a challenge to a dominant (medical) paradigm. However, in this study, knowledge and confidence deficits threatened nurses' ability to implement empowered caring, as opposed to simple power issues. This reflects the complex and dynamic nature of power issues that Endacott *et al* (2008) alluded to and challenges empowered caring theory to explore beyond notions of power.

While doctors had the dominant voice in DFLSTs, nurses had a greater role in EOLDs, emphasising the earlier point about the increasing Involvement in care (OT 3) for nurses progressing along the continuum (see figure 8. and figure 9.). Many doctors discussed nurses' inclusion in DFLST processes, but this was not always reflected in nursing accounts. This highlights Johnson *et al* (2000)'s point that other voices contribute to EOL narratives in varying, and sometimes unequal, ways. Supporting colleagues was important, however, there was little allusion to this being about power or wanting to progress in nursing or gain medical respect.

As I described in Sections 6.5 and 6.4.3, nurses may not lead decision-making but, depending on confidence and experience (only sometimes commensurate with grade), do challenge doctors' decisions and might influence DFLSTs or EOLDs. In this study,

nurses showed varying levels of input in decision-making, and therefore differing individual meanings applied (GOT 2), but perhaps surprisingly in light of the literature in Chapter 2, some did not necessarily seem to want greater involvement. Equally, families did not demand greater involvement of nurses. One patient however emphasised the advocacy role of nurses in managing expectations. This echoes Zussman's (1992) perception that nurses have a particular advocacy role in critical care. Advocacy in my research was important for unconscious patients, especially in the absence of family, and was about increasing the patient perspective, where the voice could not be heard. This was interesting because some nurses held team values in decision-making above prioritising patients. The patient as priority has greater resonance in the final Section (7.3) in this chapter where there is split between care for families and care for patients, as reflected in OT 1: Family versus patients: split loyalties.

This study has shown that some nurses do not see decision-making, and subsequent withdrawal, as their role and indeed do not want that responsibility at all. This demonstrates, again, how these participants ascribe, what might be construed as, lesser meaning to decision-making (GOT 2) in their role. Active withdrawal was, incorrectly, associated with killing by two nurses, reiterating knowledge issues that would need addressing before greater involvement could be contemplated. Doctors and nurses found meaning in their team decisions through examining their own values and also through how they facilitated decisions for families and patients. There was much conscious reflection on how self impacts EOLDs and DFLSTs. Patients articulated the importance of family involvement in decision-making, and families expressed their perceptions that they were involved (contributing to OT 3), in line with a shared approach, that they would rather not have the responsibility of involvement, or that the situation was out of their control because the patient decided when to move to EOL. These findings are similar to Johnson *et al* (2000) and Slomka (1992) who found that a negotiated, shared approach dissipates responsibility to everyone involved. This might ameliorate some of the personal dissonance (OT 4) referred to earlier.

Personal philosophical stances on how far life should be preserved were reflected in doctors' and nurses' notions of black, white and grey philosophies of DFLSTs. Involving a senior nurse to advocate for patients did not always appear to help, contrasting with some literature (Vincent, 1999; Kirchhoff and Beckstrand, 2000; Prendergast and

Puntillo, 2002; Ferrand *et al*, 2003),[30] but echoing the SUPPORT study findings (SUPPORT Principal Investigators, 1995). Slomka's (1992) theory, which pertains only to doctors, suggests the limits of technology and medical failure accepted had to be reconciled in order for death to be negotiated. Yet, as my research highlighted, nurses', patients' and families' roles have to be considered because they have such an impact on death trajectories. As we have seen here, there is a genuine desire by consultants to 'do right' by the patients and families, involve nurses and to get DFLSTs, EOLDs and EOLC right.

7.2.3 Empowering involvement: a *non-sequitur* with dying patients?

Facilitating involvement in care (OT 3) requires active engagement of those with whom decisions are made. A distinction can be drawn here between empowered caring and empowering nursing practice. Empowerment is the process by which people gain mastery over their lives (Rappaport, 1987). Being aware of nurses' own norms and how these influence practice is essential for empowering others, in this case patients and families. In this study, there were some slightly controversial issues around empowerment. This related to family and patient involvement but also to nursing and other specialities involvement in clinical decisions, not just EOLDs. In critical care, empowerment is rarely used in the sense of true user engagement and involvement, as there is an inherent power imbalance located in the extreme illness of the patient. This was evident in patient communication and delirium problems, and for families, with the extreme emotions induced by critical situations. Johnson *et al* (2000) delineated the imbalance of power with families and patients set against professionals, but my research raises deeper issues of power differences between professional groups and between patients and families.

Patients who died evidently had limited association with empowerment and again the locus shifted to families. A recurrent problem of *family versus patient: split loyalties* OT 1)*,* arises. How do we know that family contributions to care reflect and mean the same as wishes of dying, incapacitous patients? In essence, at whom is empowerment targeted? As seen in this study, for dying patients, it is targeted at families because autonomy is limited. Empowerment is also an issue for surviving patients who felt they

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[30] None of these are UK based studies. The BMA (2007) recommends senior nurse presence at EOLD/withdrawal.

had a diminished voice when in critical care. Critical illness, unwillingness and ignorance around facilitating communication and family involvement sometimes took precedence over patients. Indeed, patients sometimes prefer to defer to doctors as the burden of decision-making is too great (like with families in 'overcooking empowerment' described in Sections 6.5.3). Although Personal dissonance (OT 4) and Emotions of EOL work (OT 9) predominantly refer to practitioners, this did also include families' feelings around EOLDs. As in the previous theme, this can be extrapolated to families. Furthermore, too much involvement may even lead to family conflict if the family feel they 'own' the decision and have internal disputes about which course of action to follow. In this study, nurses encouraged but did not pressurise involvement, an empowering activity that arguably led to family feelings of being truly '100%' involved. However, nurses could have facilitated patient involvement better by working harder at communicating with those impaired in this respect.

7.2.4 Emotions and associated strategies

Emotions of work (OT 9), particularly in DFLSTs also proved an important part of EOL and the continuum as described in 6.5.4. Emotion ranged from feeling 'cold', experiencing conflict to finding it 'hard'. Where it was hard, some nurses and doctors tried to disengage — to step away from travelling patients' and families' journey, even if only temporarily (i.e. they chose not to engage fully with families and *not* to plan for EOL) — affecting subsequent prospects for EOLC. Consequences of dealing with uncertainty, prognostication, patients, families, decision-making and EOLC can be very emotionally laborious (introduced in Section 1.6) for doctors and nurses, as this study shows. Indeed, this labour may even preclude or delay prognostication and subsequent decisions affecting rapidity of dying (and sometimes deterioration) described in Section 7.1.

Yet, if no decisions are made, as in Section 6.4.4, *non-decisions*, the patient remains in limbo and does not move to EOL and cannot receive EOLC, threatening the prospect for a timely and good death. This, like truth-telling, represents a threat to the trust that Seymour (2001) articulates. Again, this lack of decision-making was related to prognostication. Displacement of decisions to patients by nurses, families and doctors (not noted in other literature), might have been a strategy to ease burdens of DFLSTs. Displacement to patients' conditions further contextualises intuitive knowing, alongside experiential knowledge, but is used to avoid additional personal burden. Nurses' personal dissonance and moral distress at this is evident in Section 6.5.4. What is

interesting for this study is how there were emotional ramifications beyond nursing, which the literature as described in Chapter 2 focuses on, to oncologists who had a covenant with patients, to (all but one) critical care consultants who talked of torture, and for palliative care doctors. Furthermore, becoming involved in decisions to move to EOL was harder if there was a background relationship with patients, building on the covenant of care theory raised previously in Sections 1.8 and 2.3 and shown in the findings in Section 6.5.3.

A perception of division of labour is seen from various participants throughout this study. Nurses and doctors both perceived that they supported families, particularly oncologists whose remit shifts once judgments of prognostication and decisions have been made to move to EOLC. This is represented in Figure 9 by the arrows for each practitioner group. For oncologists in particular, their work in particular moves to realms of emotional labour (Hochschild, 1983), since their knowledge and specialty is no longer essential, but their relationship with patients and families is: a medical endeavour switches to a humanistic endeavour. A personal penalty of having to live with the consequences of any decisions, makes consultants simultaneously more likely to engage and collaborate with others to dissipate that burden or emotional labour, but equally, may also make them less likely to take on board everyone's wishes because unilateral decisions might be easier. Individual doctors too, did not appear to act in consistent ways; responding to families' differing needs as I described in Section 6.6.4 in a case-by-case manner. Styles and personalities can account for this too. Nurses here did not fully recognise doctors' personal burdens, or emotional labour, and equally, did not seek greater involvement in DFLSTs to counter doctors' prominent role. One possible reason for this is that greater involvement in DFLSTs would require greater emotional labour investment. Countering this, as discussed in Section 1.6, emotional labour has been regarded as key to successful care for nurses. Whether they should avoid it or force themselves to engage is debatable and is developed in Section 7.3.2. This also draws in issues around caring and engaging, raised by one nurse, where there may be little reciprocity (see Section 1.6), because of unconsciousness or grief. Compelling unwilling nurses to participate in emotional engagement around DFLSTs and EOL risks increased emotional dysfunction, delayed EOLDs and potentially poor family communication. While it could be argued that retaining choice is necessary to avoid emotional dysfunction (related to Emotions of EOL work OT 9) (and recognising that this is a coping strategy), such avoidance could increase negative consequences for families and patients. As such, nurses' complicity through self-protection and coping could be challenged from an ethical and moral

perspective. Allowing prolongation of dying, once futility has been defined and reached (OT 5), goes against our professional code and there is a moral imperative to challenge — although nurses need support to do so — so that nurses can reflect the virtue ethics associated with nursing raised in Chapter 1.

For inexperienced nurses, lack of critical care and ethical knowledge further prevented them from contributing to DFLSTs and some EOLDs which could address their frustrations at perceived 'wrong' choices in decisions and prognostication. This not only creates moral distress, as Seymour (2001) notes, but also personal dissonance (OT 4), for this study. Periodic disengagement and, or, detachment (and I will describe this in Section 7.3.2) were ways of managing this, as was putting aside one's emotions after the event. Importantly though, satisfaction was noted where engagement did occur, which might mitigate emotional costs.

Seymour (2001) suggests nurses are particularly at risk of moral distress because of the importance placed on the emotional component of critical care nursing in the context of diminished power and a sense of anger and frustration. She outlines twin demands on nurses of maintaining subjectivity and managing emotions. Nurses in this study were expected to display presence, as part of their caring attributes, but as we saw there are emotional implications for nurses doing this. That a patient talked about emotional cost to staff was of note, as was the value that families placed on overt display of emotion (reflecting Emotions of EOL work: OT 9). Practically, therefore, there might be value in nurses being aware of how families positively regard displaying emotions, but to also consider emotional costs in doing so.

7.3 Reaching the end of the continuum

Reaching the final stage encompasses how, once dying is known and has been diagnosed, dying trajectories are managed in the context of technology. This stage describes how aligning families', practitioners' and patients' needs in differing ways, through emotional engagement or even disengagement at EOL (beyond DFLSTs), to reach the culmination of the continuum, seen in Figure 9. and the final of the three global order themes (also incorporating OT 2): a good death.

7.3.1 Knowing

An emerging awareness of dying, raised first in Section 6.3.3, for families and practitioners, and subsequent decisions made, characterised what it was like and what it meant to consider EOL for practitioners, families and to some extent patients.

For bereaved families and patients who did not survive, hope for survival was diminished to the point that it needed reframing to hope for a good death. Such rapid adjustments required coping strategies and professional skill (Pattison and Lee, 2009). Avoiding the *unthinkable* (referred to in OT 6), even when facing overwhelming evidence, was not limited to families and patients. Here again, practice elements surface around early discussion and truth-telling and focus on coping strategies.

As discussed in Section 7.2, nurses and doctors have the opportunity to affect and influence progression of patients' trajectories which are heading, at varying paces (but, in these latter stages usually at a much quicker pace), along the continuum toward death (seen in Figure 9.). Opportunities are fed by clinical cues for families and nurses. Clinical information is interpreted to reach conclusions about patients' conditions. In turn, cues corroborated the consultants' and nurses' feelings that patients were dying before they were actually able to articulate this in quantitative values of futility (e.g. they had a 1% chance of survival). Deterioration, independent of withdrawal actions, made this element concrete and accelerated this part of the journey. Developing the earlier concept of knowing in relation to DFLSTs in Section 7.2, here there was tacit knowledge of dying, which might manifest as intuition. One doctor and one nurse talked of knowing when to move to EOLC, even before clinical cues and legal points for withdrawal of care and decision-making could be articulated. This related to reaching

and defining futility (OT 5). Doctors also recognised that nurses also knew which patients would decline and need EOLDs. This issue around tacit knowledge emphasises how difficult it is to move between stages along the continuum. It is not always clear where patients should be, and legal issues around withdrawal compound this.

One nurse, however, was very clear that intuition played no part in her knowing. For that nurse, when a patient was dying, clinical cues, such as skin colour, informed her knowledge about when patients were dying. She articulated those cues and drew on a lot of death and dying experience, in contrast with other participants. She could prognosticate dying. A practice issue arises here of how to teach recognition of those very subtle clinical cues around not only knowing when to raise the DFLSTs but also in recognising imminent dying. There was often convergence with nurses' and doctors' perceptions of knowing, but not always.

A parallel to diagnosing dying can be found here, essential for timely EOLC. Furthermore, diagnosing dying enables moves forward along the continuum (visually represented in Figure 9) and prevent prolonged dying. Indeed, this cornerstone of good EOL practice is iterated in this study and dealt with in more detail towards the end of this chapter. Moreover, this study highlights how, at any point, further critical illness deterioration can accelerate the trajectory and even turns it into an 'unexpected' death. Death was not always expected, perhaps as DFLSTs were only made in the last hours of life, or the historical antecedent of cancer was not an issue because it was not diagnosed until the patient was dying, or the patient was in remission. Unexpected death, as raised in Section 7.1, (and likewise a rapid deterioration that accelerated the continuum) was perceived as difficult to manage by participants but even in situations of unexpected death, families could still regard death as good, moderated through excellent care. No patient talked of wanting what I term here as sudden death.[31] In fact, no patient talked of the importance of rapidity of dying at all. Unexpected death undoubtedly affected the rapidity of moving to EOL and potential for EOLC, but this was not insurmountable in achieving a good outcome: good death. This is discussed further in section 7.3.5.

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[31] As distinct from sudden death, where there is no warning, here there may be a few hours warning

7.3.2 Engaging or detaching in EOLC

Building on earlier notions of empowerment, nursing involvement and emotional costs from Section 7.2.4, the potential for nurses' roles in EOLC increased once DFLSTs had been made. Indeed, nurses might take ownership of EOLDs but not get as involved in DFLSTs, as outlined earlier in relation to OT 3: Involvement in care. Their prominence along the continuum was less notable until this point, the final stages. Yet, a phenomenon of disengagement was also noted for some nurses in EOLC. When palliative care became involved or critical care doctors directed EOLC, those nurses' EOLC practices were shaped by doctors, rather than being critical care nurse-led, despite an opportunity for nurses to develop niche care. Conversely, when nurses did engage in EOLC, it provided a sense of meaning about their care practices that transcended preoccupation with technology in critical care. Critical care doctors frequently talked of involving oncology expertise, which related to respect for different disciplines and their knowledge (OT 7), and some talked of drawing on palliative expertise at EOL, in contrast with some nurses who were more likely to 'make do' with their level of knowledge or step back and hand over EOLC planning to specialists, rather than involve others to enhance their knowledge. This contrasts with another of my studies where senior critical care outreach nurses would actively seek this involvement to enhance their care.[32] Whether critical care nurses actually want to participate, and thus specialise, therefore becoming emancipated as some might term it, is the crux. Nursing empowerment, as I discussed in Section 7.2.3, was the confidence to take control and make autonomous decisions. This requires skill, assertion and recognition of one's own strengths and in this study appeared to only come with cancer, critical care (technical and physiological) and ethical knowledge, alongside experience. Nurses were described as showing caring behaviours such as 'presencing', giving personal explanations, dealing with anxiety, actively listening, hand-holding, described by Locsin (1998) as true caring actions. This demonstrates how patients and families experience presence, authenticity and caring at EOL within a critical care environment where technology usually predominates (and still may coexist, or even direct at EOL). Caring nurses were described by all families and all but one patient, who held a contradictory view. The depth of caring at EOL was noted by families and patients who remarked where nurses had gone 'the extra mile' and really engaged. In Section 1.6 I argued for a different kind of engagement, as a nursing fundamental, to that presented by existing theory. With families, engagement is more

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[32] See Appendix 8 for forthcoming related publications.

obvious but with patients who cannot respond, existing notions of engagement and presence, such as that identified in Finfgeld–Connett (2008c), have to be challenged. Seymour (2001) describes how nurses express their emotional engagement through bodily care of patients. Yet, for these nurses it was more than bodily care and was about empathy and presence.

Disengagement might then be viewed as a coping strategy to deal with emotional costs of caring for the dying (OT 9), as it was with non-decisions in the previous section (7.2). Some nurses evidently saw patients' dying well as successful care; shifting emphasis from a curative stance and further emphasising how emotional investment and engagement might mean successful care. Dying well then becomes these critical care nurses' revised covenant, whereas before the goal was survival.

Ensuring patient and family involvement at this final stage (see Figure 9) lay in personal philosophies of care and was not uniform. Nursing accounts showed increased need for nurses to take ownership of their level of involvement — either through experience, cancer knowledge acquisition (as nurses working in a cancer critical care) — application and acquisition of ethical principles and, or, confidence to challenge. By doing so, nurses might be able to engage with the continuum at earlier stages (around diagnosis, critical illness and DFLSTs), thereby increasing their advocacy and EOLC potential. This is extrapolated in the next chapter in relation to the general potential around cancer nurses' roles before critical care nurses become involved.

7.3.4 Patients, practitioners and families: contrasting pictures of good death

Patients' talked about what was important to them at EOL. Family presence and reaching conclusions, such as having affairs in order to relieve families' future burden, were important. Patients did not intimate that preserving the integrity of personhood, Seymour's (2001) second principle, was important in their accounts. Yet, families' and nurses' findings did point to the importance of personalising care activities that affirm personhood, such as applying perfume, to represent valuing patients. Zussman's (1992) threats to personhood related to patients being reduced to medical pathologies, which was not an evident issue in my research. I therefore, concentrate on Seymour's notion of personhood. As I discussed in Section 1.9, Seymour's (2001) theory seems to allude to familial interpretations of personhood. Both families and nurses described

ensuring the patient remained a person as contributing to a good death and important part of EOLC. No patients, however, raised this as important. Ensuring patient as person, Seymour's (2001) personhood, would seem to correlate with the pervading theme of families versus patients (OT 1). This would suggest that patients place less value on preservation of personhood and highlights where there might be scope for development in her theory through further research.

All but one critical care doctor felt it would be important in a 'good' critical care death for patients to remain unconscious in order to minimize potential pain and discomfort. Literature around good and bad death in Sections 1.7 and 1.8 suggests awareness of dying as a prevailing principle for good death. However, this study's findings suggest otherwise. Patients and families did not raise this as important in their experience. End-of-life care, therefore, needs to encompass both family and patient needs.

Developing this good death issue further, there appears to be an opportunity for development in Seymour's (2001) and Lofland's (1978) theories around rapidity of the trajectory of dying and potential of human agency on good death. The essence of the findings: the continuum (represented in Figure 9), is about the trajectory of moving toward dying through each of the GOTs. Lofland's (1978) trajectory of dying refers to modern dying and the issue of technology in death, which Seymour (2001) developed. A high level of technology means that "deceleration of mortality-producing processes is maximized" (Lofland, 1978, p.27). This is a prolongation of dying. Conversely, this study showed that once DFLSTs or EOLDs are made to withhold or withdraw technological intervention, death can even appear to be accelerated at times. Reaching and defining futility (OT 5) is an important facet to this perceived acceleration. This is seen in nursing accounts where death is described as quick. Too quick is also seen as 'bad', relating to my earlier discussion on expected and unexpected deaths in Section 7.1.2. There is limited opportunity for adjustment at each stage of the continuum because events happen too quickly. For instance, a dying patient on the continuum, despite delay or not delay in EOLDs, who rapidly deteriorates (because of natural events or human agency), will accelerate through the stages in Figures 8. and 9: DFLSTs, withdrawal or withholding, and EOLC, towards death.

Seymour (2001)'s mismatched dying trajectories raise how technological recognition of dying lags behind acknowledgement of fact. Negotiation of natural death, where dying is resolved in the minds of those involved (Seymour, 2000; 2001), was alluded to in certain professional accounts, notably one critical care doctor, but this was not seen as

entirely necessary for a good death, as exemplified through unexpected death. In my research, technology was used to aid recognition of dying but nurses (and only nurses) also talked of how a person looked to determine their view of whether a person was dying or not. To make nursing visible in this study, as discussed in Sections 1.5 and 2.4.3, nurses might apply their knowledge of knowing when patients are dying, legitimise this through watching patients' demise through technology, and potentially control it (as described next). This was part of reaching and defining futility (OT 5) described earlier. Johnson *et al* (2000) explains the role of technology in creating and effecting a 'neutral' death: yet, as I outlined in Section 1.9, technology could be used to manage movement along the dying continuum (see Figure 8) and even help create a good death. This would suggest that technology is far from neutral in the context of my research.

Technology might aid in articulating nurses' knowledge about when patients will die. Conversely, at EOL the dilemma of monitoring was also raised: monitoring might make the very final stages of dying easier to diagnose but nurses were loathe to encourage monitoring because families fixated on monitors rather than patients. The nurses' role and practice implication here then was to refocus the family on the patient and away from monitors. Nurses or doctors could manipulate technology in order to facilitate diagnosing dying; but families could use it to help recognise dying, which was useful for two participants. This suggests that dispensing with technology when families want it is inappropriate (where patients are unaware).

7.3.5 Choreographing death: a realistic prospect in critical illness?

Death could also be choreographed through technology, as I discussed in Chapter 2 and as exemplified in GOT 3 and in Figures 8. and 9. However, orchestration and control was difficult when the trajectory was accelerated or stages almost bypassed (such as when patients were diagnosed in critical care with an aggressive cancer), iterating the limited opportunities for adjustment through each stage as raised in Section 7.3.1. Playing God, the crux of human agency, as two nurses identified in relation to withdrawal, has further emotional implications which also need consideration beyond Sections 7.2.3 and 7.3.3. Withdrawal or withholding and DFLSTs were enacted by nurses and doctors, as Sections 6.5 and 6.6 outlined. There was an element of individualism there too in doctors accounts; not all doctors allowed nurses to withdraw and not all nurses wished to do this. Limited self belief in some nurses who were

reluctant to engage in EOLC suggests they did not trust themselves to provide good EOLC, or found it too emotionally taxing, reflecting how emotions associated with EOL work (OT 9) could impinge on ability to care. Poignantly, nurses who *did* enact withdrawal practices gained some satisfaction from doing so, contrasting with rationales for disengagement. These nurses were reconciled to the ethical implications and practical consequences, i.e. death. They understood their actions were in contexts of patients who were going to die anyway and their actions did not cause death but merely precipitated inevitable death in dying patients at earlier times. Until the moment of withdrawal there is an argument that dying would be prolonged but this is an unknown entity in many senses. Whether death would have been quicker with no critical care intervention is debatable and uncertain.

Trajectories of dying, therefore, could be even be enhanced by sensitive and supportive withdrawal practices. This is where Involvement in care (OT 3), at the final stages, became important for nurses who could maximize their contribution and shape the course of the final stages. Reluctance was expressed where families were not known to nurses, emphasising the importance of rapport when carrying out an intimate and consequential act. Families who experienced nurses as those carrying out withdrawal or withholding saw these processes as signifying good death. However, occasionally withdrawal practices meant dying was protracted, which created dissonance for nurses in particular. This reiterates my earlier point that human agency impacts upon a good decision. The decision to withdraw might be 'good' (Johnson *et al,* 2000) but I extend their notion that this equates to good optimal care and suggest that this is not necessarily the case. Prolonged dying might occur as a result of poor EOLC, beyond decisions. I make a distinction between the theory that focuses on decision-making being indicative of good EOLC and argue that while they are interwoven, EOLC needs also to be considered as a separate entity. This has been made clear through the findings and in each of the figures 7. 8. and 9.

Death, the culmination of the continuum, had many facets. As described thus far these did not always adhere to notion of good or bad death outlined in Sections 1.7 and 1.8. Good death had elements of preparedness in Chapter 1, but in this study in unexpected death there were family accounts of the end process being good. Small improvements were suggested to enhance EOLC (outlined in findings and Chapter 8 next) and EOL but overriding feelings were of positivity, suggesting that even in critical care, good death is possible. Facilitation of good death depended on human agency, either through advocacy, humanising care, personalising care and facilitative practices.

Being in control of the trajectory of dying was explored in the findings but was a limited concept for patients; family empowerment was more applicable (see Section 6.5.6 and 7.2.3). Being comfortable was universally regarded as important with differing approaches according to medical and professional specialty. Although comfort issues were discussed throughout Seymour's (2001) accounts, explicit principles of comfort care were not drawn in Seymour (2001), Melia (2001; 2004) or Johnson *et al* (2000). Comfort principles were an area that nurses could take ownership of and, as described previously in relation to OT 3 and OT 7, it is here that EOLC holds particular importance. They could and did manipulate technology and drugs to enhance patients' comfort, demonstrating how nurses could shape trajectories through their knowledge-base, in effect choreographing aspects of dying to ensure a good death (GOT 3). Nurses also talked of family comfort, for instance facilitating family members to share patients' beds at the very EOL where appropriate. Comfort for critical care doctors focused on maintenance of an unconscious state, through adequate sedation and analgesia, whereas nursing aspects of comfort were wider and encompassed personalised comfort (applying patients' favourite lotions; using patients' own pillows, nighties and blankets; playing patients' music. More usual aspects of nursing comfort included: positioning; ensuring pressure relieving devices were used; ensuring warmth; regular mouth, eye and skincare; ensuring hygiene needs were met and patient aesthetics were maintained). These were distinct and more practical helpful nursing behaviours than those noted in Section 2.4.3.

Knowing and meeting the minutiae of comfort care highlights where nursing knowledge at EOL might surpass medical critical care knowledge. Palliative care specialists viewed this aspect more holistically, talking of choreographing death and acting according to patients' wishes. They were clear their focus was the patient, which, as we saw in OT 1: Family versus patient: split loyalties, was not always so clear for some critical care doctors and nurses, particularly around DFLSTs and timing.

At the point just before death and dying along the EOL continuum, a greater unified approach became clear; a drawing together of all disciplines for the benefit of patients and families. The arrows representing practitioner involvement in Figure 9 show how for a brief time practitioners are all engaged in the process but critical care doctors, oncologists and even palliative care specialists were unlikely to be as involved in EOLC as nurses at the end of the continuum. Sharing control was therefore one aspect. Specialities differed in their philosophies of EOLC, also evidenced by various literature

(Melia, 2004; Johnson *et al,* 2008; Parker *et al,* 2008) described in Chapter 2. The main element of transferability or *moderatum* generalisation (Williams, 2000) in relation to specialities is that the patient remained the priority over all for palliative care and oncologists, which highlights differing philosophies that have to align when caring for the patient. There were more subtleties in critical care nursing and medical practices with family priorities at times superseding patients', such as delaying withdrawal to allow families to arrive in time to witness death.

A sense of closure, which patients indicated would be important by setting affairs in order, was not always achieved. Achieving closure was an important part of Kehl's (2006) concept analysis for a good death, but it was not always possible and despite its absence it did not detract from an overall sense of a good death. For families and nurses, participating in after-death care contributed significantly to a sense of closure. While noted in Chapter 2 as a helpful nursing behaviour, professional doctorate limitation mean that this aspect of the findings is dealt with outside the confines of the thesis (see Appendix 8). Closure could also be achieved by enacting withdrawal for doctors and nurses. Rapidity of reaching death was very fast, the mechanics of withdrawal difficult, and this structured participants' responses to death. Timeliness was crucial to processes of EOLC and featured highly throughout, at prognostication, decision-making and at EOL. Nurses and doctors could use critical care technology to alter the chronology of death: even delaying or hastening it to meet patient and family needs.[33] Time to death from withdrawal is consistent with the UK median: 2-4 hours (Wunsch *et al*, 2005), and faster than local hospital ward time of 40 hours.[34] Prolonging dying was at times evident and ostensibly was done to enhance family's sense of closure. Indeed, it may be unethical to rush families and make DFLSTs so patients can be transferred from critical care, the implied dilemma in the 'difficulties' referred to in *Comprehensive Critical Care* (DH, 2000). However, this has to be tempered aginst patients' autonomy. Such actions could arguably undermine the value of the dying patient, and iterates a recurrent issue for practice: prioritising patients against families. Yet, dignity and individualism in care practices demonstrated valuing patients.

Family burdens were deemed important by patients and clinicians alike, although none of the families interpreted their experiences as a burden, more as painful experiences.

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[33] Hastening only takes place within legal parameters and doctrine of double effect

[34] According to local audit data for the LCP-ICU from 2007-2009, a local audit for hospital deaths in CCU in 2007 and an LCP audit for all ward deaths in 2007

Privacy was important for families, but interestingly not discussed by patients. One family member described how no time alone was afforded to her son to be with his dying father, outlining the importance of privacy. Dissonances in communication, or facilitating communication, also negated trust in, and between, professionals. Distrust therefore had prospects for family involvement, rapport, and EOLC. This was particularly important to families and patients (as shown when contradictory information was given to families, for example).

Linking back to Seymour's (2001) notion of integrity of the natural order, the manner of death affects the legacy for families. How patients die affects those who witness it. A new diagnosis of cancer or a sudden unexpected critical illness versus a more expected death, as seen in the excerpts throughout this study, impacted on EOL in different ways, but not always as anticipated. Even when a cancer had been diagnosed for many years, critical illness-related death could still be unexpected and shocking. Curative intent of cancer treatment, and remission, in relation to patients' deaths and families' subsequent acceptance cannot be underestimated. However, as I have argued and, in accord with Seymour (2001), good death could still be achieved in high technology death. I would further suggest it is possible even in unexpected death.

Nurses' communication with families about patients as people was highly valued by patients and nurses alike and was a simple way of illustrating how a legacy is left. This behaviour is resonant of that seen as helpful nursing behaviour at EOL in Chapter 2. The study interviews themselves became a legacy in which families could share their feelings and experiences about patients' death and care. I did not simply turn up, turn on the tape recorder, interview and then leave. I was invited to have coffee, lunch, view family homes as part of the interview process. In bereaved families' interviews, a tangible presence in the form of photos and belongings of the patient who had died was evident in the naturalistic setting of home. This highlights the benefit to families of bereavement interviews in reconstructing the person as a legacy and the cathartic, therapeutic nature of interviews noted in Section 4.2.

The moral rectitude of ignoring family wishes because of presumed patient wishes is difficult because families needs also have to be met and are verbalised, whereas patients' are not. Prolonging dying is one example of this, though prolonging suffering was seen as unacceptable. If the patient was not apparently suffering then family autonomy was occasionally placed over that of patients. Furthermore, patients held

care of their loved ones as utmost and in this sense the moral dilemmas in this regard are mitigated.

7.4 Summary

In conclusion, this chapter has outlined study findings against the conceptual and theoretical underpinning outlined in Chapter 1 and introduced further issues not previously seen. Practice implications are made explicit in the concluding chapter. Recognition of impending death undoubtedly impacts on the possibility for a good death and yet, for families, time was less relevant. Even in very rapid death, families, by proxy, experienced 'good death'.

This study gives a whole picture of what EOLC is like and the experiences and emotions of being part of, bearing witness to, deciding about and providing care in EOL. The continuum I presented in Figure 9. gave a visual representation to what was happening around EOL in cancer critical illness and the experiences in my research. Cancer patients entered a continuum toward death at the onset of critical illness, and this critical illness might have been present at diagnosis or the critical illness might precede the diagnosis (as in the trajectory described with patients with certain haematological cancers). At this point patients and families outlined oncologists as their primary source of contact, and although other health care professionals such as cancer and community nurses will accompany patients as they present with critical illness, in these patients and families' experiences oncologists were prominent and remained closely alongside during the critical illness and beyond.

I changed my methodology to reflect this phenomenon as this study evolved, as I described in Section 4.4. Critical care doctors and nurses were introduced at this point (and critical care nurses might also have been involved around onset of critical illness in the form of critical care outreach, alluded to in one or two accounts). As DFLSTs were made, professional roles converged and everyone was involved at this point of the continuum and although how much individuals engaged with decision-making varied, each group was still present. As the continuum progressed towards withdrawal and EOLC, oncologists stepped back from the continuum. Critical care doctors and nurses shared withdrawal but EOLC was predominantly within nurses' domain. Critical care nurses' roles became increasingly prominent toward death, with families viewing them to be highly important in withdrawal and EOLC. The palliative care team, when

they did get involved, sometimes also helped with DFLSTs and were important at the EOLC of the continuum, but they did not get involved with minutiae of care and patients and families did not see their contribution in their experiences. Nurses varied in their contribution with some articulating their presence and role clearly, particularly around managing timing and speed along the continuum for the benefit of families and (or) patients, and in these experiences there was greater satisfaction and reward in their care.

The key theoretical contributions from my research are summarised below. The continuum develops the theories of Seymour (1999, 2001), Melia (2004), Johnson *et al* (2000), Slomka (1992) and Lofland (1978) in the following respects:

- In *Stepping onto the continuum* (Section 7.1) I explored the notion of natural order and a neutral death and related this to the continuum presented here. I concurred that subversion of the natural order, with unexpected death, was a threat to natural or 'neutral' death. However, in this study, unexpected death was an unusual phenomenon because all patients had cancer. Participants varied in their beliefs about whether cancer meant having forethought about dying and EOL. This was particularly evident with the first theme presented in the findings and stepping onto the continuum. Unexpected death did not necessarily preclude achieving good death, which develops Seymour (2000; 2001), Lofland (1978) and Johnson *et al* (2000). A distinction between theory and the findings can be found in speed of dying trajectories. Speed through human agency actions (e.g. controlling dying) is not addressed in the theories explored. Nursing influence in relation to controlling and rapidity of dying is not explored in existing theory, both of which proved important in this study. Furthermore, the unique participant characteristic of cancer also affected speed as outlined above. Having both cancer and critical illness made it more difficult to decide how quickly to progress along the continuum for various reasons discussed above.

- I have expanded Seymour's notion of personhood to include patient perspectives. No clear conclusions could be drawn because some patients did not wish to engage with EOL issues but for those who did; preserving personhood was not seen as an issue. Yet, consonant with Seymour (2000; 2001) and Melia (2004), in my research it was important for families and professionals. Ensuring personhood was, however, contradictory for

professionals who felt an tension between treating families and patients. This issue can be seen as a development on the theories described. Tensions in caring for both pervaded my study which has not previously been alluded to in research.

- The principle of integrity of trust between families and health care staff could again be related to information–giving in this study and prognostication. Articulation by participants about *Dual prognostication* and *Thinking the unthinkable* raised the notion of threats to trust. Doctors talked of needing to be clear of where patients were heading before making DFLSTs. Leaving patients in limbo threatened trust. Some nurses also displayed reluctance to trust their own ability to provide EOLC and contribute to DFLSTs and prognostication. Here overlap between Locsin (1995; 1998), Falk-Rafael (1998) and Seymour (1999; 2000; 2001) is evident. Knowledge and confidence were necessary for nurses to have trust in their own practice at EOL.

- The duality of prognostication develops the ideas from the main theories discussed that uncertainty creates tensions in decisions to move to EOL (Johnson *et al*, 2000; Seymour, 2001). I have outlined how another level of uncertainty confounds and compromises the potential for moving to EOL. My findings in relation to heuristics and prognostication, in particular, develops Seymour's concept of 'knowing' as a factor in moving to EOL for doctors. I concur and suggest this knowing extends to nurses too. Where they are confident in their beliefs about expected trajectories for patients, this will impact on their feelings about how DFLSTs are managed. These feelings can be dissonant or positive, depending on the congruence between doctors and nurses, and the autonomy afforded to nurses to carry out EOLC, and be involved in DFLSTs (and at the very least in EOLDs). This emphasises the team-working and importance of consensus that Melia (2001) discussed. However, I develop Melia (2001; 2004) by suggesting nurses and doctors roles are not clear-cut and that, as we saw, doctors displayed caring, wished to carry out withdrawal and expressed emotion in EOLC.

- Decision-making and EOLC are, on one hand, inextricably bound because, in EOLC, actions to withdraw can precipitate death and, therefore, planning is important. There is a distinction between EOLDs and DFLSTs, and nurses have

greater prospects for involvement here, which challenges Melia's (2004) theory that this is under doctors' domain. Lofland (1978) described the factors necessary for the briefest duration of dying but did not outline how human agency around planning for EOLC could impact on death's brevity, which has been revealed in this study. I further develop existing theory (Johnson *et al,* 2000; Melia, 2001 and Seymour, 1999) by retaining some distinction between decision-making and EOLC, and its subsequent potential for a good death. The planning element of EOLDs mitigates the potential for bad death. Nurses' involvement in this was key. They may not necessarily always be part of the DFLSTs, but however involvement in EOLDs and how to withdraw in particular was an important nursing role. They could, and sometimes did, control and enact withdrawal that was indicative of good quality EOLC.

Furthermore, I have developed good death theory by demonstrating the application of a continuum that allows for death in an acute and critical care setting with unaware, unconscious patients. There is a unique perspective, not previously researched, with surviving patients' wishes in the absence of acutely dying patients' voices. These patients contributed from both a cancer perspective — living with life-limiting illnesses that equally did and did not define their responses, and from a critical care survivor experience — they were expected to die and did not. Those who could, contribute their vision for EOLC, which centred less on self and comfort, related more to concern for family. This contrasts with family, doctors and nurses, who universally felt EOLC was about ensuring comfort. A sense of a good death for clinicians in particular was primarily about an unaware death; a sedated and analgesia supported death. Living with an acute and/or chronic illness, like cancer, did not somewhat surprisingly, necessarily predispose thoughts of dying and death. As in Seymour (2001) death was perceived in many cases as unexpected. This study's findings have developed the ramifications of these for EOLC and subsequent emotional costs.

Shared care has not previously been described in other theory and my research related to care between oncologists, palliative care and critical care doctors in relation to decision-making. This held challenges but there was deep respect for others' knowledge domains and a mutual sharing of knowledge, particularly around prognoses, that enabled mutual collaboration and there was a sense that generally this was essential for decision-making. Occasionally, particularly with unexpected dying trajectories, either because of rapid demise, new cancer diagnosis or remission, diagnosing dying was delayed or avoided, for emotional or knowledge reasons, and

decisions were displaced to patients. This had adverse implications for enacting EOLC, because there was limited time as a result of a non-decision. The speed of the trajectory and progression through each stage was fundamental to this study. The role each health care group played, along with family and patients, was evident and subject to many different factors, such as confidence, emotions and knowledge.

What is also unique to my research is the added complexity in prognostication in situations where patients might present critically ill (which can be related or unrelated to their cancer), and also have a prognosis from cancer that needs consideration. This requires assessment of prognosis and creates an added level of uncertainty beyond critical illness that is described in theory, and as we saw affects the potential for EOLC. There was still a sense from palliative care that, in some cases, palliative care should take over all care and patients be transferred. This was at odds with patients, families, critical care doctors and nurses, none of whom expressed a wish for EOLC to be outside critical care. This was a surprising finding, given the current UK policy drivers for preferred place of death in a hospice or at home.

End-of-life decisions and care were inextricably linked in participant accounts. End–of-life care plans, as part of EOLDs, were made sometimes at DFLSTs or later at EOLDs (sometimes these processes were indistinct and were combined), but sometimes not and they were decided by either bedside nurses, or the doctor undertaking withdrawal of treatment. Many nurses lacked confidence to contribute fully to EOLC partly because of the added aspect of dual prognostication and cancer knowledge deficits. However, nurses' voices, when articulated, were heard by doctors. When it came to EOLC, nurses varied in regard to enacting withdrawal with some assuming responsibility for this.

'Patients versus families' is not expressed in the continuum in Figure 9 but was an underlying dialogue throughout for this patient group. At the very end of life this was particularly pertinent because many doctors and nurses talked of caring for family and placed less emphasis on the patient. This may be because of the very fact these patients are deeply unconscious often right from admission. There were considerations around assuming patients' wishes, but in the absence of those patients' wishes, it was difficult to avoid and families were relied on. Families relived dying patients' death and lived with the legacy which had implications for the need to care for families, as long as dying was not overly prolonged.

These comprise the essence of the findings, the continuum presented in Figure 9. Implications for nursing and wider practice, each of which will be discussed in depth in Chapter 8, can be summarised in the three stages in Sections 7.1, 7.2 and 7.3 leading up to EOL, managing decisions and finally, EOLC and good death:

Leading up to EOL (Sections 7.1 and 7.2):

- Facing mortality and ongoing waning positivity for survivors needs to be addressed (OT 8: Story of cancer and critical illness).
- Earlier discussion should be had around EOL issues (GOT 1: Dual prognostication; OT 8: Story of cancer and critical illness)
- Prognostication should be accurate (GOT 1: Dual prognostication; OT 7 Domains of knowledge)
- Stories offered participants some therapeutic benefit (OT 8: Story of cancer and critical illness)
- Nurses' role in prognostication and DFLST could be increased (GOT 1 and 2: Meaning of Decision-making; Dual prognostication; OT 3: Involvement in care)
- Nurses' confidence and technological competence needs to be considered at EOL (OT 7 Domains of knowledge; OT 3: Involvement in care)
- The importance of advocacy is highlighted (OT 1: Family versus patients: split loyalties; OT 3: Involvement in care)
- Health care professionals care facilitate acceptance for families and patients (OT 3: Involvement in care; OT 6 Thinking the unthinkable)
- The speed of progressing towards dying is often unknown but at EOL withdrawal processes can shape the timing of death (OT 2: A good death; GOT 3: Care practices at EOL: Choreographing a good death)

End-of-life care and good death (Sections 7.2 and 7.3)

- There were burdens for doctors and nurses imparting information and in giving EOLC (OT 4: Personal dissonance; OT 9: Emotions of EOL work)
- Emotional costs had ramifications for practice (OT 9: Emotions of EOL work; OT 3: Involvement in care)
- Varying approaches to DFLSTs were noted (GOT 3: Care practices at EOL: Choreographing a good death; OT 3: Involvement in care)

- Engagement could enhance the EOLC experience (OT 9: Emotions of EOL work)

- Palliative care involvement could enhance the EOLC experience (GOT 3: Care practices at EOL: Choreographing a good death)

- Practicalities of EOLC were managed well by nurses and doctors (OT 2: A good death; (GOT 3: Care practices at EOL: Choreographing a good death)

- A good death could be had in critical care (OT 2: A good death; (GOT 3: Care practices at EOL: Choreographing a good death)

- Planning because of the rapidity of death was essential (OT 2: A good death; OT 5 Reaching and defining futility; OT 6 Thinking the unthinkable; GOT 3: Care practices at EOL: Choreographing a good death)

- Caring needed to underpin EOLC (OT 3: Involvement in care)

- Good EOLC means quality EOLC (GOT 3: Care practices at EOL: Choreographing a good death)

The findings in this study not only develop the work of Seymour but also present a possibility for application beyond cancer to other critical illnesses. This is developed further in the concluding chapter.

Chapter 8. Conclusion and implications for practice

This concluding chapter emphasises practice implications arising from study findings and makes recommendations for future practice, since the underlying impetus for this study was to explore and improve practice. I begin by briefly recapitulating points made in each chapter. The final sections outline practice and research implications arising from the study. I conclude with a final summation.

8.1 Chapter Summary: From Introduction to Chapter 2

The introduction provided a background for the study and outlined policy around why critical care patients might die in critical care and drew a distinction between EOLC and palliative care. It introduced the influence of technology on dying critical care patients and why cancer patients might require critical care. I placed my personal practice background within this policy and wider background. Chapter 1 then presented conceptual and theoretical concepts related to the main study issues. I outlined curative paradigms in cancer and critical care. Good death was characterised in this chapter as knowing and expecting a trajectory of death and good death theory is centred on palliative care patients, families or professional perspectives. Surviving critically ill cancer patients' potential contribution to this theory was explored. I explored caring in both cancer and critical care nursing and how this might affect EOLC in practice, and noted emotional labour in both cancer and critical care nursing. Distinctions and similarities between cancer and critical care nursing attributes were drawn, in particular the need for technical competence. In chapter 2 I noted a particular focus in the literature on outcomes research in palliative care, EOLC and critical care EOL with qualitative studies concentrating primarily on professional perspectives and, less so, family perspectives. Patient perspectives were minimal in cancer care, but present, yet in critical care they were absent. Themes for research centred around decision-making with few studies exploring good death and EOLC. A dilemma was highlighted around gaining dying critical care patients' perceptions of care. This provided evidence for using family, and surviving patient sources. Having cancer added a dimension to critical care EOL research not previously studied. Furthermore, this chapter highlighted how no EOL studies in critical care had sampled patients, families,

nurses and doctors from varying specialties. Cancer and critical care studies were critiqued in the literature tables. Descriptive or interventional methods, most notable in the literature tables, would not answer *why* EOL was experienced how it was. I described how using qualitative methods, and a collaboration of proxy assessments (surviving patients, families and nurses) would enhance understanding of EOLC in critical care for cancer patients, and *how* nurses, doctors, patients and families experience this. Nurses' voices in DFLSTs and EOLDs were less notable than doctors', which is inevitable when doctors take overall responsibility for DFLSTs. Critical care nurses, on whom the nursing focus is in this study, struggle with EOLC but are well placed to act as advocates. Level of involvement and literature pertaining to involvement in EOLC or DFLSTs were discussed, with an overriding theme of families, patients and nurses wanting a greater role. Chapter 2 also delineated how despite established cancer research in palliative care there are no published studies that encompass critically ill cancer patients moving to EOL and EOLC. Cancer adds a complexity to critical care not previously considered in the literature and in, turn, critical illness threatens the course of cancer treatment.

8.2 Chapter Summary: 3-5

In Chapter 3 I outlined why interpretive hermeneutic phenomenology was appropriate from a nursing, philosophical and methodological perspective. I drew on some of Heidegger's central tenets such as *Dasein* and the premise of revealing the hidden, the true meaning of being. I introduced Heidegger's hermeneutic circle, moving between the parts and the whole, as method. I also outlined my own personal reasons for choosing phenomenology in relation to my orienting framework. Chapter 4 provided methods used in this study. Processes for accessing participants, ethical issues, and analysis were outlined. I outlined changes to the sample as I progressed and reached a final sample of: bereaved families, critical care nurses, critical care consultants, palliative care consultants, oncology consultants, and surviving patients. Aims of the study can be summarised as establishing what EOLC was happening around EOL in a cancer critical care through experiences; what that was like; what that meant for participants; the timeliness of moving to EOLC; the impact of cancer on all of these issues and subsequent implication for nursing practice. I undertook in-depth interviews, using a hermeneutic phenomenological approach. Analytic processes were exemplified through seven stages of analysis using study findings to show how themes were

reached and coding processed. A rationale for using Attride-Stirling's (2001) thematic network analysis alongside van Manen's (1997) coding frame was given for managing the large volume of data generated. I outlined issues of transparency and rigour in my processes. Chapter 5 explored reflexivity in professional doctoral research and how it related to practice issues I encountered. Levels of reflexivity and the importance of supervision and research diaries were noted. How reflexivity might help illuminate and challenge some of the realities and tension surrounding practitioner-research was examined. Reference was drawn to doctoral outputs to account for changes made to practice during the doctoral process, which could not all be discussed within the confines of a professional doctorate thesis.

8.3 Chapter Summary: 6-7

Arguably the most important chapter, the findings, outlined the main themes and essence. It presented the unique experiences of witnessing, experiencing, moving toward and providing EOLC to dying patients in a cancer critical care unit. I outlined three main, global order themes (GOT) and two organising themes (OT). These themes were *dual prognostication (GOT 1)*; *thinking the unthinkable (OT 6)*; *meaning of decision-making (GOT 2)*; *involvement in care (OT 3)* and *care practices at EOL (GOT 3)*. These five themes were regarded as aspects of the journey to death, the primary issues affecting EOLC provision. They represent the essence of the findings: a trajectory of dying along a cancer continuum toward death and beyond. What happens in a critical care unit was represented by experiences throughout the findings. The impact of cancer had many facets and affected stages all along the continuum (see Figure 8). Families and patients travelled the entire continuum. The trajectory along the continuum could be quick, especially in unexpected death or newly diagnosed cancer. The speed or rapidity of moving along the continuum was influenced by cancer and critical care prognosis; decisions; emotions; families; withdrawal or withholding practices. Each of these was considered for their impact on timing and the professional interaction between nurses and doctors in particular that might potentiate these issues.

Critical care doctors were particularly involved at critical illness, prognostication, DFLSTs but varied in degrees of involvement at EOL and EOLC. Some were happy to devolve responsibility and others preferred to enact withdrawal. These doctors saw it as too great a responsibility for those not making DFLSTs. Some nurses, however,

expected to undertake this as part of their role in EOLC. Where nurses' roles were prominent and diminished was noted. Opportunities for nurses to be protagonists of EOLC were not always seized. This was partly because doctors did not allow this by retaining ownership of most aspects of care, even at EOL, but also related to some nurses not engaging in EOL issues, including DFLSTs, for reasons related to confidence, emotions, knowledge or experience. Advocacy in nursing was expected by some patients and families. This would enhance patient and family autonomy but advocacy was not always upheld to the level it could be, especially where nurses did not fully engage. As the continuum progressed beyond DFLSTs, nurses' roles became more prominent and some nurses assumed total responsibility for withdrawal practices and EOLC. This depended on nursing confidence and being reconciled to patients' deaths. Many nurses delineated how they managed EOLC, by facilitative family working, centring on patients, team working, respecting wishes, respecting patients as people and advocating for patients. In unexpected death, this continuum of life, cancer and death in critical care was expedited and heightened, and the role of critical care doctors and nurses was more pronounced. Nurses then saw they were travelling more of the journey with patients and families, and in new diagnosis, all of the journey. Palliative care input was limited to the very EOL but could be useful as mediators between nurses and doctors. Where doctors based DFLSTs on 'knowing' doctors, they waited until they had a clear indication of futility, or fact of dying, before making DFLSTs. Some patients faced an uncertain future after critical care; this was seen in waning positivity. Critical illness, and facing death, had brought their mortality to the fore, even more than their cancer for some. The inability of patients who are dying to contribute at EOL emphasised the voices of patients who had survived, but these patients showed greatest concern for their families after death. Their own concerns related only to general notions of being comfortable. Awareness of dying or preparedness for dying was not noted as important by patients or families. Importance was placed by all participants on privacy, dignity and comfort at EOL. Oncologists had a greater role than anticipated at the outset of the research, supporting patients and families all along the continuum. They were, however, felt to be less evident at the very final stages of EOL and not involved in EOLC.

Participants' experience of witnessing or being near death was generally good, and perhaps surprising given the failure to meet conceptual interpretations of good death raised in Section 1.7 and the literature chapter which highlighted various deficits in EOLC. There was a notable issue around treating families versus critically ill unconscious patients. This was a tension for all except palliative care. Families

reached realisation of inevitable death and moving to EOL at different stages of the continuum. Realisation could be facilitated by nurses and doctors. The continuum presented highlights the significance of timeliness of each stage and how that influences potential for a good death.

Interviews helped give meaning to experiences and helped some participants to piece together what had happened. There were emotional implications for families of moving along the continuum, as expected, but for nurses and doctors there were emotional consequences to their practices. Burdens of EOLC and decision-making for doctors and nurses were noted and coping strategies drawn on. Engagement and detachment was seen as a professional coping mechanism along the continuum and some nurses, in particular, chose to avoid EOLC and leave it to palliative care specialists. Varying engagement and detachment throughout did not appear to affect families' or patients' experiences adversely.

The meaning EOL and EOLC held for participants varied, emphasising the individual nature of EOL. Care was regarded by participants as good communication, honesty and involvement in care and DFLSTs, which echoes helpful nursing behaviours in Section 2.4.3. It was also represented by nursing as a profession, the care given at EOL, family support, and the empathic, sometimes emotional, demeanour professionals maintained. Caring was not unique to nursing but nurses played a greater role in caring at EOL and especially in sensitively supporting families. Technology could be distracting from care, but equally it could be used to enact good EOLC. Nurses were the key players in managing technology at EOL, but technological competence was rarely mentioned by family and patient participants as important. Importance of family, and patients where possible, in contributing to DFLSTs and EOLC plans was clear. Despite apparent focus on family needs, each professional talked of patient comfort as paramount. Achieving good EOLC and a good death was influenced on many levels. A prevailing finding was that good death could, and almost always did in family experiences, occur. Patients raised little to suggest how care in critical care at EOL could be improved. Small suggestions from families and patients were incorporated into practice developments. From professionals there was an inference that palliative care and EOLC could be improved but how this should occur was not always clear.

The discussion chapter revisited literature, concepts and theory from earlier chapters and applied these to the findings. I developed the essence of the findings: the

continuum in light of theory. I explored literature and theory in stepping onto the continuum, travelling along the continuum and how human agency affects the trajectory and reaching the end. Development of theory from Seymour (1999; 2000; 2001), Lofland (1978, Johnson *et al* (2000) and Melia's (2001; 2004) theory in particular was explained. I noted potential for development to her theory of a negotiated natural death in relation to the fact that all patient participants had cancer. Unexpected death did not preclude achieving good death which contrasts with that implied in Seymour's (2000; 2001) concept of subversion of natural order. This might be related to the fact all patients had cancer, even in those diagnosed in critical care, or in remission. Cancer and critical illness made it more difficult to decide how quickly to progress along the continuum because of difficulties in prognostication which added another level of complexity to the fatality aspect of Lofland's (1978) dying trajectory and Johnson *et al* (2000) notion of indeterminacy. The rapidity, and influence of human agency, of how patients and families move along the continuum to EOL, was not seen in Seymour's work. The role of nurses, beyond EOLC, was also not evident. I discussed her concept of personhood and developed this to include patient perspectives but found it difficult to draw clear conclusions because some patients did not wish to engage with EOL issues. Interestingly, for patients who did, preserving personhood was not seen as an issue. Managing tensions in treating patient versus family was a development on Seymour's (1999; 2000; 2001) and Melia's (2001; 2004) theories. Threats to trust present in Seymour (2001) extended beyond information-giving to encompass nurses' reluctance to trust their own ability to provide EOLC and contribute to DFLSTs and prognostication in my findings. I highlighted that knowledge and confidence were necessary for nurses to have trust in their own practice at EOL. I also developed Seymour's (2000; 2001) premise that intuition legitimised DFLSTs. Heuristics seemed to have greater prominence than intuition in this study, with doctors and nurses using heuristics to inform choices. The discussion around emotional labour developed both Seymour's (2001) and Melia's (2004) belief about nurses' moral distress and extended it to explore how emotional labour, particularly for doctors, may even preclude or delay prognostication, subsequent decisions and lead to periodic disengagement along the continuum. I drew on Hochschild's (1983) emotional labour work to highlight the emotional cost of EOLC work and extended this beyond nursing to examine the clear burden on doctors.

I finally developed the area of EOLC, since this did not form part of Seymour's (1999; 2000; 2001), Melia's (2001; 2004) or Johnson *et al*'s (2000) work which concentrated on natural dying or neutral death. I discussed how decision-making, withdrawal and

EOLC were often difficult to separate and controlled timing toward death. I suggested critical care nurses might develop this area of practice as an area they can possess expertise over, superseding other specialities and creating a knowledge base that becomes associated with this aspect of their profession. This led onto Falk-Rafael's (1996; 1998; 2001) model of empowered caring. I challenged her notion that empowered caring related to power bases and suggested it was, in this study, more about nurses' confidence in their knowledge base that prevented them from undertaking empowered caring. Empowered caring in nursing was evident where technological and pathophysiological knowledge were combined and interwoven with the art of nursing and caring. The main difference between her theory and the findings appeared to be that nurses did not relinquish caring attributes in order to move ahead in nursing. If anything, nurses who gained some reward or satisfaction from EOLC embraced caring attributes. Here nurses applied their critical care nursing knowledge to provide empathic caring and presence for the benefit of patients and families. They might demonstrate this through management of technology, such as being able to undertake withdrawal and disregarding monitoring. Consonant with Seymour (2001) this was also about preserving patients and families sense of self, respecting them as people and facilitating some kind of normality.

Application of Locsin's (1995; 1998) theory of technological competence in caring can also be seen in discussion of the findings, developing the issue of empowered caring. Nurses did seem to need technological competence, confidence and knowledge to enact withdrawal and manage EOLC fully.

8.4 Implications for practice

Having laid out my desire to change practice at the outset in the introduction, I now outline potential practice development areas.

I see implications from this study arising in several areas: leading up to EOL, EOLC and ensuring a good death and after-death care. I relate these to the findings and to the thematic translation and description and the continuums presented earlier (Figures 8, 9 and 10). I have focused on nursing implications for practice, since this is a Doctorate in Nursing Science but where wider professional implications were clear I have raised these. I suggest areas for potential practice development in this chapter and have outlined areas developed through practice in Appendix 8. After-death care is dealt with outside of this thesis. I outline these in a loosely constructed manner that follows the continuum but some of the principles overlap.

8.4.1 Leading up to EOL

1. Facing mortality and ongoing waning positivity for survivors needs to be addressed.

1. Findings associated with the Organising Theme (OT) 1: Story of cancer and critical illness outlined how patients who survive cancer critical care have specific survivorship issues that extend beyond simple critical care survivorship issues. These patients step off, even if only temporarily, the continuum towards death, but may encounter the same issues at a later time in their illness course. This means there are complex issues that may need to be followed up. Facing mortality and potential ongoing waning positivity about cancer needs to be addressed. Specific physical sequelae related to pain, that might suggest recurrence, is not seen in other critical care follow-up models. Therefore, there is scope to develop cancer critical care follow-up.[35] Current practice models frequently use nurses as key-workers in cancer care and nurse-led critical care follow-up. Therefore, nurses are well-placed to take on and move forward with this development.

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[35] The Clinical Nurse Specialist in critical care and I have recommended the follow-up clinic in critical care. I have recently applied for, and won, funding to undertake more research into this area which is underway.

2. Earlier discussion should be had around EOL issues

2. Alongside OT 1 where stories encompassed having to consider what a cancer critical illness means for their mortality, findings from Global order theme (GOT) 1: Dual prognostication iterated how facing mortality might mean that earlier discussion around preparing for dying and death is warranted; particularly as long-term survival of these patients is poorer. Discussion of the potential for critical illness might also be necessary earlier along the cancer treatment pathway. Who should carry out these discussions is subject to debate, as exemplified in OT 3: Involvement in care. If nurses do not possess adequate knowledge about facts and figures around survival in this area, doctors might be better placed to do this. Yet, as we saw, prognostication is difficult for anyone in this arena because of paucity of data. However, there would be a nursing role in supporting these discussions, particularly where nurses might be patients' key cancer workers. It should also be noted that families and patients might not wish to hear this information. Being aware of patients' and families' readiness to hear this information should be carefully judged. Hope held deep meaning for participants in this study. As such, there is an argument about preserving personhood and autonomy in respecting this and balancing between truth-telling and preserving, or reframing hope.

3. Prognostication should be collaborative and accurate

3. Progressing along the continuum, the importance, and duality of prognostication (GOT 1) becomes even clearer when faced with critical illness alongside cancer. Defining futility (OT 5) was a consequence of prognostication. Where possible, prognostication should be as accurate as possible. To optimise this, both cancer and critical care specialities should liaise before discussing with families and patients to ensure the picture they present is consistent and unified. Prognostication is a shifting dynamic and as such needs revising at various points along the trajectory, emphasising the need for repeated family and case-conferences. Where poor prognosis is clear there should be early introduction of palliative care, and nurses should be able to initiate this, where appropriate, so that patients' symptoms are well managed and EOLC timely.

4. Relaying stories can offer participants some therapeutic benefit

4. The opportunity to tell stories, as OT 1 outlined, offered participants a way of remembering and making sense of the critical care experience. This extended beyond OT1 to each of the other OTs and GOTs, including specifically OT 9: Emotions of EOL work, for practitioners. For some participants this contributed to closure, either of the critical care episode or, for some families, formed part of bereavement processes. Some patients with cancer highlighted the value in having the opportunity to discuss EOL issues. This highlights the importance of bereavement research, and in-depth research with patients about EOL issues, which is often shied away from. In this research, my being a nurse and practitioner-researcher helped credibility in accessing these participants.

5. Nurses' role in prognostication, DFLSTs and EOLDs could be increased and management of technology might be key to increased prominence

5. There is potential for nurses to increase their prominence and role in DFLST and EOLDs. This was evident in GOT 1: Dual prognostication and OT 3: Involvement in care, and beyond that to GOT 2: Meaning of decision-making, and eventually to managing EOLC in GOT 3: Care practices at EOL..Nurses also have a role in prognostication of death, where they can use their critical care knowledge to accurately predict death timing. This means death and EOLC can be planned for in a timely manner by those at the bedside. Nurses need increased knowledge to make meaningful contributions around prognostication and need confidence to challenge doctors in this regard. Confidence and knowledge building I therefore see as essential for nurses. Lack of nursing confidence in knowledge about ethical and cancer issues in this study could potentially be ameliorated by increased cancer knowledge. Limits to knowledge, however, have to be acknowledged. Not every nurse can know everything, and perhaps it is sufficient to allow those with greater knowledge and confidence to participate more. Allocating patients at EOL to those with confidence in their ability to contribute and provide EOLC might mean greater nursing involvement, less disenfranchisement and timelier EOLC. Those lacking in confidence might learn from shadowing these nurses. Developing this, technological competence in critical care is important. Nurses first need to understand technology to be able to manage it at the difficult scenario of EOL, and even use it to enhance EOLC. As the sampling issues highlighted, very junior nurses are not best placed to care for these patients as they are

still learning the technology. This then, might affect their ability to confidently judge when and how to enact withdrawal and stop or reduce technological interventions so family members can focus on their dying relative, rather than surrounding technology.

6. The importance of advocacy is highlighted

6. The importance of advocacy for patients and families is apparent in OT 3: Involvement in care and GOT 2: Meaning of decision-making. Nurses were the natural choice for advocates but struggled with tensions between managing patient and family care. Sometimes, dying was prolonged as families' needs were met. Patients also emphasised the need for nurses to facilitate communication through adequate aids, in order to ensure patients' participation in their day-to-day care planning. Nurses, therefore, have a role to play in advocating for both families and patients and have to return to core nursing principles of respect for care, comfort, privacy and dignity to ensure EOLC and EOLDs are optimal.

7. Health care professionals' care can help facilitate acceptance for families and patients

7. Reconciliation to death, and facilitating acceptance was the role of both doctors and nurses. This was exemplified in OT 6: Thinking the unthinkable and in aspects of the GOT dual prognostication (in relation to diagnosing dying or predicting death). Families reached realisation that death was inevitable at varying points, as OT 5 showed. Nurses could subtly manipulate information from clinical cues to suggest to families what, and when, the outcome was likely to be. Explanation through visual recognition helped in this (e.g. nurses pointing out to families when patients' colour changed, indicating more imminent death). This nursing skill of reinforcing the expected should be fostered by nurses and the wider team. Sensitively approaching truths about patients' conditions was one way of facilitating acceptance around this.

8. The speed of progressing towards dying is often unknown and subsequently affects potential for EOLC

8. The speed at which families and patients moved along the continuum varied highlighting a role for reiteration of information. Their information needs were evident in GOT 1: Dual prognostication (and this could sometimes even coincide with information needs around diagnosis). Who should impart this information depends on the point along the continuum and nature of the information (see practice implication 2). There is a need to recognise the varying speeds and how human agency (such as reaching and defining futility [OT 5] and GOT 2: Meaning of Decision-Making) can have an effect on speed. This issue of speed also has ramifications for practice tools such as the LCP-ICU, which at present is limited to prompts and is an unwieldy document to fill in given the short timeframe to death, following diagnosis of dying.[36] We have reviewed and revised this into a shorter document in light of audit and these research findings.[37]

Leading up to EOL, in particular, has implications for processes of care; recognition that patients are dying must be achieved before further stages are properly considered. However, as we saw, this is incredibly complex and requires a team approach for prognostication, diagnosis of dying and preparation for EOL. The context within which these processes occur, namely the critical care environment, the speed of the trajectory, the dual prognoses and impact of cancer has a huge bearing on how EOLC will be played out and the practice implications for EOLC are discussed next.

8.4.2 End-of-life care and good death

9. Emotional costs have ramifications for practice

9. The burdens, emotional costs and personal dissonances experienced in EOLC were, at times, great for doctors, families and nurses, as seen with OT 9: Emotions of EOL work and OT 4: Personal dissonance. Collaboration between teams eased burdens,

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[36] Less than 25% of eligible deaths in CCU were placed on LCP-ICU. Compliance with filling it out was poor (see Appendix 5).

[37] I was originally reluctant to consider use of LCP-ICU for this reason, believing it to prescribe withdrawal but on examination I noted some scope for individualising care and withdrawal practices and therefore opted, along with the generic LCP nurse, to make RMH an early interest site.

especially through early introduction of palliative care, emphasising the importance of shared care and DFLSTs in cancer critical illness. Rare conflict between oncology and critical care was not necessarily threatening but viewed as part of medicine. Families were not always clear how much they should be involved in DFLSTs and the level of responsibility they had in decisions. Relinquishing involvement was also noted as a coping mechanism for burdens in families thus, teams should be sensitive to families' needs around too much empowerment. This raises a potential need for a framework to assess how much families wish to be involved in DFLSTs, EOLDs, and EOLC, and in what regard, which could be explored in a future study.

10. Varying approaches to DFLSTs have different consequences for moving to EOLC

10. Doctors varied widely in their approach to DFLSTs which in turn had consequences for nurses' roles and EOLC. Involvement in care, OT 3, encompassed this aspect of nurses' roles and how much they became involved in DFLSTs. Different approaches were also related to the meaning doctors applied to their decision-making (GOT 2) and personal dissonance felt (OT 4). Transparent decisions were important, emphasising the need for everyone to articulate their thoughts and processes. However, standardising approaches would not allow for individuality in care. Therefore, practice should focus on acceptance of different approaches and nursing strategies to ensure their voice is clear in all stages of the continuum. There is also a suggestion put forward here that to ensure transparency and unified DFLSTS, the healthcare team should meet before family conferences to discuss what will be said. Decisions were sometimes displaced to patients and became non-decisions: nature taking its course. However, this potentially could impact on EOLC, emphasising the need for continual assessment of the need for EOLC and palliative care involvement.

11. Engagement could enhance the EOLC experience

11. Engagement and disengagement was noted throughout the continuum. The 'Mother test', or a personal frame of reference, was also used by nurses and doctors as a way of humanising and personalising DFLSTs and EOLC. This was an important facet of two themes: OT 3: Involvement in Care, and OT 9: Emotions of EOL work. Varying levels of detachment throughout did not appear to affect families' or patients' experiences adversely. Engagement, however, enhanced care. Nurses and doctors

used disengagement as a coping strategy and perhaps this can be respected as long as patients and families always have access to support from at least one practitioner group: oncologists, palliative care, critical care nurses or doctors. Strategies to enhance engagement, such as talking about patients' personal lives, showing empathy and active listening, should be encouraged.

12. Palliative care involvement could enhance the EOLC experience

12. End-of-life care could be enhanced by palliative care involvement which moved beyond general principles of comfort, dignity and privacy to also consider in greater depth about what patients might have wished for. Nurses, as well as palliative care specialists, could also fulfil this role and where they did they gained satisfaction in applying their technological knowledge to EOLC. This, again, signified how the theme OT 3: Involvement in care was important and warranted specific inclusion in the findings. However, to do this, nurses needed to want to engage in palliative care, and have knowledge and confidence. Domains of knowledge, OT 7, proved important here. At this stage, the very EOL, cancer knowledge for nurses was less relevant. Involving families in practicalities of EOLC enhanced their experiences, emphasising how involving families in minutiae of care (e.g. washing) could help.

13. Nurses and doctors are well placed to manage practicalities of EOLC

13. Practicalities of EOLC included: how withdrawal was enacted and processes at EOL and was represented in OT 2: A good death and GOT 3: Care practices at EOL: Choreographing a good death. Withdrawal was within both critical care doctors' and nurses' domain. Choosing extubation appropriately, choosing how to manage technology and understanding consequences to different withdrawal approaches suggests nurses need technical and ethical knowledge of each aspect before they assume this role. Doctors differed in allowing nurses to assume this role for varying reasons of nursing confidence, doctors' sense of ownership, protectiveness over nurses, sensitivity and concern for nurses. This was legitimised by the reluctance of some nurses to assume this role. In practice, nurses who feel confident to carry out withdrawal should be allowed to. Support should be given to those reluctant to do this, alongside examination and teaching of ethical principles around withdrawal. Different

approaches for withdrawal were noted to allow for individuality in care, suggesting standardisation of care in this respect is not appropriate.

14. A good death could be had in critical care. Planning because of the rapidity of death is essential.

14. A good death was possible in critical care, regardless even of new diagnosis, remission and unexpected death. Achieving it required factors outlined previously but also consideration of rapidity of death after withdrawal. This emphasises need for planning around withdrawal so that the rapid death that follows it can be optimised, and a good death achieved. Careful and timely planning is part of achieving a good death (GOT 3). Patients had greatest concern for their families, rather than themselves at EOL, and talked of vague notions of comfort as important in good death. Implications for practice in this respect are hard to draw on, other than underlining how patients believe family also assume priority at EOL.

15. Caring needs to underpin EOLC

15. Caring was important, and noted by every family and many patients. Caring attributes centred on showing they were concerned with patients and families as people, ensuring dignity, facilitating privacy but also being present, listening, demonstrating emotion and personalising comfort care. Caring was also noted in doctors' interactions, indicating that it is not limited to nursing. Nurses had a greater role in supporting and caring for families, as described in Chapter 7 in relation to OT 3: Involvement in care, implying they could foster this as well in increasing their role in EOL. Ensuring these aspects of caring permeates all aspects of EOLC is something to strive toward in practice.

16. Good EOLC means quality in EOLC

16. Quality was represented through communication, empathy, engagement and practical personalised care, and it can be achieved even in difficult circumstances of critical care. Forethought and planning helped ensure quality, however, even in circumstances where planning was difficult, because patients were rapidly or suddenly

moving along the continuum, there were perceptions of quality EOLC. This emphasises practice implication 14 above, and the how GOT a good death can be achieved through quality. How quality could be measured broadly was not outlined in the findings but Chapter 2 delineated appropriate measures of quality of dying in critical care. This is one potential way of managing issues around quality. Furthermore, ensuring user engagement in care planning and service planning might provide quality indicators that are meaningful to users.

8.4.3 Further implications for nursing

These implications highlight components of care, namely dignity, privacy, comfort, engagement and caring. These are outlined as specific contributions for improving EOLC, alongside other elements of planning.

I have outlined tensions for nurses in particular in managing these processes, contexts and components of care discussed above. These nurses had to integrate three knowledge bases: cancer, critical care, palliative and EOLC care. The difficulties in doing this were apparent, yet integration was still achievable. Many of these nurses engaged, and demonstrated empowered caring that reflects the changing power dynamic of critical care environments. This dynamic was tempered by a lack of confidence and this is an issue for nurses travelling the journey along the continuum with patients. The technological emphasis in critical care, as described in Sections 1.4, 1.5 and throughout, underpins the nursing in critical care. This emphasis requires critical care nurses to grapple with technology and successfully integrate it with the humanistic endeavours required at EOL for a good death. Helping nurses find ways of managing those tensions is an important dialogue to be engaged with and extends beyond nurses to doctors. I concentrate here on nurses, however, as they spend their 12 hours at patients' bedsides and encounter much of the sharp end of death and dying in critical care. If critical care nurses engage in this aspect of care, EOLC, this would have wider implications for the health service to provide adequate emotion support to these nurses for EOLC, such as providing (as we now do following on from this study), staff bereavement, counselling support and regular debriefing sessions. Partly addressing this, in the EOLC chapter I have written for a critical care manual that hopes to become standard text for critical care nurses (see Appendix 8d), I address technological issues in EOLC and withdrawal, to give scope for nurses to take the lead on this area of practice, and explore core nursing attributes such as engagement.

Giving nurses the confidence to take part in DFLSTs, and subsequently even take ownership of EOLDs and EOLC, also seems to require engagement with the knowledge base of cancer and a sound ethical understanding of withdrawal practices. This iterates policy deficits around knowledge and competencies raised at the beginning of the thesis in Section vi. Critical care doctors and nurses could be classified as Group B workers who have frequent contact with palliative care in the NHS core competencies in EOLC document (www.endoflifecare.nhs.uk) and, as such, should attain a certain level of competency (including a possible need for specialist training). These centre on five principles: 1. Communication, 2. Skills, Assessment and Care Planning, 3. Symptom management, maintaining comfort and well being, 4. Advance Care Planning, 5. Overarching values and knowledge. The competencies are not currently mandated and, therefore, require professional 'buy in', which risks poor uptake. A debate surfaces as to whether EOLC should be entrenched in everyday knowledge and practice or whether it should be a sub-specialty in critical care? This might be an area for further exploration in future research and practice endeavours. We try to equip nurses with a set of skills so they can deal with EOLC confidently but there is still scope for specialist practice and champions in critical care who could model these practices for others. Knowledge acquisition and confidence building are things we continue to address, with all new staff encouraged to undertake cancer care modules or the cancer diploma or degree, rotation options into cancer care, and teaching in critical care modules specifically around ethics and ethics in cancer care. Developing nurses' negotiation skills, to give them the confidence to challenge once they have the requisite knowledge and understanding, is a difficult area but needs addressing further, as does the fostering of a critical care environment that values each and every opinion. This needs strong modelling from senior nurses and medical staff and encouragement for nurses to give their opinion and to take on this aspect of care that could be a specialist area for critical care nurses to excel at, as we saw in some accounts. In choosing how certain care practices are implemented around withdrawal, for instance, nurses could demonstrate specialist and distinct knowledge. This would help address a lack of clarity in the critical care nursing role at EOL raised in Section 2.5. Further policy issues arise in relation to engaging users in service and care planning, and as advocates, nurses have a moral responsibility to ensure patients and family representation.

Moreover, a lack of nursing theory in critical care as raised in Chapter 1, and the limited applicability of existing theory that requires two-way processes between patients and

nurses, adds weight to an argument for development of a critical care nursing theory addressing this sensitive dynamic between caring for unconscious patients as well as families. Reciprocity was not necessary for caring and good quality EOLC, which present a challenge to theory.

8.5 A wider inference

Although the study aims related to the impact of cancer on EOLC experiences in critical care, the figure presented in Chapter 7 could be considered within a wider chronic or acute illness context of a patient and their teams and families encountering critical illness and moving toward dying and death. Figure 10 demonstrates how this continuum could be regarded for illness beyond cancer that has characteristics of the trajectory that cancer can take. Patients may present with illness, and diagnosis may or may not be given before that patient becomes critically ill. Critical illness might mean that stages to death are difficult to traverse, may be swift and EOLC may be difficult to plan for because of unknown elements in disease processes and prognostication. This uncertainty might be mitigated through good and frequent interprofessional communication. Dual prognostication can be fully explored between specialist and critical care teams and patients' conditions regularly reassessed for appropriateness of considering DFLSTs.

This continuum might apply to chronic illness like ischaemic heart disease, where patients might have symptoms managed for years before dying or where patients could present acutely unwell and die rapidly with diagnosis first made at critical illness, or to acute onset illnesses such as acute renal failure and immunologic or neurologic disorders. The role of nurses and palliative care might differ slightly in different areas of care but the level of involvement is likely to be similar. Nurses travel along the continuum with patients and families and, therefore, need to consider what skills and support nurses need to be able to access for this. Furthermore, emotional implications of travelling along the continuum extend to doctors and specialist doctors in particular. The support necessary for doctors to fully engage, and to do so without compromising their care covenants (which, in turn, might adversely affect moves toward EOL), needs further assessment. Furthermore, while patients and families travel the continuum their involvement is not always clear and as I have argued, nurses have a moral duty to ensure patients and families can contribute to care planning around EOLDs and

DFLSTs. As such, their involvement must be integral to each stage and practitioner groups need to be transparent in all decisions.

This study has also raised an issue around the split loyalties nurses feel in caring for patients who cannot respond and their families at EOL which could be extrapolated to other similar settings such as neurological nursing, nursing delirious patients and dementia care, to name a few.

Furthermore, while this thesis presents critical care nurses' roles, there is the potential for the nurses working with patients before they are admitted to critical care to shape the earlier course of the trajectory (Figure 10.). As I described in Section 2.5, junior cancer nurses (and even palliative nurses expert at EOLC), are sometimes reluctant to put themselves forward to influence DFLSTs. This, too, might be related to experience and knowledge, which would be worth exploring in the future. Here, specialist and non-specialist nurses have an important role in future care planning, as described in the implications section above. These nurses (such as clinical nurse specialists, critical care outreach nurses) can draw attention to prognostication, realigning expectations, and what that might mean for patients and families, as well as considering how delaying DFLSTs might affect future prospects for a good death and EOLC, particularly around admission to critical care (which has not been discussed in this thesis, but is an equally important and large area for discussion).[38] In contrast to critical care nurses' need for cancer knowledge, these specialist nurses (like specialists doctors) would need to understand what admission to critical care entails and the Pandora's box it potentially opens up to patients and families.

Palliative care team involvement might bridge the EOLC knowledge deficits that have been outlined in recent policy (DH, 2008; NAO, 2008) and there is scope for their involvement earlier in the continuum. With routine invitation into specialist and MDT discussions (as I described in relation to my own practice) they might also be able to contribute to treatment and care planning, at the dual prognostication stage.

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[38] I have also carried out research in relation to outreach and EOL decision-making prior to admission to critical care see forthcoming publications in Appendix 8.
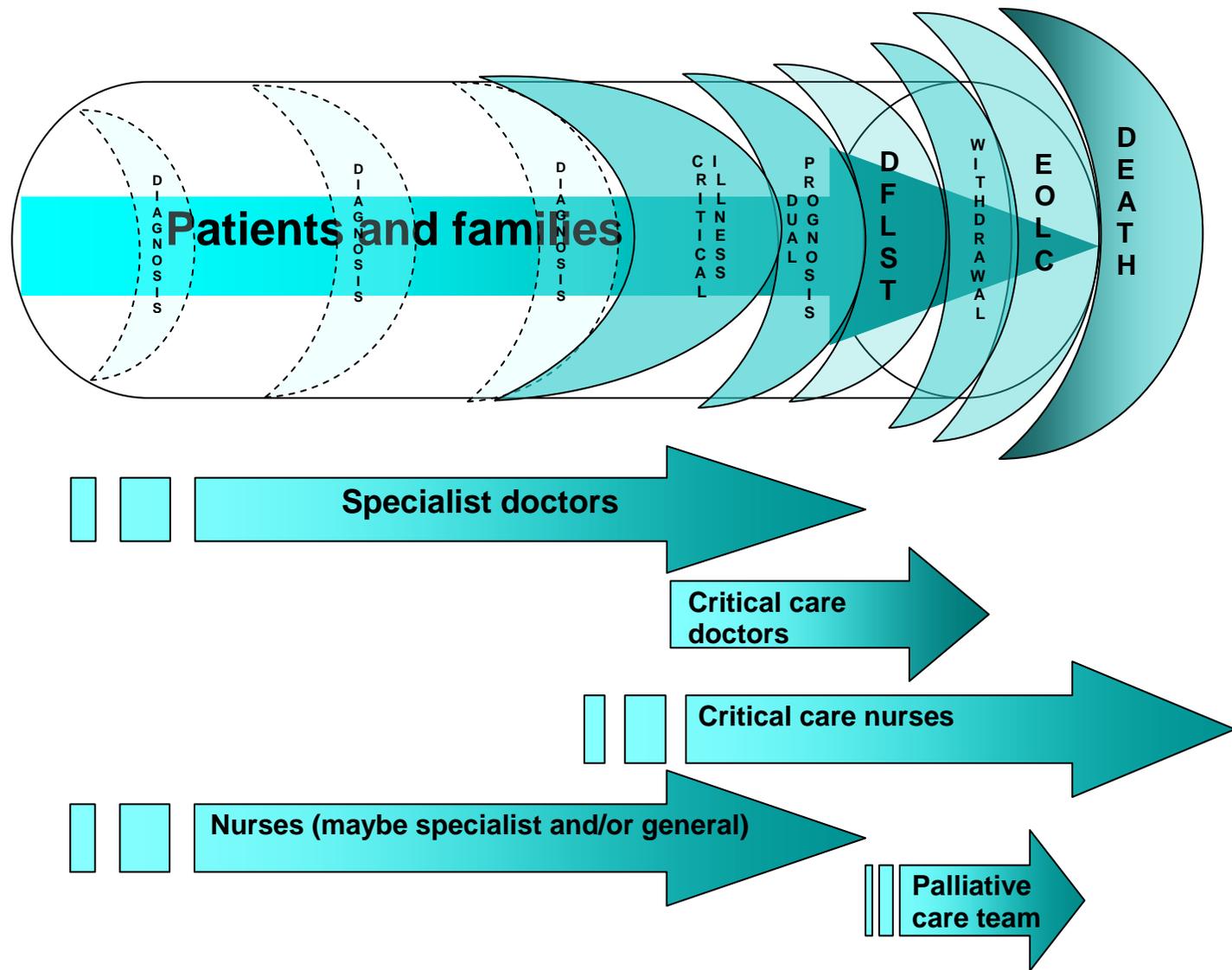
Figure 10. An End-of-Life Continuum in Chronic or Acute disease via Critical Illness

8.6 Limitations and future research implications

8.6.1 Limitations

In this section I outline practical, methodological and theoretical limitations of my research. Inclusion of dying, critically ill patients was obviated by their unconscious condition, therefore this aspect was missing. Recovered patients, therefore, provided patients' perspectives. However, because they were not actively dying when interviewed — although living with cancer *and* having been near death may have offered a unique perspective — this perspective was limited. Furthermore, I knew some of these patients, as I did some families, and this undoubtedly shaped the research interaction (although as I have discussed in chapter 5, I do not necessarily believe this was adversely). I was discomfited when dealing with poor practice disclosures where my colleagues were named, but I discussed this with participants as to what they wanted me to do with the information and how to address issues. I believe this issue would have been less awkward had I not been a practitioner-researcher.

The study setting is a specialist hospital. More complex cases may be admitted to critical care, cases that in other units may be denied admission. This may have had an impact on death and dying trajectories, limiting applicability. As a qualitative study, generalisability is limited to commonalities in experiences but, like applicability, these can be regarded in the context of wider literature, which suggest similar issues and my continuum demonstrates wider applicability. I have not presented what can be termed 'theory' as I defined it earlier but have developed others' theory through my work and have presented my findings conceptually using a continuum that can be applied beyond my research. Theoretical development might be part of a broader portfolio of future research that will be discussed in the next section.

The phenomenological method applied was not pure phenomenology. According to varying critiques, this is difficult to apply to nursing study method, but I have attempted to ensure transparency about all my methodological choices so as to provide meaningful answers to questions about EOLC experiences.

Specific limitations related to my sampling; I sampled few palliative care doctors and oncologists and with hindsight I would have increased the sample in this respect. However, their experiences still contributed valuable perspectives on EOLC and presented challenges for practice. I chose not to include specialist registrar doctors (at that time the most junior doctors in the unit) who may have had a different perspective than that of the consultants who are responsible for DFLSTs. Critical care outreach nurses, as I have mentioned, also have an important role to play in facilitating access and for critically ill cancer patients who do not access critical care their dying trajectory is quite different. I will discuss the implications for this as a potential future research study shortly. Patients I chose to sample varied in their ability to conceive death, perhaps because they still had cancer, and while it is possible this may have been a reflection on me and my interviewing (and I reflected on this in supervision), it might also have been reflective of those patients who chose not to discuss death as a personal issue, but more of a hypothetical possibility.

There is also a methodological issue around recall bias and timing of interviews. I did not interview straight after discharge or death for the good reasons I outlined in Section 4.3 but this inevitably might have had an effect on participants' recall, as verified by other research (Addington-Hall and McPherson, 2001; McPherson and Addington-Hall, 2004). Indeed, it might even have been too early at three months.

Several issues arose, outside of my aims, from the research prompted me to reflect on my aims, including lengthy discussion on futility from doctors, post-critical care recovery from patients and after-death care from nurses and families. Each of these I have utilised in different areas of my practice to ensure these findings are not 'lost' (see Appendix 8) but they did not necessarily contribute to my aims. However, I felt it was important to allow participants to discuss them as this contributed to the overall discussion about death and dying, which included EOLC.

The continuum I have presented describes what is happening and it does not prescribe for good death. However, this was not my aim. I wanted to capture experiences. Several issues arose around how withdrawal practice should be carried out and I have discussed these in Section 7.3. From a practice

perspective I would have liked to have developed this aspect further, and this again is a potential for future research in order to fully scope what quality EOLC entails from a practitioner perspective in relation to withdrawal and EOL practices. From family perspectives EOLC was good, although issues that arose from patients outlines areas, such as communication with communication-impaired or unconscious patients, in which nurses and doctors could improve their practice. I have taken these practical issues back to practice and tried to embed them in general teaching but it remains an ongoing process (as my current research – see Appendix 8 – is testament to).

I had originally set out with the idea that EOLC could be explored as distinct from decision-making, but as I have discussed, this was not feasible given their interwoven nature and this highlights the necessary role of planning for EOLC. I am not sure that this necessary created a limitation as I quickly responded to this as the participant accounts around care-planning testify.

I introduced the LCP-ICU part-way through the research, which was difficult as we needed to embrace it as an early-implementation centre but not all of the consultants were fully supportive of it in practice (although none discussed these concerns with me when I introduced it). I actually found significant discrepancies with it in use personally, especially in terms of its unwieldiness given its length, the dual prognostication that created difficulties in agreement between critical care and oncology teams who need to agree and diagnose dying, and the rapidity of dying in critical care. This led to a personal frustration that we needed a better document (see Appendix 8) and I have consulted the nursing staff in relation to this.

Furthermore, I am not sure I have fully considered how nurses could influence policy beyond the education and confidence issues that arose but, perhaps, this in itself is an important finding: nurses did not always make clear their role, nor how they could change practice. Those nurses who did describe their role in EOLC demonstrated a distinct role that could exemplify specialist practice and a, promisingly, more prominent nursing voice.

8.6.2 Future research

Future research implications fall into different areas and can be considered under broad portfolios of cancer and critical illness. I note areas for nursing and those outside of nursing and highlight only those I see as high priority.

Beyond nursing, there is scope to develop research into prognostication and prognostic modelling in cancer critical illness, since prognoses had a large bearing on the ability to move to EOLC and along the continuum, and the subsequent speed of movement. To date, this has been researched in relation to existing models but not models specific to cancer and this would equip teams with better information about expected survival and thus might change admission criteria for critically ill cancer patients. This might also include the influence of prognostic modelling education interventions on doctors and critical care outreach nurses. As I described in Section 8.5 interventions that encourage regular collaborative, interprofessional, reassessment of prognoses would also help address uncertainty and would potentially clarify EOL planning issues earlier. Measuring such interventions, and the effect of communicating prognoses, would have the potential to make a meaningful contribution to this area.

This issue of prognosis, therefore, needs to be addressed both during, and prior to, critical care admission. Formally involving palliative care teams and measuring the subsequent impact of their interventions on patients', families' and unit outcomes (e.g. location of care, location of death and quality of care) is also important.

In relation to nursing, critical care outreach teams, often nurse-led, are involved in prognostication debates earlier on patients' critical illness trajectories and exploring how these expert nurses manage clinical and decision-making situations would be valuable in relation to early discussion and patient advocacy.[39] In relation to this, and as I developed in Section 8.5, there is the potential for nurses working with patients before they are admitted to critical care

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[39] Please see previous footnote and Appendix 8 for information regarding my outreach research in this area.

to shape the earlier course of the trajectory. These nurses (such as clinical nurse specialists, critical care outreach nurses) can draw attention to prognostication, realigning expectations, and what that might mean for patients and families. The influence nurses can have on patients' dying trajectories is an interesting area for further development, given that nursing power varies in different disciplines. Lessons around leadership in EOLC can be applied to areas where nursing is weaker from areas where nursing is strong. Furthermore, how to prepare families for the difference in speed of patients' demise, and who should do it and at what point along the trajectory is another potential area for advancement. There is debate over who should discuss moving to EOLC with nurses believing it can be them and doctors strongly disagreeing (Sulmasy *et al,* 2008). Given the role that experienced nurses demonstrated in my study around sensitive communication with families and the potential of those who were also confident in cancer care, this would be worth exploring, but only if there were a possibility of this becoming policy. As such, this is another area where nurses could explore their potential for future practice.

In terms of EOLC, little research exists into detailed withdrawal practices in critical care in general and, in particular, into the potential impact this has on families who witness it and patients, which would provide an important area to develop. This would help address the uncertainty in symptom control that exists in EOLC, in critical care because patients are unconscious and cannot contribute. Withdrawal practices are where the LCP is particularly lacking, as it was designed to be a prompt tool, rather than practice prescription. Current research focuses on measurement of documentation as an outcome for LCP and there are methodological issues in trying to assess impact beyond documentation but it would be another important area to try to explore. Examining the feasibility and impact of an amended LCP-ICU would also be worth exploring to see if it resulted in greater uptake.

In terms of the continuum presented, theoretical testing would be the next step to see if the concept could be developed into theory. In particular, I would like to explore whether the proposed wider application of the continuum (Figure 10.) beyond cancer stands up in practice. In relation to my unusual findings about patients' needs set against families' wishes, I would like to explore this further

both in and beyond the context of EOLC to see if this inconsistent practice recurred. This has theoretical implications for critical care nursing theory and for nursing caring theory, particularly with regard to caring for unconscious patients who cannot reciprocate when caring theory (as I outlined in Section 1.2 and 1.4) argues this is essential.

As outlined above, study design limits generalisability. A study spanning different practices across the few cancer critical care units worldwide would be interesting to see if there are similarities in EOLC issues that are distinct to this type of critical care unit. An important side-issue from the research, not discussed here, was after-death care posing important questions around how we support practitioners and bereaved families. This research pointed to support measures needed for participants around bereavement and after-death care and empirical testing of effectiveness of these measures would help advance care.

Research I have begun and undertaken as a result of some of the findings includes developing research in cancer critical care follow-up to support patients who have been very ill but have survived and still live with cancer. This was a particularly interesting part of the research for me as a cancer-trained nurse, given the current National Cancer Survivorship Initiative vision (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010) in the UK.

From a policy perspective, NICE (2004) suggested there is scope for development in several areas of palliative care around training of staff, early discussions, and also individual assessment each of which resonate with this study's findings. Increasing the nursing role in these might also be a way of enhancing nursing profiles in EOLC.

8.7 Final summation

This study has drawn on participant's meanings about *what is happening at EOL, what it is like, what it means, the impact of cancer and the timeliness moving to EOL*. Interpretations have led to the essence of the findings: cancer critical illness as part of a continuum toward death and the pivotal and complementary roles the key players have within each stage. Nursing and wider practice implications have been identified for each of these aspects has been identified. I wished to present real phenomena around EOLC in cancer critical illness and not force pre-conceived truths or concepts on these phenomena. However, this research was undertaken in a practice context and personal experience that affirm these findings, as well as a large body of corroborative literature. Consequently, I have maintained transparency to enhance the data credibility and trustworthiness of the findings, in which I have confidence that they reflect participants' meanings. As such, a rich picture has been given of what it was like to *witness*, *provide* and *experience* care at the end of life in the context of a cancer critical care unit. The resulting picture, that I was privileged to uncover, outlines the deep complexities associated with cancer critical illness for all participants.

Appendix 1: Search strategy

Comprehensive review

Research question tentatively formulated based on initial forays into literature (2003)

Initial search strategy to assess feasibility of research question

Papers identified (literature from 1998*-2009). Abstract review.

Exclusion**: Case reports/studies; Non-open access doctoral studies; Research specific reporting on drug-related symptom management; Euthanasia and assisted dying literature; Neonatal and paediatric literature (although this has been loosened when general principles could be applied).

Research question revisited and refined

144 articles identified for review (see Appendices 2, 3 and 4)

Search terms: critical care; intensive care; death; dying; end-of-life care; end of life; palliative care; terminal care; decision-making; patients; families; nurses; professionals; doctors; cancer; doctors; end-of-life decisions; technology

Search carried out using metasearch engines: NORA (included ASSIA, CINAHL, MEDLINE), Google, NeLH. Government databases (Department of health) databases also searched: handsearching, snowball searching and grey literature. (NB Further inclusion: Delphi/consensus guidelines. Research was found through snowball effect of searching elsewhere.)

At least biannual review of literature up to 2009

Handsearches from literature identified up to 2009

*Literature spans from 1998 onwards, with some seminal earlier work also included, since this was five years prior to my commencing the doctorate and this literature informed how my research question developed.

**Exclusion criteria have been loosened where grey literature revealed pertinent studies that would technically have been excluded. Research relating to the conceptual framework also contributed to the literature review and again exclusion criteria were loosened (in terms of date, for example) around this.

Appendices 2-4: Literature Tables

Appendix 2: Table 1. Literature on EOL Decision-making in Critical Care

Appendix 3: Table 2. Literature on EOL Decision-making and Practices (not limited to Critical Care)

Appendix 4: Table 3. EOL Withdrawal processes and EOL practices (Critical Care)

Name	Year/ place	Sample /population	Design	Main questions /aims /interventions	Number	Key findings/ Outcomes	Relevance to my question/ comments
Abbott, K.H. *et al*	2001 USA	Families from 6 ICUs	Interviews	Discussion of families needs after DFLST, areas for support and conflict	n=48 (half agreed)	1 year on: sources of conflict identified. Pressure to make DFLST for resource reasons. Nurses contribution to care only mentioned in 31% of cases. Nearly half (46%) of respondents perceived conflict (between families and staff and involving communication or perceived unprofessional behaviour) during their family member's ICU stay. Two thirds (63%) of families had spoken with the patient about EOL treatment preferences, which helped to lessen decision burdens. Forty-eight percent of family members reported the reassuring presence of clergy, and 27% commented on the need for improved physical space to have family discussion and conferences with physicians. Forty-eight percent of family members singled out their attending physician as the preferred source of information and reassurance.	Conflict over pain control. Nurses not mentioned much as primary contact for families. Nurses role less prominent. Implications related to needing information from doctors as preferred source.
Bach, V. *et al*	2009 Canada	Nurses	Interviews	Nurses roles in EOL decision-making in ICU	n=14 (2 units – cardiac ICU and critical care, one hospital)	Grounded theory revealed a core concept, Supporting the Journey which became evident in four major themes: Being There, A Voice to Speak Up, Enable Coming to Terms, and Helping to Let Go. Nurses described being present with patients and families to validate feelings and give emotional support. Nursing work, while bridging the journey between life and death, imparted strength and resilience and helped overcome barriers to ensure that patients received holistic care	Nursing role in helping families come to terms with EOLD and process information. Focus of study is on EOLD and how nurses can support families rather than their input into EOLDs.
Baggs, J.G. Schmitt, M.H	1995 USA	Nurses and doctors: Purposive sample – 1 hospital	Questionnaire	Factors perceived as influential in level of aggressiveness of care Who should be involved Collaboration in DM Questionnaires then applied to 314 cases	n=33/57 (doctors /nurses)	Doctors more satisfied in decision-making processes than nurses.	Questionnaire included DNR, comfort care only" as an option.
Bryce, CL *et al*	2004 USA	General population	Questionnaire	Assessing the importance placed on end-of-life treatment in the intensive care unit	n=104	Respondents prepared to shorten life in order to received better EOLC. Several respondents did not perceive ICU as a caring place.	Patients may never have experienced ICU, and may be misinformed about what it entails. Notions of general public about care in ICU.

Campbell, M.L.	1996 USA	Patient cases: 1 centre, eight year review	Chart review/ outcome analysis	Efficacy of a comprehensive supportive care team for EOLC	n= 1353, n=969 with interventions n=35 families; n= 27 random staff surveyed	CSCT = advanced practice nurse and staff physician. Family satisfaction with care measured. Staff satisfied with service. Average TISS value 15 before referral, 7.5 after referral and CSCT palliative care plan. Suggest that even when ventilated can be nursed with a CSCT plan on general-surgical units.	Controversial suggestion that ventilated pts can be cared for outside ICU if needing palliative care. Not ICU specifically.
Campbell, M.L. and Guzman, J.A.	2003 USA	Patient cases: 1 ICU	Chart review/ intervention	Case finding approach to EOLC for critically ill patients and proactive palliative care intervention	n= 18/22, 20/21	Palliative care interventions for dying ICU patients. Retrospective cohort showed time lag (4.7 +/- 2.5 days) between identifying DNR poor prognosis and EOLC treatment goals. Proactive cohort reduced this.	Time from futility/poor prognosis to end of life care considerable, suggesting decision-making or care planning lacking. Avoiding protracted dying.
Carlet, J. et al	2004 USA	Conference	Consensus (Delphi Technique)	International consensus to establish care in end of life in ICU	n = unknown	Questions identified: e.g. Is there a problem with end-of-life care in the ICU? Shared approaches to DM advised. Respect for autonomy, respect for families' wishes necessary. Resolution of conflicts outlined. Nurses must be involved in the process. Patient must die pain-free, double effect must not detract from need to provide good EOLC.	Nurses' involvement stressed. International differences identified. Optimal care outlined.
Cartwright, C. et al	1997 Australia	Nurses (critical care and general), GPs and general population; random sample	Questionnaire	Issues of death and dying, and the perspective of critical care nurses	n=231 (79%) of critical care nurses responded.	Use of advanced directive supported, proxy appointment, need for good analgesia (even if hastened death) by critical care nurses. Critical care nurses views reflected general population's re: euthanasia and Dr-assisted suicide. More communication between nurses and doctors, and doctors and patients stressed.	High response, critical care nurses have a high interest in this area. Clear role for nurses as advocates.
Cassell, J. et al	2003 USA, NZ	Patients, staff and relatives: Three ICUs	Ethnography	Comparing and contrasting end of life care in open, closed and semi closed units	n=600 (nurses, Doctors, A H. P., patient, family members and friends	Timing different between disciplines of surgery and intensive care for shifts from cure to comfort/ DM. Covenant of care surgeons vs resource management by intensive care doctors. Mixed units experienced conflict and miscommunication.	Administrative models have significant impact on how end of life care is enacted. No patients interviewed only observed: therefore no preferences established.
Clarke, E.B. et al	2003 USA, Canada	14 ICUs (US), 1 Canada Clinicians	Consensus	Robert Wood Johnson Foundation (RWJF) consensus to address documented deficiencies in end of life care and intensive care	n=36 R WJF members 15 nurses/Doctors	7 domains: patients and families centred decision-making; communication; continuity of care; emotional and practical support; symptom management and comfort care; spiritual support and emotional and organisational support for clinicians. Quality indicators identified	Explicit care instructions for EOLC patients identified for nurses and doctors.
Cook, D.J. et al	1999	1 ICU Doctors; one	Ethnography and interviews	Understanding the purposes for which life support is withheld,	n = same as above (but 9	Life support technology being used to orchestrate dying. Withdrawing or withholding	Process oriented as well as outcome

	Canada	nurse manager ; three pastoral workers; one dietician; one ethicist and families of two patients	(same study as Johnson *et al*)	provided, continued or withdrawn in the ICU	ICU nurses)	life support can help determine prognosis processes of withdrawal improved methods and timing of death. Decisions are socially negotiated to synchronise understanding expectations for family and clinicians. Life support technology as one discrete support vs. general concept.	oriented uses of technology.
Curtis, J.R. *et al*	2001 USA	ICU nurses, no sampling data	Focus Groups (x2)	What roles nurses play in family conferences	n= 8/11	Giving information to family. Discussing with family issues of importance to family and patient Offering family opportunity to discuss feeling and concerns.	Nurses role to ascertain any difficulties families perceive with care plan. Supporting family the focus.
Desbiens, N.A. *et al*	1998 USA	5 hospitals Patients	Observational and interventionist (two phases)	SUPPORT: preferences for pain control against pain after specialist nurse intervention to try and reduce pain	n=2820 patients	Half said that they preferred a course of care in the relieving pain and half were very unwilling or would rather die in the permanently in pain. At later interview 23.2% reported severe pain; despite earlier preferences.	Doctors not accustomed to discussing pain. Not cancer/ICU specific.
Dowdy, M.D.	1998 USA	Patients: 1 ICU	Ethics consultation	Assess efficacy of pro-active ethics consultations on care decisions for critically and terminally ill patients	n=99 ICU	Patients >96 hrs: pre-treatment, intervention and control. Prompting questions used to focus DM and action strategies suggested. Case conferences upon request. Post-discharge chart reviews: length of stay reduced, more frequent and documented communications.	MDT of ethics consultants. Discussed only doctors.
Elstein, A.S *et al*	1999 USA	Doctors (members of Canadian Critical Care Society) Random sample of 120 targeted	Survey : Questionnaire and Vignettes	Assessing the effects of prognostic estimates, perceived benefits of treatment and practice style in DM in critical care	n=37	Doctors given vignettes with 2 options: one scenario with optimistic survival and one with a pessimistic survival. Practice style appeared to affect DM but principle of maximising expected utility and Rule of Rescue did not.	Doctors only. Perceived benefit did not seem to be an important factor in DM.
Evans, L.R. *et al*	2009 USA	Surrogates (inc families)	Semi-structured interviews	Study to understand surrogate decision makers' views regarding whether physicians should discuss prognosis in the face of uncertainty	n=179	Constant comparative technique. Eighty-seven percent (155/179) of surrogates wanted physicians to discuss an uncertain prognosis. Main reasons for this: surrogates' belief that prognostic uncertainty is unavoidable, that physicians are their only source for prognostic information, and that discussing prognostic uncertainty leaves room for realistic hope, increases surrogates' trust in the physician, and signals a need to prepare for possible bereavement. Twelve percent (22/179) of surrogates felt that discussions about an uncertain prognosis should be avoided. The	Surrogates did want uncertainty discussed. Implication is uncertainty is better than nothing. Belief that prognostic uncertainty is simultaneously unavoidable and acceptable.

						main explanation was that it is not worth the potential emotional distress if the prognostications are incorrect. Surrogates suggested that physicians should explicitly discuss uncertainty when prognosticating.	
Ferrand, E. *et al*	2001 France	Patients consecutive sample from 1 ICU	Chart review and Questionnaire: Assessment of DM capacity	Evaluation of capacity to nominate a surrogate within 24 hrs of admission	n= 415 and 80	Decision-making (DM) capacity with MMSE and GCS defined by doctor >70% did not have DM capacity. Nurses' evaluation of patients.	Nurses evaluated GCS. It was not evaluated if patients wanted surrogates to participate in DM or just as conduit for information.
Ferrand, E. *et al*	2003 France	Nurses (counted physios and NAs as nurses) -133 ICUs	Questionnaire	Satisfaction of nurses vs. doctors with EOL decision making	n=3156 (512 doctors, 3156 nurses)	Doctors more satisfied in DM processes than nursing staff (73 vs. 33%) ; 90% believed in collaborative working but 50% and 27% felt nurses were involved.	Legal ramifications on DFLSTs. No discussion of care practices.
Glavan, B.J. *et al*	2008 US	Families; 10 ICUs multi-centre ICU	Chart review and family survey	Quality markers for death and dying from records measured along with QoDD for families	n= 356 families of patients who died invited	QoDD scores higher with AD and no CPR in last hour of life; withdrawal of tube feeding; family presence and discussion of patient's wish to forgo-life-sustaining treatment at family conference. Use of standardised comfort care orders and occurrence of a family conference.	QoDD scores could serve as target for measuring and improving EOLC in ICU.
Hawryluck, L.A. *et al*	2002 Canada	Intensive care directors; intensivists; coroners	Consensus panel: Delphi technique	The development to establish consensus guidelines on analgesia and sedation in dying ICU patients that help distinguish palliative care from euthanasia.	n=28	Role of palliative care established: specifics about dosages of analgesia and sedation outlined. Goals of palliative care outlined alongside support for staff and palliative care consults.	Protecting clinicians from double effect and murder charges.
Heyland, D.K. *et al*	2003a Canada	Families/ surrogates: 6 ICUs	Questionnaire	Decision-making in ICU : substituted decision-maker perspectives	n=789 families took part)	Not ICU EOL specifically. 70% response rate. Respondents were most satisfied with the frequency nurses communication and least satisfied with frequency of doctors communication. In terms of overall satisfaction with decision-making, 560 (70.9%) of the respondents were either completely or very satisfied. The majority (81.2%) of respondents preferred some form of shared decision-making process. Factors contributing the most to satisfaction with DM included: complete satisfaction with level of health care the patient received, completeness of information received, and feeling supported through the decision-making process. Satisfaction with DM varied significantly across sites.	Most substitute decision-makers for ICU patients wanted to share decision-making responsibility with physicians and that, overall, they were satisfied with their decision-making experience. Adequate communication, feeling supported, and achieving the appropriate level of care for their family member were key determinants of satisfaction with

Author	Year/Country	Sample	Method	Focus	n	Findings	Commentary
							decision-making in the ICU.
Hodde, N.M. *et al*	2004 USA	Patients: 1 hospital	Questionnaire and chart review	Exploring factors associated with nurse assessment of the quality of dying and death in the intensive care unit; using nurse ratings	n= 178	Higher scores associated with having someone present at the time of death, having life support withdrawn, an acute diagnosis, no CPR in last eight hours of life, neuro service care. Evidence of the potential targets for interventions to improve the quality of dying some patients: no CPR in last eight hours and having someone present at death.	Appropriateness of using nurses more than doctors established since doctors may be less objective evaluators if primarily responsible for patient care. Nurses spend more time with patients than doctors and are in a better position to evaluate.
Jacob, D.A.	1998 USA	Family members (recruited from newspaper)	Interviews	Family experiences with DM for incompetent patients	n=17	Clinicians can best support by helping them arrive at a judgment about condition.	Nurses can encourage discussions when pt still competent. Raises question around recruitment: do families tend to respond with agendas?
Jezuit, D.L.	2000 USA	Nurses – one centre	Interviews (pilot study)	Nurses experience of suffering with EOL Decisions	n=6	Nurses feeling moral distress at lack of control of decisions to forgo life-sustaining treatments (DFLST). Ideal of care held: all possible treatment to all pts not necessary. 4/6 intended to leave CCU nursing. Upholding pts moral beliefs necessary.	Nurse felt distress at having control of narcotics after DFLST: concern at double effect. Ideal of care.
Kennard, M.J. *et al*	1996 USA	Nurses (involved in SUPPORT were interviewed) – 4 hospitals (1 site didn't interview nurses)	Interviews (using structured questionnaire)	SUPPORT: role of nurse in DM process	n=1427	Nurses' preferences influential/ useful in family/pts decisions in 25% doctors reported only 4% that nurses preferences had sig. influence over them. 77% felt had no felt no influence. 30% nurses felt excluded despite 95% offering info to team DM.	Nurses despite claiming to be advocates, only 50% advocate. 70% do not discuss preferences/ prognosis.. Doctors don't view nurses as influential as pts/families do.
Kirchhoff, K.T. and Beckstrand, R.L	2000 USA	A. A. C. N. Nurses (randomised stratified sample of 1%)	Questionnaire	Nurses perceptions of obstacles or helpful behaviours in providing end-of-life care in intensive care setting	n=199	Issues: family understanding of the meaning of life support; not accepting prognosis; request the more technical treatment than the patient wished; anger; doctors' behaviour. Helps included: agreement about care; dying with dignity; families' acceptance. Nurses do not acknowledge having difficulty providing care dying patients, aside from conflict.	Death as an inevitable life event rather than undesirable medical outcome.

Kirchhoff, K.T. et al	2000 USA	Nurses: 2 hospitals (4 ICUs)	Focus groups: Interviews	Describing end-of-life care in ICU as perceived by critical care nurses	n= 21 (random selection)	Good EOLC means being pain free, in comfort and dignity, involving family. A clear accurate prognosis also needed. Shift to comfort care difficult. Nurses' personal discord highlighted.	Awkward shift to comfort care from curative not easily resolved. Differences in shift timing for relatives vs. staff.
Kirchhoff, K.T. et al	2002 USA	Families: 8 intensive care units	Focus groups: interviews	Understanding the experiences of family members when a loved one died in intensive care unit	n=8	A vortex: prognosis; difficult DM; feelings of inadequacy and loss. Inadequate communication exacerbated families' uncertainty.	Report of low response rate. Focus groups became like individual interviews. Technology versus individual choice as a dilemma.
Lilly, C.M. et al	2000 USA	Patients, families and care providers: 1 ICU	Before-after intervention study	Comparison of usual care with an intensive communication intervention on length of stay and costs of ICU stay SUPPORT	n=530 patients (134 before, 396 after)	Face-to-face structured interviews (surveys). Goals and expectations discussed together in ICU (meetings within 72hrs of admission). Milestones indicative of recovery discussed. Intensive communication significantly reduced length of stay (and therefore cost) and allowed dying patients access to palliative care was not associated with increased mortality.	Palliative care does not equate to quicker death processes. Patients, family and critical care team discussed the care plan and the patient goals.
McClement, S.E. and Degner, L.	1995 USA	Nurses. 2 ICUs; 2 hospitals	Interviews	Describe expert nursing behaviours in the care of dying patients.	n=10	Themes: responding after death has occurred; responding to anger; the family; colleagues; providing comfort care and enhancing personal growth.	There is clearly defined role for nurses in providing terminal care in critical care.
Mosenthal, A.C. et al	2008 USA	1 ICU	Pre-post Intervention study	Changing culture around EOLC in trauma ICU through intervention of early bereavement support; assessment of prognosis; patient preferences; and interdisciplinary meetings within 72 hrs.	69% patients received all interventions and 83% all bar meeting.	Discussion of goals increased to 36% from 4 of pt days. Mortality/ DNR/withdrawal rates all unchanged but DNR orders were introduced earlier and ICU LOS decreased in patients who died.	Intervention may change culture.
Nelson, J.E. et al	2001 USA	Patients – 1 ICU	Questionnaire	Exploring symptom management: self-reported symptom experience of critically ill cancer patients receiving intensive care.	n=100, recruited only 50 participated because of lack of capacity	ESAS scale used to assess symptom severity, even ventilated patients participated (not at end of life necessarily though). 55-75% of patients reported pain, thirst, discomfort, anxiety, sleep disturbance, hunger (moderate to severe). Additionally, routine procedures and interventions caused discomfort.	Critically ill cancer patients' comfort needs not met. (May have been active patients who were having treatment with curative intent still and therefore comfort outweighed by life-sustaining treatments.)
Nordgren, L. and Olsson, H.	2004 Sweden	Nurses, Doctors (convenience sample) – 1 unit	Interviews	Interdisciplinary interviews around the palliative care provision in a coronary care unit	n= 9 (2 doctors, 7 nurses)	Conceaptients arising: dignified death, prerequisites for providing good palliative care and obstacles that prevent such care. Nurses highly motivated to ensure dignified and good death.	Failing in intentions because of practicalities: implications for unnecessary suffering

Pettila, V *et al*	2002 Finland	Intensivists – 5 Finnish ICUs	Questionnaire	Factors influencing doctors decisions to make EOL decisions	n=41	Case studies used to make DFLST and factors such as no of organ failures and pt factors	Discusses actions taken after DFLST e.g. 51% would try to transfer out Care related to withdrawal discussed e.g. stopping ventilator /inotropes, starting analgesia.
Phillips, R.S. *et al*	1996 USA	Patients	Survey: face to face	Choices that seriously ill patients about cardiopulmonary resuscitation: SUPPORT	n= 1955	28 percent of patients did not want CPR. 29 percent of patients had discussed preferences with doctors: the rate of discussing CPR was low even for patients who did not want CPR. Patient preferences and not to receive CPR were associated with a small decrease in intensity of care but no difference in hospital survival.	Early reporting of support study; contrasts with other SUPPORT findings.
Pochard, F. *et al*	2001 France	Families -43 ICUs	Questionnaire (HADS tool)	Influence of anxiety and depression in families of ICU patients: decision-making capacity	n=920	Anxiety and Depression in 69% and 35%, even higher in spouses.	Concluding that involvement of anxious or depressed family members should be carefully considered. Highlights value of regular doctor/nurse family meetings.
Pochard, F. *et al*	2001 France	Patients, consecutive sample 1 ICU	Chart review: prospective.	Establishing how far French intensivists apply American recommendations regarding decisions to forgo life-sustaining treatment	n= 208 patients that died	One-month study: Decisions to forgo life-sustaining therapy were preceded by 2.5 deliberation sessions; proxies were informed and 59 percent of cases but participated in only 17 percent of decisions. Quality-of-life rarely evaluated, patient wishes rarely evaluated.	Highlighted paternalistic attitude of doctors; nurses not documented as part of the decision-making process.
Prendergast, T.J *et al*	1998 USA	Patients: 131 ICUS.	Chart review	A national survey of end-of-life care for critically ill patients	n=6303 deaths	23% had full ICU care; 22% received full ICU care without CPR; 10% had life support withheld; 38% had life support withdrawn. Wide variation in practices emphasised.	Limitation of life support is predominant practice in ICUs
Puntillo, K.A. *et al*	2001 USA	Nurses (random stratified sample of AACN members)	Questionnaire	End of life issues in intensive care units: A national random survey of nurses' knowledge and beliefs	n=906	30% response rate: clinical scenarios used to gauge nurses' opinions. Most felt dying patients received inadequate analgesia. >80% disagreed with assisted suicide, 95% with euthanasia, nearly all approved of DFLST. One third felt they had acted against their conscious in providing critical care caring for patients deemed futile.	Highlights personal dissonance in caring for dying patients and role of conscience.

Seymour, J.	2001, 2000, 1999 UK	Nurses, doctors families and patients	Ethnography	Negotiating a 'natural' death in critical care.	Two ITUs	The trajectory of dying is complex in ITU, leading to the establishment of a `technical' definition of dying-informed by results of investigations and monitoring equipment over and above `bodily' dying informed by clinical experience. The alignment of technical and bodily dying must have no perceived causative link to death. The balancing of medical action with non-action, allows diffusion of responsibility for death to the patient's body. The incorporation of patient's companions and nursing staff into the decision-making process was also explored.	Highly pertinent to the thesis. Difficulties in care outlined. Nurses role in decision-making outlined but little on their care practices after DM. Patients too ill to contribute to DM.
Slomka, J.	1992 USA	n/a	Case study	Clinical decision-making at the end of life: negotiating death to define the meaning of the situation and the meaning of technology	n/a	Cascading of the decision-making process outlined: the moral responsibility for patients death by withdrawing treatment is shared with family but, in withholding, this is displaced to patients. The patient's demise becomes a negotiated death; technology to prolong life or death.	Nurses' role not discussed in relation to end-of-life care or decision-making, highlighting these nurses' diminished role.
Swigart, V. *et al*	1996 USA	Families – 1 ICU	Interviews	Assessing families' willingness to forgo life sustaining treatment	n=30 family members of 16 patients	Letting go: seeking information about critical illness, reviewing the life story – seeking meaning in their life and critical illness, struggling to maintain roles /relationships. When families felt all had been done, then goals of critical care could be relinquished.	Transitions from cure to comfort only reconciled when families perceived all had been done.
Teno, J.M. *et al*	2000 USA	Patients (who had spent more than 14 days in ICU) – 5 hospitals	Survey: face to face	Decision-making and outcomes of prolonged ICU stay in seriously ill patients: SUPPORT	n=1494 /9105 recruited into SUPPORT study	Almost 50% of patients who expressed preferences for palliative care believed that care they received was contrary to this. Issues were compounded by lack of doctor-patient communication.	Comfort preference disregarded by doctors.
SUPPORT Principal Investigators	1995 USA	Patients; clinicians; families; 5 hospitals	Randomised controlled intervention and chart review	Efforts to improve communication about critically ill patients (not necessarily ICU patients) preferences for end of life care	n= 4301 (phase 1) n=4804 (phase 2)	Increased efforts to improve communication about patient preferences for end of life care do not impact on care actually provided despite randomised nursing interventions to convey those preferences to physicians.	Nurses were not involved in the design, nor in conduct or write up. Implications of critical care environment and end of life care not addressed.
Tilden, V.P. *et al*	1995 USA	Families - 1 ICU	Interviews	The impact of doctors behaviour on the family at EOL DM	n=32	Helpful vs. unhelpful behaviours Delaying withdrawal once decisions made unhelpful as well as withdrawing from the family. Supportive behaviours included providing comfort care. Families adjusting to intervention vs. less intervention.	Implications for care after DM.

Trovo de Araujo, M.M and Paes de Silva, M. J.	2004 Brazil	Nurses 2 ICUs; one hospital	Interviews	Perceptions of nurses of the establishment of communication with patient beyond therapeutic possibility as an effective palliative therapeutic resource	n=10 nurses	Themes- Value of communication terminal patients , the obstacles found during the process, the need to identify the individual demands of each patients iv, be able to use communication as to the palliative care of dying patients	Communication as a therapeutic palliative resource. Nurses' own feelings of death confronted
Walter, S.D. *et al*	1998 Canada	Clinicians –37 hospitals	Questionnaire	Examining clinicians confidence in EOL decisions using case studies	n= 1361	Confidence in decision making less as decisions/cases less extreme. ICU nurses more aggressive than Intensivists	Care after DM not discussed.
Wunsch, H. *et al*	2005 UK and Ireland	Patients - 127 ICUs	Cohort study	Data from case mix programme database; ICNARC regarding decisions to withdraw all active treatment.	n= 11,694 of 118,199 patients	Decision to withdraw all active treatment were made for 9.9 percent of patients. 30.8% died before discharge. Median time for admission to ICU to withdrawal=2 days. Characteristics of patients described (e.g. medical; older; male; pre-morbidity; recent CPR) Time to death 2-4 hours.	No specialist units included. Highlight general acceptance of withdrawal of treatment and how wide variation remains.

Name	Year/ place	Sample/ population	Design	Main questions /aims/interventions	Number	Key findings/Outcome	Relevance to my question/ comparison/ comments
Abel, J. *et al* (2009)	2009 UK	1 hospital in SW England	Descriptive study	To ascertain how many patients who died in a district general hospital (DGH) might have been able to be cared for at home. To obtain the cost of each inpatient stay and make an estimate of the maximum resource implications of care packages for these patients, and to calculate the savings in hospital admissions that could be used for the development of community services	Case note review of all patients who died from beginning of June 2006 - end May 2007. A total of 599 case notes of 627 patients who died in the study period were reviewed	A total of 331 patients (56%) were *not* assessed as being in the last year of life. For remaining 44%, 152 (26%) were clearly in the last year of life and 110 (18%) were 'probably' in the last year of life. A total of 399 (67%) of patients were appropriately admitted to hospital for their final illness, 194 (33%) could have been looked after at home. At least 119 (20%) clearly and 75 (13%) probably could have stayed at home. The mean cost of admission was £3173 per patient. A total of 77 (13%) of patients were admitted from nursing homes and 53 (69%) of these could have stayed in the nursing home to die. A total of 44% of all patients who died within the district general hospital had chronic life threatening illnesses.	EOLC strategy implementation evaluation and scope for community EOLC development Implications for EOLC in chronic disease and EOLC at home. A third of patients could have been cared for at home (but only *if* excellent EOLC services were available).
Addington Hall, J. *et al*	1998 UK	Families (person registering death) in 1 Inner London Health Authority	Questionnaire (RCT)	Views of Informal Carers Evaluation of Services (VOICES): measuring the quality of care, service use and unmet needs. RCT exploring postal versus face-to-face questionnaire methods for VOICES	n=69	Reliability not tested. VOICES has 158 questions. Response rate did not differ significantly between postal and interview groups (interview; 56% (69 of 123), postal: 52% (161 of 308). Responders did not differ in sociodemographic characteristics. Postal questionnaires had significantly more missing data, particularly on questions about service provision and satisfaction with services. Responses to questions differed between the groups on 11 of 158 questions. Interview group respondents were more likely to give top ranking responses to questions on service satisfaction and symptom control.	Developed from Cartwrights *et al*'s (1973) Life before Death work. Uses proxy measures of interpretations of dying. Quality of care appears to be main thrust of questionnaire but care not defined. Less of a study about quality of care and more about method differences.
Addington-Hall J.M. and O'Callaghan, A.C.	2009 UK	Families from a random ONS drawn sample of 800 deaths in S. London. Of those 48% responded and of those 40 cancer patients whose informant reported both a	Questionnaire	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.	n=384: 40 deaths	Statistically significant differences between hospice and hospital care on eight out of 13 variables measuring aspects of satisfaction with care. All respondents rated hospice care more positively than hospital care. No differences in experience of pain and breathlessness in the two settings, but respondents rated pain control by the hospice as more effective. In comparison to hospital care, from the perspective of bereaved relatives, hospice in-patient care	Pain control and communication in hospices better, other symptom management equitable. Hospices more favourably regarded and rated. Unclear why greater dignity and why better medical and nursing care.

		hospice in-patient admission and a hospital admission in the last 3 months of life were identified				provided better pain control, better communication with patients and families, and better medical, nursing and personal care, which treated the patient with more dignity.	
Barthow, C. *et al*	2008 NZ	Nurses	Interviews	Factors that influence nurses' involvement in providing treatment decisional support in advanced cancer	n=21	Nurses had varied opinions about the meaning and importance of their roles in treatment related decision making. This variation led researchers to undertake secondary exploration of factors that impacted on nurses' involvement in the provision of decisional support. Four key groups of factors were identified. These were factors relating to degree of knowledge, level of experience, beliefs and understandings about nursing roles and cancer therapies, and structural interfaces in the work setting.	Provides some understanding of clinical drivers associated with nurses' decisional support work with patients who have advanced cancer Degree of confidence and experience an issue in nurses involvement in DM.
Beland, D.K. and Froman, R.D.	1995 USA	Healthy Adults: convenience sample – 1 hospital	Questionnaire	Life Support Preferences questionnaire for patients	n=116.	Preliminary validation to check consistency	Nurses as patient advocates will often be at forefront of presenting life support information.
Beckstrand, R.L. *et al*	2009 USA	National survey sample of oncology nurses	Questionnaires	To determine the magnitude of selected obstacles and supportive behaviours in providing EOLC to patients with cancer as perceived by oncology nurses.	n=375 out of potential 907	41% response rate. Items with highest perceived obstacle magnitude were (a) dealing with angry family members, (b) families not accepting what they are told about patients' poor prognosis, and (c) nurses being called away from dying patients to care for other patients. The three-highest scoring supportive behaviours were (a) allowing family members adequate time alone with patients after they died, (b) having social work or palliative care staff as part of the patient care team, and (c) having family members accept that patients are dying.	Cancer nurse specific study: Deemed - dedicated, experienced, and comfortable handling most issues in EOLC. Recommendations to support include strategies to interact effectively with angry, anxious, or overly optimistic family members as well as involving social work and palliative care staff on the oncology MDTs. Information re obstacles and supportive behaviours can be used to facilitate discussion and change

							in oncology MDTs and improve EOLC for patients with cancer and their families.
Bradley, E.H. *et al*	2001 USA	6 hospitals Nurses	Questionnaire	The use the palliative care practices by nurses caring for terminally ill patients in the acute care setting	n= 180 ICU nurses excluded	Most nurses reported using palliative care practices when caring for their terminally ill patients (nurses with hospice experience excluded). Explicit palliative care skills outlined and assessed (e.g. active passive listening).	Cancer nurses were more knowledgeable about palliative care practices than general nurses.
Carline, J.D. *et al*	2003 USA	Patients , families, doctors, nurses, social workers (purposive sampling)	Focus Groups	Doctors interactions with health care teams and systems in the care of dying patients: perspectives of patients , families, health care professionals	n=137	Two domains related to doctors' interactions: Access and continuity; Team communication and coordination. Taking time to talk and respect highlighted as very important.	Coordination of care needs to be improved. Directing of care not outlined. Requires patients to be well enough to participate in focus groups. Raises issue of ethics of focus groups in this situation.
Cohen, J. *et al*	2007 Europe (Denmark, Sweden, Switzerland; Belgium;	Doctors	Death certification study	Decision-making (DM) preceding death explored retrospectively through questionnaires to certifying doctors	n=12492 deaths	Among all non-sudden deaths the incidence of several end-of-life decisions varied by place of death. Physician-assisted death occurred relatively more often at home (0.3–5.1%); non-treatment decisions generally occurred more often in hospitals (22.4–41.3%), although they were also frequently taken in care homes in Belgium (26.0%) and Switzerland (43.1%). Continuous deep sedation, in particular without the administration of food and fluids, was more likely to occur in hospitals. At home, end-of-life decisions were usually more often discussed with patients. The incidence of discussion with other caregivers was generally relatively low at home compared with in hospitals or care homes.	EOL DM varies significantly according to place of death (and country).
Curtis, J.R. *et al*	2002a USA	Patients doctors	Focus groups	Patients perspective of physician skill at EOLC: differences between COPD, cancer and AIDS	n= 11 focus groups. 79 patients with three diseases: COPD (n = 24), AIDS (n = 36), or cancer (n = 19).	GT and content analysis. Remarkable similarities were found in COPD, AIDS, and cancer groups, including the importance of emotional support, communication, and accessibility and continuity. However, for patients with COPD, domain concerning physicians' ability to provide patient education most important. Patients with COPD desired education in: diagnosis and disease process, treatment, prognosis, what	Focused on how doctors should provide EOLC, does not discuss wider arena in which health care exists and nursing implications. No clear outcomes pertaining specifically to cancer patients other than

						dying might be like, and advance care planning. For patients with AIDS, the unique theme was pain control; for patients with cancer, the unique theme was maintaining hope despite a terminal diagnosis. Patients with COPD, AIDS, and cancer demonstrated many similarities in their perspectives on important areas of physician skill in providing end-of-life care, but patients with each disease identified a specific area of end-of-life care that was uniquely important to them. Physicians and educators should target patients with COPD for efforts to improve patient education about their disease and about end-of-life care, especially in the areas defined above. Physicians caring for patients with advanced AIDS should discuss pain control at the end of life, and physicians caring for patients with cancer should be aware of many patients' desires to maintain hope. Physician understanding of these differences will provide insights that allow improvement in the quality of care.	maintaining hope, as there were with AIDS and COPD patients.
Curtis, J.R. *et al* USA	2002b	Families	Questionnaire	A measure of Quality of Death and Dying (QoDD): Initial validation with families using after death interviews (NB/ not open interview, face to face questionnaire)	n=205 (27% of all county deaths over a year)	QoDD score higher if patients died at home or in place patient desired than in hospital (p=<0.01). Lower symptom burden (p=<0.01) and good communication (about treatment preferences etc) (p=<0.001) also associated with better score. Total score was not associated with having an advance directive (AD); higher scores associated with communication about treatment preferences (*p* < 0.01), compliance with treatment preferences (p< 0.001), and family satisfaction regarding communication with the health care team (p< 0.01).	Implications for improving communication (thought not outlined in what regard, limitation of questionnaire) with the patient and family and improving symptom assessment and treatment. Health care professionals should focus on continuity of care at EOL.
Degner, L.F. *et al* USA	1991	University faculty; one palliative unit.	Interviews	Describing behaviours associated with positive and negative attitudes to care of the dying in palliative care	n=10 palliative care nurses; 10 educators	7 nurses' behaviours identified: responding to death scene, providing comfort care, enhancing personal growth, responding to colleagues, enhance the quality of life during dying, responding to the family.	Differences between experienced and inexperienced nurses outlined.
Emanuel, L.L. *et al* USA	2001	Patients: nationally representative sample	Focus groups and Interviews	Concise screening questions for clinical assessments of terminal care: the needs near the EOLC screening tool	n=988	Four core themes of palliative care: Needs (social); Existential matters; symptoms; therapeutic matters (NEST tool developed).	Useful for prompting questions about care at EOL for clinicians.

Escher, M. *et al*	2004 Switzerland	Doctors	Questionnaire survey	Survey of what influences doctor's decisions about admission to intensive care	n=402/232 responded	Prognosis, decision-making and the acute illness very important in decisions to admit; patient personality influences decisions as does bed availability. Patients with cancer were not discriminated against.	Prognostication important, and ethically problematic issues do influence doctors decisions.
Farber, S.J. *et al*	2003 USA	Doctors, patients and families	Interviews	Study of the perceptions of patients, caregivers, and physicians who are already connected with one another in an EOLC experience.	n=42 patients and 39 caregivers facing EOL - interviewed either alone or together after referral by their physicians	Content analysis approach used. Participants identified four primary issues related to their experience of EOLC: awareness of impending death, management/coping with daily living while attempting to maintain the management regimen, relationship fluctuations, and the personal experiences associated with facing EOL. Participants expected their physicians to be competent and to provide a caring relationship. Found that awareness of these crucial patient and caregiver EOL issues and expectations and how they differ from clinician perspectives can assist clinicians to appropriately explore and address patient/ caregiver concerns and thereby provide better quality EOLC.	Used data from previous study – only about doctors and no discussion of other care providers (e.g. community nurses etc.).
Fetters, M.D. *et al*	2001 USA	Doctors – 1 hospital	Qualitative interviews	Decision making when there is conflict between patients and doctors	n=158	Negotiating with and educating patient; Deferring to pt requests for benign/ uncomplicated treatment; refusing; convincing patients around DFLSTs; using family, not offering futile treatments.	Collaborative working not considered e.g. asking for help from nurses who know patient or ethicist.
Fins, J.J. *et al*	1999 USA	Patients : consecutive sample – 1 hospital	Chart review	What are comfort care plans and what constitutes comfort care	n= 200/205 consecutive deaths	Identifying patient as dying DNR orders and comfort care plans (46% had comfort care plans but still underwent blood sampling or antibiotics).	Medical notes only, nursing input (or family/patient) not discussed.
Gilbert, M. *et al*	2001 USA	Patients (1 hospital) who had undergone CPR	Chart review	Determining how useful patients' advance directives (AD) were to members of the health care team in deciding treatment and EOL decision-making	n=135	35/135 had ADs. However, ADs were found to be vague and non-directive, requiring further clarification. Staff don't understand ADs or timing of when to address ADs.	ADs have limitations of treatment preferences. Implications for patients' understanding of coma/illness/ICU etc.
Groenewoud, J. *et al*	2000 Holland	Doctors – stratified sample of deaths (and	Questionnaire	Decisions to withdraw treatment at EOL	n= 4666	General patterns of withdrawal; non-treatment decision made in 30% of cases, e.g. hydration/nutrition most frequently	No findings related specifically to care at end of life, study

		attending doctors for those deaths) over 3 months				foregone.	relating to withdrawal.
Harstäde, C.W. and Andershed, B.	2004 Sweden	Patients 1 hospital	Interviews	To describe what patients with cancer who are in the final stage of life consider good palliative and end-of-life care to be and where they think such care should be carried out.	n=9	Grounded Theory study: three main categories (and 7 subcategories) emerged during the analysis: safety, participation, and trust. Concept of wheel presented that rolls along smoothly as long as the care is good and all 3 categories are present. Safety, participation, and trust were interwoven with patients' beliefs about where care should be carried out and most said this should be hospital.	Patients receiving palliative EOLC. Patients wanted care in hospital – dissonance between UK policy and this study.
Hearn, J. and Higginson, I.J.	1999 UK	Staff and patients across 8 palliative care services	Questionnaire	Development and testing of the Palliative care Outcome Scale (POS)	n=148 patients (exact numbers for staff given nowhere)	Staff collected data routinely on patients in care long enough to be assessed (n=337). Of these, 262; 148 (33%) completed questionnaire. Main measures - POS, EORTC and the Support Team Assessment Schedule. POS consists of 2 almost identical measures, one for staff, the other for patients. Agreement between staff and patient ratings acceptable for 8/10 items. Construct validity (Spearman rho = 0.43 to 0.80). Test/re-test reliability acceptable for 7 items. Internal consistency good (Cronbach's alpha = 0.65 (patients), 0.70 (staff)). Change over time was shown, but not statistically significant. Addresses certain physical issues, anxiety, feelings, time wasting over the previous 3 days	Highlights issues of attrition in palliative care research. Critique possible of questions being potentially leading but useful as a short, unobtrusive questionnaire for dying patients.
Heyland, D.K *et al*	2000 Canada	Seriously ill patients (including cancer patients) 1 hospital	Face to face questionnaire (not interview as described)	Establishing the determinants of a good decision and process	n= 37	9/37 had advanced directives (not in notes at all). Shared decision-making (DM) preferred.	Moving DM model from paternalistic to shared depending on patients needs.
Heyland, D.K. *et al*	2003b Canada	Patients (some cancer):	Questionnaire	Seriously ill patients preferences for care. Prospective cohort study of hospitalized patients with end-stage congestive heart disease, chronic pulmonary disease, cirrhosis, or metastatic cancer.	n=135 patients	The majority of patients (103, 76%) had thought about end-of-life issues although only 48 (36%) had discussed them with their doctor in the hospital. With respect to preferred role in decision making, in the scenario of a competent patient, 14 (10%) preferred to leave all decisions to the doctor, 12 (9%) preferred that the doctor make the final decision after considering their opinion, 43 (32%) preferred that the doctor shared	Preferred roles in decision-making is variable and difficult to predict but patients did want to discuss DM with doctors.

						responsibility with them to make the decision, 32 (24%) patients preferred to make the final decision after considering the doctor's opinion, 21 (16%) preferred to make the treatment decision alone, and 13 (10%) did not answer. Physicians were not able to accurately predict patient's preferred role nor could the variability in patient choice be accounted for by demographic or symptom covariates.	
Hickman, S.E. *et al*	2001

USA | Families; 1 centre | Questionnaire | Assessment of dying patients' distress: the adaptation of tool (MSAS_GDI) to assess global symptom distress in the last week of life (Family MSAS-GDI) | n=130 | Adaptation of the Memorial Symptom Assessment Scale Global Distress Index (MSAS-GDI), measuring patient global symptom distress, for use in a retrospective study of family reports about EOLC. 11 symptoms: Psychological symptoms: worry, sad, irritable and nervous; Physical symptoms: pain, lack of appetite, lack of energy, feeling drowsy, constipation, dyspnoea and dry mouth.
 The majority were able to respond to the scale items. The mean Family MSAS-GDI score was 1.14 (SD = 0.87) Scale demonstrated good internal consistency (alpha = 0.82) and average item-total correlation was r = 0.49, average inter-item correlation was r= 0.30. | Highlighted how it is problematic conducting research with dying patients. Family members as useful proxy sources of information about patients' last days of life. Only moderate correlations (0.49 and 0.30) with total scores and each item. Social and spiritual aspects of care or structure of care not addresses. Issue re: preferences for care not addressed. |
| Hines, S.C. *et al* | 2001

USA | Patients and surrogates – sampling unclear | Telephone Survey-questionnaire | Differences in values and preferences for care as reasons for why families are ill informed to act as surrogates | n=242 pairs of patients and relatives | Surrogates lack info needed to make decisions because they don't discuss such values with patients but more conversations about EOL issues didn't increase knowledge about preferences. Surrogates less likely to want to prolong life and needed to be more certain before stopping life-sustaining treatments. | Surrogates misjudge patients' wishes, as with Lynn *et al* 1996. |
| Hopkinson, J.B. *et al* | 2003

UK | Newly qualified nurses in 2 acute care hospitals | Interviews | Caring for dying people in hospital: perceptions of nurses working in acute medical settings in relation to experience of caring for dying people | n=28 | Six essences: personal; ideal; actual; unknown; alone; tension; anti=tension. Tool developed to help nurses understand. | Potential use for tool as support to impact upon care positively – particularly for newly qualified /inexperienced staff. |
| Jackson, V. *et al* | 2009

USA | Oncologists in 1 centre | Interviews | A Qualitative study of oncologists approaches to EOLC | n=18 | Face-to-face survey and grounded theory interview (semi-structured) Oncologists viewing their role as encompassing both biomedical and psychosocial aspects of care, reported a clear method of communication | Important comparison for oncologists in my study, although study separates oncologsits into two distinct types |

						about EOLC, an ability to positively influence patient and family coping with and acceptance of the dying process. Oncologists described process of communication, using an individualized approach, and viewed the provision of effective EOLC as very satisfying. In contrast, those outlining a more biomedical role reported a more distant relationship with the patient, a sense of failure at not being able to alter the course of the disease, and an absence of collegial support. Describing communication encounters with patients and families, these oncologists did not seem to feel they could impact patients' coping with and acceptance of death and made few recommendations about EOL treatment options to patients.	when in reality oncologists might assume approaches from each type. Consequences for this not outlined in this study, i.e. options for EOLC.
Johnson, C.E. *et al*	2008 Australia	Oncologists, colorectal surgeons, haematologists, respiratory physicians	Questionnaire	Exploration of factors related to referral of palliative care and specialities' referral patterns	n=669	Response rate = 669/1788. Nearly half reported referring >60% of patients to Specialist Palliative Care (SPC) services. Most frequent reasons for referral were: the future need for symptom control, the presence of a terminal illness or uncontrolled physical symptoms. Reasons for not referring included: ability to manage patients' symptoms; the absence of symptoms or rapid deterioration. Predictive factors: Female doctors ; >10 years of practice in the speciality; agreeing all people with advanced cancer need referral, referral for the purpose of multidisciplinary management and having SPC services available.	Issue of skills notable in reasons for not referring, palliative care skills seeping into other specialities?
Kai, I. *et al*	1993 Japan	Patients at three hospitals; all capacitous in-patients	Questionnaire	Communication between patients and doctors about terminal care including the accuracy of doctors' estimation of patient preferences	n = 201	80% of patients preferred candid information regardless of the nature of the disease. Doctors were only correct in estimation of preferences half the time.	A culture favourable for paternalism: patient preferences often guessed wrong.
Kristjanson, J. *et al*	1993 Canada	Advanced cancer care patients	Questionnaire	Satisfaction questionnaire assessing information giving, availability of care; physical for patients and psychological care (FAMCARE)	n=20 for qualitative research and Q-sort cards; n=30 for main sample	FAMCARE Scale was developed based on qualitative research and Q-sort cards identifying indicators of family care satisfaction The pilot of FAMCARE used a convenience sample. Internal consistency: 0.93; test-retest correlation: 0.91. Cluster analysis of the scale suggested 4 sub-dimensions.	No spiritual care addressed, not a comprehensive assessment of needs in questionnaire. Missing domains included: place of death, emotional care and

							support. Bias of using convenience sample and sample skewed toward doctors. Sampling unclear in relation to what 'advanced' might mean (EOL or in receipt of palliative care).
Lautrette, A. *et al*	2007 France	Families in 22 ICUs	RCT	Families randomised to routine EOLC or to communication strategy and EOL brochure versus normal EOL conference	n=126	Participants in the intervention group had longer conferences than those in the control group and spent more of the time talking. On day 90, the 56 participants in the intervention group who responded to the telephone interview had a significantly lower median IES score than the 52 participants in the control group (27 vs. 39, P = 0.02) and a lower prevalence of PTSD-related symptoms (45% vs. 69%, P = 0.01). The median HADS score was also lower in the intervention group (11, vs. 17 in the control group; P = 0.004), and symptoms of both anxiety and depression were less prevalent (anxiety, 45% vs. 67%; P = 0.02; depression, 29% vs. 56%; P = 0.003).	Providing relatives of patients who are dying in the ICU with a brochure on bereavement and using a proactive communication strategy that includes longer conferences and more time for family members to talk may lessen the burden of bereavement.
Lynn, J. *et al*	1997 USA	Surrogate decision makers/ seriously ill/ older patients: five hospitals	Chart reviews and structured interviews (verbal questionnaire)	To characterise the experience of dying from the perspective of surrogate decision makers. A SUPPORT study	n=4124 (patients), n=3357 (surrogates)	45 percent of patients were unconscious throughout the last three days of life. Most conscious patient were able to communicate with their surrogates. Actual care reported to be at odds with pref. for treatment.	Families wanted more comfort measures at the end of life. Study showed major disparities between family and patient perceptions of EOL needs
Morita, T. *et al*	2002 Japan	Families	Questionnaire	A questionnaire to assess satisfaction with various aspects of care including: nursing care; information; staffing levels; symptoms and costs of treatment: the Sat-Fam-IPC	Pilot n=60; Main sample n=850: 50 palliative care units	A postal self-completion questionnaire 850/1344 responses. Reliability and validity examined after responses were randomly divided into 2 groups: training set in development phase (n=500) in testing set in validation phase (n=350). Items reduced from 50 to 34 through psychometric techniques in development phase. Final Cronbach's coefficient alpha was 0.98. Factor analysis revealed seven subcategories: Nursing Care, Facility, Information, Availability, Family Care, Cost, and Symptom Palliation. Total scale score	Certain psychological and spiritual aspects of care (e.g. place of death, autonomy) were not addressed. Also not clear at what point on dying trajectory the questionnaire was administered and was meant to relate to.

						significantly correlated with global satisfaction (Spearman's r=0.78).	
Morita, T. *et al*	2004 Japan	Families: home and hospital (where palliative care received)	Questionnaire	A questionnaire to evaluate care at EOL: the CES	3 groups: across 70 palliative care units –n=485; 310; 202	485/800, 310/425, 202/281 responses from a postal self completion questionnaire re: final palliative care episode. Families asked to complete CES as well as satisfaction and experience measures (degree of expectation, Centre for Epidemiologic Studies Depression Scale and Social Desirability Scale). CES Cronbach's alpha 0.98; test-rest Correlation Coefficient 0.57. Factor analysis showed 10 subscales: physical care (by physicians, by nurses), psycho-existential care, help with decision-making (for patients, for family), environment, family burden, cost, availability, and coordination/consistency. Subscales were only moderately correlated with perceived-experience and satisfaction levels of corresponding areas (r=0.36-0.52 and 0.39-0.60, respectively). CES score not significantly associated with the degree of expectation, the changes of depression, or the Social Desirability Scale, suggesting it is reliable.	Issue related to measurement of experience. Test-retest correlation coefficient not high. Measures family's perception of the necessity for improvement in structural/procedural aspects of palliative care and evaluates the structure and process of care. Did not address certain psychological and spiritual care in EOL issues (e.g. dignity, place of death, autonomy) . From articles unclear exactly where this is overlap and difference from Sat-Fam –IPS.
Parker, M.H. *et al*	2008 Australia	All registered medical practitioners (doctors)	Questionnaire	Comparison of attitudes and practices of Australian doctors, by specialty, to a range of medical decisions at the end of life (particularly euthanasia).	n=2964 (1478 valid responses)	Response rate = 53%. Assessed doctors' willingness to give symptom relief which might also hasten death; provision of terminal sedation and euthanasia. Participants more willing to comply with a patient's request for increasing symptom relief, even at risk of hastening death, than for terminal sedation. >25% would provide terminal sedation to competent patients on their own initiative. A small number of respondents would intentionally hasten death. Oncologists, palliative care physicians and geriatricians were least likely to actively hasten death, and more likely to act unilaterally to relieve symptoms as a medical necessity.	Was unclear if Darwin was part of sample (distinct euthanasia laws there). Oncologists least likely to want to hasten death in contrast with what might be expected.
Patrick, D.L. *et al*	2001 USA	N/A	Questionnaire	Development of a tool to assess the Quality of Death and Dying (QoDD)	N/A	A model was proposed for evaluating the quality of dying and death based on concepts elicited from literature review, qualitative interviews with persons with and without chronic and terminal conditions (however this is from author's previous research, not new data), and consideration of desirable	This relies on proxy assumptions about what a person would have wanted for death and dying; and perceived meeting of those expectations

						measurement properties. QoDD is: whether a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others. Expected level of agreement is modified by circumstances surrounding death that may prevent following patient's prior preferences. Qualitative data analysis yielded six conceptual domains: symptoms and personal care, preparation for death, moment of death, family, treatment preferences, and whole person concerns. The six domains consisted of 31 aspects that can be rated by patients and others as to their importance prior to death and assessed by significant others or clinicians after death to assess the quality of the dying experience.	around death and dying with previously expressed preferences. Tested in Curtis *et al* 2002a (above).
Pincombe, J. *et al*	2003 Australia	Patients (deemed terminal <6 days to live) (convenience sample)	Interviews and Non-participant observation	A study of the care given to dying patients in two acute care Australian hospitals	n=20	Contextual themes: organisation; environment; human factors. Presence of family /friend influenced amount of care given to patient. If not present – dying process isolating.	Principles of palliative care still to be incorporated into acute care. Inappropriate care as emphasis on routine and efficiency, or looking after improving patients.
Roche-Fahy, V. and Dowling, M.	2009 Ireland	Nurses in 1 small hospital	Interviews - phenomenology	Acute Care nurses experiences of giving comfort care to patients in their palliative care trajectory	n=12	Gadamerian hermeneutic phenomenological study. Main findings revealed four major themes (with sub-themes) that described the lived experience of providing comfort to palliative care patients in an acute setting: time needed to provide comfort, emotional cost to the nurse in providing comfort, a holistic approach in the provision of comfort, and the role of education and the expert team in providing comfort. Environment – provision of facilities Issues regarding place of care. Space and dignity; Reciprocity and the nurse-patient: providing comfort therapeutic relationship; Ethical comportment Engagement and detachment; Nurse advocacy and the role of mediacy, empowerment and enabling on behalf of the patient/family; Communication skills their role in providing comfort Involvement of palliative care experts; Physical needs providing comfort and spiritual and emotional needs.	Many nursing issues resonant of my own findings including emotional labour. However, no allusion made to nurse as part of a wider team. Decision-making issues less evident and practical aspects of acute care impinging on EOLC not apparent.

Rose, J.H. *et al*	2000 USA	Patients (several hospitals, N not given) Matched sampling	Prospective Cohort Study	Identifying similarities and differences between primary care and attending doctors and outcome sin seriously ill cancer patients: SUPPORT	n=642 (data over 5 yrs).	Length of survival measured: comparable care practice (number of care topics discussed with patients/ families; total hospital costs; length of stay; survival rates; CPR; perceptions of pt wishes for rescue care; between two groups of doctors. TISS used to measure nursing load.	Generalists vs oncologists (cannot assume primary care are generalists in US system)? Future studies should compare palliative care practices. TISS used by doctors not nurses (and it is controversial to use to measure workload as it misses a lot of comfort/ communication metrics). Relied on prognostication and doctors had not cared for patients on a long-term basis, therefore risk of bias and perhaps untrue practices.
Sahlberg-Blom, E. *et al*	2001 Sweden	Patients-consecutive patients admitted to 6 specialised clinics (with survival expectancy of 2-6 months)	Questionnaires	A study of the quality of life at the end of life: experiences of a group of cancer patients in two different care cultures	n=47	EORTC QLQ-C30 used. Tendency for those cared for in the cure-oriented care culture to report more symptoms than those in the care-oriented care culture. An exception to his was pain, reported more in the care culture.	Quality of life questionnaires used as patients initially not imminently dying. Pain greater in care domain than in cure domain, implying it is addressed more or that the culture in care domains means it is not reported as much?
Seymour, J. *et al*	2003 UK	Patients - from 3 studies spanning the north, south and middle of England	Interviews	A synthesis of three palliative studies of palliative care in the UK; ascertaining patients reported expectations and experiences of specialist palliative care	N = 37	Four areas outlined from the synthesis: 1) knowledge and information about the services 2) meeting practical and psychosocial needs 3) lack of control 4) family atmosphere	Although not limited to ITU, raises questions about atmosphere in ITU and highlights how nurses are well-placed to carry out palliative care activities. Early referral to palliative care therefore unable to include patients who are incapacitous and at the very end of the terminal stage.
Singer, P.A.	1995	Public: Quota	Questionnaire	Effect of key changing	n=2019	DFLST supported by 85% of public if unlikely	About decisions not

	Canada	sampling		factors in EOL DM. The influence of prognosis, practices (FLST vs. ass. suicide vs. euthanasia) and process		to survive. 10% said they had a living will. Prognosis has major effect.	EOLC specifically. Important public finding that prognosis has an significant effect.
Singer, P.A. *et al*	1999 Canada	Patients -with renal failure/ HIV or long-term care facility residents	Interviews	Quality end of life care from the perspectives of patients	n= 126	5 domains identified: receiving adequate pain and symptom management; avoiding inappropriate prolongation of dying; achieving sense of control; relieving burden; strengthening relationships with loved ones	Focal points of EOLC including prolongation of dying as an issue. Advance directive patients only.
Solomon, M.Z.	1993 USA	doctors and Nurses – 5 hospitals	Questionnaire	How do professionals assess care at end-of-life? Assessment of whether patients' rights are respected.	n= 687 / 759	70% said they had acted against conscience in providing care at EOL. Nurses and House Officers less satisfied with how much families are involved in DM. House Officer (junior doctor) views more aligned with nurses than senior doctors.	Technology and dying. Inadequate pain control at EOL. Care practices related to DM e.g. stopping hydration precipitating death. Implications for support and experience.
Spichiger, E.	2009 Sweden	Patients	Interviews: phenomenology	Being in the hospital: an interpretive phenomenological study of terminally ill cancer patients' experiences	n=10 (+ closest relative)	Study explored meanings patients assigned to hospital as their temporary residence. Patients' care was observed and participants were interviewed repeatedly. Existence described as in the hospital on a continuum from "prison" to "heaven." For most of their stay, patients occupied some place between these extremes and patients accepted hospital as necessity but were longing for home. Quality of hospital life was not constant rather, patients' experiences were transitory and some faded away. Patients' experiences of the hospital were as a temporary residence. Recognizing patients' views of hospital as their temporary living place might allow professionals to individualize patient care.	Description sounds more like phenomeno-ethnographical study than phenomenological. Implications for EOLC not that clear, is homeliness needed for a good death and EOLC? Individualised care noted. Link to effect of environment.
Steinhauser, K.E. *et al*	2000 USA	Patients, families, friends, care providers – 2 medical centres, 1 hospice	Focus groups and interviews	Exploring patients', families' and providers perceptions of what constitutes a good death.	n= 75	GT used to analyse data Six themes: symptom control, clear DM, preparation for death, completion, contributing to others, affirmation of the whole person. Need for information during course of illness highlighted; as well as need for empathetic care providers. Professional roles influenced views and doctors retained a biomedical view of death. Also their discomfort with death and	It is hard to know if all these would apply in ICU, priorities may focus on relief of comfort for example, but 'person as whole' is an important conceptual issue in ICU

						dying, perceptions of failing also noted.	
Steinhauser, K.E. *et al*	2001 USA	Patients: one centre	Questionnaire	Assessment of QUAL-E psychometric properties	n=248	(Patients participated with stage IV cancer, congestive heart failure with ejection fraction < or = 20%, chronic obstructive pulmonary disease with FEV1 < or = 1.0 1, or dialysis-dependent end stage renal disease). Compared QUAL-E with 5 other measures: FACIT quality of life measure, Missoula-VITAS Quality of Life Index, FACIT-SP spirituality measures, Participatory Decision Making Scale (MOS), and Duke EPESE social support scales. A four-domain structure (25 items) in QUAL-E: life completion (alpha = 0.80), symptoms impact (alpha = 0.87), relationship with health care provider (alpha = 0.71), and preparation for end of life (alpha = 0.68). Convergent and discriminant validity and reliability demonstrated.	Acceptable as a tool for dying patients to use. Less medically oriented than other patient measures.
Steinhauser, K.E. *et al*	2008 USA	Patients: Inpatients/outpatients/ Hospices	Pilot RCT	Preparation and life completion discussions improving functioning and quality of life in seriously ill patients	n=82 (n=48 with cancer)	3 arm RCT – control, attention control and intervention arms: prefs for EOLC discussed in intervention arm through 3x facilitated discussion of issues related to life review, forgiveness, and heritage and legacy. Attention control just did structured relaxation. Measurements: Memorial Symptom Assessment Scale, QUAL-E, Rosow-Breslau ADL Scale, Profile of Mood States anxiety sub-scale, the CESD short version, and the Daily Spiritual Experience Scale. The 'outlook' intervention was acceptable to patients from a variety of backgrounds. Offered a brief, manualized, intervention for emotional and spiritual concerns. Intervention showed improvements in functional status, anxiety, depression, and preparation for end of life.	
Sulmasy, D.P. *et al*	2002 USA	Patients – DNR and not DNR	Questionnaire	The scale for measuring patients perceptions of the quality of end of life care and satisfaction with treatment	DNR: n=206; not DNR n=51 (consecutive sample)	Quest scores lower with DNR patients, scores correlated with severity of symptoms. Useful in assessing quality of care and satisfaction given by nurses and doctors to hospital patients attended life. Surrogate ratings also collected but uncorrelated with patient ratings.	Reiterates other findings that relatives do not assess patients' symptoms correctly.
Sulmasy, DP and McIlvane, J.M.	2002	Patients - cross sectional survey	Questionnaire (using QUEST	Patients' ratings of quality and satisfaction with care	n= 84 (incapacitious	Patient ratings higher with doctors than with nurses in quality of care and satisfaction.	Nursing care rated lower than doctors care

	USA	sample (??1 place)	tool)	for medical inpatients, especially those near the end of life	patients excluded by MMSE)	Ratings for doctors' quality lowest for D. N. R. Patients were treated by junior doctors.	but issues why are unclear.
Teno, J.M. *et al*	2001b USA	Families, outpatient hospice service in one area	Questionnaire	Toolkit After-Death Bereaved Family Member Interview (TIME)	n=156	Telephone administered questionnaire. 63.4% response rate. Interviewed between 3 and 6 months after death. The 8 proposed domains of care, as represented by problem scores or scales, were based on a conceptual model of patient-focused, family-centred medical care. Domains: Informing and making decisions; Advance care planning; Closure; Coordination; Achieving control and respect; Family emotional support; Self-efficacy; Ratings of care. Correlational and factor analysis: Cronbach's alpha scores varied from 0.58 to 0.87, with two problem scores (each of which had only 3 survey items) having a low alpha of 0.58. moderate correlation (i.e., from 0.44 to 0.52) with overall satisfaction. Family members of persons who died with hospice service reported fewer problems in each of the six domains of medical care, gave a higher rating of the quality of care, and reported higher self-efficacy in caring for their loved ones. Psychometric properties noted that warrant further testing in 7 out of 8 domains. Closure demonstrated a poor correlation with overall satisfaction and requires further work.	Conceptual model for care outlined: patient-focused, family-centred *medical* care: 1) institutions provide the dying with the desired level of physical comfort and emotional support; 2) promote shared DM; 3) focus on the individual through medical care that treats the dying person with kindness, facilitates the dying person taking the desired level of control over daily decisions, and facilitates closure; 4) attend to the needs of family members, including both practical support for caregivers and emotional support prior to and after the patient's death; and 5) ensure coordination of medical care. Again, focus is on medical care, and nursing remit is not raised at all.
Tilden, V.P. *et al*	2001 USA	Families and Clinicians (doctors and nurses) 4 hospitals	Chart review and Interviews and later, questionnaires	Families vs. clinicians reasoning about EOL DM. Assess family stress at time of EOL DM	n= 51 decedents; 45 clinicians; 74 family members (65 at second interview)	Stress levels high, especially in absence of advanced directive. Families, more than clinicians, wanted everything done to prolong life.	NB/ bereaved relatives contacted early on for interviews (initial contact 7-10 days and then 1 and 6 months). Unsurprising finding re: families.
Toscani, F. *et al*	2003 Italy	Patients	Semi-structured interviews	Life at the end of life: beliefs about individual life after death and 'good	n= 8 (four believers/four non)	Believers in life after death felt that deaths was a passage to new dimensions and preferred to be unaware of dying. Non-	Raises issues of religious and spiritual connotations of patients

				death' models - a qualitative study		believers felt that death was the end of the individual and preferred to be conscious until the end. The concept of the good death was similar: people close by, expert assistants, the preference for soft atmosphere were aspects raised by both groups.	and highlights how the practicalities of a good death are similar despite differing spiritual beliefs.
Van der Heide, A. *et al*	2003 Europe	Patients (deaths from death registries); Doctors (attending), unknown number of hospitals	Questionnaire and death certificate review	Investigation of the frequency and characteristics of EOL DM practices in Belgium, Holland, Denmark, Italy, Sweden and Switzerland. (EURELD consortium)	n=20,480 deaths; no numbers for doctors.	Response rates 44-75% to questionnaires (depending on country). Death expected in 2/3 cases. Proportions of death preceded by EOL decisions ranged between 23-51%. Significant variation between countries in whether families, nurses, patients were involved in DM.	Paternalistic practices in DM prevail in Europe, particularly in Sweden and Italy where 50% of decisions are NOT discussed.
Weeks, J.C. *et al*	1998 USA	Patients and doctors ; 5 hospitals	Questionnaire	Differences between patients and doctors prediction of prognosis and associated preferences for treatment	n=917	Part of SUPPORT study. Patients overestimated survival at 6 months but doctors quite accurate. Patient estimates affected preferences for treatment.	Disparities between predictions show lack of communication between doctors and patient, and clearly affect preferences for treatment.
Wenrich, M.D. *et al*	2001 USA	Patients with chronic and terminal illnesses, family members, health care professionals from hospice or acute care settings, and physicians with expertise in EOLC.	Focus groups	To determine which aspects of communication between patients and physicians are important in end-of-life care	n=137 from 20 focus groups	Communication with patients was identified as one of the most important domains. Issues included: Talking with patients in an honest and straightforward way, being willing to talk about dying, giving bad news in a sensitive way, listening to patients, encouraging questions from patients, and being sensitive to when patients are ready to talk about death. Dying patients also identified the need to achieve a balance between being honest and straightforward and not discouraging hope.	Study relates to communication. They also highlight the need to approach communication about end-of-life care as a spectrum that requires attention from the time of a terminal diagnosis through death

Name	Year/ place	Sample /population	Design	Main questions /aims /interventions	Number	Key findings/ Outcome	Relevance to my question/ comparison/ comments
Ahrens, T.*et al*	2003 USA	Patients – 1 ICU	Randomised Intervention study:	Improving family communications at the end of life: implications for length of stay in the intensive care unit and resource use	n=151 (43 intervention, 106 standard care)	Patients judged at high risk of death who had communication team talks to improve opportunities for patients and families to process information e.g. about goals of care had shorter stays in ICU and in hospital than those receiving standard care.	Nurse specialist as part of team, highlighted need for doctors to draw on nurses and MDT support in communication.
Angus, D.C. *et al*	2004 USA	Patients in 6 states (non-federal hospitals)	Chart review	Description of the use of ICU care a the EOL in the US	n=552, 127 (deaths)	ICU at EOL highest for infants (43%); from 18-26% for older children and adults, and >85yrs: 14%. Average length of stay 12.9 days (3days longer than outside ICU for terminal hospital episode).	Offers death data rather than a description of ICU EOLC, no characteristics of episodes researched. Argument for rationing and care elsewhere.
Badger, JM	2005 USA	Nurses – 1 (medical) ICU	Interviews and Ethnography	Description of coping strategies used by MICU nurses during transitions from cure to comfort care.	n=24	Nurses showed a variety of coping strategies: cognitive; affective; behavioural techniques to cope with EOL transitions. Giving futile care and conflict with families caused greatest distress	Nurses' perceptions and discomfort at EOL transitions articulated. Research undertaken in Mitchell Levy's unit. Nurses' lack of autonomy implicit.
Beckstrand, R.L. *et al*	2006 US	Nurses from American Association of Critical Care Nurses	Survey	To gather suggestions for improving EOLC from ICU nurses	n=861/ 1409	Random sample of nurses, 61.1% response rate. 485 offered 530 suggestions. Barriers to providing good deaths included nursing time constraints, staffing patterns, communication challenges, and treatment decisions based on doctors' not patients' needs. Suggestions for providing a good death included facilitating dying with dignity; not allowing patients to be alone while dying; managing patients' pain and discomfort; knowing, and then following, patients' wishes for EOLC; promoting earlier cessation of treatment or not initiating aggressive treatment at all; and effective team communication. Educational initiatives suggested. Good death was the major theme. Ensuring death with dignity and peace was also key.	Much overlap with this study in terms of suggestions. Not allowing patients to be alone, might contradict good death if it is about what other want not what we presume they want.. Does highlight about following patient wishes. Good death as key.

Christakis, N.A. and Asch, D.A.	1993 USA	Doctors – University Dept Medicine (24 hospitals)	Questionnaire	The different ways in which doctors choose to withdraw life support (General: not ICU)	n=481	Vignettes with Likert scales. Iatrogenic complication (less likely to withdraw), duration of prior therapy (newer more likely), timing of death (rapid rather than delayed preferred), diagnostic uncertainty (slow rather than rapid withdrawal methods)	Biases are associated with social, clinical and ethical consequences.
Cook, D. *et al*	2003 Canada	Patients – consecutive sample –35 ICUs	Chart review	Understanding the factors associated with doctors decisions to withdraw ventilation in anticipation of death	n=851	Of 851; 146 died whilst ventilated, 539 weaned successfully and 166 had ventilation withdrawn. Need for inotropes and doctors prediction of survival, doctors perception of patients wishes at less than 10% associated with withdrawal of ventilator (more critically ill patients).	Prognostication issues: here futility could be perceived at 10%, substantially higher than in other literature. Even after SUPPORT findings, doctors still presume to know patient wishes.
Counsell, C. and Guin, P.	2002 USA	Families (1 ICU)	Interviews	Needs of families at withdrawal in ICU	n=20	Un-anticipation of death outlined. Clear communication essential. Environmental issues e.g. quiet rooms.	End-of-life wishes into plans of care. Nurses obliged to be advocates
Curtis, J.R. *et al*	2008 US	Nurses and families of identified patients (n=590)	Intervention	Before-after study to assess intervention to improve Quality of Death and Dying	N = 275 families ; 593 nurses)	Intervention was clinician education, local champions, academic detailing, feedback to clinicians, and system support. Response rate 55% (low, non responder bias?) Families no improvement on QoDD scores but nurses improvement noted. Also significant reduction in ICU days before death.	Intervention did not help families, therefore needs to be targeted at them more, with more direct contact
Fridh, I. *et al*	2009 Sweden	Nurses (1 ICU)	Interviews	Exploration of nurses' experiences and perceptions of caring for dying patients in an intensive care unit (ICU) with focus on unaccompanied patients, the proximity of family members and environmental aspects.	n=9	One main category was noted that centred on Doing one's utmost, described by four generic categories and 15 sub-categories, comprising a common vision of the patients' last hours and dying process. This description was dominated by the nurses' endeavour to provide dignified end-of-life care (EOLC) and, when relatives were present, to give them an enduring memory of their loved one's death as a calm and dignified event despite his/her previous suffering and death in a high-technological environment. Nurses' mainly described family interaction but while those who died alone were considered tragic these patients left a lesser impression in the nurses' memory.	Content analysis approach could be questioned for appropriateness to this question (exploration of experiences)? Interestingly, it gives a glimpse of concentrating on patients not just families so has implications for this study.
Garros, D. *et al*	2003 Canada	Patients – paediatrics: 1 ICU	Chart review and survey	A prospective evaluation of the circumstances surrounding end of life in a paediatric intensive care	n=99 (deaths)	27 /99 died after failed CPR; 39/99 after DFLST; 20/99 were DNR and 13 were brain deaths. Families initiated DM in 24% of cases.	One of few studies to talk about families initiating EOL DM.

				unit		Consensus in DM often took 2 or more meetings to be reached. In DNR and DFLST cases death occurred at 24 and 3 hrs. Family present in 75% of cases.	Distinction made between DNR and DFLST, since patients may be made DNR but not have treatments withdrawn/withheld.
Goh, A.Y.T. *et al*	1999 Malaysia	Patients (1 ICU)	Chart review	Comparing modes of death and factors leading to withdrawal of treatment for paediatric ICU patients in a developing country	n=148	Limitation of treatment as mode of death in 68 cases; failure of active treatment in 61 withdrawal of ET tube in 7. Justification with prognostication. Ethnic issues acknowledge in refusal for withdrawal.	Increasingly proactive practice in managing death and dying in PICUs in developing countries.
Halcomb, E. *et al*	2004 Australia	Nurses – convenience sample (1 ICU)	Interviews	Nurses experiences of withdrawal/withholding of treatment in the ICU	n=12	Themes: Comfort and Care; Tension and conflict; Do no harm; Nurse-family relationship; Invisibility of grief and suffering. Nurses feelings of failure abated through care at end-of-life. Ability to provide appropriate palliative care was a positive experience. Nurses providing comfort through being able to reduce technology.	Improvements in communication benefits care. All nurses demonstrated concern for physical well-being. Parallels of 'do no harm' and comfort and care.
Hall, R.I. and Rocker, G.	2000 Canada	Patients -2 ICUs	Chart review	Comparison of use of technology, pharmacology and Dr variability in patients dying with or without life support. Treatment provided when care was or was not withdrawn.	n= 174	Once DFLST death in 4.3hrs; patients who had active life support treatment had more interventions at death. Morphine dose higher in patients undergoing withdrawal.	Comfort measures: narcotics, sedation. Nursing care: suction/positioning continued. Spiritual and emotional support provided.
Hanson, L.C. *et al*	1996 USA	Patient/doctors – 1 hospital	Interview (structured) /chart review	Differences in which doctors are more willing to use LSTs (General: Not ICU)	n=357 patients and of those 158 doctors	doctors recommended CPR and ventilator use if survival chance >48% but required 74% with cancer patients. Cardiologists more willing to use LSTs and oncologists least. End stage cardiac patients more likely to use LSTs than cancer patients.	Concludes that intensive care works favourable with end stage cardiac patients. doctors (mis) perceptions of QoL.
Heyland, D.K *et al*	2001 Canada	Families (also pre-tested with health care profs)	Questionnaire	Family Satisfaction in the ICU (FS-ICU) tool development and testing	n=21 (pre-tested) and then 22 families of non-survivors	Pre-tested the questionnaire in 21 family members and 16 professionals. To assess validity, they measured correlation between satisfaction with overall care and satisfaction with DM; and for reliability they sent it to next of kin of surviving patients on discharge and 7 to 10 days later. 22/33 were usable. 25 families	Did not oversample dying patients, and only 166 of 624 patients (27%) died in the study, so power for FS-ICU could be debated.

						participated in the test-retest: 47 respondents, 84% were very satisfied with overall care and 77% were very satisfied with their role in the decision making. Showed good correlation between satisfaction with overall care and satisfaction with DM (correlation coefficient =.64). The assessment of overall satisfaction with care was shown to be reliable (correlation coefficient =.85).	
Heyland, D.K *et al*	2002 Canada	Families 6 ICUs	Questionnaire	FS-ICU questionnaire large multi centre study	n=624	624/891 returned (70% response rate). Most were satisfied with overall care and DM (Means= 84.3 +/- 15.7 and 75.9 +/- 26.4). Families reported greatest satisfaction with nursing skill and competence (92.4 +/- 14.0), the compassion and respect given to the patient (91.8 +/- 15.4), and pain management (89.1 +/- 16.7). They were least satisfied with the waiting room atmosphere (65.0 +/- 30.6) and frequency of physician communication (70.7 +/- 29.0). Regression analysis showed significance with completeness of information received, respect and compassion shown to patients and families, and the amount of health care received. Satisfaction varied significantly across sites.	Notable that greatest satisfaction was with qualitative skills such as: nursing skill and competence, compassion and respect.
Keenan, S.P. *et al*	2000 Canada	Families – 1 ICU	Questionnaire	How the family feels about withdrawal of life support in ICU	n=29	83% felt death was dignified. When FLST went ahead as expected and pt appeared comfortable (as well as other family needs met) families were more satisfied.	Importance of family needs highlighted.
Keenan, S.P. *et al*	1997 Canada	Patients (3 ICUs)	Chart Review	Determining the proportion of patients who died as a result of the withdrawal or withholding of life support	n= 419	Why/ when/how the process was conducted? 70% of ICU patients died after DFLST. Death occurred soon after. Preference for withdrawing ventilation last. Morphine and sedation used.	Nurses involved 16% of the time only. Must be team oriented.
Keenan, S.P. *et al*	2003 Canada	Nurses Physios (14 hospitals)	Questionnaire	Level of satisfaction with withdrawal among nurses and physios and between different institutions	n=412/ 117	Being involved in plans for DTLST; comfort with discussion; comfort with sedation; and increasing experiences of DFLST associated with satisfaction.	Nurses involvement with DFLST increases satisfaction
Kirchhoff, K.T. *et al*	2004 USA	Patient's charts	Chart review	Documentation on withdrawal of life support in adult patients	n=50 charts	Decision-making documented in all charts but nurses role in two thirds of charts. 16% no DNR documented, documentation of time of initiation poor, as was documentation of meds administered. One quarter did not document whether patient was extubated.	Poor prognosis defined. Few documented whether nurse was present at death. Monitoring at ELC was not raised. Nursing care documented in some cases.

Johnson, N. *et al* (NB same study as Cook *et al* 1999)	2000 USA	1 IT U. doctors; one nurse manager ; three pastoral workers; one dietician; one ethicist and families of two patients	Ethnography and interviews	How end of life narratives are constructed in intensive care units; how withdrawal processes contributes towards perceptions of a good death	N = 16. Ethnography of 25 ICU rounds	Themes: hope dispelled; physiology of dying; withdrawal and withholding of life support as a therapeutic act -technology as villain; stepping back; what patient would wanted; disappearing the patient as person.	What death means and how death is constructed in intensive care.
Latour, J.S. *et al*	2009 Europe	Nurses attending conference	Questionnaire	EfCCNA survey of nurses' attitudes and beliefs about EOLC	n=164	Response rate of 39%. The majority of respondents (91.8%) indicated direct involvement in EOL patient care, while 73.4% reported active involvement in decision-making process. 78.6% of respondents expressed commitment to family involvement in EOL decisions, however only 59.3% of the participants said that this was routinely undertaken (p < 0.0005, Z =.4.778). In decisions to withdraw or withhold therapy, 65% would decrease the flow of inspired oxygen, 98.8% provide continuous pain relief and 91.3% endorse open visiting. The majority (78%) disagreed that dying patients should be transferred to a single room. A division of views was observed in relation to 44% agreeing that patients should be kept deeply sedated and equal numbers contesting the continuation of nutritional support (41.6% versus 42.3%).	The involvement of European intensive care nurses in EOLC discussions and decisions is reasonably consistent with many engaged in initiating dialogue with co-workers. In general, views and experiences of EOLC were similar, with the exception of the provision of nutrition and use of sedation. Relevance to practice: Use of formal guidelines and education may increase nurses' involvement and confidence with EOL decisions
Levy, M. *et al*	2005 USA	Doctors, nurses and families	Questionnaire	Quality of Death and Dying between clinicians and families in two ICUs	n=68 patients (68 deaths by health providers/50 by families – 38 deaths by all raters)	Family members and attending doctors gave most favourable ratings of death, while nurses and residents provided less favourable ratings Sig diffs (p < 0.01) on items related to patient autonomy: maintaining dignity, being touched by loved ones, and overall quality of death. Perceptions vary considerably between participants.	Utility of the ICU QODD instrument for assessing and improving the quality of end-of-life care in the ICU needs exploring.

Manara, A.R. *et al*	1998 UK	Patients (1 ICU, 4 years)	Chart review	Frequency and reasons for withdrawing treatment in ICU	n= 220	Reason for withdrawal was imminent death in 45% of cases; qualitative considerations in 50% and legal in 5%.	Treatment commonly withdrawn as a result of QoL implications as often as imminent death
Robichaux, C.M. and Clark, A .	2006 USA	Nurses (expert)	Qualitative interviews (narratives)	Explore the practice of expert critical care nurses in EOL conflicts and to describe actions taken when the nurses thought continued aggressive medical interventions were not warranted	n= 21 from 7 centres in SW US states	Protecting/speaking for patients. Presenting a realistic picture, experiencing frustration and resignation. Advocacy preventing further technological intervention/ intrusion: permitting dignified death. Realistic picturing to help families reframe and see potential (or lack of) recovery. Inability to affect situation led to frustration and resignation.	ICU nurses as advocates at EOL. Expert nurses (only) able to prevent unnecessary intrusion and promote peaceful death, but also feel frustration when unable to affect. Poor response from community hospitals. Question arises around nurses as moral agents? Only nurses' views, no team perspective.
Melia, K.M.	2001 Scotland	Nurses and 2 doctors from other research) (4 areas CCU, ICU, PICU, cardiac surgery)	Interviews	View of nurses intensive care ethics at withdrawal of treatment	n=24	Lack of nurses input into DM but closest to its consequences. Decision to withdraw carried out in phases: 24 then 48 hrs. Tendency to let it drift. Moral dissonance and disagreement. Nurses geared to sustaining life. Nursing care only unpopular at times with nurses, undermining the intensive care work occurring after withdrawal. Need for team consensus, power/ legal issues with medicine.	Implications for end-of-life care and medical withdrawal: nurses being left with care. Nurses needing buzz of ICU. Only nurses' views, no team perspective.
Mularski, R. *et al*	2005 USA	Families; 4 ICUs	Questionnaires	Quality of Death and Dying family ratings	n=94 family members from 38 patients	They explored associations between ICU experience and overall rating QoDD experience. Overall, family members reported that symptoms were poorly controlled: pain under control most or all of the time in 47%, and breathing comfortably most or all of the time in 3% of patients. Families expressed a moderate and variable view of the quality of dying resulting in an overall ICU QODD score of 60 ± 14 (on a scale of 0 to 100) [mean ± SD]. Higher ICU QODD scores were associated with control of pain (r = 0.42, p = 0.009), control of events (r = 0.62, p < 0.001), a "preparation for death" aspect of the dying experience—feeling at peace with dying (r = 0.69, p < 0.001), and a "whole-person concern"—keeping one's dignity	Care at the end of life in the ICU should include not only managing pain, but also supporting dignity, respect, and peace, and maximising patient control.

						and self-respect ($r = 0.50$, $p < 0.001$). Adjusting for symptom / personal care scores, certain whole-person and death preparation aspects of dying (not aggressiveness of EOLC), remained the most associated to quality ratings.	
Popejoy, L.L. *et al* USA	2009	Medical Surgical Neuro ICUs	Focus groups	Study aim was to prepare for a formative evaluation project to design a palliative care program in adult intensive care units – secondary aim: to elucidate nurses' viewpoints of caring for critically ill and dying patients in ICUs.	n=22	Five major themes were identified in the analysis: (1) helping the patient through, (2) telling bad news, (3) grieving as a process, (4) family as the patient, and (5) the dying patient's effect on the nurse. Nurses also identified how palliative care was currently being used in the ICU.	Findings support the need to build strong collegial relationships between members of the healthcare team in order to effectively support communication about EOL DM in the ICU setting. Focus remains on EOLD not EOLC and role for nurses within teams unclear.
Prendergast, T.J Puntillo, K.A. USA	2002	Health Professionals	Case study	Intensive caring at the end of life: a need for care practices at withdrawal	n/a	Highlights importance of symptom control: mechanics frequently coordinated to align with family (societal, ethical, religious) wishes. Discusses use of algorithms. Involving families in caring processes such as hygiene care.	Mechanism of withdrawal influence provision of care at EOL.
Rocker, G.M. *et al* Canada	2004	Patients: consecutive sample, 1 ICU	Chart review	Most critically ill patients perceived to die in comfort during withdrawal of life support: a Canadian multi-centre study.	n=206	Ventilation withdrawn in 75.2% of patients; 62.6% died after extubation and 37.4 with airway in place. Drugs most often used: morphine, midazolam, lorazepam. Family members perceived their loved ones to be totally, very or mostly comfortable in most cases. Perceptions of comfort were not associated with the mode or sequence of withdrawal/ time to death.	Extubation part of this unit's practice, not so common in other areas, issues therefore of applicability to other ICUs.
Sprung, C.L. *et al* Europe	2003	Patients: consecutive patients - 37 ICUs	Chart review	ETHICUS study: end of life practices in European intensive care units (Israel, Spain, Switzerland, Sweden, Ireland, Finland, Germany, Portugal, UK, Denmark, Belgium, Turkey, Austria, Czech R., Greece, Holland,)	n= 4248 patients who'd died or had a treatment withdrawn or limited	10 percent of all admissions had limitations of treatment (72.6% of 4248) - significant variability between countries found in: the manner and dying, CPR, brain-death, withholding therapy, withdrawing therapy and active shortening of dying.	Doctor still paternalistic, cultural implications for withdrawing treatment highlighted but severity scores for illness not analysed.
Sprung, C.L. *et al* Europe	2007	Patients who survived; Nurse;	Questionnaire	ETHICATT study: end of life attitudes in Europe for patients who survived, families of patients who were dying and nurse and	n=1,899	Only other study with same sample as mine. 4389 invited only 1,899 took part. In Czech Republic, Israel, The Netherlands, Portugal, Sweden, and the UK. QoL and value of life more	Professional assumptions about aggressiveness of care wrong but in

		Doctors; Families. ICU in 6 countries		doctors		important for profs then families and patients. Professionals wanted to be *less* aggressive in face of terminal illness than patients and families. More professionals felt hospice or home more appropriate than patients and families did.	other direction to previous research. Place of death does not have to be home or hospice. Implications for policy and my research. Also sample same.
Stayt, L.C. UK	2009	Nurses 1 ICU	In-depth interviews	Death, empathy and self preservation: the emotional labour of caring for families of the critically ill in adult intensive care	n=12	Study explored emotional labour nurses' face when caring for relatives of the critically ill in intensive care unit. Phenomenological interviews revealed: significance of death, establishing trust, information giving, empathy, intimacy and self preservation. Emotional work forms an important part of the critical care nurses job. The significance of death, breaking bad news and interpersonal relationships are sources of emotional stress for the critical care nurse caring for the family of the critically ill. The impact of this stress on the nurse and the care they deliver requires further investigation. Potentially, unless appropriately supported and managed, emotional labour may lead to occupational stress and ultimately burnout.	Emotional implications resonate with Seymour's study. Registered nurses caring for families who have relatives in adult intensive care units expand considerable emotional labour. Specific only to nurses, not wider team.
Teno, J.M. *et al* US	2005	Family members	Survey	A comparison of dying and quality end-of-life care in different regions (high and low intensity areas of intensive care use)	n=778	Dying in area with higher use of intensive care facilities is *not* associated with improved perceptions of quality EOLC. Inadequate emotional support noted in high intensity areas.	Care in high intensity areas mean that patients may experience less respect and poorer symptom control: implications for technology debate around having high intensity/technology treatment at EOL.
Treece, P.D. *et al* USA	2004	Nurses / Patients - 1 ICU	Questionnaire/ Chart Review	Implementation of a standardised order form for withdrawal of treatment; satisfaction and chart review. Pre and post-intervention.	n= 143 / 61	Nurse-assessed quality of death and dying in intensive care. Use of sedation/analgesia at time of death increased when order form implemented. Quality of death and dying not significant with form. Doctors satisfied with sedation and ventilation sections. Form helpful..	QODD tool adapted for ICU use. Increased use of sedation/narcotics does not equate to patient comfort necessarily (but not critiqued). Unclear why nurses felt form made no difference.
Treece, P.D. *et al*	2006	Nurses	Development	Development of nurse-focused	1 hospital but	Clinician education to increase knowledge and	Focus is on nurses to

	USA		of framework: description of an intervention (description of method, not yet complete study)	quality improvement intervention: self efficacy behaviour to change doctors behaviour 'Integrating Palliative and Critical Care'	6 ICU centres: 65 ICU beds	awareness; local champions for role modelling; academic detailing of nurse /ICU directors to outline barriers; feedback of local quality improvement ; leaflets, info, palliative care order forms and other system supports to promote palliative care in ICU.	get doctors to change their behaviour, rather than doctors to changes their behaviour, therefore arguably destined for a degree of failure. Feedback based on family satisfaction, problems of proxy assessment arise.
Wall, R.J. *et al*	2007 USA	Families – 7 ICUs	Questionnaire	Refinement of Family Satisfaction-ICU (includes and analyses bereaved families as well as those of survivors)	n=1038	Compared against QODD in factor analysis. Fifteen questionnaire items highlighted for possible removal. After consensus with the developers, ten items were dropped (and 24 were retained in the final instrument). Factor analysis explained 61.3% of the total variance using a two-factor model. The first factor pertained to satisfaction with care (14 items). The second factor encompassed satisfaction with decision making (10 items). In validity testing, the FS-ICU was significantly correlated with the Family-QODD total score (Spearman's .56, p < .001) as well as individual QODD items such as quality of care by all providers (.64, p < .001). The FS-ICU also correlated significantly with multiple nurse-assessed quality indicators. Shortened FS-ICU measures two main conceptual domains-satisfaction with care and with DM. Scores on the FS-ICU show good validity against other indicators of ICU quality.	The instrument might be useful outcome measure in EOLC ICU, as well as outside EOL situations.
Vincent, J.L.	1999 Belgium	Doctors	Questionnaire	Views of European Intensivists regarding DFLSTs	n=504 (16 countries)	73% frequently admit patients with no hope of survival (which only 33% wanted to do). 80% wanted written DNRs to be applied more. Withholding more common that withdrawing. 40% would administer large doses of drugs until death ensued (inc. NL). Only half included families in DFLST. Family pressures mean unnatural life is easier than natural death. Cultural implications.	Focus was on DM, EOLC not part of survey. Implications around not including family members.
Yang, M. and Mcilfatrick, S.	2001 Taiwan	Nurses – 2 ICUs	Interviews	Intensive care unit nurses experiences of caring for dying patients: a phenomenological study	n=10	Core themes: nurses' attitudes to dying; stressors associated with care and coping strategies. Cannot be presumed that caring for dying patients in other settings will prepare nurses for this role.	Education needed for ICU nurses. Previous experience in palliative care has limitations in ICU.

Appendix 5: LCP-ICU and audit findings

5a. Baseline Audit LCP-ICU

5b. Post LCP-ICU Audit

Please see the Marie Curie Palliative Care Institute at Liverpool for the LCP-ICU <u>http://www.mcpcil.org.uk/liverpool-care-pathway/lcp-specialist-icu.htm</u> (Accessed 10th May 2010)

5a. Baseline Audit LCP-ICU

The Royal Marsden Hospital

Critical Care Unit
BASE REVIEW FEEDBACK

April 2006 – April 2007

3 Sections of the LCP:

1. Initial assessment and care
2. Ongoing assessment and care
3. Care after death

Goals of care for patients encompassed by the LCP

- Physical
- Psychological
- Religious / Spiritual
- Social

The Royal Marsden Hospital

Critical Care Unit
BASE REVIEW FEEDBACK
RESULTS
April 2006 – April 2007

Demographics (n=20)

Variable		Frequency
Gender	Male	12(60%)
	Female	8(40%)
Age	Median	60
	Range	(36–79)

Demographics (n=20)

Diagnosis	Frequency
Lymphoid, haematopoietic C81-96	13(65%)
Female genital organs	2(10%)
ENT (1), Breast (1), Small cell lung (1), Bladder (1), Colon (1)	5(25%)

SECTION 1

Initial Assessment and Care

Psychological / Insight

Goal 1   **Ability to communicate in English assessed as adequate:**
  1.1   Patient
  1.2   Family/Other

Goal 2   *Insight into condition assessed:*
  Aware of Diagnosis
  2a1   Patient
  2a2   Family/other

  Recognition of Dying
  2b1   Patient
  2b2   Family/other

Psychological / Insight

Goal 3:   **Plan of care explained & discussed with:**
  3.1   Patient
  3.2   Family/other

Goal 4   **Family/other express understanding of planned care**

Psychological/Insight (n=20)
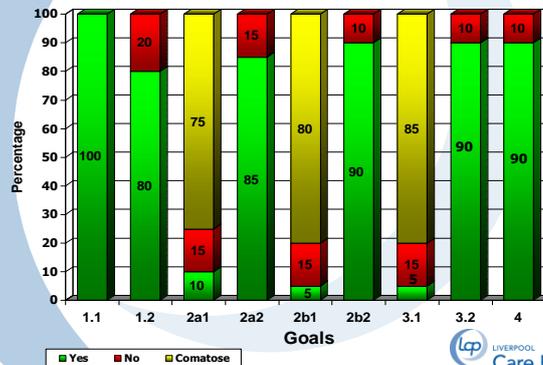
Comfort Measures

Goal 5   **Current medication assessed and non-essentials discontinued**

Goal 6   **As required subcutaneous drugs written up according to protocol**
  6.1   Pain
  6.2   Agitation
  6.3   Respiratory tract secretions
  6.4   Nausea and Vomiting
  6.5   Dyspnoea

Comfort Measures (n=20)

Chart: Percentage vs Goals (5, 6.1, 6.2, 6.3, 6.4, 6.5)

| Goal	Yes	No
5	15	85
6.1	90	10
6.2	60	40
6.3	5	95
6.4	35	65
6.5	55	45

Legend: ■ Yes ■ No
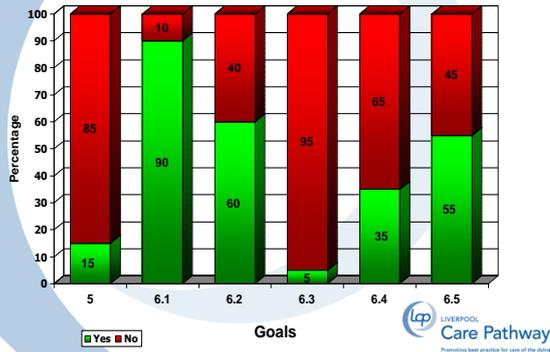
Comfort Measures

Goal 7   **Discontinue inappropriate interventions**

7.1	Blood tests
7.2	IV Antibiotics
7.3	IV fluids
7.4	Not for Cardiopulmonary Resuscitation
7.5	Deactivate Cardiac Defibrillators
7.6	IV Vasoactive Medications
7.7	Electronic Monitoring
7.8	Dialysis
7.9	Reduce Ventilatory Support
7.10	Extubate

Comfort Measures

Goal 7   **Discontinue inappropriate interventions**

7.11	Remove NG Tube (Gastric Secretions)
7.12	Remove NG Tube (Feeding)
7.13	Stop PEG Feeds
7.14	Physiotherapy

Comfort Measures (n=20)

Chart: Percentage vs Goals (7.1–7.8)

Goal	Yes	No	N/A
7.1	20	80	
7.2	35	60	5
7.3	10	75	15
7.4	85	15	
7.5	5		95
7.6	35	35	30
7.7	15	80	5
7.8	20	25	55

Legend: ■ Yes ■ No □ N/A

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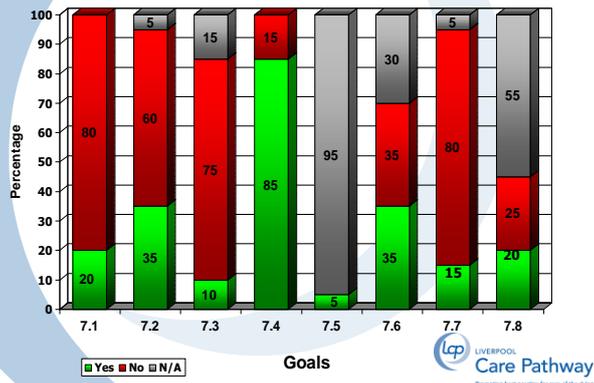
Comfort Measures (n=20)
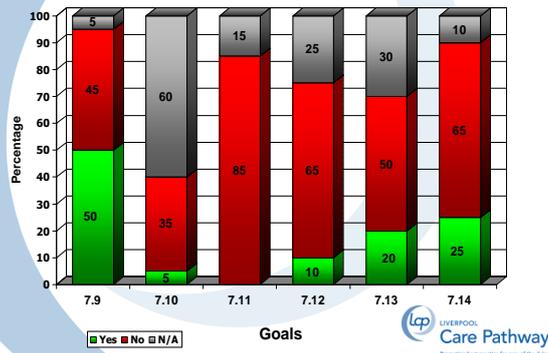
Religious/Spiritual & Communication

Goal 8	Religious / spiritual needs assessed with:
	8.1 Patient
	8.2 Family/other

Goal 9	How family/other to be informed of patient's impending death

Goal 10	Family/other given hospital/hospice information leaflets
	(Accommodation, car parking, dining room facilities etc)

Religious/Spiritual & Communication

Goal 11a	Decisions to discontinue inappropriate nursing interventions taken

Goal 11b	Syringe Driver to be set up once prescribed by the doctor

Goal 12	General Practitioner is aware of patient's condition

Religious/Spiritual & Communication (n=20)
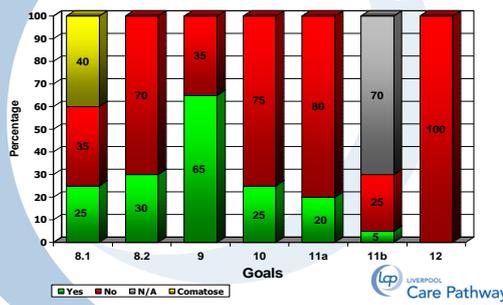
SECTION 2

Assessment and Ongoing Care

Assessment of Ongoing Care

- Pain, agitation, respiratory tract secretions, nausea and vomiting, dyspnoea

- Mouth care, micturition, medication given safely and accurately, syringe driver checked (where appropriate), bowels assessed

Assessment of documentation of ongoing care

Bar chart. Y-axis: Percentage (0-100). Categories with Yes (green) / No (red):
- Pain: Yes 45, No 55
- Agitation: Yes 50, No 50
- RTS: Yes 15, No 85
- Nausea: Yes 5, No 95
- Dyspnoea: Yes 65, No 35

Assessment of documentation of ongoing care

Bar chart. Y-axis: Percentage (0-100). Categories with Yes (green) / No (red) / N/a (grey):
- Mouth Care: Yes 25, No 75
- Micturition: Yes 75, No 25
- Medication: Yes 70, No 30
- Syringe Driver: Yes 5, No 15, N/a 80
- Bowels: Yes 30, No 70

290
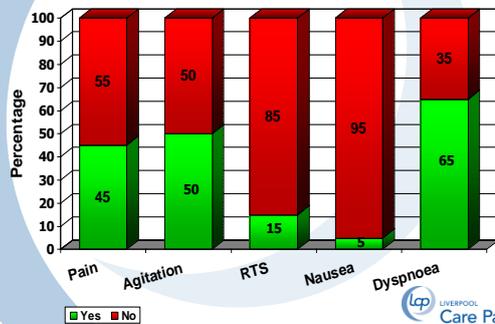
SECTION 3

Care After Death

Care After Death

Goal 13	**GP Practice contacted re: patients death date**
Goal 14	**Procedure for laying out followed**
Goal 15	**Procedure following death discussed or carried out.**
Goal 16	**Family/ other given information on procedures**
Goal 17	**Hospital Policy followed for patients valuables & belongings**
Goal 18	**Necessary documentation and advice is given to the appropriate**
Goal 19	**Bereavement leaflet given**

Care after Death (n=20)
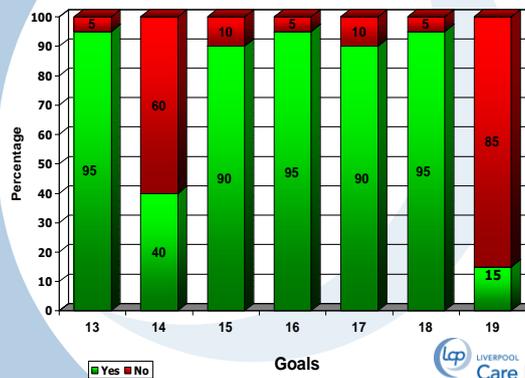
Conclusions

- Base Review uses the LCP to identify the level of *documented* care at 'baseline'.

- The results are not necessarily reflecting the standard of care delivered, merely the standard of documentation of care.

The LCP - The Way Forward
10 Step Approach to implementation

Month 1
- Establishing the project
- Development of documentation
- Retrospective audit of current document

Month 2 - 5
- Induction - Education Programme
- Implementation - Education Programme
- Reflective Practice

Month 5 - 6
- Evaluation and Training Needs Analysis

Month 7 - 9
- Maintenance - Education Programme

Month 10 - 12
- Training The Teachers
- Programme of ongoing feedback from analysis of the LCP

5b. Post LCP-ICU Audit

Title: **Review of documented care of patients dying in the Critical Care Unit (CCU) following introduction of the Intensive Care Unit Liverpool Care of the Dying Patient Pathway (ITULCP).**

Results

Brief Summary of Audit Results stating: *Whether standards / guidelines have been met.*
If improvements since last audit, state type and degree of improvement.

Having introduced the adapted Liverpool Care of the Dying Patient Pathway to the Trust's Critical Care Unit (CCU) in September 2007, this post pathway audit (PPA) aimed to assess whether the tool had made any difference to the way end of life care was documented within the unit. The generic LCP is used to support over 50% of all inpatient deaths on the Trust's wards, yet in CCU the ITULCP has only been used in approximately 28% of deaths. It was hoped this audit might help to identify reasons for this and whether there are gaps in our documentation of care.
The data from 15 consecutive ITULCPs used within CCU between November 2007 – August 2009 was sent to Liverpool. The national data collection proforma was used to collate the data. The Liverpool Central UK Team carried out initial analysis of the data.

Results
The median age of patients in this sample was 65 years. Patients' care was supported by the ITULCP for a very short number of hours. The median was 5 hours but was skewed by two patients for whom the ITULCP was started in Step Up prior to transfer out to a ward for end of life care. The majority of CCU patients were only supported by the ITULCP for 2-3 hours before their death.

Aspects of documentation which had improved with use of the LCP
Section 1 Initial Assessment
The PPA reveals an improvement in reviewing/ discontinuing medications in the context of the patient's deterioration. This was documented in 73% of cases as oppose to 15% in the baseline audit (NAR 188)
Goal 7 addresses documentation of decision making related to discontinuing interventions no longer deemed to be appropriate. This audit shows considerable progress with this goal e.g. Goal 7.1 documentation related to reviewing blood tests has increased from 20% in the baseline to 93% in the PPA e.g. reduction of ventilatory support (Goal 7.9) was documented here in 73%, up from 50%. However the PPA still shows a considerable amount of missing data within this group of goals, and the CCU team may wish to review the length and content of the interventions listed within goal 7.
Within the initial assessment the LCP prompts staff to consider the spiritual needs of the patient and family (Goal 8.1 & 8.2) and information needs of the family (goals 9 &10). The pathway seems to have encouraged better documentation of Goal 8.2 (up to 73% from 30%) and Goal 10 (up to 67% from 25%).
Use of Section 2- Ongoing Care
This section of the LCP records the condition of the patient at specific time points, rather than providing evidence of care delivery. Staff are expected to review the patient's physical symptoms a minimum of 4 hourly, though within the CCU setting to reflect the rapid change in the patient's condition it is recommended this is done 1-2 hourly. Broader aspects of care such as bowel care, spiritual needs and family support are assessed by each shift of staff. This audit suggests the LCP helps to ensure this data is recorded in a more consistent way and appears to be the best utilised section of the ITULCP.

Aspects of documentation which appear unchanged with use of the LCP
Use of Section 1- Initial Assessment
The first 4 goals of the ITULCP explore the patient and family's insight in to the diagnosis, prognosis and reviewed direction of care. These were generally well addressed and documented by the CCU team prior to using the LCP, and this audit implies little change since the introduction of the care pathway. Despite the LCP offering a framework for recording this data a similar percentage was missing when compared to the baseline audit.
Within the initial assessment the LCP prompts staff to inform the general practitioner (GP) of the patient's deterioration (Goal 12). This continues to be poorly documented, only recorded in 7% of situations.

Aspects of documentation which appear less well documented with use of the LCP
Use of Section 3 – Care after Death
Ironically the PPA suggests documentation of aspects of care delivered to the patient and family after death is worse when the ITULCP is used to support care. There was a considerable amount of missing data in this section of the ITULCP .The only goal to show improvement was Goal 19 which relates to giving information about bereavement. This goal is currently addressed by the staff in the Facilities Office.

Conclusions
The ITULCP seems to have helped to improve the documentation of some aspects of end of life care although in other areas documentation has deteriorated and there is a considerable amount of missing data.
This and the infrequent use of the ITULCP might imply that the current document is too long to be used completely and appropriately when patients' end of life care lasts for a period of a few short hours.

Will implementation of Audit recommendations lead to change in practice?		
Action(s) to be taken *resulting from audit findings*	By whom? Natalie Pattison and Judith Coleman	To be completed by when? (date)
Results of audit have been forwarded to senior CCU nursing and medical staff	Judith Coleman, Generic LCP Facilitator	December 2009
Small working party of CCU staff to consider ways of modifying current ITULCP to make it more succinct and practical for use in the short timeframes in which end of life care is delivered in CCU	Natalie Pattison (Clinical Nursing Research Fellow) will take the lead	Spring 2010
Will it be appropriate to re-audit when actions have been implemented?	Yes	It may be helpful to re-audit once 5 modified ITU LCPs have been used.
*Retention period for audit data agreed?	No	

Appendix 6: Exploration and defence of the critique of phenomenology

This appendix provides a more in-depth exploration of the background phenomenology and a defence of the critiques often levelled at it in nursing. Firstly, I give more background than described in Section 3.2, and then, secondly, provide examination of specific phenomenological concepts of: temporality, *Sorge*, care, intentionality, death, dying, truth, phronesis and techne in relation to my research. Lastly, I outline the main points of criticism outlined by critics of phenomenology in nursing.

Background

Husserl had approached phenomenology with the idea of bringing into view the function of consciousness as transcendental subjectivity (Palmer, 1969). Phenomenology is inherently critical of objectivism; the notion of meaning in independence of mind and being is inconceivable (Crotty, 1996; Paley, 1998) and is diametrically opposed to Cartesian dualism: the distinction between subject and object. Heidegger, Husserl's one-time student and later contemporary, critiques Descartes for not questioning beyond how we know what we know to what it means to 'be' a person and how the world is understandable to us at all (Leonard, 1994). As Reed (1994) articulates, because people are immersed in the world they do not think of it as something that needs further enquiry. The potential and choices of people can be forgotten.

Phenomenology stemmed from a movement or '*Kreis*' (circle) initiated by Husserl, in conjunction with Geiger, Pfänder, Reinach and Scheler, joined later by Heidegger and Becker. They shared a common conviction that it was only by return to the primary sources of direct intuition, and insights into essential structures derived from those intuitions, that philosophical concepts and problems could be resolved and articulated (Speigelberg, 1969). Phenomenology did not emerge in a vacuum but was placed within a context where Husserl, who had studied under Brentano exploring whether arithmetic could be derived from psychology, was stimulated by not only Brentano but also Frege, Mill and Stumpf to use philosophy in the critique of psychologism; known as logical psychologism. Husserl was studying human phenomena: thoughts, feelings and emotions, by describing the experiences of the things that gave rise to those phenomena: this would be known as psychology. His theory developed towards the

notion of a descriptive study of the processes in which the entities studied in pure logic are presented. Post-modernist philosophy, emerging in the 1950s as an alternative to positivism and logical idealism, rebuffed previously held assumptions that science and mathematics offered a neutral point of view on the world. Heidegger, among others such as Derrida and Wittgenstein, re-examined the fundamentals of knowledge; they argued that rationality was neither as sure nor as clear as modernists or rationalists assert (Harvey, 1990).

Phenomenology was essentially a post-modern philosophy in that it rejected the assumptions of natural science and instead veered toward scientific realism. Post-modernism cleared the methodology of prescribed rules and boundaries, which act as barriers to revealing new truths (Mishler, 1979). Phenomenology is one way, which Leonard (1989) outlines, of searching for different possibilities in the quest to both make sense of human life and to do justice to unfixed notions of much of human experience.[40]

Heidegger, exploring Husserl's notion of transcendental subjectivity, saw that within that subjectivity was a vital element of one's being-in-the-world, both a historical and temporal concept. Heidegger believed that the facticity of being was more fundamental than the matter of human consciousness and knowledge (Palmer, 1969). This was in contrast with Husserl's belief that even the facticity of being could be regarded as a datum of consciousness (Spiegelberg, 1965). For Heidegger, phenomenology need not be construed as necessarily a laying open of consciousness; it can also be a means of disclosing being, in all its facticity and historicality (Heidegger, 1927). He felt that phenomenology would allow things to become manifest as what they are without forcing our own categories on them. Things show themselves to us. It implies that interpretation is not grounded in human consciousness and human categories but in the manifestness of the thing encountered, the reality that comes to meet us.

For Heidegger, our way of being is not in the way we think, but in our existence in a place with particular things and established ways of doing things. What *Dasein* is can only be interpreted or read off the world as it acts, or is seen as, in the world[41].

As Palmer (1969, p.131) asserts in his interpretation of Heidegger's essence of understanding:

> "the essence of understanding lies not in grasping one's situation but in the disclosure of concrete possibilities for being within the horizon of one's place in

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[40] Post-modernist thinking however, could also be perceived as a critique of phenomenology, by suggesting it failed to account for the structure of experience and consciousness that determine the meaning of experiences.
[41] In essence, by experiencing something we encounter it, it becomes *Dasein*.

the world. For this aspect of understanding Heidegger uses the term 'existentiality'."

In Heidegger's work, existence is nothing if not a matter of being-in the world. Any analysis of this being must be made on the basis of '*explicata*' proper only to it (Kaelin, 1967. This philosophy underpinned his work and was a common phenomenological idea shared by Husserl, Sartre and Merleau-Ponty. Explicata refers to a way of understanding beyond the reductionist categories of natural science. Heidegger also believed *existentalia* could add to this understanding by analysing the human subject's[42] openness to the world and indicates the primacy of affectivity in our knowledge of both ourselves and the world. Kaelin (1967) questions what affectivity means:

> "what is affectivity if not a perception of ourselves caught in a certain pose before the objects of the world, if not one act of the corporeal *cogito*?" (Kaelin, 1967, p.62)

Temporality, *Sorge* and Care

Heidegger views temporality in terms of things being connected rather than in terms of linear or chronological time. This notion remains a theme throughout his work. Benner (1994) summarises temporality as the experience of lived time, the way in which one projects oneself into the future or understands oneself from the past. According to Heidegger (1927), temporality is relational and directional and applies to being, not physical objects.

Temporality can therefore be considered as a way of understanding through reminiscing in the past, awareness of the present and also hypothesising in the future. A personal concept of time can be distorted, e.g. when a patient is dying, their, and their loved one's notions of time may be very different to chronological time and this, therefore, affects their lived experience. To extend this example further: family anxieties about the patient's death are informed and constituted not only by the actual experience of that death, the past, but also by what that death means for the future. Having-been-ness, sometimes used to describe ruminations (Leonard, 1994) and reflections on the past, along with being-expectant, used to describe an awareness of what the implications are for the future, informs our being-in-time. The essential structure of being, of being human, Heidegger describes in one section of his essay on temporality as 'care'.

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[42] It could be argued that this is an odd term for a philosopher who is acutely aware of subject-object terms to use and so diametrically opposed to the concept of humans being reduced to bodies and minds, since this term is strongly associated with the natural science and reductionism paradigm.

> "'Earlier' than any presupposition, which *Dasein* makes, or any of its kind of ways of behaving, is the '*a priori*' character of its state of Being as one whose kind of Being is care." (Heidegger, 1927, p.249)

This is perhaps not care as we might construe it in a nursing sense, and which will be explored in the literature section, but rather 'being concerned'. Heidegger uses *Sorge* for this notion, which does not directly correspond to the literal translation of care in German. In his use of *Sorge* he refers to care as the structure of our being, expressed by how we interact with our world and relate to the entities within it (Heidegger, 1927). Dunlop (1986) interprets this idea of care as a deep involvement with the world, and necessary for human activity. Heidegger (1927) progresses the notion of *Sorge* uses 'solicitude' (*Fürsorge*) to denote care in the context of dealing with people. Care for things, he refers to as 'concern', and care for other *Daseins* he terms solicitiude. Using Heidegger, nursing is a form in which solicitude can be expressed (Crotty, 1996). Heidegger's (1927) consideration for others is expressed by "Leaping in" (einspringen) and "leaping ahead" (vorspringen). As Frie (2003) makes clear, when one leaps in for the other person, that person is relieved of responsibility, but with the result that he or she may become dominated by those who leap in or dependent on them. As a result that person's capacity to achieve authenticity is taken away. Conversely, it may be in leaping ahead of the other person, that one seeks to help that person to become transparent to him or herself, and to see the truth of his or her condition and become free for it. Leaping ahead constitutes an authentic relationship (Frie, 2003).

Dunlop (1986) outlines the problem with solicitude for those who would seek to develop nursing as science, since she believes that to examine it using science that is part of its product is an absurdity. However, while I disagree with this notion, she goes on to argue that "caring can be viewed as a mode that being-in-the-world can adopt" (Dunlop, 1986, p.666), an expression of *Sorge* and, as such, it can be viewed against its background and subjected to examination.

Resonating in Spichiger *et al*'s (2005) work is the Heideggerian idea that caring is not something that can be defined as a set of behaviours, intentions, actions and sentiments for instance. Caring requires phronesis, the idea of practical wisdom (which I shall return to shortly), and depends on the concerns that define a persons's self and lifeworld, and the caring needed to restore any deficits in self and lifeworld (Spichiger *et al*, 2005).

Intentionality

Intentionality refers to phenomenological concepts of relatedness or directedness. It is the interdependence of subject and object and the idea that human consciousness is always consciousness of something and therefore must be related to objects. Holloway and Wheeler (1996) succinctly summarise it as the process whereby the mind consciously directs thoughts to an object. Intentionality refers to the psychology of phenomena raised earlier in the discussion around Husserl and the history of phenomenology: he believed that thoughts are always directed at objects (Husserl, 1913). Leonard (1994) discusses how intentionality in human action is shaped by a person's concerns, goals, purposes and commitments. McNamara (2005) suggests that intentionality, in eliminating the subject-object divide, encapsulates Husserl's radical departure from many of the positivistic assumptions of objectification in natural science. The interdependence of subject and world is captured in the notion of human beings as beings-in-the-world, he will always be directed and open to their world. This represents an important aspect of phenomenology, experience in the world cannot be divested from the world itself, a criticism frequently targeted at those in nursing who are researching the lived experience. Intentionality is transcending the natural attitudes, common sense beliefs about the nature of things and existence in the everyday world and reaching the phenomenological standpoint (Priest, 2002). It is the inseparable connection to the world, the act of researching, questioning and theorising, that is the intentional act of attaching ourselves, or becoming the world (van Manen, 1990).

Phenomenology: Death and Dying

Heidegger used death and dying to illustrate his concepts of *Dasein*. I address this here since the essence of the study surrounds death. It is important for me to explore Heidegger's notion of death when undertaking a phenomenological study that relates to death. Heidegger (1927) conceptualised death as an actual event versus a possibility of our own being: that is, death as a life event versus being-toward death. His notion of an inauthentic death was to render death as belonging to someone else, an object to be feared. This fear can also be placed in a context of an increasingly death-denying society (Seale, 1998; 2006).

In other words, to be authentic in being-towards death it could be argued that one has to be reconciled with death. As Gelven (1989) delineated, for death to become meaningful

for oneself it must be seen as a possibility, not an actual event belonging to another. Being reconciled with the idea of death and facing up to the existential possibility of death also forms the basis for patients' experiences of end-of-life care. Reconciliation and confrontation then leads us onto Heidegger's concepts: *erwarten* and *vorlaufen*. *Erwarten* is looking toward something as an actual event, whereas *vorlaufen* is looking toward something as a possible 'way to be' (Heidegger, 1927). Importantly for this study, he raised the possibility that you could experience death of others (Heidegger, 1927). This possibility becomes fundamental when exploring the proxy sources for EOLC that this study uses.

Heidegger (1927) also discusses the issue of corporeal death: where someone is being-no-longer-in-the-world his being is still being, as in being present-at-hand but his being is not corporeal. This can be equated with certain religious doctrine which holds that there can be disembodied existence (bodily death) versus the death of the person as a whole. Using Cartesian notions of a mind-body split, a patient classified as having a brainstem death is, to all intents and purposes, dead. Under a dualistic philosophy that considers the mind and body together, this is hard to reconcile, since the body is alive but the mind is dead. Somatic, molecular or social death as a total, collective construct means death. Walter (1994) raises the notion that the social person may not die when the body does. Their standing in society might remain for a while longer. The palliative care movement, as Sandman (2005) argues, is premised upon the prevention of demise of the social self, social death, before bodily death. In other words, ensuring dignified death and care after death means the person will not experience untimely social death (Pattison and Dodds, 2008). For the purposes of this study it is important to consider existential notions of death since they will underlie many of the responses from participants. Wrathall (2005) attends to Heidegger's concept of death as being the way we experience ourselves, human beings, as mortal. Again this reaffirms the underpinning concepts in the end-of-life care literature and in the patient and family populations in this research study that people have to confront death when considering end-of-life care. To summarise with Heidegger (1927) facing death gives *Dasein* its goal outright and pushes existence into its finitude.[43]

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[43] I interpret finitude here as referring to the possibility of a person's finite existence; death will have to be faced

Truth

Heidegger's concept of truth is addressed here, for it is this that informs his ontology: truth in his philosophy is wholly different from scientific notions of truth, and this is what differentiates phenomenology from natural science. Heidegger's search for truth encompassed genuineness, correctness and truth experienced at the disclosure of the phenomenon. His truth went beyond factical truth. The essence of truth is the disclosure of being. Being open to truth, or by opening one's field of consciousness of, as Kaelin (1967) states, so that disclosure and concealment can take place, is the metaphysical precondition of having any truths at all. Being illuminated in such a way, in relation of person to being, means that truths can be revealed to us, or as Kaelin puts is: 'truth happens' (Kaelin, 1967, p.72). In fact, Heidegger used truth to question the use of historical artefact to explain scientific theory that we use in technological practice, suggesting that this idea of truth is not ideal (Smith, 2008). He refers to an ontic truth: uncovering of entities to help us see things as they are (Heidegger, 1927).

Heidegger (1927) moves away from the assertion of truth as an element that can be attributed to something and toward the notion of truth as both something to be considered from the perspective of the concealed and unconcealed. He later went on to write *On the Essence of Truth* (Heidegger, 1930) in which he attended to Plato's notion of the cave: that which is in the shadows in hidden. Taking Plato's notion further, that which is not seen or understood is hidden. Truth, the 'unhiddenness' of beings, is found through a process of finding things that have been hidden. His idea of unhiddenness means that something is hidden, and then uncovered. What has been hidden can be found. This concept can again be used to underpin the aim of phenomenological research. Whilst the idea of a phenomenological method is to elicit the hidden, or reveal the concealed, the extraordinariness in the ordinariness is represented here: people may not wish to reveal the hidden nor wish to explore or find the hidden.

Phronesis and Techne

Techne, for Heidegger was not mere practical skill or accomplishment (Kaelin, 1967), it went beyond that and embodied a way of knowing. His idea of knowing means to have seen (Heidegger, 1927) and can be considered in the sense of grasping what is present. To understand the methods of phenomenology, art and technics have to do with knowing, knowing with seeing, and in seeing grasping what is present as it is present to

us (Kaelin,1967). To exemplify phenomenological anaylsis, Kaelin refers to analysis of art: we must produce a description of works of various kinds, whether or not there is a single description of the 'essence' of the art. This can be extrapolated to phenomenological analysis of spoken and textual works….

The Greek concept of phronesis (practical wisdom) is more akin to virtue knowledge (Palmer, 2001). It is a sense of good judgment, and common sense, that is learned by experience and allows extension beyond the rules. One learns such wisdom through experience. Although Palmer (2001) identifies that practical wisdom goes back to Aristotle, it also goes beyond modernity in accrediting something that is not verifiable knowledge but which is more valuable in certain situations, namely common sense. Phronesis has additionally been defined as practical moral reasoning (Aristotle, 1976). Benner (1994) gives the example of stories being told about heroic treatment that had become futile, prolonging dying rather than promoting recovery; a counter would be given that there was a danger in being too certain of no hope of recovery. Phronesis can give us an insight into the practical reasons for how and why certain experiences occur, enabling one to reflect and arrive at a meaning from that.

Critique of phenomenology

In this section, I briefly outline Heidegger's nefarious politics and then concentrate on a response to the critique of phenomenology in nursing.

Firstly, there is the problem of politics, which Habermas (1998) and Sheehan (1988), among others, outline. Heidegger opposed the holding of 'values' but his political influences, namely Nazism and fascism, informed his philosophy. In fact, as a mouthpiece for Nazism pre-Hitler, it has been suggested that Heidegger used Nazism to his own end to promote his academic position (Sheehan, 1988; Farias, 1989; Holmes, 1996; Habermas, 1998). There is debate over whether his involvement was related to the early widespread national enamourment with Nazism, or whether he was essentially a fascist. Whilst his views modified after the fall of the Third Reich, his silence over the atrocities that occurred was starkly evident. Some have suggested that his politics and his philosophy were distinct (Levinas, 1989), but it is difficult to see how this could be the case since politics and philosophy are inextricably linked.

Holmes (1996) suggests that in view of this Nazist link, nursing should reject much of his work, since it is at odds with the philosophies upon which nursing is founded. However, Holmes (1996), Corben (1999) and Barnett (2009) all agree that some aspects of

phenomenology can be useful to nursing but that the assumptions, consequences and implications of choosing such a methodology must be carefully considered.

Beyond politics, one of the major criticisms, from a philosophical perspective, centres around Heidegger's apparent disregard for the notion of the 'body' in Being and Time (Sartre, 1943). For this study, I believe this is an important issue to address. He did address it in subsequent works, including the Zollikon Lectures (Heidegger, 2001), where he offered a thematic account of the body (similar to Merleau-Ponty's (1945) *Phenomenology of Perception*) in response to Sartre's criticisms.

In fact, Aho (2005) argues that the body is tackled in *Being and Time* (Heidegger, 1927), since Heidegger's core concern is to unearth the essential, 'ontological-existential' structures of *Dasein* that make it possible to being regional investigations in to the problem of the body in the first place. I find this difficult to accept since regionalising the body may replicate the reductionist and positivistic assumptions that the body can be regionalised. It is not inherently clear in Heidegger's earlier work what his notions of body constituted, only that he reviled any concepts of a dualistic mind-body split. This notion of body can also be considered against his notion of person.

In Being and Time, Heidegger talks about embodiment, instead of the body since, as Cerbone (2000) outlines, Heidegger's apparent reluctance to discuss 'the body', in connection with his explication of *Dasein*, would be at odds with the kind of investigation his 'phenomenology of everydayness' is meant to be. Cerbone (2000) goes on to suggest that in spite of Heidegger's omission of the discussion of body in Being and Time, it can be considered in Heidegger's other terms: readiness-to-hand and presence-at-hand (Being and Time) and in earlier works related to biological organisms (Fundamental Concepts of Metaphysics). Askay (1999) counters such critiques by suggesting, as does Aho (2005) to an extent, that the body can be regarded ontologically. Heidegger's account was that while our bodily being is essential to our being-in-the-world, it is our being-in-the-world (our openness, our understanding of being) which is primordial from an ontological perspective. According to Heidegger (1927) bodily being, his preferred term over 'the body' is necessary for us to be related to the world in any situation, and therefore is intrinsic to any being or interaction.

Secondly, phenomenology carries with it distinct problems for application. Its inaccessibility means the 'how to' aspect of phenomenological research is not easy to grasp. Heidegger has been critiqued for his overly literary style, rendering it difficult for the inexperienced philosopher to understand. Furthermore, he uses many made-up

words in German that are very difficult to translate, and despite his attempts to articulate his meanings in German there are nevertheless, problems in the translations.

Koch, a nurse phenomenologist, highlights the 'amorphous' philosophical areas in phenomenology as a potential minefield (Koch, 1996), and indeed it could be perceived to be amorphous at first glance. However, Koch predominantly focuses on Gadamer's (1975) work on phenomenology. Gadamer, a student of Heidegger, who took phenomenology further in the context of language analysis, concentrates on linguistic and language interpretations of understanding in phenomenology. Gadamer, like other phenomenologists provides no method for interpretation, adding to the complexity of analysing data derived from phenomenological method. Koch herself uses no questioning at all in her approach to phenomenological interviewing, which would lead to the question of how realistically can a particular, or for that matter any, story be extracted without even an opening gambit?[44]

Paley (1998; 2002; 2005), a primary critic of nursing's application of phenomenology, in particular the work of Benner (Paley, 2002), levels much of his criticism at how nursing misinterprets phenomenology from a philosophical perspective and indeed how nursing often misinterprets positivist and natural science assumptions.

His disparagement seems to stem from how nurses in particular use phenomenology as method. He believes that fundamental mis-assumptions are made about Kantian and Cartesian conceptions in Benner's work, for instance, since she fails to articulate what Kantian thinking is but still ascribes her participant's thinking to be influenced by remants of Kantian and Cartesian thinking (Paley, 2002). In Benner's defence, this is not to say she does not understand it, or indeed has mis-interpreted it, but she does not articulate her understanding, which makes it harder for the reader to see from where her concepts might have arisen. Benner argues that interpretive phenomenologists look for commonalities in culturally grounded meanings. Again it is her failure to articulate 'culture' and to use culture to envelope sub-cultures, that incurs Paley's disdain. He argues that she is attributing causal processes to cultural practices. His main complaint is that culture, and perhaps by extension, life-world, can be multi-faceted and Benner's work does not account for this. This would seem to be a fair criticism since he argues that you can pick up additional 'meanings' from another culture round the corner (Paley, 2002). Taking this further, using *Dasein*, Paley suggests that one's ways of being, doing and saying are borrowed from others or the 'they'. Returning to Heidegger (1927), he first suggested this idea in his concept of *das Man*.

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[44] Please see findings chapter for an interviewing issue that confirms this point.

> "The 'they' is there alongside everywhere, but in such a manner that it has always stolen away whenever *Dasein* presses for a decision." (Heidegger, 1927, p.165).

Paley's argument seems to be against Benner rather than, in this case, Heidegger, since Heidegger himself warns against misinterpreting and misrepresenting the notion of culture. van Manen (1994) discusses how borrowing experiences, and reflections on experiences, are essentials features of phenomenology: it allows the researcher to better understand an aspect of human experience. This is, therefore, not to say that the representation given by the 'borrowed' and the 'borrower' cannot themselves be borrowed.

In Paley's (1998; 2002; 2005) critiques of phenomenology in general, rather than one person's (Benner is most notably criticised) use of it as method, he argues that it is incompatible with trying to find the essence of experience. Paley (1998) talks about how experience cannot be 'stripped off' the world, and nurses who attempt to do so are guilty of perpetuating a subject-object divide. This is exactly to the contrary of what they were trying to achieve in using phenomenology. Paley asserts how positivism and science are not the same thing. Indeed, phenomenology is not a polar of natural science and is often viewed sweepingly as at odds with positivism. Science is known for positivistic assumptions but also has foundations in realism, and it is this which causes Paley (1998) concern. Nursing phenomenologists, he argues, misinterpret Heidegger's work: it addresses scientific realism rather than positivism *per se*.

> "Their [lived experience researchers'] preferred alternative to positivism involves an appeal to the principal of incorrigibility, which Heidegger rejected, and which reintroduces Cartesianism by splitting reality off from experience."
> (Paley, 1998 p.818)

To summarise, therefore, he wishes for nurses not to feel they have to choose between phenomenology and positivism but to recognise that positivism is only one of several differing conceptions of natural science. Incorporating realism into phenomenology is both necessary for understanding, especially to ensure that Cartesian traits of stripping experience off the phenomena are not undertaken (Paley, 1998).

Paley (1998; 2002; 2005), however, is at risk of sweeping generalisations himself, in that he collectively disparages all nursing phenomenologists as not having explored their assumptions. This view is echoed by McNamara (2005). McNamara accuses nurses of doing and not knowing phenomenology. However, some nursing phenomenologists recognise the limitations of aspects of phenomenology such as misinterpretation of

philosophical text from which the method is drawn, making broad generalisations (Reed, 1994; Little, 1999), and have responded to this (Darbyshire, 1994; Darbyshire *et al*, 1999), as well as responses to the poor accounts of how to do phenomenology (Koch, 1996; van Manen, 1997; Caelli, 2001).

Koch (1996) outlines the exceedingly complex fields where each theoretical position carries with it major contradictions in terms of methodological implications. Husserlian practices of bracketing versus Heidegger's 'being-in-the-world' are examples of this. Bracketing makes us put everyday meanings aside, or as Crotty (1998, p.82) suggests, it makes us hold 'in abeyance and open ourselves to the phenomena in stark immediacy to see what emerges for us.' Indeed, Paley (2005) particularly criticises the notion of being able to bracket out our assumptions. For Heidegger (1927), this is the antithesis of understanding; one cannot suspend or bracket beliefs. Husserl undertook what could be held as a 'pseudo' scientific approach to phenomenology. He studied phenomena in a detached, unemotionally involved way, similar to the positivists approach.[45] Heidegger's disregard for Husserl's bracketing can be seen in his notions of *fore-having (Vorhabe)*, where we come to a situation with a practical familiarity (our background practices make interpretation possible); *fore-sight (Vorsicht)*, because of that background we have a point of view from which we make an interpretation and *fore-conception (Vorgriff)*, because of our background we have expectations of what we might anticipate in an interpretation (Heidegger, 1927). For Husserl, his descriptive phenomenology presents essential features of phenomena; for Heidegger interpretive phenomenology uncovers meanings hidden within text (Maggs-Rapport, 2001). Beck (1994) ascribes credibility to phenomenological research that uses bracketing, without delineating which school of phenomenology the nursing studies she reviews are from.[46]

Corben (1999) and Annells (1996) both point to the difficulties of analysis in phenomenology. Both identify studies, including that of Benner, that fail to address analysis adequately in the methods. Interpretation are not explicit and the absence of how categories are reached adds weight to the argument that phenomenology is difficult to use. Koch (1994; 2006) reiterates the need for decision trails and explicit accounts of analysis in phenomenology. van Manen (1990), whose framework of analysis I used, contributes significantly to phenomenological research by providing explicit details of how to analyse.

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[45] In describing, and strictly bracketing oneself from the phenomenon being explored, it could be argued that Husserl's descriptive phenomenology then embraces the very objectivity he tried to distance phenomenology from.
[46] Interpretive phenomenology does not use bracketing in the same way that Husserlian phenomenology does. It is not essential for understanding the essence of the phenomenon.

Articulation around the application of phenomenology seems to be one of the fundamental critiques. Crotty (1996) therefore addresses this in exploring the value of phenomenological research in nursing. Crotty (1996, 1998) is also well-known for his criticism and critique of phenomenology. By engaging with phenomenology we will not simply assume to have reached behind everyday meanings and encountered the things themselves. Nurses have to reflect on whether does what people describe stem from their experience or from another source and are we reflecting the essence of that experience (Crotty, 1996). He asserts that nurses should only undertake it when fully aware of the implications of doing so. He suggests that a person's *experience of a phenomenon* is not *the phenomenon,* to accept uncritically what others tell us they experience, when their perception may, in fact, be mistaken, is not true phenomenology in the philosophical tradition. Frameworks, such as that of de Witt and Ploeg (2006), for establishing rigour in interpretive phenomenology may help counter some of the claims of poor scholarship levelled at nursing application of phenomenology. Darbyshire *et al* (1999) among others, including Benner (1996) negate this suggesting a limited interpretation of phenomenology. Furthermore, his critique pertains directly to nursing and Barkway (2001) is amongst those who raise the criticism that Crotty was himself not a nurse and cannot truly understand what it is to be a nurse. Darbyshire *et al* (1999, p23), responding to the critique of phenomenology, summarise thus:

> "The central task of interpretive phenomenology is to interpret everydayness as a pathway (method) that attempts neither to deny human agency nor to valorize it. We have attempted to show some of the possibilities for critiquing in the context of interpretive phenomenological nursing scholarship. Humans are enabled by everydayness as the shadow they cannot jump over. Interpretive scholarship works to point to possibilities in order to enrich human existence through increasing understanding of the everydayness of being human. Interpretive phenomenology realizes the limitations of reducing existence to transcendental ideals or mechanistic atomisms. Humans are an integral part of the tradition in which they are immersed. It is in the context of everydayness that shared practices and common meanings contribute to the interplay of meanings and understandings."

In Section 3.3.1 I responded to this critique by exploring the value of phenomenology and providing a clear rationale for its use in this study. This research was not intended as an exploration of phenomenological application to research but instead used phenomenology as the most appropriate method for answering the research questions posed. Generalisability, as with much qualitative research, is not possible given the critique I have outlined around subjectivity. However, like van Manen (1990) and Darbyshire *et al* (1999), I would argue that some degree of commonality of lived experience and transferability is possible. The findings in Chapter 6 are testament to this.

Appendix 7

Example of Invitation letters, Information Sheets and Consents (families example given)

7a. Invitation letter families

THE ROYAL MARSDEN

Date

Natalie Pattison
Nurse Researcher: Critical Care Nursing
Royal Marsden Foundation NHS Trust

Dear Sir/ Madam,

I would like to invite you to look at the information sheet enclosed regarding a research study we are undertaking at the Royal Marsden Hospital.

I am undertaking a project to learn more about how we can improve care for critically ill cancer patients at the end of life. It is known from experience and previous research that there are areas for improvement in care for these patients. Patients who are at the end of life may not always be able to tell us what good care at the end of life might entail. It is important, however, that patient views are considered. As the relative or friend closest to your loved one you will have some insight into how care could be improved. I would be very interested in your opinions but recognise this might be a sensitive area. When conducting the interviews I will be aware that this might be the case and be receptive to how you feel, and how much you wish to share.

It is hoped that the study, which has been approved by the research ethics committee, will help cancer nurses and doctors make improvements to patient care. The information sheet attached outlines what the study is about and why this study is important for patients with cancer. It gives further details about the purpose of the research and what will happen if you decide to take part. There is no obligation to take part at all and talking to me does not mean there is any commitment to participate.

Please read this when you have a spare moment. I am happy to come and talk to you in detail about the study and what your potential involvement might mean. Please could you send back the reply slip overleaf to indicate if you are interested in hearing more about the study. If you are interested, I will contact you by phone to discuss the study (or arrange a convenient time to discuss it). Of course, this does not commit you to taking part at all and please be reassured that you will not be contacted you again if you do not fill in the reply slip.

Please do not hesitate to contact me on 0207 811 8054 if you have any further queries.

Thank you for your time,

Natalie Pattison
Nurse Researcher: Critical Care Nursing

Please tear off the slip below and send back to me in the envelope provided by .../.../…

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I am happy to be contacted about the study
  yes/no

If yes, please indicate which is your preferred method of contact by ticking in the box:

- I am happy to be contacted at home to discuss this further ☐

- I would like the nurse researcher to visit me at home to discuss further ☐

- I will make contact with the nurse researcher in my own time ☐

Name:

Signature:

Thank you for your time

7b. Information Sheet families

The Royal Marsden Hospital

"Improving care in a cancer critical care unit"

Research Study Protocol:
Principal Investigator: Natalie Pattison

First of all let me introduce myself, my name is Natalie Pattison and I am Nurse Researcher in Critical Care Nursing. I am undertaking some research as part of a doctorate and would like to invite you to take part in a research study. Before you decide 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 discuss it with friends, families and your GP if you wish. It may be that the subject of this research and talking about difficult issues could be distressing to you.

Please ask 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. Thank you for reading this.

1.   What is the purpose of the study?

This study aims to improve care for cancer patients who are critically ill in the critical care unit. Very little is known currently at the research about what families want for their loved ones who are in the critical care unit, especially those who are at the end of their life. It is hoped that the study will help the critical care team examine our practice and see how end-of-life care can be improved for patients and families or friends. The study will last for eighteen months.

2.   Why am I being invited to take part?

Since your loved one was in the critical care unit it is likely that you will have an insight into end-of-life care in the unit. I am interested in your thoughts and reflections upon the care that your loved one received, whether you were involved with any decisions about care and also how you felt about the care they received when they were at the end of their life.

If you can remember, I would like to know what was important to you when your loved one was critically ill, and what might be important to you with hindsight. It is very difficult to research patients who are actually at the end of their life. Therefore, I am asking patients' families or friends who were there on or around the time their loved one died to give us their opinions instead. Few studies have asked patients' families or friends, in depth, what they might want. It is important that patients' families or friends contribute to how care is planned because it may be that loved ones are unable to contribute when they are critically ill.

I am asking patients who have experienced critical care recently, families and friends of patients who have died, as well as critical care staff, what can be done to improve end-of-life care in a critical care environment. It is hoped that approximately ten patients, ten to twenty family members/friends, ten nurses and seven doctors will be interviewed.

3.   Do I have to take part?

It is entirely up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to change your mind or withdraw at any time and without giving a reason.

4. What will happen to me if I take part?

You will be asked to take part in an interview with the researcher. This interview will be a one-off and will last about an hour. The interview will take place wherever is preferable to you. It can be at your home, or at the hospital, wherever is easiest for you.

5. What do I have to do?

You will be required to give up one hour of your time for the interview.

6. What are the possible disadvantages and risks of taking part?

The interview may bring back sad and distressing memories for you of the time your loved one was in critical care. You may even cry or become upset when remembering certain issues.

I appreciate this may be difficult and will be sensitive as possible about this. You will retain control over what is and what is not disclosed in the interview. If at any time you wish to take a break, change the subject or even stop the interview, it is your right and I will respect this (You may like to know I have considerable clinical nursing experience in both cancer and critical care).

I would like you to choose somebody that I could contact on your behalf, such as a family member, good friend, GP, imam or priest for instance, just in case you became particularly upset and needed some immediate support after the interview.

If you would like I can provide you with information about counselling services in the hospital and outside of the hospital.

7. What are the possible benefits of taking part?

The information gained from this research will be used to improve care in critical care unit. I hope you will gain something from the research too, by reflecting on the care your loved one received and knowing your recommendations will contribute to future improvements. This study, however, is unlikely to directly benefit you but may benefit people in the future.

8. What happens when the research study stops?

When the research study is completed, findings will be made available to all participants. If you would like a copy please let me know at any time.

9. Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. Any information will have your name and address removed and any identifying information will be anonymised. Your name, or any identifying details, will not be used in any report or publication.

I am also obliged to let you know that there are some limits to confidentiality if any illegal practice is disclosed. If this situation were to arise I would discuss with you immediately how we should proceed.

10. What will happen to the results of the research study?

The results of this study are likely to be available in Summer 2007. If you would like a summary of the results when available please inform the nurse researcher at any time and I will send you a copy. It is hoped that the findings will be published in journals and presented at conferences so that any new knowledge can be shared.

11. Who is organising and funding the research?

The study is supported by the Royal Marsden Foundation NHS Trust and the University of Northumbria at Newcastle. This research is being carried out as part of a doctoral qualification.

12. Who has reviewed the study?

This study has been approved by the University of Northumbria Research Ethics Committee and The Royal Marsden Hospital Trust Research Ethics Committee. It has also been submitted to the Central Office for Research Ethics Committees (COREC).

13. Contact for the Further Information

If you have any further questions about taking part in this study please don't hesitate to contact Natalie Pattison, Nurse Researcher on 0207 811 8054. If you would like to speak to an independent person about the research please contact Shelley Dolan (Nurse Consultant Cancer: Critical Care; Chair of the Royal Marsden Ethics Committee and Practice Advisor)

Thank you very much for considering taking part in this study. Should you choose to take part you will be given a copy of this information sheet and the consent sheet to keep for your records.

7c. Consent form

Study Protocol Number:
Ethics Protocol Number:
Patient Identification No. for this trial:

CONSENT FORM: Patients/Families

Title of Project: *Care needs at the end of life in a cancer critical care unit*

Name of Principal Investigator: Natalie Pattison

Please Tick Box

1.   I confirm that I have read and understand the information sheet dated ../../.. the above study and that I have had an opportunity to ask questions. ☐

2.   I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason. ☐

3.   I agree to participate in the above study. ☐

4.   I would/would not like to be informed of the results of this study. (Please delete as appropriate). ☐

_____   _____   _____
Name of Patient   Date   Signature

_____   _____   _____
Principal Investigator   Date   Signature

1 copy for Patient, 1 for Principal Investigator, 1 for Hospital Notes

Appendix 8

Doctoral outputs

8a. Representation of outputs for Pattison et al (submitted)

8b. Outputs for practice

8c. Personal outputs

8d. Related chapters and articles

8a. Representation of outputs

Diagram from submitted article

A Reflection on the Effervescent
Fountain of the Professional
Doctoral Research Process

Clinical contact; Service
development;
concurrent research;
Supervisor interaction

Unit guidelines; Practice
development; Practice advisor;
Supervision; Changes in service
provision; Method changes; Chairing
groups; concurrent research

Professional/Practice Outcomes
International/ Local presentations;
Book chapters; Articles
commissioned/ non-commissioned);
Teaching Modules on University
affiliated to work; Supervisory
interactions/collaborations and further
work New Research Studies;
Guidelines development: Practice

Dissertation and Practice development

8b. Outputs for Practice

Patients' findings – Psychological and Follow-up implications

Recommencement of follow-up nurse-led clinic for all patients >48hrs stay run by CNS cancer critical care and NP jointly (incorporating NICE, 2009 guidelines)

Spin-off Research: Principal Investigator (PI) for MDT Qualitative Patient Satisfaction Study with consultant intensivists and FY2; PI for After Critical Care Study (longitudinal email, quality of life and questionnaire study)

"Get to know me" posters; CAM-ICU introduction (NP as lead); communication folder

Delirium working group (NP Chair); Psychological implications article (Pattison, 2005)

Families

CCU Bereavement guidelines (guidance for caring for families)

Organ donation chapter in *Key Concepts in Palliative Care*

After Death Articles including bereavement information (Pattison 2008a; 2008b)

Practical solutions e.g. around waiting tea and coffee/TV in relatives' room; bereavement guidelines

Refresher session for unit staff re: privacy, dignity and communication issues

Practitioners

Palliative care into critical care MDTs

Facilitated debriefing sessions (inc. confidence building)

EOL and ethics teaching Cancer Critical Care modules 3 x year at School of Cancer Nursing

EOLC in acute care on palliative care modules

After death care (guidance for CCU nurses and doctors) – used in CCU unit guidelines (multi-disciplinary)

Liverpool Care Pathway (ICU) Lead: pre and post audit work; revision of document work; Chapter in Critical Care Nursing Manual on 'Withdrawal of Treatment and End of Life Care for the Critically ill Patient'.

8c. Personal Outputs

8d.Related Chapters and Articles

Pattison, N.A. (2004) 'Integration of palliative care and critical care at end of life.' *British Journal of Nursing* 13(3) pp132-139

Pattison, N. (2005) 'Psychological implications of admission to critical care.' *British Journal of Nursing* 14 (13) pp 708-714

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Pattison, N. (2006b) 'Integration of palliative care and critical care at end of life.' Chapter 13 in Woodward, S (ed) *Neuroscience Nursing* London: MA Healthcare (revision of Pattison N (2004) in BJN)

Pattison, N., Dolan, S., Townsend, P. and Townsend, R. (2007) 'After critical care: a study to explore patient experiences of a follow-up service.' *Journal of Clinical Nursing* 16 pp2122-2131

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Pattison N and Lee, C (2009) 'Hope against hope in cancer at the end of life.' *Journal of Religion and Health* doi: 10.1007/s1094300992657

Pattison *et al* (20--) 'Encouraging reflexivity in the context of a professional doctorate: insider perspectives.' (Submitted for peer review)

Pattison N *et al* (20--) 'Thirty day mortality in critical care outreach patients with cancer: An investigative study of predictive factors related to outreach referral episodes.' *Resuscitation* (In peer review)

Pattison N *et al* (20--) 'Nurses and doctors experiences of referrals to outreach: An investigative study related to outreach referral episodes and management of referrals.' *Nursing in Critical Care* (In peer review)

Pattison N (20--) 'Organ Donation.' In Baldwin M. and Woodhouse, J. (eds) *Key Concepts in Palliative Care*

Pattison N (20--) 'Withdrawal of Treatment and End of Life Care for the Critically ill Patient.' In Mallett, J; Albarran, J. and Richardson, A. (Eds) *Critical Care Clinical Procedures and Competencies: A Manual*

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