THE EXPERIENCES OF REGISTERED NURSES IN DELIVERING END-OF-LIFE CARE FOR VULNERABLE OLDER ADULTS: AN INTERPRETIVE PHENOMENOLOGICAL ANALYSIS

Doctor of Advanced Healthcare Practice

2018

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SUMMARY

Background

The largest numbers of people dying in the UK are over 85. They are more likely to have multi-morbidity and frailty contributing to vulnerability at end-of life. This study critically explores seven registered nurses (RN's) professional experience of delivering end-of-life care for vulnerable older adults.

Method

Data was collected using minimally structured interviews. Interpretive Phenomenological Analysis (IPA) was employed and assisted in 'giving voice' to the concerns of these RN's. The RN's were asked to describe a memorable clinical experience(s) of end-of-life care involving vulnerable older adults with frailty. This approach was designed to provide focus and to elicit their experiences grounded in clinical practice.

Consistent with the philosophical approach of IPA, the RN's individual experiences were analysed descriptively, conceptually and linguistically. They were subsequently combined to elicit their shared experiences. A review of the literature concerning the experiences of delivering end-of-life care was subsequently interwoven with the findings of this study. Finally to deepen the analysis, their stories were interpreted using the theoretical frameworks of comfort theory, awareness and temporal aspects of dying, and knowledge-in-practice-in-context. A section on reflective practice concludes this discussion.

Findings

Much of the RN's experiences are not novel. The overarching shared experience is that memorable clinical dying and death experiences are imbued with 'emotional work'. This is underpinned by the common themes of 'knowing' and 'doing'.

Facilitation of the good enough death involved awareness of dying, recognising imminent dying and being able to provide comfort for the patient and their loved

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ones. Barriers involved futile treatments, staff and family's unpreparedness, and inability to provide sustained comfort.

The original contribution of this study includes a little gem "*older people's deaths are more run of the mill*", the problem of a good enough death for whom, and IPA contributing to the development of reflective nursing knowledge and practice.

ACKNOWLEDGMENTS

DECLARATION

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

Signed   Denise Shanahan (candidate)   Date   19.12.18

STATEMENT 1

This thesis is being submitted in partial fulfillment of the requirements for the degree of DAHP

Signed   Denise Shanahan (candidate)   Date 19.12.18

STATEMENT 2

This thesis is the result of my own independent work/investigation, except where otherwise stated, and the thesis has not been edited by a third party beyond what is permitted by Cardiff University's Policy on the Use of Third Party Editors by Research Degree Students. Other sources are acknowledged by explicit references. The views expressed are my own.

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PROLOGUE

My first encounter with a family death was that of my grandfather when I was seven years old. At the time I didn't understand why I was excluded from grieving family members or the funeral service. I was aged 22 when my next grandparent died. At my grandmother's instruction, following the church service men only were 'allowed' to attend the crematorium. These personal experiences were shrouded in concealment and to some degree, lack of closure.

As a student nurse the first patient death that I encountered was whilst working a late shift during my care of the elderly placement. I had just entered my second year of student nurse training. I was not allocated to the care of this particular patient during my shift but I remember having a discussion with the ward sister because I was aware that I had not been exposed to peri-death care, unlike most of my peer group. The ward sister was concerned for this junior student's well-being (me) and advised that as it was a late shift and would be my first exposure to a patient death that she didn't want me to be burdened with this experience overnight. On reflection this created additional anxiety for me; fear of the unknown. It was over a year later before a patient died in my care. As a third-year student nurse working night duty on a medical ward, the staff nurse and healthcare support workers expressed disbelief at my lack of experience. The staff nurse allocated an experienced healthcare support worker to support me to undertake the last offices for this individual female patient: an experience I still recall.

Now as a registered nurse with over 30 years nursing experience, I have had varying experiences caring for people who are dying, their deaths, and interactions with their loved ones and after death care. I do have some very warm memories of involvement in the end-of-life care of individual patients', but I can still remember a small number of patients that I felt had suffered unnecessarily because of the omission or commission of interventions.

As part of my nursing career I moved from working with frail older people into a specialist stroke rehabilitation environment. During these few years my involvement in end-of-life care was negligible. Still specialising in stroke care, I changed roles and moved to a district general hospital. I was suddenly re-exposed to dying and death. It

was during this time that the need for improvement in end-of-life care of frail, vulnerable older people became particularly visible to me. This was sensitised by experiences of older people who had suffered a stroke and were dying. At the time, it was recognised that about a third of stroke patients would die, however end-of-life care was only just being considered as part of stroke clinical guidance.

Paradoxically during this period my own dad, a young 65-year-old, died as the result of a catastrophic intracerebral haemorrhage. He died in the emergency unit of our local hospital. Whilst he was laying on a trolley in a cubicle, deeply unconscious and approaching death, there was mention of him being moved to a bed on a medical ward. For reasons I cannot adequately articulate I felt fearful. I mentioned to my sister, who is also a registered nurse that I was worried about the care he (and we) might receive on the ward. This experience still perplexes me. On reflection I was in shock, I may have been fearful of potential lack of privacy, being excluded and potentially 'poor' care; whatever poor care of an unconscious dying man might be. As it happened he died peacefully, in a cubicle, on a trolley in the emergency unit with numerous family members present. The irony was that at the time there was significant news coverage and concern about people being on trolleys in emergency and assessment units for significant periods of time.

I subsequently moved into my current role as consultant nurse for older vulnerable adults which initially involved much 'safeguarding' work with older people. Whilst I am now rarely involved in the direct care of dying older people, end-of-life care continues to feature within my professional role. Poor end-of-life care for older people is threaded within both protection of adults at risk and the experiences and concerns raised by families. It remains an issue that warrants further exploration and understanding.

During the planning and undertaking of this study, my immediate family have experienced a number of significant 'life events'. These include two deaths, two marriages, five births and a number of hospital attendances and admissions.

My eldest granddaughter, Amelia 'lost' her great-grandfather; my extended family. 'Grampy walking-sticks' was living at home, with a recently delivered poor prognosis.

He was expecting to live for months if not years. The day he unexpectedly died, Amelia, then aged three, solemnly explained that 'grampy walking-sticks':

> "is going away. He's going to the sky. I won't be able to see him again (pause) because you can't see people in the sky (pause) and the clouds, (long pause) but I've still got my grampy Bern, grampy Mario and gramps"

For me, this poignant nugget captured the essence of being human; love, loss, and being mortal. It also demonstrated her attempts at making sense of feelings of sadness and loss which accompanied her first (recognised) encounter with death. It also involved my interpretation of her sense making; a double hermeneutic as part and parcel of our temporal and relational lived world.

I began this study with the intention to explore nurses' experiences in order to facilitate (perhaps naïvely) a healthy death for older people. This concept began to feel incongruent and was modified to a good death, which subsequently became a 'good enough' death. As 'grampy walking-sticks' died unexpectedly, and it appears without a decision regarding resuscitation, the ensuing chaos created increased distress for his immediate family. Their experiences have augmented a question that emerged for me during this study, 'a good enough death for whom?'

CHAPTER 1 - INTRODUCTION

1.1 INTRODUCTION TO THE THESIS

As a Registered Nurse (RN) who has predominantly worked with older people throughout my career, I have acquired expertise in the care of vulnerable older adults with frailty. Undisputedly people are particularly vulnerable at end-of-life (McNamara et al., 1995), and I have developed an interest in understanding the 'good enough' death (McNamara, 2004). By critically exploring seven RN's experiences of delivering end-of-life care, focused on vulnerable older adults I will add, albeit in a small way, to the existing knowledge exploring this phenomenon. The use of Interpretive Phenomenological Analysis (IPA), facilitates the aim to understand and 'give voice' to the concerns of these RN's involved in delivering end-of-life care.

This thesis explores the literature in relation to contextual structures that influence RN's experiences of delivering end-of-life care for older adults with frailty. It will begin by setting the scene by exploring the historical context of dying and death, end-of-life care policy, demographic changes and the concepts of vulnerability and frailty. It will conclude with an exploration of the literature concerned with social aspects of dying and death. A more traditional review of the literature concerned with experiences of delivering end-of life care is presented later in this thesis, and is interwoven with the findings taken from the analysis of the participants' stories.

Much of my professional work is concerned with complexity, difficult decision-making and aspects of perceived or actual poor care in the context of vulnerable older adults with frailty. This serves to drive a passionate endeavour to facilitate enhanced understanding and improvements in practice. The concept of the 'good enough death' will be explored. However end-of-life is an emotive subject and can encompass difficult experiences for the individual person, their loved ones and, at times, for staff members. Stories of experiences of poor care, including end-of life care are readily available in both the public and professional domains. This troubling phenomenon exhibits ethical and moral tensions in practice. For these reasons the concept of poor

care is examined to explore the understanding and recognition of when and why the 'good enough' death becomes 'not good enough'.

This study will attempt to understand and interpret the RN's experiences of memorable clinical cases of dying and death with a focus on older people with frailty. As part of the analysis, a section will explore the RN's use of language and its influence on 'meaning making'. Underpinning this study are philosophical, phenomenological, and theories used in nursing. These include comfort theory, the social features of dying including awareness and temporal aspects of the dying trajectory, knowledge-in-practice-in-context and reflective practice. The RN's experiences are explored using these theoretical frameworks.

1.2 ORGANISATION OF THE THESIS

I have divided the thesis into four parts. Part 1 sets the scene for the study and provides the structural and theoretical context.

Part 2 is concerned with the research process. It begins by describing the research design, methods and data generation procedures. It also presents an introduction to IPA.

Part 3 explores and describes the participants' stories and experiences from an idiographic perspective. In order to take the analysis deeper the participants' use of language and linguistic devices are explored and then with care, patterns across cases are elicited.

Part 4 locates RN's experiences in the wider context. A chapter on reflexivity is also included in this section. The final chapter concludes by describing the original contribution of this research and implications for practice.

1.3 JUSTIFICATION FOR THE STUDY

In recent decades there has been a drive to improve end-of-life care. Whilst it is recognised that some people experience excellent care, it has been reported that the reality is that many do not (Gawande, 2015; National Institute for Health and Care Excellence, [NICE], 2017a; Parliamentary and Health Service Ombudsman, 2015). Historically, high quality end-of-life care has largely been facilitated through the hospice movement and palliative care services (Sugar, 2008), traditionally with an

emphasis being placed on palliative cancer services to the detriment of non-cancer services (NICE, 2017a; Palliative Care Cymru Implementation Board, 2011). The vision in Wales is for people "to have a healthy, realistic approach to dying, planning appropriately for the event [...] whatever their underlying disease or disability" (Welsh Government [WG] 2017a p.24). This is relevant for older adults who are more likely to experience chronic disease, multi-morbidity and frailty at end-of-life (WG, 2017a). Most end-of-life care involving older adults with frailty is provided by generalists where care of the dying is not the principle focus of their work but they do routinely provide care for people with advanced illness, including end-of-life care (Dixon et al., 2015; NICE, 2017a). Dixon et al. (2015) also found that people aged 85 or over received proportionately less specialist palliative care than other age groups. This is also relevant to the people of Wales as those aged 75 or over are less likely to access specialist palliative care, and only 10% of those aged over 85 do (WG, 2017b). Given the prevalence of multi-morbidity, a range of specialists may also be involved in the care of the individual, but as older people's end-of-life care is predominantly delivered by generalists this thesis will not focus upon specialist palliative care.

The English national bereavement survey of 2015 (Office for National Statistics [ONS] 2016) found that whilst the majority (75%) of end-of-life care was rated as either excellent or good, 10% of respondents rated it as 'poor'. Within the hospital environment a concerning 31% of people rated the quality of care as 'fair' or 'poor' compared with 18% for care homes. Hospital staff were criticised for not always showing dignity and respect but 74% of respondents felt hospital was the right place for the patient to die, despite the fact that only 3% of those who died had reportedly expressed a preference to die in hospital (ONS, 2016). In Wales, 56% of deaths occur in NHS hospitals, 23% at home, 16% in care homes and only 3% in hospices (WG, 2017b). Although end-of-life care involves multiple healthcare staff, RN's are generally a core professional discipline within the multi-disciplinary and multi-agency teams. They are the professional group that regularly deliver intimate end-of-life care. Nursing staff will be involved in the care of many of these people's deaths as 75% of people who die need palliative end-of-life care (WG, 2017b). This justifies a need for better understanding of patients, carers and nurses experiences surrounding end-of-life care to enable improvement. This thesis will focus on the experiences of RN's in delivering end-of-life care for vulnerable older adults with frailty.

1.4 KEY DEFINITIONS RELEVANT TO THIS THESIS

The concept of a good death was changed to the concept of a good enough death in recognition of the fact that people may experience aspects of the same death differently, but also to reflect the philosophical contentions surrounding the ideology of the good death (Hart et al., 1998; McNamara et al., 1995). Whilst the terms end-of-life, care, older people, vulnerability and frailty will be further explored within this thesis, it was important for me to succinctly clarify operational definitions to assist my own understanding and focus. As such end-of-life, particularly concerning older adults is an imprecise term. There is much discussion surrounding the recognition of the last year of life (National Gold Standards Framework Centre [GSF], 2016; NHS choices, 2015; WG, 2017b) with a focus on anticipatory care planning, and whilst being important, my focus of interest is RN's experiences of delivering end-of-life care in the context of the individual older adult approaching, or being near death. Within this thesis, I have understood the term care to be understood as the delivery and or receipt of clinical and interpersonal attention, situated within the structure of health services.

There is a debate about what constitutes old age given that the National Service Frameworks for Older People in England (Department of Health [DH], 2001a) and Wales (Welsh Assembly Government [WAG], 2006a) refer to adults aged 50 years and above, albeit with the intention of promoting healthy ageing. In addition, the legislation for the Commissioner for Older People (OPC) in Wales and Northern Ireland define older people as being over the age of 60 (2006; 2011). Within the Western world old age is generally understood to equate with being 65 years and older (World Health Organization [WHO], 2009) and historically has been aligned to a state pension age. Presently the United Kingdom (UK) is undergoing state pension age increases associated with an increasingly ageing population, driven because people are living longer and generally enjoying better health in their 60's. The proportion of the population aged 65-74 who were economically active in 2011 almost doubled the proportion reported in 2001 (ONS, 2013). The fastest growing part of the UK's population is now aged 85 years and older (ONS, 2012; 2015a; 2017b), but there is also the dilemma of chronological or biological age, with frailty described as a valid and reliable proxy of biological age (Dupre et al., 2009). Given these complexities the term 'older' is not specifically defined.

Frailty is understood as a clinical syndrome rather than a diagnosis. It is the state of "limited functional reserve" or "failure to integrate responses in the face of stress" (Cornwell, 2012: p.2). This leads to an eroded ability to recover or regain a previous level of health and functional ability. Frailty is also associated with increased vulnerability and dependency (British Geriatric Society [BGS], 2014). The cumulative deficit approach to defining frailty incorporates co-morbidity and disability as well as cognitive, psychological and social factors (BGS, 2014) which are important for older adults particularly those needing formal health and social support.

The vulnerable patients I predominantly work with are older adults with frailty. They are perceived as the oldest old by definition of years lived, their multi-morbidity and their limited functional and physiological reserve. As Theou et al. (2015) point out, as people age they have an increased risk of death, the frailest having the greater risk. Many of the patients I encounter are also likely to trigger a no response to the 'surprise' question "would you be surprised if the patient were to die in the next year, month's weeks or days?" (GSF, 2016) which by default signifies a propensity towards end-of-life which also explains the relevance of this topic in relation to my clinical practice.

1.5 THE RESEARCH QUESTION

Motivated by the aim of facilitating a good enough death for older adults with frailty, the central research question was developed:

- What are the experiences of registered nurses with regard to achieving a good enough death for vulnerable older adults with frailty who require end-of-life care?

1.5.1 THE SUB QUESTIONS:

- What are the experiences of registered nurses in delivering end-of-life care for older adults?

- Do registered nurses have a shared understanding of the meaning of a good enough death?

1.5.2 THE RESEARCH AIMS:

- To critically explore the experiences of registered nurses, in respect of the good enough death within their field of working with vulnerable older adults with frailty.

- To critically explore the understanding and meaning of the good enough death with registered nurses who work with vulnerable older adults with frailty.

- To make explicit the similarities and differences of experiences of registered nurses who work with vulnerable older adults with frailty with regard to the understanding of the good enough death.

1.5.3 THE RESEARCH OBJECTIVES:

- To identify and make explicit the determinants that facilitate the delivery of the good enough death.

- To identify and make explicit the determinants that pose barriers to facilitating the good enough death.

1.6 CONCLUSION

Chapter 1 has presented the focus of the research as the experiences of RN's in delivering end-of-life care, with a particular emphasis on the care of older adults with frailty. It has set out the organisation of this thesis and has provided a rationale as to why this thesis will not focus on specialist palliative care. It has also drawn attention to people's poor experiences of end-of-life care that have been reported in the public domain, and has made reference to 'the good enough death'. This chapter has also succinctly presented relevant key definitions and has concluded with the research questions, aims and objectives. Chapter 2 will set the scene and provide an overview of the structural context of end-of-life care for vulnerable older adults with frailty.

2.1 INTRODUCTION

This chapter provides an overview of the structural context that underpins contemporary end-of-life care with a particular focus on vulnerable older adults with frailty. The structural context includes a historical perspective of dying, death and UK policy. It also discusses demographic changes, the concepts of vulnerability and frailty, and references publicly available reports detailing concerns about poor care and adult safeguarding practices. Vulnerability will be explored further using a composite clinical case as an exemplar of vulnerability to demonstrate the application of current policy and law.

2.2 HISTORICAL CONTEXT OF DYING AND DEATH

> "An entire generation has come to expect that all aspects of dying will be taken care of by professionals and institutions, potentially undermining personal and community resilience in coping with death, dying and loss as part of the cycle of life"

(Scottish Government, 2015: p.8)

To be human is to be mortal. It is fact, albeit an uncomfortable one. It has been argued that both birth and death share the feature of 'non-reversibility' (de Vries, 1981) which emphasises a sense of absoluteness. To become a human-being requires conception, birth and as part of the lifecycle, inescapably death. Birth and death are both significant biological status passages but can also be viewed as socially constructed realities (de Vries, 1981) which historically were constrained by limited knowledge of disease management and prevention.

Ariès (1981), a historian of death, emphasised that changes in people's attitudes towards death throughout the centuries has tended to take place very slowly, and between periods of little change. Historical collation of information on death and dying is derived from literature, art, and archived records (Kellehear, 2008). As such it reflects a specialist history (Kellehear, 2007). That said Kellehear set out four ages in the social history of human dying (Kellehear, 2007; 2008). The first and earliest age portrays the sudden death 'died where stood' of the hunter-gatherer (Kellehear, 2008). Throughout the ages most religious beliefs hold notions of a continued existence after

death (Bloom, 2007) with Kellehear (2008) pre-dating this to prehistoric times. Death can be perceived as a transition to an afterlife, hence as something that can be celebrated or assisted along the 'otherworld journey'. In contrast to modernity, historically dying took place after biological death and involved the deceased surviving or succumbing to the 'tests and trials' of this otherworld journey (Kellehear, 2007).

The second age relates to medieval times (Kellehear, 2007; 2008). With the exception of male warriors and war, the majority of people died at home. Taking a more artistic stance, Ariès (1981) argues that during this time the 'tame death' was the 'good death'. The 'tame death' was anticipated, commonly by the person dying himself. It was allegedly stoically and calmly accepted. Ariès and Kellehear agree that death was familiar; it was a ritual that involved the dying person being surrounded by people, hence communal. They argue that death was 'tamed' by these communal rituals and beliefs.

War and urbanisation later led to the third age which Kellehear (2007; 2008) conceptualises as the 'managed death'. Here pre-planning for financial and social provision for family and friends became common. The last and fourth age is described as the shameful cosmopolitan death. This relates to Ariès (1981) observations that in the Western world a community-oriented personal identity was gradually replaced with a radical individualism "an enormous mass of atomized individuals" (p.613). Secularisation, arguably due to increased scientific knowledge and societal individualism has eroded the 'tame death'; we do not generally have personal or communal resources that enable us to give death a purposeful meaning (Ariès, 1981). Despite the social construction of human dying and death through the ages, it is an inevitable biological fact that individuals, communities and society at large cannot physically avoid. Predictably the planning for, and the delivery of end-of-life care is embedded within UK policy.

2.3 END-OF-LIFE CARE POLICY IN THE UNITED KINGDOM

The provision of high quality end-of-life care in the UK has largely been facilitated through the hospice movement and palliative care (Sugar, 2008), traditionally with an emphasis being placed on palliative cancer services to the detriment of non-cancer services (NICE, 2017a; Palliative Care Cymru Implementation Board, 2011). Inequity in

service provision and standards exist, with large gaps in provision depending on geography and diagnosis (Addicott, 2010). A continued drive to improve and prioritise end-of-life care remains evident (NICE, 2017a) and in addition, the complex needs of older adults with frailty are becoming better understood. This group of people are more likely to experience chronic disease and multi-morbidity which requires multifaceted holistic assessment and intervention (NICE, 2016), but they have not necessarily been the focus of policy and practice. Contemporary end-of-life care policy development is outlined next.

The 1990's saw recognition of the need to spread the high standard of palliative and hospice care into general hospitals, and to extend this for the care of non-cancer patients (Edmonds et al., 2001). In England and Wales the 'Calman-Hine' report (DH and Welsh Office, 1995) recognised that hospice provision had developed in an ad hoc manner and emphasised the need for future planning. Subsequently the strategy for palliative care services in Wales was published (WAG, 2003).

In 2006 the all Wales care pathway for the last days of life was endorsed (WAG, 2006b). A Palliative Care Planning Group was commissioned which made key service recommendations (2008). These were later progressed by the Palliative Care Cymru Implementation Board. The last days of life pathway was later revised, renamed and re-launched as the all Wales Last Days of Life Integrated Care Priorities (Palliative Care Matters, 2012). In the meantime, significant concerns about the Liverpool Care Pathway (LCP) had been reported in the media; some by eminent health professionals (Millard et al., 2009). This led to a major review which resulted in the withdrawal of the LCP (Neuberger, 2013). This withdrawal does not appear to have detrimentally affected standards of care as continuous improvement against audit standards has been demonstrated since its withdrawal (Royal College of Physicians [RCP], 2016). In Wales, the End of Life Board commissioned a major review of the Integrated Care Priorities and the Care Decisions in the last days of life tool (Palliative care in Wales, 2016; WG, 2013a). Interestingly, Watts (2012) observed that the LCP approach privileged the biomedical model and proposed that discourse was more important. The importance of discussion and planning is now embedded in policy (WG, 2017a) and promoted in practice (Dying matters, 2015). Specialist palliative care services in Wales now acknowledges both cancer and non-cancer diseases. These services work

closely with generalist staff and involve NHS specialist palliative care consultants, specialist nurses and therapists along with third sector organisations (WG, 2017a).

The Gold Standards Framework (GSF) introduced in 2000 has continued to develop and guide the delivery of end-of-life care. Quality and choice have been prioritised (DH, 2003) and the NHS end-of-life care programme launched (DH, 2004). Along with promoting choice, intent to decrease the number of emergency admissions of patients who have expressed a preference to die at home, decrease the numbers of patients transferred from a care home into hospital, and support for generalist staff to increase knowledge and skills to improve end-of-life care were articulated. These ambitions persist within contemporary services.

Since 2007 a number of publications and reports have been released identifying practice care standards for the delivery of end-of-life care (DH, 2008b; DH, 2009; DH, 2015b; House of Commons Public Accounts Committee, 2009; Leadership Alliance for the Care of Dying People, 2014; National Audit Office [NAO], 2008; NICE, 2015; 2017a; Parliamentary and Health Service Ombudsman [PHSO], 2015; RCP, 2016; WG, 2016b). These all emphasise the need for improvement.

As with the rest of the UK, the Scottish Government (SG) accepted the recommendation that the LCP should be phased out. They adopted four principles (SG, 2014): informative, timely and sensitive communication; significant decisions require multi-disciplinary discussion; the need to encompass physical, psychological, social and spiritual components; and consideration for the wellbeing of relatives or carers. Latterly the strategic framework for action on palliative and end-of-life care was published (SG, 2015). Current policy sets out a shared vision where by 2021 everyone who needs palliative care will have access to it, acknowledging that palliative care can be delivered by both specialists and generalists.

In Northern Ireland the palliative and end of life care strategy Living Matters, Dying Matters (Department of Health Social Services and Public Safety Northern Ireland [DHSSPSNI], 2010) has been supported by the Transforming Your Palliative Care Programme (Public Health Agency, 2011). A recent review by the Regulation and Quality Improvement Authority (2016) reported that whilst initiatives to improve awareness of palliative and end-of-life care have been undertaken, a significant lack of

understanding about these services amongst service users and staff persists. They have recommended the development of a new action plan to take this strategy forward.

2.3.1 CONTEMPORARY HEALTHCARE IN WALES

This study has been conducted in Wales although it is anticipated it will be relevant to other parts of the UK. Myself (the researcher), the sponsoring University and the participants have been immersed in a Welsh policy context. Contemporary policy has been stimulated by discussions concerning value and prioritisation of healthcare and the future sustainability of NHS Wales. In this context, the then Minister for Health and Social Services in Wales introduced the concept of prudent healthcare (Drakeford, 2014). The discussions have progressed over the last few years and four principles have been adopted (Public Health Wales [PHW], 2014; 2017). These interrelated principles apply to all aspects of healthcare including end-of-life care for older adults with frailty.

- Achieve health and wellbeing with the public, patients and professionals as equal partners through co-production.
- Care for those with the greatest health need first, making the most effective use of all skills and resources.
- Do only what is needed, no more, no less and do no harm.
- Reduce inappropriate variation using evidence based practices consistently and transparently.

(PHW, 2017)

Prudent healthcare is an approach where people and professionals share power and work together in equal partnership, a philosophy seen to underpin current policy (WG, 2018b). This partnership is particularly relevant to advance care planning for those who have a terminal diagnosis, a progressive degenerative condition, or are of advancing age and considering their own mortality.

Emergency care in the NHS instinctively prioritises those with the greatest need (PHW, 2014; 2017). However clinical priority should be the basis for decision-making in other services. In making the most effective use of skills and resources it is important to acknowledge that much palliative care is provided by generalists (Dixon et al., 2015; NICE, 2017a), particularly those working with older adults with input from specialist palliative care teams for complicated symptom management. There is considerable drive to keep people at home, to avoid unnecessary hospital attendances and

admissions, and this is predominately directed towards people with chronic disease and older adults with frailty (NAO, 2013; WG 2018b). Whilst care closer to home may be the strategic direction (WG, 2018a; b) older adults are more likely to need additional support to remain out of hospital. WG states "hospital will also be orientated to ensuring that people who are frail or at the end of their lives are placed in the most appropriate setting" (WG, 2018b: p.11). Prudent healthcare requires a cultural shift involving hearts and minds as well as different ways of working.

The third prudent principle is concerned with doing 'only what is needed, no more, no less and do no harm'. For example, falls in institutional care are recognised as a predictor of poor survival (Liu et al., 2015; Nurmi et al., 2004; Snooks et al., 2014); there are varying clinical definitions of a fall but a general definition has been adopted for hospitals in Wales (WG, 2016c). Seemingly benign interventions for those with increasing frailty, can, in an attempt to prevent harm, result in unintended consequences. For instance this may lead to a protective strategy of reduced mobilisation for someone at risk of falling, which may result in deconditioning, loss of strength, reduced independence and by default create increased dependence and risk of falls (WG, 2016c). Dawn, one of the participants in this study, told the story of a lady who had been found by her carers to be laying on the floor at home on the morning of the day unit consultation appointment. She subsequently fell (or collapsed) whilst on the oncology day unit and died a few hours later. This story epitomises falls and frailty as indicators for poor survival. Arguably a fall might tip the person from being pre-frail into the category of frailty or be a symptom of frailty (Roberts, 2017). There is a positive association between fall risk and mortality risk (González-Henares et al., 2016). Steindal et al., 2013 found that for the oldest of the old (>85 years) falls were more than four times higher in the last phase of life and as such recurrent falls, increasing frailty and being the oldest of the old may be indicative of transition to end-of-life. In section 4.5 I will present the story of a gentleman in a care home and the approach to managing his risk of falls in order to demonstrate the insidious medicalisation of this individual's risks and quality of life.

The fourth prudent principle refers to reducing inappropriate variation using evidence based practices consistently and transparently. With regard to end-of-life care in Wales, a new patient symptom assessment sheet has been modelled to reflect the

embedded National Early Warning Score (1000livesplus, 2013). The symptom assessment specifically considers pain, agitation or distress, nausea and vomiting, respiratory secretions and has opportunity to add other symptoms. Colour coding reflects the severity of the symptoms from none (white) through to severe (dark red). The process requires clinical agreement that the patient is in the last days of life and encourages clear decision-making about hydration, nutrition and clinical interventions such as blood tests, recording of vital signs and care and management of implantable cardiac devices. The care decisions guidance is designed to help facilitate a patient-centred approach focussing on communication, comfort and compassionate care for the patient and those important to them wherever possible. However a poor uptake of this guidance in practice suggests that this may be a low priority in practice (Personal Communication; Palliative Care Implementation Board Welsh Government, 2017.).

Whist the need for better access to palliative care services for those with a non-cancer diagnosis and the multi-morbidity of advanced aged patients has been acknowledged, a report by the Marie Curie organisation (2015b) only mentioned frailty once and this appeared to be associated with dementia. Frailty is predominantly aligned to the specialism of gerontology which may explain its near exclusion within palliative care reports. Alternatively this near exclusion could inadvertently be associated with societal values and the apartheid of older people, particularly those with frailty. A recent WG (2018b) publication has prioritised 'frail elderly' and end-of-life care as part of their transformation programme for improving quality and value. This demonstrates a newly recognised need for prioritising improvement for this vulnerable group.

The seminal of works Glaser (1966) observe that older dying people are associated with a lower social loss, with the middle years and young adults correlating with the highest social loss. Whilst there is a drive to recognise and promote the contribution older people make to society in economic and active citizenship terms (Iparraguirre, 2014; Royal Voluntary Service, 2011), ageism still persists within society, and is observed within healthcare services (The Commission on Dignity in Care, 2012). Considering attitudes towards older people, Oliver (2008) argues that blatant ageism can be seen in healthcare practice, and draws attention to the common usage of pejorative language within the hospital environment such as 'acopia', 'social admission', 'inappropriate admission' and 'atypical' which tend to pervade

unchallenged. In an attempt to combat this, examples of innovations to improve intergenerational activity are gaining momentum (Burke and Somers, 2017; United for all ages, 2017), and aims to tackle the roots of societal ageism.

2.4 OLDER PEOPLE: DEMOGRAPHIC CHANGES

Global demographic changes show an increase in the ageing population. The fastest growing part of the UK's population is now aged 85 years and older (ONS, 2012; 2017b). There are more people aged over 90 year on year and the number of centenarians living in the UK rose by 72% between 2004-2014 (ONS, 2015a) and continues to rise (ONS, 2017b). Historically the UK's population was depicted as a pyramid. Infants and children formed the base of the pyramid and each successively older cohort was represented as a smaller and smaller group. The pyramid in the Western world has been changing shape and is now being referred to in terms of a 'rectangularisation' of survival (Gawande, 2015). For a number of years it has been known that UK hospitals are largely occupied by older people (DH, 2001) and in Wales most people who die within three days of an emergency admission are aged 85 and over (WG, 2017b). A one-day census of hospitalised patients in medical beds found the average age was 82 years old, with 10 per cent of patients over 90 (Tadd et al., 2011). There is a perception that the average age has increased in my local hospital with various figures and different ways of collating and displaying the data.

Successful service delivery requires planning to understand current and future need. To inform England and Wales, Gomes and Higginson (2008) undertook a secondary analysis of official statistics from 1974-2003 to forecast place and numbers of death up until 2030. Between 1974 and 2003 the death rate (per thousand population) declined from 11.8 to 10.2; the number of people dying at the age of 85 and above doubled during this period. They forecasted a dramatic increase in the number of deaths from 2012 onwards, with implications for either a substantial increase in institutional deaths or need for increased community support. This has implications for society, particularly intergenerational relationships, support and the availability of appropriate health and social care personnel and services (WHO, 2004). This dramatic increase in UK deaths has not yet been recognised (ONS, 2017c) but the largest numbers of people dying are the over 85's (ONS, 2017a). A contemporary challenge is rising numbers of people with dementia which affects 30% of dying older people (Alzheimer's Society, 2014). These

combined factors mean that increasing numbers of vulnerable older adults with frailty will need sensitive and skilled end-of-life care.

There is a need for increased community support and resource to meet the aspiration to facilitate care of the dying at home for those with this preference (WG, 2013b). This is particularly important for vulnerable older adults with frailty who may have limited physical and social reserve. A clinical case from practice illustrates this; it involved an older male in his late 80s who was known to the district nursing team. He had been widowed some years previously and wished to return home for end-of-life care but lacked social support. He recognised that he needed more than four district nursing calls per day and requested twenty-four hour seven-day week support to go home to die. He had a combination of limited physical, social and financial reserve; he was an older vulnerable person with frailty. Sadly, the services were not available to provide the level of support he needed and he died in hospital against his expressed wishes. This scenario involved both the hospital and the district nursing services. It was an unsatisfactory situation for the patient, the hospital staff and the district nursing team who were unable to support his end-of-life care expressed wishes. In order to reduce the numbers of older adults unnecessarily dying in hospital, particularly those who do not want to be there, and recognising that those over 85 year of age are also more likely to die within three days of admission (WG, 2017b) helps to demonstrate the argument that different ways of working are needed. A cultural shift in which conversations about death, dying and bereavement are promoted is crucial (Dying matters, 2015) but in all likelihood, institutional deaths will continue as 'the norm' for the majority of vulnerable older adults with frailty.

2.5 VULNERABILITY AND FRAILTY

When considering older adults care, vulnerability and frailty are particularly but not exclusively relevant. As people we tacitly experience feelings of vulnerability, either personally or by association, regardless of our age. However McNamara et al. (1995) describe the final stages of the disease process as rendering the dying person "emotionally and physically exhausted, frail and vulnerable" (p.228). At the end-of-life people are particularly vulnerable because they generally need the support of other people. Conversely frailty is not a universal concept, although debatably as people are

nearing death there is either a predisposing frailty or an increased propensity in becoming and being recognised as frail.

Vulnerable has been defined as "exposed to the possibility of being attacked or harmed" (Oxford Dictionary and Thesaurus, 2007); a threat to our physical or psychological well-being. Vulnerability is the state of being exposed to this threat and has been linked to ageing, especially to physical, cognitive, and functional limitations (Goergen and Beaulieu, 2013), which pose risks for healthcare complications, adverse events, and poor outcomes within the concept of individualised ageing (Cline, 2014). Vulnerable adults may range from adults who are incapable of looking after any particular aspect of their lives, through to individuals experiencing a short period of illness or disability. There are a number of factors that can contribute to vulnerability but it is broadly accepted that certain groups are at enhanced risk: older people, people with frailty, people with a mental disorder including dementia, those with a significant and impairing physical or sensory disability, people with a learning disability and people with severe physical illness (BMA, 2018). The latter particularly might be associated with potential dying. They also identified unpaid carers who may be overburdened or isolated, homeless, those living with someone who abuses drugs or alcohol and a section of society, particularly women who may be vulnerable as a result of isolating cultural factors (BMA, 2018).

In Welsh legislation the term 'vulnerable' has been replaced by 'adult at risk' in the context of abuse or neglect. The adult at risk will have needs for care and support, and as a result of those needs is rendered unable to protect them-self against the actual or risk of abuse or neglect (Social Services and Well-being Act (Wales) 2014 [SSWBA]). There are various definitions of abuse but an internationally adopted definition is "a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person or violates their human or civil rights" (Action on Elder Abuse, 2017), or more simply, mistreatment by any other person or persons.

In the context of older adults, being described as frail is not uncommon. Synonyms of frailty include: infirmity, weakness, feebleness, debility, incapacity and impairment (Roberts, 2017). Associated depictions of debilitated people expose them as vulnerable. Age UK and the British Institute of Human Rights (2011) highlight older

adults as being especially vulnerable to ill treatment and human rights abuses in a health and social care context because of their dependency on others for their basic needs. Frailty is however a contemporary clinical syndrome, frequently employed in the assessment and care of older adults. Physical vulnerability due to dis-regulation of physiologic systems (Koller and Rockwood, 2013) is a biomedical explanation which corroborates frailty as a useful marker of vulnerability towards adverse outcomes (Eeles et al., 2012; Searle et al., 2008). Frailty can be defined as a clinical syndrome in which three or more of the following criteria are present: unintentional weight loss, self-reported exhaustion, weakness (grip strength), slow walking speed, and low physical activity (Fried et al., 2001). The BGS (2014) identified five frailty syndromes: falls, changes in ability including immobility, delirium, incontinence and susceptibility to the side effects of medication. Frailty can also be measured in clinical practice in relation to the accumulation of deficits using a frailty index.

Frailty can be understood as a consequence of interacting physical, psychological and social factors (Koller and Rockwood, 2013). As it is the state of 'limited functional reserve' or 'failure to integrate responses in the face of stress' (Cornwell, 2012: p.2) it embodies a threat to our physical or psychological well-being and exposes vulnerability. This partly explains the relevance of frailty in the context of end-of-life care. One clinical frailty scale defines very severely frail as completely dependent, and approaching the end-of-life (Dalhousie University, 2007-2009). Eeles et al. (2012) studied the impact of delirium with frailty; survival was reduced for both fit and frail patients but the combination of frailty and delirium imparted a particularly poor prognosis. Delirium is a common, serious clinical syndrome which is characterised by disturbed consciousness, cognitive function or perception (NICE, 2010). This is an important consideration in the assessment, care, management and planning for older adults with frailty, and also demonstrates a unique illness and dying trajectory for this vulnerable group.

By recognising and measuring frailty objectively, clinicians can be better placed to engage patients and their loved ones in difficult discussions about future care needs and prognosis (Koller and Rockwood, 2013). In turn, this may improve palliative care outcomes. These potential communication opportunities may also help alleviate concerns about receiving inappropriate treatment and interventions; that is over

treating or under treating certain conditions which aligns with Welsh strategy, prudency and co-productive health and social care (PHW, 2014; WG, 2018b).

The Gold Standards Framework (2016) encourages the use of three triggers which suggest that patients are nearing the end-of-life. These are the 'surprise question', general indicators of decline and specific clinical indicators related to certain conditions. As such, frailty can be useful in clinical practice as a trigger for further communication and to encourage advance care planning (ACP). Whilst ACP has been discussed in the UK for over 20 years, the Mental Capacity Act 2005 (England and Wales) provides a clear statutory framework which allows a person aged 18 and over, whilst having the capacity to do so, to make an advance decision to refuse specified medical treatment (ADRT) for which at a later time they might lack the capacity to consent or refuse. Scotland's Adults with Incapacity (Scotland) Act 2000 includes provisions around advance directives (AD's). Although AD's are not legally binding they can be very helpful in guiding treatment decisions. Northern Ireland's Mental Capacity Act (2016) does not put ADRT's in the legal framework but pledges to review this in the future. In the United States of America (USA) the Federal Patient Self Determination Act (PSDA, 1990) also recognised AD's including living wills or durable power of attorney for healthcare. The PSDA requires Medicare and Medicaid providers to give individuals information about their rights under state laws governing AD's, decision making, accepting or refusing treatment, and information on the healthcare provider's policies. Hence caution is required when comparing reports from different countries.

In summary, frailty as a consequence of interacting physical, psychological and social factors (Koller and Rockwood, 2013) and as a state of 'limited functional reserve' (Cornwell, 2012) embodies a threat to our physical or psychological well-being and exposes generalised aspects of vulnerability in dying people. Frailty syndrome is relevant to end-of-life care and may also be a useful trigger for ACP discussions. Older adults with frailty are acknowledged as being vulnerable (BMA, 2018) as they may be unable to take care of themselves, or unable to protect themselves from harm or exploitation. This is likely to be due to both frailty and the health conditions that led to them needing care and support in the first place.

2.6 CONCLUSION

This chapter has set the scene for this thesis. It has presented a historical context of dying and death which was followed with an overview of contemporary UK end-of-life care policy. Demographic changes show that globally we are seeing an ageing population, and in the UK the largest numbers of people dying are now over the age of 85. Older people who are dying can be described as vulnerable as they generally need the support of other people; they also have either a predisposing frailty or a tendency towards frailty, which has been shown to increase their need for care and support. The next chapter will explore the concept of the 'good enough death'.

3.1 INTRODUCTION

This section begins with the concept of a healthy death, and moves towards a good death in order to justify the positioning of the 'good enough death'.

3.2 THE GOOD ENOUGH DEATH

Initially my interest was concerned with achieving a healthy death. This had been stimulated by a challenge read during my MSc preparation, whereby Russell and Sander (1998) and Saan (2001) proposed that a spiritual dimension of health promotion such as healthy dying needed to be explored. Indeed, contemporary Welsh policy promotes a 'healthy, realistic' approach to dying (Welsh Government, 2017a). This led to consideration of the dominant paradigms within health promotion, notably involving primary, secondary and tertiary prevention (WHO, 1998). During the active dying phase, the aim is not usually to prevent death, although the goal may be to prolong life, but a common aim is to prevent and relieve suffering; hence tertiary prevention. The alternative framework of salutogenesis (Antonovsky, 1993; 1996) was appealing. It is stress resource orientated with successful coping at the core of the salutogenic paradigm. Antonovsky (1993) presented this as a sense of coherence, the components of which are comprehensibility (making sense), manageability (coping) and meaningfulness (care). He proposed a continuum model of health, with total health at one imaginary pole and total illness at the opposite pole. For me the model also evoked the life continuum of birth through to death. Within this conceptualisation of 'health ease-dis-ease' a salutogenic approach could be used to facilitate ease, which was persuasive. My focus of interest was moving from a healthy death to 'ease' or relief of symptoms and fear.

Contemporary discourse promotes a 'good death' with a significant drive to engage society in discussions in order to plan and enable us to express our personal wishes and preferences around dying and death (Dying matters, 2015; Noble et al., 2014). Likewise the Neuberger report *more care, less pathway* (2013) strongly advocates for the promotion of public awareness of dying, death and bereavement. Death is part of

the continuum of life, yet the culture within the UK has rendered death, particularly our own, taboo (Dying matters, 2014). When we discuss death it tends to be focused on the future or past, something that will happen or something that has previously happened. It is perhaps unsurprising given the sensitivities and uncertainties around dying and death that in day-to-day clinical practice diagnosing and communicating active dying can be problematic. For older adults who are unable to communicate their needs this becomes increasingly complex (Österlind et al., 2011) requiring skilful holistic assessment. Granda-Cameron and Houldin (2012) specifically highlight the vulnerability of those with cognitive impairment in that practitioners may hold misconceptions about their quality of life which in turn can negatively affect the care provided at end-of-life. They also draw attention to the challenges of providing end-of-life care in the hospital due to the curative-orientated environment.

There is a plethora of concern focused towards achieving a 'good' death within the literature, and in the media. The contemporary good death movement was initially associated with euthanasia and assisted suicide (Hart et al., 1998; Kehl, 2006) a practice that remains illegal in the UK (Noel Douglas Conway v The Secretary of State for Justice, 2017). Regardless of the legalities, the good death remains concerned with individual autonomy. McNamara et al. (1995) emphasise that within the hospice movement the good death involves awareness, acceptance, and preparation by all those concerned with the death. Granda-Cameron and Houldin (2012) undertook a concept analysis of the good death in terminally ill patients and found the common attributes included pain and symptom management, being aware of dying, accepting the timing of one's death, autonomy, keeping hope alive, preparing for departure, and making the decision where to die. Similarly Kehl (2006) found the common attributes of dying included it being a process rather than an event, which involved being in control, being comfortable, a sense of closure, affirmation and recognising the value of the dying person, trust in care providers, recognition of impending death, honoured beliefs and values, minimised burden, relationships optimised, appropriateness of death, leaving a legacy, and family care. These values can be seen as underpinning current end-of life care policy.

Whilst there are numerous definitions of a good death, there is no consensus (Kehl, 2006). Alternative terminologies found in the literature are presented in tables 1.

Table 1: alternative terms used to describe a 'good' death

'peaceful'	(Callahan, 2003; Dick and Frazier, 2006; Espinosa et al., 2008; Hov et al., 2009; Lander and Graham-Pole, 2008; Li and Ng, 2008; Maeda et al., 2006; Rubinstein, 1995; Small et al., 2009; Sorensen and Iedema, 2007; Touhy et al., 2005);
'gentle'	(Graham et al., 2005)
'nice' or 'smooth'	(Seale and van der Geest, 2004)
'comfort(able)'	(Hattori et al., 2005)
'dignified'	(Bratcher, 2010; Doorenbos et al., 2006; Franklin et al., 2006; Hunter et al., 2006; Pleschberger, 2007; Ternestedt and Franklin, 2006; Woolhead et al., 2004)
'with composure'	(Kelly and Minty, 2007).

The good death has also been characterised by nurses' comfort with events and interactions (McNamara, 2004). This was later mirrored in Noble et al.'s (2014) findings that staff find it challenging when carers resist truth telling. This may negatively impact on the nurses' comfort when providing end-of-life care.

From the position that dying and death can be 'good', one would anticipate that 'bad' dying and death would also be recognised. Arguably this is reflected in policy that recognises a need to improve end-of-life care, especially for vulnerable older adults. Table 2 contains some alternative terms that describe the opposite of the good death.

Table 2: alternative terms used to describe the opposite of a 'good' death

'bad' death	(van der Geest and Seale, 2004)
'dying ugly'	(Thompson et al., 2006)
'traumatic'	(Sorensen and Iedema, 2006; Tan and Cheong, 2011)
'decrepit'	(O'Connor, 2009)
'undignified'	(Calnan et al., 2006)

The terminology used is both powerful and emotive. There are claims that the good death in modern Western society has become death in old age (Howarth, 2007). Erikson (1997a) rather unsurprisingly identified old age as the eighth, the last stage of the life-cycle; his bereaved wife went on to develop a ninth stage of the lifecycle to address the perspective of the oldest of the old, people in their 80's and 90's (Erikson, 1997b). She points out that despite efforts to maintain strength and control, the body loses its autonomy which then challenges ones independence and sense of dignity. Like Glaser (1966), Erikson (1997b) describes older people at end-of-life as being perceived in terms of a low social loss in contemporary society. Whilst Erikson (1997b) declares that in the ninth stage of the lifecycle 'death's door' is open, and not so far away, the eighth and ninth stages (Erikson, 1997a; Erikson, 1997b), painted perhaps a rather dismal existence. This does align with the assertions of Kellehear (2007) that the dependency brought on by frailty is a contemporary stigma associated with shameful dying. In this context, death in advanced old age may be seen as timely in terms of a long life lived, and a release from the failing body. Perhaps these are the contexts for a good enough death being viewed as death in old age.

As stated, much of end-of-life care policy promotes a good death involving forward planning and clear decision-making (Noble et al., 2014). Advance or anticipatory care planning is reportedly often undertaken too late (Dying matters, 2014; Shucksmith et al., 2013). A systematic review and narrative synthesis of USA and UK literature concerning public and healthcare professionals attitudes in relation to discussions about end-of-life care revealed that only a minority of frail older individuals would not want these discussions, however most had not had this opportunity (Sharp et al., 2013). The biggest barriers were reluctance of family members to discuss end-of-life, the passive expectation that family members, God or others would decide on their behalf, and lastly, the significant uncertainly concerning future illness and decline. Nevertheless, this and the findings of commissioned research (Dying matters, 2014) suggests that the majority of people will not have expressed their wishes or treatment preferences. In contemporary Western culture this may limit the possibility of achieving a good death. Sensitivity for the needs of those with cultural differences is implicit, with both Granda-Cameron and Houldin (2012) and Kehl (2006) recognising that the good death may vary depending on whose perspective it is.

Walters (2004) describes an interesting concept; 'dying with panache'. He describes it as having the sense of dying in one's own way, in one's own style, that is with autonomy. Death will arrive but all the problems may not be resolved. The individual may display elements of protest, complaint, awkwardness, humour and even be perceived as challenging. Hart et al. (1998) argues the ideology of the good death "constructs a socially approved form of dying and death with powerfully prescribed and normalised behaviours and choices" (p.72). This dying with panache is quite in contrast to the managed "proper way to die" (Zimmermann, 2007: p.310).

McNamara (2004) argues that the hospice model of the good death, particularly the expectation of awareness and acceptance has become increasingly inappropriate in contemporary society which values patient autonomy and consumer choice. To deal with this she argues that practitioners prioritise the physical aspects of care as they can be proactive in alleviating patient's pain and physical discomfort, the death is then 'good enough'. She warns that this apparent compromise in palliative care delivery, although an ethical way to practice, in turn masks a return to routine medical practices and a hierarchy of care which prioritises the physical management of symptoms. The 'good enough' death ideology resonates with my personal and professional experiences.

3.3 CONCLUSION

The aim of this thesis moved from exploring RN's experiences of the healthy death, to the good death and finally the good enough death. There was also a risk that the utility of a healthy or good death as a shared goal of nursing practice would be particularly limited. The good enough death has also been characterised by nurses' comfort, or lack of comfort with events and interactions surrounding the death which can also be influenced by lack of truth telling and openness.

The perceived requirements are that preparation is required to enable a good enough death, but it is reported that older adults infrequently discuss their preferences. This will likely create difficulties given the complex, heterogeneous needs of this particularly vulnerable group. Hence the 'good enough death' may in fact not be good enough, particularly for older adults with frailty. The following chapter explores this further by considering the concept of poor care.

4.1 INTRODUCTION

Given the intense media coverage and plethora of poor practice reports as well as my professional experiences, this chapter aims to better understand the concept of poor care, to explore what it is and what contributes to its occurrence in practice. This chapter considers standards of care, published concerns, a clinical scenario from practice, expectations of care standards, and professional regulation and inspection. It explores the concept of poor care along with recognition and reporting thresholds. Its purpose is to better help understand and recognise when the 'good enough' death becomes 'not good enough' with the potential to apply this knowledge in practice.

4.2 STANDARDS OF CARE

Good standards in healthcare should be a given. Good standards of care can be difficult to articulate, but we can see and feel it; we experience it. We also experience healthcare which we may perceive as not good enough. That said discussions concerning standards of healthcare are all around us, often framed within the experiences and consequences of substandard care. However it is important to note that the concept of poor care and neglect is not confined to the UK, it spans both the developing and Western world (Pillemer et al., 2016; WHO, 2008).

Monitoring, measuring quality, service user satisfaction and quality improvement is mainstreamed throughout health services (1000 lives improvement service, 2018; Healthcare improvement Scotland, 2011; Institute for Healthcare Improvement, 2016; NHS England, 2016; Organisation for Economic Cooperation and Development, 2016). Campbell et al., (2000) observe that quality of healthcare has only two dimensions for individual patients, these are access and effectiveness. Effectiveness in this context is concerned with clinical and interpersonal care which frontline nurses deliver. This interpersonal component extends to families and carers. Satisfaction can be derived from an outcome of these interactions but there has also been criticism of the reliance on satisfaction surveys (Rogers et al., 2000). In defining poor care it is important to recognise that clinical perspectives may differ from service user perspectives. The definition and understanding of poor care will undoubtedly vary across cultures, health

systems and individuals. However for vulnerable adults, arguably their perspectives should be prioritised.

4.3 CONCERNS: POOR QUALITY OF END-OF-LIFE CARE

It is difficult to avoid stories about people's experiences of poor care, in particular nursing care; a search of the BBC web page using the term 'nursing care' evidences this (BBC, 2017). In recent years there have been a number of reports detailing poor care, principally concerning vulnerable adults (Andrews and Butler, 2014; Care Quality Commission [CQC], 2015; DH and NHS Commissioning Board, 2012; Flynn, 2015; Francis, 2013), some of whom would be described as having frailty with implications for end-of-life care. The recent Gosport inquiry (Gosport Independent Panel [GIP], 2018) substantiates deeply concerning historical practice. The report details numerous older people who died prematurely as a result of clinically inappropriate opiate prescribing and administration. Its description, "a picture of care which fell well below the expected standards of nursing practice at that time. It is a picture which demonstrates a lack of concern and regard for individuals' assessed needs, as well as a lack of challenge to the prevailing prescribing practice at the hospital" (GIP, 2018: p.48); it is disturbing. Public calls for prosecutions have followed from the report (BBC, 2018), a decision that will be made by the police and CPS (House of Commons, 2018). It also may reignite coverage of the LCP (House of Commons, 2018) and will likely escalate public concerns and potentially shape their expectations of care.

More generalised concerns about the quality of end-of-life care are widely reported. The Parliamentary and Health Service Ombudsman (PHSO, 2015) reports that too many people are dying without dignity. Dignity is not defined but appears to relate to different aspects of 'poor interpersonal care'. Key recommendations include improvements to culture, behaviour and training, the provision of integrated 24/7 palliative and end-of-life care, leadership and commissioning (House of Commons Public Administration and Constitutional Affairs Committee, 2015). Flynn (2015) 'typically' found a lack of attention and respectful care at the end of people's lives. This provides an ethically troubling description of the findings. A prior analysis of complaints and concerns of four hospital Trusts found that 4% of these were associated with end-of-life care (National End of Life Care Programme, 2010). The dying well matters programme in Wales similarly uncovered several concerns. These

concerns include delays in receiving adequate analgesia, poor management of constipation, inadequate communication, a risk averse approach to patient management, defensive staff attitudes, and delays in seeking professional colleagues help to support complex needs (Palliative Care Cymru Implementation Board, 2011). More recently the VOICES survey (ONS, 2016) based on the opinions of relatives who rated the quality of care provided to their friend or relative, found that relatives of people who died in hospital rated overall quality of care significantly worse than any other place of death; perhaps suggestive of the balance of power leaning towards the professionals. Research has also contributed to the description of problems surrounding end-of-life care and has identified persistent inequalities and variation in care, poorly coordinated services and limited access to specialist palliative care for those with conditions other than cancer (National Institute for Health Research Dissemination Centre, 2015). Whilst the PHSO (2011) reports that older people in hospital are not treated with sensitivity, compassion and professionalism, those with frailty (GIP, 2018) or dementia are highlighted as being at particular risk of receiving poor end-of-life care (Alzheimer's Society, 2012; Marie Curie, 2015a). There are of course reported experiences of good or excellent care, and whilst these are in the majority (ONS, 2016), a quarter of respondents who assessed and rated the quality of care of their loved one were of the opinion that they had endured fair or poor care.

Given these concerns and the fact that older people, particularly those over 85 constitute the largest number of those dying in the UK (ONS, 2017a), serves to demonstrate this is of contemporary significance for nursing staff and their practice in the delivering of older adults end-of-life care; particularly as this group of people are exposed as vulnerable to receiving poor care. The published literature and reports detailing poor care suggest that for vulnerable older adults with frailty, poor care can be insidious, difficult to pinpoint, or hidden. The next section explores the policy and law related to vulnerable adults as this is relevant in the context of care delivery for older adults including those with frailty needing end-of-life care.

4.4 ADULTS AT RISK: POLICY AND LAW (UK)

This thesis is concerned with RN's experiences of delivering end-of-life care in the context of vulnerable older adults with frailty. The Nursing & Midwifery Council (NMC) is the regulator for nursing and midwifery in England, Wales, Scotland and Northern

Ireland. As registrants we are bound by 'The Code' (NMC, 2015a), which specifies the professional standards that RN's and midwives in the UK must uphold. This includes a duty to "have knowledge of and keep to the relevant laws and policies about protecting and caring for vulnerable people" (p.13). This section discusses the development of relevant policy and law in the context of the care of vulnerable adults.

Following the Second World War the European Convention on Human Rights was agreed. In 2000 the Human Rights Act 1998 came into force making the main Articles from 'the Convention' enforceable under UK law. Nevertheless, the Human Rights Act has been absent in much UK government policy concerning older people (Age UK and British Institute of Human Rights, 2011). The United Nations (UN) declared 18 principles for older persons in 1991. These principles are grouped into five themes: independence, participation, care, self-fulfilment and dignity (UN, 1991). In contrast to the Human Rights Act, these can be seen underpinning UK policy relating to older adults such as the Older People's Commissioner for Wales (2014b) and the Commissioner for Older People for Northern Ireland (2013). These principles have also been embedded in law as the Social Services and Well-being (Wales) Act 2014 (SSWBA) imposes a duty of due regard to the UN principles for older persons. The Act also makes provision for safeguarding 'adults at risk' from abuse and neglect which for the first time aligns adult protection with child protection arrangements. The Adult Support and Protection (Scotland) Act 2007, and latterly the Care Act 2014 (England) also places adult protection into statutory frameworks but adult protection in Northern Ireland currently remains policy based. These duties importantly make provisions for the protection of our increasingly ageing, and potentially increasingly vulnerable population.

Abuse and neglect remain uncomfortable concepts, particularly at end-of-life but reflecting a perceived need, the SSWBA 2014 amended the Public Services Ombudsman (Wales) Act 2005 to extend to concerns regarding privately arranged, funded social care and independent palliative care services. In England, the Health and Social Care Act 2012 extended the definition of 'public function' to include care to an individual under a local authority contract (DH, 2008a), but this does not include privately arranged care. NICE (2018) also identified variation in organisational attitudes to, and perceptions of risk in both domiciliary care provider and commissioner

organisations. At end-of-life individuals may become particularly vulnerable and are potentially 'at risk'. This emphasises the need for continued vigilance, especially given the gaps in robust safeguards which reemphasises the vulnerability of this group of people.

Identifying neglect is not always straightforward (Mandelstam, 2014). Neglect and errors do not necessarily result in actual harm but the potential is evident. In England and Wales the Mental Capacity Act 2005 (MCA, 2005) introduced the criminal offence of ill treatment or wilful neglect of a mentally incapacitated adult by anyone responsible for that person's care. More recently the Criminal Justice and Courts Act 2015 introduced a new offence of ill treatment or wilful neglect by a care worker of a person with mental capacity as a response to one of the many recommendations made in the report of the public enquiry into failings at the Mid Staffordshire NHS Foundation Trust (Crown Prosecution Service [CPS], 2017). The CPS lists examples of behaviours and examples of possible offences along with the relevant legislation (CPS, 2011).

The law is complex. The standard of proof in criminal law is beyond reasonable doubt, but in the civil courts and in clinical and professional practice it is on the balance of probability (Strafford Kent law, 2017). Whilst only a very small proportion of neglect and abuse meets a criminal threshold, it can also be hidden or unintentional and unrecognised. There are also convictions of wilful neglect with no evidence of enduring harm (R v Heaney, 2011; R v Kenyon, 2013; R v Patel, 2013). These include omitting to attempt cardiopulmonary resuscitation for a resident in a nursing home despite conclusions that successful resuscitation would have been unlikely, purposefully omitting to attend to the needs of residents in a care home, slapping a resident, and adding seven or eight teaspoons of sugar and additional vinegar to a confused resident's drink. Conversely whilst a number of individuals were prosecuted for ill-treatment or wilful neglect following the Gwent police investigation Operation Jasmine, many convictions were overturned in the Court of Appeal (Flynn, 2015).

More generally, good clinical practice in decision making has always involved consideration of the wishes, feelings, beliefs and values of the individual involved. The MCA 2005 takes this further, demanding that any decision or act made on behalf of a person who lacks capacity must be made in the person's best interests. This legislation

is clear in that as far as is reasonably ascertainable, in determining what is in a person's best interests all the relevant circumstances as detailed in the MCA 2005 and code of practice (Department of Constitutional Affairs [DCA], 2007) including the person's past and present wishes, feelings, beliefs and values that would likely influence the decision, must be taken into consideration. Where a welfare attorney or guardian has been appointed with healthcare decision-making powers, the healthcare practitioner must seek their consent where is it practicable and reasonable to do so in England, Wales and Scotland. In the future this will extend to Northern Ireland (MCA NI, 2016) following implementation of the Act. Section 5 of the MCA 2005 provides protection from liability; it allows necessary caring acts or treatment to take place as if a person who lacks capacity to consent had consented to them. That is provided the person is reasonably believed to lack capacity to give permission for the action, and the action is in the person's best interests (DCA, 2007).

A practice exemplar involves the administration of medication covertly which raises ethical and legal concerns in practice. This has been reported as a common practice in nursing homes (Haw and Stubbs, 2010) with published guidance available (NICE, 2017b). This practice was scrutinised in the Court of Protection (AG v BMBC & Anor, 2016). The judgment recognises that covert medication administration amounts to treatment without consent, a serious interference with a person's autonomy and right to self-determination under Human Rights legislation; accordingly there must be proper safeguards. The judgment states that the use of covert medication is an aspect of continuous supervision and control and is likely to be a contributory factor giving rise to a deprivation of liberty. Reference to covert administration of medications also factors in a number of NMC hearings (2017b). This judgement and other developments in legislation are demanding that people working and caring for vulnerable adults are familiar with and abide with relevant policy and law.

In summary, contemporary regulation, law, legal rulings and policy reflect the rights and needs of our increasingly ageing, and increasingly vulnerable population. In doing so they have mandated aspects of practice which must be applied when assessing, delivering and evaluating the care of and for vulnerable older adults. Whilst the vulnerability of this group of people is largely addressed by the law, loopholes still exist.

4.5 POLICY AND LAW IN PRACTICE: AN EXEMPLAR

My professional role is concerned with older vulnerable adults with increasing frailty. The role descriptor specifies a need to protect patients from harm and inappropriate care. This helps explain why I have a focused interest on perceived or actual poor care and clinical practice identified through concerns, observation, audit and clinical incident reporting. This section draws on a composite case using clinical experience to demonstrate the implications of policy and law for all staff including RN's in the context of poor care, neglect and abuse of 'at risk' vulnerable adults. This case has been adapted but is based upon actual situations.

Whilst this clinical case description does not focus on imminent end-of-life care, it does describe an older individual who can be seen as vulnerable in several contexts and subsequently does die. Bill (pseudonym) also has frailty and as a consequence is vulnerable due to a 'limited functional reserve' or 'failure to integrate responses in the face of stress' (Cornwell, 2012). Bill's family also formalised concerns about the standard of his end-of-life care.

Bill had fallen and sustained a fractured neck of femur. This was reported as a serious incident (NHS Wales, 2011) and given a two month time frame for investigation. Unfortunately the person leading the investigation unexpectedly required extended sick leave and I was asked to finalise the report. Bill was in his mid-80s and suffered multi-morbidity including dementia. He had been admitted to hospital with several acute exacerbations of congestive cardiac failure within the previous twelve months. On this occasion he was acutely unwell and had an overlying delirium. His acute exacerbation of congestive cardiac failure, chest infection and delirium settled with treatment. At this point it was anticipated that Bill would be fit to return home in a day or so but unfortunately he suffered an injurious fall from bed sustaining a fracture which required surgery. Sadly Bill died a week later.

I began by reading the collated information and listening to an audio recorded concerns meeting. Aspects of the explanation surrounding the circumstances of the injurious fall were unclear; the description and conclusion 'didn't feel right'. There was a suggestion that Bill exited the right side of his bed without assistance, became tangled in his bed sheets and then leaned on a wheel-mounted sphygmomanometer which moved as he fell. A recommendation was to re-emphasise lean principles (Jones

and Mitchell, 2006) as part of quality improvement work (PHW, 2014). This action focused on the environment of care and reflected the interim findings, skills and knowledge of both the original investigating officer and the ward sister.

On reviewing statements provided by staff, information such as whether the fall was witnessed or not were missing. I met with the RN in charge of Bill's care on that particular shift, she was able to show me the model of bed and bed space Bill had occupied. This was a standard hospital profiling bed with integral three-quarter length bedrails, raised on each side at his request because he felt safer as he was used to sleeping in a double bed. This information was reflected in his assessment. Bill had suffered several falls at home and needed the assistance of one person to transfer from bed to chair, and two people to transfer to use the toilet. This too was evident in his care notes. He was nursed in a shared ward area with other patients. Bill's family had advised staff that he no longer had the skills to use the bedside call bell and would need observation because as his physical condition improved he was more likely to attempt to get out of bed unaided. Bill lacked insight into his reduced ability to safely mobilise independently and he could not recall any recent falls. Bill did not use the call bell but he claimed it was because he didn't like the noise. His usual method of alerting staff to his needing assistance was to wave his arms and call out.

At the time of the injurious fall a healthcare support worker (HCSW) was stationed in Bill's bed area whilst the other staff were delivering patient care in a different area of the ward. The patients in Bill's part of the ward had been generally settled during the night including Bill. At about 06:00 hours a loud bang was heard. The nurse in charge ensured that the patient she was with safe and then responded to the noise. Two of her other colleagues were able to respond immediately. The nurse described the position of Bill in relation to the bed and sphygmomanometer. This did not correlate with the statement provided by the HCSW or the interim findings of the draft investigation. The on-call doctor was also interviewed. There were discrepancies between staff statements, the incident report(s) and the medical assessment as to which side of Bill's body he was observed to be lying on. The nurse and doctor described Bill's position similarly in that Bill was on the floor, laying left of centre in front of the end of the bed, on his left side. He sustained a fracture to his right hip. This was different to the HCSW's existing statement which involved Bill leaning on the

sphygmomanometer to the right of the bed. I asked about tangled bed linen reportedly around his feet and legs but the nurse disputed this. This information triggered concerns in my mind.

- Why the discrepancies?

- Had left and right been assessed from different orientations with the bed?

- What was the significance of the description of the involvement of the sphygmomanometer and tangled bed linen?

- Why didn't the HCSW see or hear Bill who had reduced mobility wriggling down the readily observable bed to get access beyond the end of the three-quarter length bedrails?

- What was the HCSW doing?

- Was the fall witnessed?

- Why didn't the HCSW meet Bill's needs in a timely manner?

- What was the HCSW reaction and action at time of the incident?

- Did the nurse ask the HCSW why she hadn't been able to respond more quickly?

- What was the HCSW's response and attitude following this?

The nurse explained that her colleague had run down the corridor and arrived at Bill's side at the same time as the HCSW. This and other responses confirmed my concern that the HCSW potentially neglected to, rather than was unable to, respond to Bill's need and that this catastrophic fall could possibly have been averted. I immediately alerted the Senior Nurse to my concerns and a referral under the Protection of Vulnerable Adults policy and procedure (POVA, 2013) was made.

This experience encouraged me to consider why I had sought clarification of certain facts and why I was sensitised to a number of warning signs pertaining to unacceptable, potentially neglectful care compared with the assessment and interim findings of a senior clinical colleague. My personal and professional beliefs hold that the more dependent the patient is, both physically and psychologically, there is a greater duty to provide care which promotes respect for autonomy and dignity whilst providing safe and effective care (values). The potential that the HCSW did not respond to Bill's care needs are at odds with my value base and triggered a warning

sign (incongruity). I began cognitively analysing information I had received in the context of my previous 'concrete' experiences in dealing with POVA referrals as a Designated Lead Manager (prior experience). I considered the warning signs and compared them to knowledge of actual cases (application of experiential knowledge). I have expertise in working with older people with frailty and have expert knowledge in the factors that contribute to falls in adult patients in hospital (expert knowledge). Undoubtedly knowledge and experience were integrated and informed my sense making of this incident.

I began to visualise Bill as a vulnerable older adult who likely lacked mental capacity to make decisions around his mobility needs. Through this cognitive processing I perceived that these events crossed a threshold that required a change from root cause analysis, an objective thorough investigation to determine the facts, to POVA as I considered potential neglect or ill-treatment of a vulnerable adult (escalation of concern). My values + incongruity + prior experience + application of experiential knowledge + expert knowledge = recognition of neglect or abuse. This personal and professionally recognised threshold required that I escalated the concern initiating a change in approach to investigation and subsequent actions.

My assessment of neglect, using incomplete information was validated as the Public Protection Unit investigated this allegation of neglect under s.44 of the MCA 2005. The case was heard in Crown Court but during the hearing it was concluded that there was insufficient evidence for criminal prosecution. The POVA final strategy meeting concluded that on the balance of probabilities neglect was proven and a referral to the Disclosure and Barring Service (Gov.UK, 2018a) was subsequently undertaken. This sombre scenario has illustrated the use of policy and law concerning the poor care and neglect of Bill, an older vulnerable adult with frailty, in practice. It has also demonstrated different perceptions of good enough, or not good enough care standards between myself and a fellow senior colleague.

The investigation concluded that poor communication was a root cause of 'not good enough' care. This was evidenced in that the family said that they were not expecting Bill to die even though a 'guarded prognosis' was recorded (Medical dictionary, 2009). Bill's family's concerns also alleged neglect in the standard of his end-of-life care which included poorly addressed pain and fluids management, lack of fundamental comfort

care involving oral care, hygiene and a perceived lack of person-centeredness. Bill's family's perspectives and the clinical teams' perspectives did not appear to be aligned. However these themes can be mapped across to the publicly available reports detailing poor care of vulnerable adults. This also begins to suggest they may be variation in expectations of care standards between clinical staff and family.

In summary, poor standards of care are detailed in numerous reports which helps explain the need for safeguards for vulnerable adults as set out in policy and law. These safeguards can also be used to support the autonomy of individuals as well as providing the basis for standards of professional practice. This section has provided an example of the interaction of policy, law, poor care, and an exceptionally poor experience for an individual and his family. Bill's story was used to illustrate the use of safeguarding policy and law in an aspect of perceived poor care and practice. It did not attempt to explore the family's experiences of poor fundamental end-of-life care.

Bill's story has been used to demonstrate my professional understanding, recognition and threshold in relation to expectations of standards of care and poor care delivery; a concept that is fraught with problems and will be explored further. Whilst this case may appear to be a rather extreme example, it reflects my professional experience as part of my role. The majority of staff may not engage with this level of inspection and scrutiny of poor practice, but it is relevant to acknowledge that my experiences will influence my judgement and perceptions. The next section will explore expectations of care standards.

4.6 EXPECTATIONS OF CARE STANDARDS

Healthcare expectations of younger generations are said to be much higher and quite different from those of the post-war population that the NHS was originally set up to serve (Ham et al., 2012). Ham et al. (2012) argue that public services are now required to meet the needs of an ageing population, to respond to the changing burden of disease and rising public expectations. Arguably poor care is not necessarily intentional but can be perpetuated by our health systems. 'Mrs Andrews Story' on hospital care for older adults with frailty (HSJ/Serco, 2014) portrays an 84-year-old woman who, after falling, spent seven weeks in hospital and subsequently never returned home. Much of her 'failed' care was attributed to the system rather than to individuals. The

OPC for Wales (2011) highlights concerns about the low expectations that many older people reportedly have of their care. She stated "we need to see people expect more. We found evidence of poor practice and this needs to stop" (p.4). Similarly the Alzheimer's Society (2013) report low expectations about the quality of life of people with dementia in care homes. Research undertaken in the service industry focussing on customer expectations suggests that expectations have two levels, that is, desired and adequate (Parasuraman et al., 2015). Parasuraman et al. (2015) describe this as a blend of what the customer believes can be, should be and will be. They depict a continuum of expectations from low to high, with a zone of tolerance at the core, bordered by the adequate and desired expectations (figure 1).

FIGURE 1: SERVICE LEVEL EXPECTATIONS: ADAPTED FROM PARASURAMAN et al. (2015:P.42).
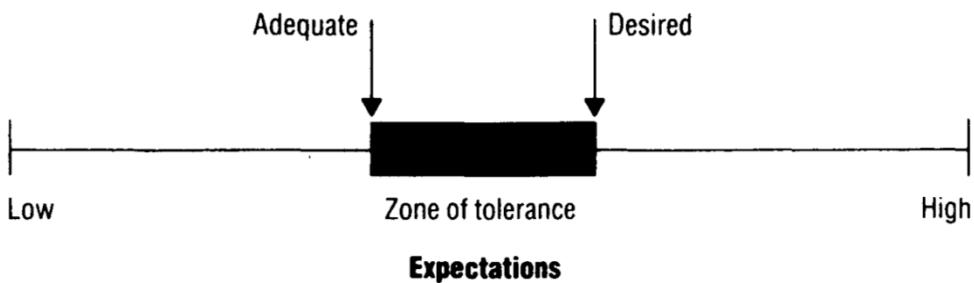
This zone of tolerance will contract and expand along this continuum dependent upon the individual's expectations. The adequate and desired expectations may possibly resonate with the dimensions of access and effectiveness described in Campbell and colleagues (2000) analysis of quality of healthcare.

Glaser and Strauss (1968) suggested that older adults sometimes felt that their care needs created too much burden on their family which led to them opting for care home residency rather than returning home. This could still be a contemporary phenomenon although people are reported to prefer to live in their own homes (Social Care Institute for Excellence, 2017). Cornwell (2012) attributes the problems older adults encounter in care provision to having roots within a wider social culture which does not value old age. She states "if older people had high status and were highly valued, it would be unthinkable to allow frail older people to be largely looked after by low paid staff with few qualifications and little or no training" (Cornwell, 2012: p.9).

Oliver (2008) also observes that the media has failed to focus on the deficiencies in the care of older adults concerning poor recognition diagnosis and treatment of common conditions such as continence problems, osteoporosis and dementia. These are arguably omissions in assessments and treatment which Mandelstam (2014) describes as systemic neglect. Are these aspects of care in old age perceived as unavoidable, and within the public's expectations and 'zone of tolerance'? Of note, healthcare professionals also make up part of the general public. When considering older adults, particularly those reliant on health and care services who are arguably vulnerable in part due to frailty, it is important to consider that their choice and availability of care provision may be limited which may serve to increase their zone of tolerance. The Flynn report (2015) details a review into the neglect of older people living in care homes in South East Wales (Operation Jasmine), and highlighted a concerning lack of choice; "for some it was a case of take it or leave it" (p.21). This provides a potential, if disturbing, explanation for these generalised low expectations. It is also suggestive of a societally tolerated actuality which affects some of our most vulnerable people.

The next section focuses on the role of professional regulation and inspection of care services in order to better understand their roles in maintaining standards of care.

4.7 PROFESSIONAL REGULATION AND INSPECTION

The Professional Standards Authority for Health and Social Care (2017) oversees the nine regulators who register health and care professionals in the UK. Its purpose is to protect patients, service users and the public by improving the regulation and registration of health and care professionals and practitioners. The NMC is the regulator for nursing and midwifery in England, Wales and Scotland and Northern Ireland. Likewise the General Medical Council (GMC) regulates medical practitioners. However both the GMC and the NMC are reported to have failed to protect the public (Gosport Independent Panel, 2018). As a UK registered nurse I am bound by the Code: professional standards of practice and behaviour for nurses and midwives (NMC, 2015a). The Code specifies the professional standards that RN's and midwives in the UK must uphold. These standards are made explicit within four domains: prioritise people; practice effectively; preserve safety; promote professionalism and trust. 'The Code' (NMC, 2015a) incorporates a duty of candour which is one of the many recommendations made as a result of the public enquiry into failings of the mid

Staffordshire NHS foundation Trust (Francis, 2013). In doing so, this acknowledges that health professional behaviours and care delivery can and do fall below acceptable standards. The use of the term 'poor care' can be seen in numerous contexts including NMC fitness for practise hearings (NMC, 2017b); however its meaning is vague at times even when associated with harm to patients. Neglect appears to be more frequently referred to in terms of professional conduct (NMC, 2017c).

All health services in Wales are required to do the right thing, in the right way, in the right place, at the right time and with the right staff and the Health and Care Standards framework is designed to help teams and services demonstrate this (WG, 2015). In addition, Health Inspectorate Wales (HIW) regulates and inspects Welsh NHS and independent healthcare providers aiming to provide assurance and promote improvement (HIW, 2017). Social care and social services are regulated by Care Inspectorate Wales (CIW) (2018). The Care Quality Commission (CQC, 2018) is the independent regulator of health and adult social care in England who also inspect against a range of standards, policies, guidance and regulations. The Inspectorates measure against a set of pre-determined standards which set a threshold to determine the level of quality. These inspection processes however did not prevent some of the significant neglect and abuse of vulnerable older people in Wales (Andrews and Butler, 2014; Flynn, 2015) or England (Francis, 2013; DH, 2012). Likewise research has found that compliance with pre-defined standards is not good enough in determining quality of care (Forbes-Thompson and Gessert, 2005).

This section has highlighted that poor care can exist but remain unrecognised or hidden. The next section considers recognition of poor care and reporting thresholds.

4.8 RECOGNITION AND REPORTING THRESHOLDS

Adults at risk policy and law were discussed in section 4.4 of this thesis. Safeguarding 'adults at risk' from abuse and neglect has been incorporated into Welsh, Scottish and English legislation. Whilst only a small proportion of 'poor care' meets these safeguarding thresholds, it has been proposed that within health and social care, breaches of individuals' dignity are often at the heart of instances of human rights abuse (Age UK and British Institute of Human Rights, 2011). It is important to note that breaches of dignity here are considered as abuse. There appears to be a problem in

both the definition of and recognition of neglect and abuse, which arguably will affect perceived and potentially actual thresholds for reporting.

The first Older People's Commissioner (OPC) in Wales used her legal powers of review to explore the treatment of older people in hospital in relation to dignity and respect (2011). She describes failures in privacy and continence care as "simply unacceptable" (p.5) but did not go as far as to label this as abuse. In 2013 the OPC (Wales) made a statement "all too often I hear about unacceptable examples of care and treatment where dignity is not just lacking but it borders on offensive and abusive" (unpaginated). Subsequently she published a report on the *abuse of, and crimes against, older people* (OPC Wales, 2014a). This emphasises the need for older people to have access to the full support of our civil and criminal justice systems. It also concludes that the term 'elder abuse' obscures the recognition of the abuse of, and crimes against, older people. More recently the Commissioner (OPC Wales, 2018) highlighted that the SSWBA (2014) changed the safeguarding working definition of harm from 'significant harm' to 'potential for harm' but provided no guidance to support decision making around the thresholds for reporting.

In the USA, Krause et al. (2011) established that there are varying definitions of reportable abuse in different states. This is not just applicable to adult abuse. The Welsh Neglect Project found evidence that there is a lack of a coherent and shared view about what constitutes neglect (Stevens and Laing, 2015). They conceptualise neglect as the result of 'not doing'. However a carer may demonstrate poor standards in 'not doing' because they do not have the practical or emotional skills or capacity to provide good care. This is suggestive of unintentional actions or inactions rather than an unwillingness to provide good care. In other cases neglect can result in intentional harm. Observations from practice suggest the applied threshold for reportable poor care standards and neglect is variable, and particularly poorly understood in the absence of apparent harm. Abuse (observed or disclosed) may be more recognisable than neglect because ill treatment which is arguably abuse, generally involves positive action rather than omission (Mandelstam, 2014).

Krause et al. (2011) also observed that reported abuse in nursing homes in the USA is significant but likely under-reported. The true incidence of abuse remains problematic

(Institute of Medicine and National Research Council, 2014) stemming from discrepancies between actual rates and the number of cases reported to authorities. Similarly, Schweitzer et al. (2006) studied the failure by medical practitioners to report suspected child abuse in Queensland Australia. They conclude that the failure to report resulted not from judgment about the presence or absence of indicators of abuse and neglect but was generated from a personal threshold. Likewise the OPC for Wales (2012) reported that Welsh research findings also found that reporting was guided by the personal ethics of the member of staff. When considering Bill's care (3.2.1) my embedded values that the more dependent the patient is both physically and psychologically, the greater the duty to provide care which promotes respect for autonomy and dignity alongside safe and effective care were integral. These values were combined with a tacit sense of incongruity using prior experience, experiential and expert knowledge in order to consider a potential case of neglect or abuse, which met an internalised threshold that resulted in my decision to report this. Not dissimilarly Schweitzer et al. (2006) recommend that rather than improving information on the signs and symptoms of abuse which reflects current training, interventions should be aimed at addressing practitioners' beliefs underpinning their reporting behaviours. Reporting thresholds are a complex phenomenon.

A different challenge was described by McNamara (2001) who emphasises the person centred and empowering constructions of a good death. However she warns that the good enough death ethic can also shift the locus of responsibility from the social collective, including professional carers to the individual who is dying. She argues that this could allow health professionals to rationalise any failures in achieving the good enough death, on the individual's decisions rather than failures on part of the organisation that is managing that person's death. This is an interesting concept in that in recognising individuality and autonomy the social structures and social construction of the good enough death and dying becomes apparent.

The next section analyses the concept of poor care to better help understand and recognise when the 'good enough' death becomes 'not good enough' with the potential to apply this knowledge in practice.

4.9 A CONCEPT ANALYSIS OF POOR CARE

In considering the concept of poor care, a preliminary search of AMED, EMBASE and Ovid MEDLINE (1946- November 2017) using the MESH term 'quality of healthcare' and search terms 'concept analysis' was performed. This search returned 23 papers, two of which were duplicates. Of the remaining 21 papers, one article reviewed consumerism in health visiting and another was concerned with envisioning healthcare five years into the future and both were excluded. The remaining 19 references are listed in table 3.

TABLE 3: RETRIEVED REFERENCES FROM SEARCH INCLUDING MESH TERM QUALITY OF HEALTHCARE AND SEARCH TERM CONCEPT ANALYSIS

Key: * denotes emphasis on positive quality of care; ** denotes emphasis on negative quality or care; * ** denotes a mix of emphasis on positive and negative qualities of care.	
Attree (1996) *	Towards a conceptual model of 'quality care'.
Almond (2002) *	An analysis of the concept of equity and its application to health visiting.
Anderberg et al. (2007) *	Preserving dignity in caring for older adults: a concept analysis.
Choi and Bang (2010) *	Quality of pediatric nursing care: concept analysis. [Korean] (findings presented in abstract).
Cline (2014) * **	A concept analysis of individualized aging.
Dennis (2003)*	Peer support within a healthcare context: a concept analysis.
Haas (1999) *	A multidisciplinary concept analysis of quality of life.
Hattori et al. (2006) *	Concept analysis of good death in the Japanese community.
Kim et al. (2015) * **	Defining attributes of patient safety through a concept analysis.
Kalisch et al. (2009) **	Missed nursing care: a concept analysis.
Manias (2010) *	Medication communication: a concept analysis.
Meghani (2004) *	A concept analysis of palliative care in the United States.
Morgan and Yoder (2012) *	A concept analysis of person-centered care.
Pang et al. (2004) *	Towards a Chinese definition of nursing.
Quirke et al. (2011) **	Suboptimal care of the acutely unwell ward patient: a concept analysis.

Key: * denotes emphasis on positive quality of care; ** denotes emphasis on negative quality or care; * ** denotes a mix of emphasis on positive and negative qualities of care.	
Tashiro et al. (2013) *	Concept analysis of reflection in nursing professional development.
Wadensten et al. (2008) **	A cross-cultural comparison of nurses' ethical concerns.
Wagner and Bear (2009) *	Patient satisfaction with nursing care: a concept analysis within a nursing framework.
Xyrichis and Ream (2008) *	Teamwork: a concept analysis.

Following a review of the retrieved abstracts, the five papers that incorporated problematic aspects of care were analysed as the basis of this concept analysis.

Cline (2014) focused on the complex interplay of past experiences and biological processes occurring within the heterogeneous population of older adults who live with multiple age-related changes and chronic conditions. Whilst this knowledge can inform healthcare professionals and improve co-productive discussion and goals of care, it was implied that this knowledge was limited within the workforce.

Wadensten et al. (2008) studied ethical concerns of nurses in China and Sweden and found similar ethical concerns regarding conflicting views on the right course of treatment. The unique findings for Swedish nurses focus on life-sustaining treatments (initiation or withdrawal) which create moral conflict in practice. The Chinese nurses' unique claim is that the patient's financial situation decides the treatment level. The researchers found commonality around workplace distress involving high demands, lack of influence, lack of respect, emotional strain and managing distress. The quality of nursing features as a shared concern due to lack of resources although there was a general satisfaction with the quality. The authors conclude that the ethical conflicts described by nurses in various countries are global in nature. Arguably these ethical conflicts create circumstances that may lead to being perceived as or experienced as poor care.

Kim et al. (2015) explored patient safety. They present the attributes of patient safety as prevention of medical errors and avoidable adverse events, protection of patients from harm or injury, collaborative efforts by individual healthcare providers and a well-

integrated healthcare system. They recognise that the consequences of patient safety can result in positive or negative experiences for the patient depending on the 'occurrence' of or 'absence' of patient safety. The responsibility for poor care can lay with the individual delivering care, the system or a combination of both.

Suboptimal care of the acutely unwell ward patient is concerned with recognising and treating the deteriorating patient. Quirke et al. (2011) found that the antecedents covered four categories: patient complexity, healthcare workforce, education, and organisation. They report the defining attributes of suboptimal care as delays in diagnosis, treatment or referral, poor assessment, and inadequate or inappropriate patient management. The authors assert that suboptimal care, in the context of the acutely unwell ward patient, can result in preventable or avoidable deaths, intensive care unit admissions or cardiac arrests. Missed nursing care by definition equates to poor care. Kalisch et al. (2009) define missed nursing care as any aspect of required patient care that has been omitted (either in part or in whole) or delayed. The consequences of missed nursing care are threats to patient safety aligning with the conclusions of Kim et al. (2015) with regard to active and latent conditions. These five published concept analyses add to the understanding of aspects of poor care but do not define it.

To further explore the concept of poor care, and explore definitions a concept analysis was undertaken using Rodger's evolutionary cycle (Rodgers, 1989; Tofthagem and Fagerstrom, 2010). Rodgers (1989) explains that analysis of the common use of a concept enables it to be defined and consequently clarified. She describes a cycle of concept development that progresses through time with three distinctive influences: significance, use, and application. She challenges the philosophical foundations of the popular Wilsonian-derived methods of concept analysis as being reductionist derived from a positivist paradigm and so sought to value dynamism and interrelationships from within an interpretive paradigm.

Rodgers (1989) emphasises that a concept analysis intends to identify commonalities in the existing use of the concept; concepts generally being expressed in statements that indicate the attributes. Rodgers evolutionary cycle uses an inductive approach (Tofthagem and Fagerstrom, 2010; Weaver and Mitcham, 2008). It has seven phases which do not proceed in a linear fashion (1987 cited in Rodgers 1989) (figure 2).

FIGURE 2: RODGERS METHOD OF ANALYSIS

Rodgers (1989 p.333) method of analysis:

1. Identify and name the concept of interest
2. Identify surrogate terms and relevant uses of the concept
3. Identify and select an appropriate realm (sample) for data collection
4. Identify the attributes of the concept
5. Identify the references, antecedents and consequences of the concept, if possible
6. Identify concepts that related to the concept of interest
7. Identify model case of the concept

Whilst the phases of the analysis are delineated, the experience of engaging with these seven phases is iterative.

The concept of interest is poor care in a healthcare context, with care being understood as the delivery and or receipt of clinical and interpersonal attention as defined in section 1.4 of this thesis. The second phase requires the identification of surrogate terms and relevant uses of the concept. Common practice is to elicit dictionary definitions. The Oxford dictionary and thesaurus (2007) defines poor as an adjective with several meanings: not having enough money to live a comfortable or normal standard; of a low standard or quality; (poor in) lacking in or deserving pity or sympathy. In describing the adjective substandard, the dictionary uses the terms bad, deficient, defective, faulty, imperfect, inferior, unsatisfactory, second-rate, third-rate, shoddy, crude, inadequate, and lastly unacceptable. The Cambridge dictionary online (2015) defines poor as having little money and or few possessions, or to have very little of a particular substance of quality, not good in being of a very low quality, quantity or standard and finally deserving sympathy. Surrogate terms for poor (care) include suboptimal, just good enough (on the cusp), bad, wrong, unsatisfactory, substandard, ineffective, unsuccessful, unmet need, inappropriate, unacceptable, deficient, neglect, defective, faulty, imperfect, inferior or inadequate.

Poor practice tends to be considered in terms of poor performance and focuses on aspects of a practitioner's practice, performance, conduct or behaviour (National Clinical Assessment Service, 2015; NMC, 2015c; Stone et al., 2011). This needs careful

consideration alongside systems and processes which also may contribute to poor outcomes as a result of poor care.

The third phase involves identifying and selecting an appropriate realm (sample) for data collection. A systematic approach for searching the literature was undertaken. The surrogate terms identified in phase 2 were incorporated into a search strategy using the MESH term quality of healthcare and combined with patient(s) care in Medline via OVID, EMBASE and AMED databases. Limitations included abstracts, adults over 19 years of age as care responsibility for children tends to be directed at family and carers, and a timeframe of 2010 - 2017 aligned with the disclosure of several major failings in healthcare (appendix 1). The search was not limited to nursing as healthcare requires integration of multiple disciplines and agencies. The search identified 50 peer reviewed articles.

The abstracts were reviewed to determine the inclusion and exclusion of papers for further appraisal. Abstracts were initially read and considered against emergent exclusion criteria: evaluation of practice against condition specific standards, training, prognostication and opinion papers. Inclusion criteria involved the delivery and or receipt of clinical and interpersonal attention (patient care). Results were recorded within a spreadsheet. Sixteen papers were included. The process is depicted in figure 3.

FIGURE 3: LITERATURE INCLUSION AND EXCLUSION PROCESS

```
                    ┌─────────────────────┐
                    │  Records identified │
                    │  through database   │
                    │      search         │
                    └─────────────────────┘
              ┌───────────┼───────────┐
              ▼           ▼           ▼
    ┌──────────────┐ ┌──────────────┐ ┌──────────────┐
    │    AMED      │ │   EMBASE     │ │ Ovid MEDLINE │
    │  2010-2017   │ │  2010-2017   │ │  2010-2017   │
    │ 34 citations │ │ 19 citations │ │  2 citations │
    └──────────────┘ └──────────────┘ └──────────────┘
              └───────────┐ ┌───────────┘
                          ▼ ▼
                 ┌──────────────────┐
                 │ 50 non-duplicate │
                 │ citations screened│
                 └──────────────────┘
                          │
                          ▼
    ┌──────────────────────────────────┐      ┌────────────────────┐
    │ Inclusion/ exclusion criteria    │─────▶│ 32 articles excluded│
    │ applied                          │      │ after abstract screen│
    └──────────────────────────────────┘      └────────────────────┘
                          │
                          ▼
    ┌──────────────────────────────────┐      ┌────────────────────┐
    │ Full text articles retrieved     │─────▶│ Full text articles │
    │ (n = 18)                         │      │ excluded with reason│
    └──────────────────────────────────┘      │ (n = 2)            │
                          │                    └────────────────────┘
                          ▼
    ┌──────────────────────────────────┐
    │ Studies included in the literature│
    │ review                           │
    │ (n = 16)                         │
    └──────────────────────────────────┘
```

The fourth phase involves identifying the attributes of the concept. Papers were read and re-read in full. The reference, sample and size of empirical research or review, country of origin, and concepts studied relating to poor experiences were listed. Attributes are described as a cluster of situations or phenomena that make it possible to identify situations that can be categorised under the concept (Rodgers, 1989; Tofthagem and Fagerstrom, 2010). The derived situations or phenomena contained in the literature were themed and are presented as the following attributes: personal traits; interpersonal dynamics; endangered self; misconceptions; and organisational constraints (figure 4).

Attributes of poor care experience

Personal traits
- knowledge
- skill
- attitude

Interpersonal dynamics
- communication
- lack of role clarity
- hierarchies

Endangered self
- loss of control
- not being listened to
- non-individualised
- feeling humiliated/undervalued
- loss of connection
- discomfort

Misconceptions
- expectations
- values
- preferences
- awareness

Organisational constraints
- threats to continuity
- communication barriers between professionals and services
- lack of equipment
- lack of privacy due to environment
- access difficulties

These themes have been mapped against the sixteen retrieved papers that informed this concept analysis (table 4).

Table 4: retrieved papers (to inform concept analysis of poor care)

Reference	Country of origin	Sample or literature review	Title	Attributes				
				Personal traits	Interpersonal dynamics	Endangered self	Misconceptions	Organisational constraints
Chan, et al. (2011)	Singapore and Australia	literature review	Buddhist perspectives on end of life care and dying educational and literature review	☑	☑	☑	☑	☑
Couldrick et al. (2010)	UK	literature review	Sexual health for people with disability proposing a new model: the recognition model and literature review	☑	☑	☑	☑	☑
Gale (2015)	UK	case study (n = 1)	Assisting patients with motor neurone disease to make decisions about their care	☑	☑	☑	☑	
Griggs (2010)	UK	community nurses (n = 17)	Perceptions of a good death	☑	☑	☑	☑	☑

Reference	Country of origin	Sample or literature review	Title	Attributes				
				Personal traits	Interpersonal dynamics	Endangered self	Misconceptions	Organisational constraints
Hinkle et al. (2015)	USA	systematic review publications (n= 23)	Factors associated with family satisfaction with end-of-life care in the ICU		☑	☑	☑	
Lindahl et al. (2013)	Denmark	patients with fracture (n = 7) Occupational & Physiotherapists (n = 23)	Continuity of care in rehabilitation post fracture (to identify good quality)	☑	☑	☑	☑	☑
McKeown et al. (2010)	UK-Scotland	medical and nursing staff (n = 25)	Team perspectives of palliative care in intensive care unit	☑	☑	☑	☑	☑
Nguyen et al. (2013)	Canada	patients with COPD (n = 12)	Perceived Advanced Care Plan (ACP) needs of people with COPD at different illness severities (with DVD)	☑	☑	☑	☑	
Phillips (2012)	UK	literature review	Care for people with learning disabilities in hospital	☑	☑	☑	☑	☑
Schonfeld et al. (2012)	USA	Physicians (n = 32)	End of life conversations with patients and families- older people with multiple morbidities (physicians experiences)	☑	☑	☑	☑	☑
Slatten et al. (2010)	Norway	CNS post palliative care education (n = 122)	Clinical competence in palliative nursing in Norway	☑	☑	☑		☑
Stein and Kerwin (2010)	USA	literature review	Disability perspectives on healthcare planning and decision-making	☑	☑	☑	☑	☑
Sturmberg (2012)	Australia	literature review	The complexity of caring for people with chronic disease (muddling through)	☑	☑	☑	☑	☑
Swarbrick et al. (2011)	UK	patient single case study	When hospice is not a haven	☑	☑	☑	☑	☑
Upton et al. (2012)	UK	AHP's (n = 154)	Newly qualified allied health professionals (AHP) attitude, uptake and implementation of evidence-based practice	☑				
Watts (2012)	UK	literature review	End of life care pathways as a tool to promote and support good death	☑	☑	☑	☑	☑

All five attributes of the concept of poor care were found in eleven of the papers. Not all the clustered characteristics of the attributes featured in each study. The five papers that did not demonstrate each of the attributes are discussed. Hinkle et al.

(2015) undertook a systematic review of published research concerned with factors associated with family satisfaction with end-of-life care in the ICU. Communication, decision making and preparation were associated with either positive or negative satisfaction outcomes. Nguyen et al. (2013) interviewed patients aiming to explore the perceived advanced care planning needs of people with COPD, hence organisational constraints were not a consideration. Gale (2015) presented a case study of a lady with motor neurone disease who was unwilling to engage with professionally led discussions about advance care planning as she preferred 'living in the moment'. Slatten et al. (2010) collected information from palliative care clinical nurse specialists on self-assessed levels of competence using the Edmonton symptom assessment system (Bruera et al., 1991) which may have improved understanding and consistency. Upton et al. (2012) studied newly qualified Allied Health Professionals attitude, uptake and implementation of evidence-based practice (EBP). The report focused on training and self-reported attitudes and experienced towards EBP only.

Unsurprisingly, positive and negative attributes of the experience of care can be found alongside one another. A good care experience may include some negative attributes but the overall experience may have been perceived as good, likewise a poor care experience may include some positive attributes but the overall experience may have been perceived as poor. The papers tended to emphasise positive aspects of care or strategies to enhance quality or experience of care as a goal of professional practice

The fifth phase requires the identification of references, antecedents and consequences of the concept. The references of the concept clarify the range of events, situations of phenomena over which the application of the concept is considered to be appropriate (Rodgers, 1989). The concept of poor care is understood in the context of the delivery and or receipt of clinical and interpersonal attention, situated within the structure of healthcare services. The antecedents are vulnerability, accessing healthcare services and interaction with healthcare personnel. Vulnerable may also be understood as an 'adult at risk' of abuse or neglect. Arguably there is a continuum of vulnerability from low risk through to very high risk.

The consequences of poor care are multifaceted. For the individual, the consequences may be positioned along several continuums: omissions or actions leading to harm ranging from negligible through to catastrophic, or experiences ranging from

unacceptable through to excellent. There are consequences for the patient with harm being categorised in the NHS as negligible, minor, moderate, major, or catastrophic (National Patient Safety Agency, 2008). If a continuum is understood as a continuous sequence in which the elements next to each other are very similar, but the last and the first very different (Oxford dictionary and thesaurus, 2007), wilful neglect can be conceptualised at one end of the continuum with beneficial assistance at the other. Levels of harm can also be conceptualised a long a continuum with no or negligible harm at one end and catastrophic harm at the other end.

Poor care, neglect and abuse can also be hidden, unintentional and unrecognised by the individual, their carer or family, or the health or social care worker. Dependent on the aspects and the level of 'poor' care there can also be a range of consequences for the individual delivering the clinical and interpersonal attention. For example, in case law, convictions of ill-treatment and wilful neglect have been made where there is no evidence of enduring harm for the vulnerable adult (R v Heaney, 2011; R v Kenyon, 2013). Bearing in mind that the standard of proof in criminal cases is beyond a reasonable doubt (Strafford Kent law, 2017), whereas in clinical practice, mental capacity is proved on a balance of probability. This highlights some of the complexity in practice.

Concepts that are related to 'poor care' interest include: quality of healthcare, and standards of care measured against published practice guidelines, professionalism measured against professional standards, negligence, and individual personal expectations and standards leading to NHS concerns. These can take the form of isolated incidents of poor or unsatisfactory professional practice, through to ill treatment or gross misconduct at the other (DH, 2015a).

The seventh phase of Rodger's method (1989) involves identifying a model case. I have used an abridged version of the case study of Donald in "*when a hospice is not a haven*" (Swarbrick et al., 2011). The defining attributes of poor care are presented alongside Donald's experiences in table 5.

Donald's experiences	The defining attributes of poor care
"*I've lost count of the number of times that I have had to move to make way for somebody else on the Ward and what that entails you know, in terms of goods and chattels being stuffed in drawers and wheeled across corridors and so on and so forth. It's just intolerable*"[…]	organisational constraints
"*Well one of the reasons is that I'm surrounded by people who are dying […] Being surrounded by death. I'm not enjoying it, but in addition to that, but the hospital regimes. It's just absolutely finishing me off*" […]	endangered self
"*The nursing regime that is verging on the punitive in regard to patients […] Whatever is on their agenda takes preference over yours*"[…]	interpersonal dynamics
"*Now it is a very curious mixture of commitment and care, and professional service, but also, you know, a 'do as I say or else' attitude is very prevalent noticeably, er and it is sometimes thinly veiled in humorous comments*"[…]	endangered self
"*Some of the nurses have rasping, penetrating voices which they use constantly, and you've no escape from it, it's all around you as they make your bed or while you're having your meal*" […]	personal traits organisational constraints
"*The main thing is, strangely enough, that the younger generation doesn't catch on, older people like to have plenty of time to rest*" […]	misconceptions
"*Somehow I think the charities get a little bit carried away by themselves. We have I think, at least two, if not three teams of elderly ladies who constantly come round with <u>massive</u> jugs of water*"[…]	interpersonal dynamics
"*Although I say, would you mind giving me half a jug, because I can't lift a full jug, they never remember*"	endangered self
Donald in Swarbrick et al. (2011)	

4.9.1 THE CONCEPT OF POOR CARE

The concept analysis did not provide a definitive answer to a definition of 'poor care' despite there being a numerous reports detailing 'poor care' involving end-of-life care for vulnerable older adults. Poor care is an umbrella term covering the unsatisfactory standard of the delivery and or receipt of clinical and interpersonal attention. Poor

care includes the omission or commission of planned or unplanned activities as experienced as an unsatisfactory standard by the patient, staff including nurses and or family or carers. The good enough death has also been characterised by nurses' comfort or discomfort with events and interactions (McNamara, 2004), which may be associated with perceptions of just good enough or not good enough (poor) care.

In a prior published qualitative study (Kalisch, 2006) identifies nine elements of regularly missed nursing care within medical-surgical wards. These include: ambulation, turning, delayed or missed feeding, patient teaching, discharge planning, emotional support, hygiene, intake and output documentation and surveillance. In my view 'missed care' equates with poor care unless there is clinical justification to omit or delay an interventions e.g. not administering antihypertensive medication when a patient's blood pressure is low. Kalisch (2006) identifies seven themes relative to the reasons for missed care: too few staff, time required, poor use of existing staff resources, it's not my job syndrome, ineffective delegation, habit, and lastly denial used as a coping mechanism. Arguably this could translate to the wider multidisciplinary team. The CQC commissioned research designed to establish people's willingness to report concerns about the standard of care in the health and social care sector. This research found that being treated with respect is the most important factor for people in the provision of health and social care, whilst fairness is also important (ICM Government & Social Research team, 2013) these findings align with the feedback received from people with dementia (CQC, 2014). This exposes an important question concerning whether the professionals' assessment of poor care and the public or patients' perceptions of poor care related to lack of respect and fairness fully align? Arguably respect could be an attitude which guides actions and inaction, and as such is core to our displaying kind and compassionate gestures in general life and work.

The research findings outlined in OPC Wales (2012) report suggest that in Wales we do not yet have a workforce that is confident in making judgements about when to raise concerns. However these are the 'spectacular' concerns. The concept of poor care more routinely appears to involve 'subtacular' concerns particularly when considering older adults. In the context of dementia care the CQC (2014) describe the experience of poor care as arising from a failing to recognise and meet the needs of individuals.

Likewise Flynn (2015) noted that managers and staff had internalised negative stereotypes of vulnerable older adults, which ignored their subjective experience and relationships. This operationalises a lack of respect. Inspections do uncover omissions in assessment and actions which result in people in vulnerable circumstances receiving, or being at risk of receiving poor care (CQC, 2014; Flynn, 2015). Missed 'required' nursing care is by definition poor care and the Nurse Staffing Levels (Wales) Act 2016 requires that there will be sufficient nurses to allow the nurses time to care for patients sensitively which may help reduce the experiences of missed care. Perhaps more importantly sensitive care embodies respectful care, particularly as the crucial feature appears to be staff attitudes, particularly towards vulnerable older adults with frailty. There is potential that as well as individual attitudes and values, organisational values, for example the negative stereotypes that governed the poor standards of care observed in Operation Jasmine (Flynn, 2015), along with generalised low expectations can obscure omissions in assessment and care. This can lead to people who are in vulnerable circumstances, receiving or being at risk of receiving poor care. It is important to observe that non respectful care interventions can be omitted or commissioned acts. The Code (NMC, 2015a) encapsulates the nursing requirements to do what is necessary in order to prioritise people:

> "You put the interests of people using or needing nursing or midwifery services first. You make their care and safety your main concern and make sure that their dignity is preserved and their needs are recognised, assessed and responded to. You make sure that those receiving care are treated with respect, that their rights are upheld and that any discriminatory attitudes and behaviours towards those receiving care are challenged"

(NMC, 2015a: p.4)

This concept analysis found that the quality of the experience of care is defined by the attributes of personal traits, interpersonal dynamics, endangered self, misconceptions and organisational constraints. It is likely that these attributes will be relevant to patients and families experiences as well as nurses and other healthcare professionals. Concept maps can capture and archive expert knowledge in a form that is easy to understand and be used by others (Novak and Cañas, 2010). The findings of this analysis of the concept of poor care have been developed into a concept map using Cmap tools (2018) and is displayed in figure 5. In nursing 'The Code' should be used to

protect the public at large and perhaps should be interpreted more stringently when protecting some of society's most vulnerable people in our care. Poor care may be an umbrella term covering the unsatisfactory standard of the delivery and or receipt of clinical and interpersonal attention but for vulnerable older adults, sensitive respectful care is crucial.

What are the antecedents and consequences of poor care?

can be undertaken to

personal attention

poor standards → for vulnerable older adults → unsensitive disrespectful care

the antecedents of which are

vulnerability, accessing healthcare services, and interaction with healthcare personnel

which may involve

a single or repeated act

by commission or omission involving the attributes

personal traits

systems, processes and organisational constraints

endangered self

misconceptions

interpersonal dynamics

which can be
- hidden
- ignored
- acknowledged
- unrecognised

and categorised as
- suboptimal
- ineffective
- unsafe
- neglect
- abuse
- wilful neglect/ criminal

with consequences

For patients

for staff

who experience variable levels of harm
- catastrophic
- major
- moderate
- minor
- negligible

-ve experience/ perception/ outcome

poor care

addressed using
- reflective learning
- criminal investigation
- education and training
- safeguarding adults at risk
- formal performance objectives
- disciplinary procedures
- root cause analysis investigation

4.10 CONCLUSION

In chapter 3 it became apparent that the 'good enough death' may in fact 'not be good enough', particularly for older people with frailty who go on to require end-of-life care. There is a plethora of published literature and reports which detail poor care particularly in relation to vulnerable older adults. In addition this can be hidden, unrecognised and in cases of abuse or neglect, unreported aggravated by threshold ambiguities.

This concept analysis was undertaken to better help understand and recognise when the 'good enough' death becomes 'not good enough'. Recognition of this transition remains problematic as whilst abuse is more readily recognised than neglect, individual reporting thresholds have been identified as a particularly complex phenomenon. This concept analysis using Rodgers evolutionary methods (1989) has found that poor care can be attributed to personal traits, interpersonal dynamics, endangered self, misconceptions and organisational constraints. It is possible that any of these can lead to the experience of poor care including the attributes of the individual patient, nurse or organisational culture. An inherent difficulty in practice is access to the dying individuals' preferences, values and beliefs and their potential lack of a voice at end-of-life. It was noted that for nurses, the good enough death had been characterised by nurses' comfort with events and interactions surrounding the death. The important features in good enough end-of-life care appear to hinge on the delivery and or receipt of respectful, interpersonal attention, which situates the individual at the centre of their care, respecting their wishes and choices whilst recognising different things will be important to different people at different times during their end-of-life care.

CHAPTER 5 - COMFORT THEORY

5.1 INTRODUCTION

My initial interest of exploring the concept of a healthy death altered to a good, and subsequently good enough death. As the focus of this thesis is the RN's experiences of delivering end-of-life care I redirected my attention from health promotion theory towards nursing. The good enough death has also been described in terms of nurses' comfort with events and interactions surrounding individuals' dying and death (McNamara et al., 1995). Kocaba's theory of holistic comfort (1994) also emerged as a fit with my personal and professional expectations. As both the good enough death and comfort theory are associated with both nurses' and patients' comfort experiences, comfort theory appeared to be a relevant theoretical framework for discussing RN's experiences with regard to achieving a good enough death for vulnerable older adults requiring end-of-life care.

5.2 COMFORT THEORY

Comfort theory's etymological roots stem from the latin word *comfortare* meaning to strengthen (Kolcaba and Kolcaba, 1991). The fundamental assumptions of comfort theory are that human beings have holistic responses to complex stimuli, comfort is a desirable holistic outcome congruent with nursing, and that human beings strive to meet or to have met, their basic comfort needs (Kolcaba, 1994). The theory uses an intra-actional perspective in which the components of the whole person response are intra-related to emphasise the holistic person. The nurses' interventions can provide comfort when the person's own reserves to counteract the dis-comfort arising from the healthcare situation are depleted (Kolcaba, 1994). Association with the concepts of frailty and vulnerability are tangible.

It is reasonable to assume that comfort and the relief of discomfort may be the goal of nursing in end-of-life care. Kolcaba describes comfort bi-dimensionally (Kolcaba, 1991; 1994; Kolcaba and Kolcaba, 1991): the first dimension consists of three states or senses of comfort and the second dimension comprises of the four contexts in which comfort occurs. Comfort theory aims for a peaceful death as an outcome of end-of-life care. The peaceful death aligns with the good enough death recognising that comfort

theory aims to enable ease, relief, or transcendence across the physical, psychospiritual, environmental and social contexts of human experience. Comfort can be perceived as objective, subjective or supportive, regardless of how it's perceived it implies that negative tensions have been reduced. This felt congruent with the good enough death ethos.

Morse (1997) similarly proposed a theory of comfort. She defines it as "a state of well-being that may occur during any stage of the illness health continuum" (Morse, 1997: p.4). She perceives that comfort relates to both the nurses comfort with providing care as well as the patient's condition. This was developed into the concept of 'compathy' (Morse, 1997; Morse et al., 1998). Compathy or physical empathy involves physical responses experienced by caregivers. Morse et al. (1998) argue that compathetic responses may benefit care by enabling intuitive assessment and intervention but can also be harmful. Overwhelming compathetic responses may result in staff shielding themselves emotionally which can result in objectifying patients, which arguably can be described as 'not good enough' or 'poor' care.

Kolcaba presents comfort as a positive outcome of nursing care, framed in meeting the needs of the individual patient. In using the theory, Kolcaba perceives that an increase in total comfort leads to the reinforcement of habits and goals that have been successful, which then provide direction for future action. She refers to these as health seeking behaviours which she considers can promote comfort and in the case of dying people, promote a peaceful death. She attributes the concept of a peaceful death as a health seeking behaviour to the work of Schlotfeldt. Schlotfeldt's model involves coping and health seeking behaviours (1972). She maintains that nurses need to be proficient "in sustaining, supporting, comforting and helping persons during periods of infirmity, deprivation, disfigurement, changes in lifestyle, crises and periods of development and decline" (Schlotfeldt, 1972: p.246). An aspiration that remains relevant for the care of older adults particularly at end-of-life. Health seeking behaviours arguably align with salutogenesis, but in this theory they are firmly rooted in a nursing and comfort paradigm.

In operationalising the theory, Kolcaba juxtaposes comfort needs with the context of experience to provide a taxonomic structure (comfort grid). Relief is the state of having a specific comfort need met, ease is the state of calm or contentment and

transcendence is the state in which one can rise above problems or pain. Providing comfort is designed to enable strengthening. She describes comfort as a desirable outcome for nursing care because it facilitates gains in physical and psychological performance. Arguably a dying person requires psychological, physical (although depleted) and spiritual strength.

The comfort grid can be used to inform care planning; "the aspects of comfort are derived from cross referencing the desired sense of comfort to be achieved with the appropriate context of the comfort experience" (Kolcaba, 1991: p.240). Kolcaba uses an example of an oncology patient who is depressed but not in pain. This patient would need to be comforted in the transcendental sense and in the psychospiritual context. She states that use of the critical grid can help nurses who know their patients are not in the state of comfort but are finding difficulty in distinguishing the reason. She also offers a care plan template for comfort which specifically considers the comfort needs for patients and family across the four contexts. This incorporates the interventions the nurse will undertake, the intervening variables, the patient's (and family's) perspective of comfort, anticipation of what next and the desired health seeking behaviour comfort (Kolcaba, 1996).

Comfort theory and its conceptual framework is presented in a diagrammatic presentation below (figure 6).

FIGURE 6: CONCEPTUAL FRAMEWORK FOR COMFORT THEORY
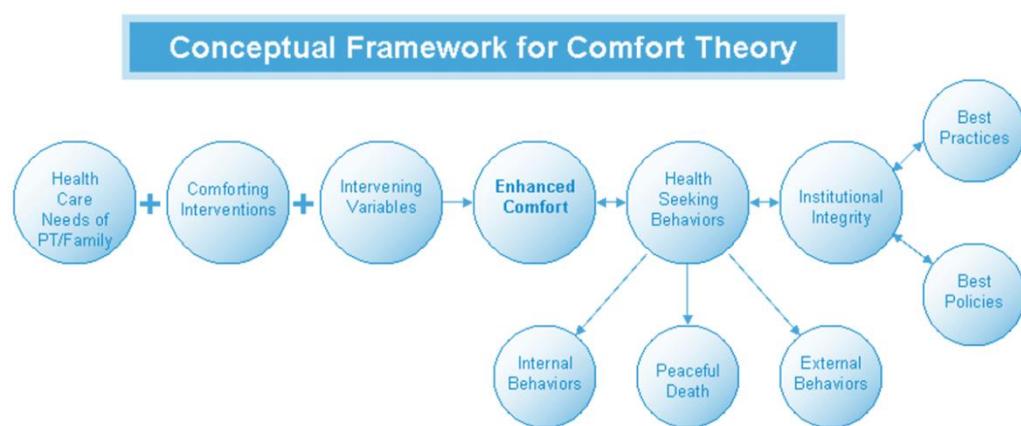
Available at comfortline: (Kolcaba, 2010b)

The NHS and increasingly nursing is the subject of much media attention which focuses on poor care. The underpinning philosophy of holistic comfort, assessment tools for practice and the potential development of instruments that measure comfort as an outcome is refreshingly positive. This aim is illustrated in an open letter to the American Nurses Association challenging measurement only of adverse events, albeit in the aim to reduce them.

> "it so much more reassuring to go to a hospital where the nursing staff is known to provide high degrees of comfort to their patients, rather than simply a staff that 'shows improvement' in the occurrence of adverse events"
>
> (Kolcaba, 2013: unpaginated)

The comfortline (Kolcaba, 2010b) hosts numerous comfort questionnaires developed for different specialities including end-of-life care in a bid to reduce the theory practice gap. It does include two nurses comfort questionnaires. The questionnaires are designed to be used to generate scores providing measurable nurse sensitive outcomes as performance indicators, or as research tools. Higher scores indicate higher comfort. This mid-range theory has been tested in practice with end-of-life care experiences of the patient (Vendlinski and Kolcaba, 1997), and the relative or carer (Novak et al., 2001), or assessed by the nurse using the Comfort Behaviors Checklist (Kolcaba, 2002). Comfort Theory has also been used in relation to nurses experiences generally (Kolcaba, 2010c) and in the context of end-of-life care and communication using the Advance Directives Comfort Questionnaire (Kolcaba, 2010a). In addition Novak et al. (2001) describe comfort as the goal of nursing in end-of-life care; as such it seemed to align with aims of this study.

5.3 CONCLUSION

It is reasonable to assume that comfort and the relief of discomfort may be the goal of nursing in end-of-life care. Comfort theory aspires towards a peaceful death in end-of-life care. The peaceful death may equate to the good enough death recognising that the theory aims to enable the ease, relief or transcendence across the physical, psychospiritual, environmental and social contexts of human experience. Comfort theory is presented as being useful in exploring nurses' comfort as well as patient and carers. I had anticipated that comfort would be an appropriate and useful nursing

theory that could be helpful in describing and understanding the RN's memorable experiences and perceptions of end-of-life care. However in practice it tended to illustrate the patient's described presentation of comfort needs and care as spoken by the RN's rather than the RN's experiences per se.

CHAPTER 6 - STRUCTURAL AND PROFESSIONAL INFLUENCES CONCERNING REGISTERED NURSES EXPERIENCES OF DELIVERING END-OF-LIFE CARE: SOCIAL CHANGES AND THE MEDICALISATION OF OLD AGE AND DYING

6.1 INTRODUCTION

There is a wealth of published literature concerning end-of-life care, death and dying from various perspectives. This research focuses on a fairly homogenous sample of RN's who work in different environments of care, delivering end-of-life care for vulnerable older adults with frailty. This chapter presents a review of the literature, to set the scene surrounding the external structural and professional factors that influence nurses experiences of delivering end-of-life care for this group of people. The review is intended to provide context and did not follow a traditional approach of a literature review. Following the data analysis in section 3, a systematic search of the literature in order to review the current state and development of knowledge of healthcare practitioners' experiences will be interwoven with the participants' experiences. There is an extant body of literature detailing social changes, the medicalisation of old age and dying, and trajectories of dying and death, but these are rarely considered together in the context of nursing older people at end-of-life. These themes are explored within this chapter.

6.2 SOCIAL CHANGES AND THE MEDICALISATION OF OLD AGE AND DYING

As presented in chapter 2, death, dying and other intimate living arrangements have become shrouded from day-to-day view but historically were usual (Kellehear, 2008). Ariès (1981) observes that as a society of 'individualism' we have constructed an 'invisible death'. This section explores the readily acknowledged demographic changes, social changes and the medicalisation of old age and dying.

Demographic changes illustrate that death in old age is a phenomenon of modernity. In contemporary society the majority of older adults die in an institution (ONS, 2015b). A shift of place of death to hospitals and care homes has been demonstrated (Ahmad and O'Mahoney, 2005), with the oldest of the old most likely to die in hospital. There are a number of other perceptions as to why there has been a change of place of death from home to hospital. One argument is that is as a society we have an emphasis on

institutional solutions to social problems (Howarth, 2007). Gawande (2015) also describes the rise of the nursing care home as an institutional solution to a social problem. His analogy suggests that there is a medicalisation of old age, particularly towards the end-of-life. Of concern he tenuously linked the conception of the nursing home with replacement of the poorhouse in the USA. This association between poorhouses and nursing care homes raises some uncomfortable issues.

Improvements in medical treatments and understanding of disease processes have added years to life, but the contribution of scientific medicine in reducing premature human mortality in the 19th-century UK does not have universal consensus. McKeown (1995) and Illich (1995) both conclude that historically medicine had a limited role in reducing premature mortality and morbidity, hence questioning the evidence base concerning the contribution of scientific medicine. McKeown (1995) argues that the main influences which reduced mortality and morbidity involved hygienic measures, nutrition and other social conditions along with a decline in the virulence of micro-organisms themselves. These hygienic measures are demonstrated in London's sewage disposal. The responsible engineer Joseph Bazalgette worked to three objectives: waste disposal, land drainage, and a safe water supply system (Cook, 2001) which successfully halted the cholera epidemic. Edwin Chadwick directly correlated poor living and working conditions with illness and disease, setting out the public health movement (Chadwick, 1842). Similarly Szreter (1995) agrees that medicine had a limited role. He argues that the reduced mortality was due to the success of public health measures, that is, appropriate social and political responses.

Closer to home Archie Cochrane is woven into the fabric of Cardiff University. His interest in evidence based practice stemmed in part from his experiences practicing as a medic in a German prisoner of war camp. Due to malnutrition, diarrhoea, typhoid, 'infectious jaundice' presumed to be a form of hepatitis, and other diseases, he expected hundreds of men to die without receiving appropriate, specific treatments. In fact the men recovered and only one disease related death occurred (Cochrane, 1989). He concludes that there was no real evidence that anything he offered had any effect. In essence his observations support the limited contribution of medicine.

Cochrane also concerned himself with the prospect that procedural interventions that he had performed may have caused individuals' unnecessary harm. In a similar but

different vein, Illich (1995) introduced the concept of pathogenic medicine and clinical iatrogenesis. Iatrogenesis can be understood as instances whereby a user of healthcare services (patient), experiences or suffers an adverse event as a result of healthcare activity or system. Illich's beliefs are framed as resulting from individual's loss of self-reliance as part of industrialisation. This perhaps explains why he also emphasises both social and cultural iatrogenesis. Social iatrogenesis alludes to the medicalisation of assessing fitness for work; in modernity the issuing of 'sick notes' and assessment for personal independence payment (Gov.UK, 2018b). But his texts also portray people with multi-morbidity as a consequence of improved medical treatments, who then require institutional care; an outcome of increased medicalisation. Illich argues that cultural iatrogenesis involves health professionals destroying "the potential of people to deal with their human weakness, vulnerability, and uniqueness in a personal and autonomous way" this is present, he argues in "the paralysis of healthy responses to suffering, impairment, and death" (p.241). He depicts the medicalisation of social aspects of life in terms of the erosion of people's autonomous resilience. Illich's underlying deep religious beliefs, and westernised industrialised institutional developments appear to be in contention. A healthy response to suffering, impairment and death could be argued as a devout response as in Ariès mid-19th-century account. Nevertheless Illich was sensitised to the risks of medicalisation becoming an institutional solution to a social problem.

Whilst scientific and medical progress has extended our lives, albeit with contested effectiveness, increasing medical technological advances have created new dilemmas. These advances are potentially capable of staving off death and adding 'extra life'. Illich (1995) rather coarsely refers to the "managed maintenance of life on high levels of sublethal illness" (p.241) reverberating with the contemporary complexity of advanced age and multi-morbidity. Houghton (2001) specifically considers the dilemma of 'switching off' mechanical equipment such as heart pumps, ventilators or discontinuing haemodialysis. I hold a particularly vivid memory which resonates with this.

Ariès (1981) proposes that in modernity, as a society we have constructed an 'invisible death' which has enhanced fear and developed into an 'untamed death'; perhaps fear of the unknown, or as Kellehear (2007) describes 'a shameful death'. Sequestration of death and of older adults care, particularly those with frailty as a concept is

compelling. Social changes and hiddenness have been observed in the gradual sequestration of death (Ariès, 1981; Kellehear, 2008) whereby physical contact with death has become remote from ordinary day-to-day experience (Fisher, 2009). This is in contrast to the common exposure of media coverage of deaths on radio, TV, books, films and the internet. Howarth (2007) argues that these 'media' deaths often contain little or no dying, for example death caused by a single bullet, and they tend to be impersonal (Fisher, 2009). Portrayals of deaths are 'othered' (Howarth, 2007); they are not deaths that people anticipate will happen to them. This view is echoed by Fisher (2009) who suggests that contemporary society maintains an illusion that death does not exist. He suggests that another way of hiding death is to segregate the elderly into institutions and hospitals where they will be out of sight. Komaromy (2009) reaffirmed this by observing that contemporary society places dying people in institutional settings away from the public gaze. Bailey et al. (2010) also found that people on the subtacular trajectory of end-of-life care were often segregated to less visible areas in the EU. Fisher (2009) develops this further by suggesting that within institutional settings the closer one is to death the more likely the individual is to be moved into a cubicle, generally only attended to by healthcare professionals. This could be symbolic of sequestration and hiding death within an institution or it could be the desire to provide privacy and maintain dignity. This is illustrated by Lawton (1998) who draws attention to the 'unbounded' body; the unwelcome escape of body fluids and unpleasant odours which at times she observes leads to sequestration within the institutional environment. Arguably this 'unbounded' body would be particularly difficult to care for in the home environment and in modern society would be considered undignified if not 'hidden'. Similarly Lawton (1998) asserts that sequestration is associated with the body and the processes taking place within it. Perhaps the rhetoric of invisibility and sequestration is linked to the medicalisation of the human body rather than dying per se.

Medicalisation can be insidious. Taylor (2006) found that professionals exhibit 'wariness of lurking conflicts' (p.1417) in considering risk in the care of older people. I will present the story of a gentleman with an advanced dementia residing in a nursing home as an exemplar of insidious medicalisation associated with poor care; his situation is not unique. This gentleman had a pre-existing history of falls, and had sustained a series of falls whilst in the care home; one fall resulted in a significant

injury. It was assessed that on the balance of probability he did not have the mental capacity to understand his risks with regards to mobilising, falls and risk of harm. Care home staff assessed that he required one-to-one supervision, 24 hours a day. He continued to walk (he always liked to walk). At times he became exhausted due to interrupted sleep and excessive walking. He disliked having 'a carer' with him and became prone to aggressive outbursts towards individual carers. Vividly he had verbally expressed "I would rather be dead". The care home continued to emphasise his safety above his quality of life. This was despite the expressed wishes of his family and assessment and advice from other health and social care professionals as part of a best interests decision (DCA, 2007). The medicalisation of this gentleman's care can be seen at several levels. Initially I only considered the custodial approach to the falls risk management but upon reflection the best interests decision was medicalised; compliant with law and incorporating his values, wishes and beliefs but led by health and social care professionals. 'We' have medicalised his life and will likely continue to medicalise his dying and death; a sobering reflection.

There is an extant body of work discussing dying trajectories which will be succinctly introduced in this section. The literature concerning the dying trajectory concept considers similarities and differences in individual's experiences as people approach death. In the 1960s Glaser and Strauss (1968) proposed three trajectories of dying. These include sudden death, which arguably reflects Kellehear's 'died where stood' age (2008), a steady decline and chronic illness. They observed that the dying trajectory of each person has a least two properties. Firstly, dying takes place over time and therefore has 'duration' which is variable, and secondly a trajectory has 'shape'. They argue that neither duration nor shape is an objective physical property but are perceived properties; the perceiver defines someone as dying, and develops expectations of how that dying will proceed. Trajectories of dying and death may also be considered retrospectively.

These perceived properties of duration and shape can be visualised as a graph; sudden death may relate to an accident, fatal heart attack or stroke, and can be visualised as a plunge straight down. The next simplified trajectory moves slowly but steadily downwards, as often experienced with cancer progression. A further simplified trajectory is that of chronic disease; the individual may have episodes of exacerbation

and crises associated with the condition which may be followed by some degree of recovery. However a crisis may lead to death. These three trajectories of dying are often referred to as sudden and unexpected, steady, or slow decline. Although older people may die along any of the three proposed trajectories, arguably the most common and complex trajectory experienced by older adults is that of chronic disease. More recently, trajectories of dying and decline have been expanded to include frailty (Murray et al., 2005; Royal College of Nursing, 2015). Figure 7 depicts a simplified illustration of the properties of levels of physical function, duration (time) and shape of contemporary dying trajectories.

FIGURE 7: CONTEMPORARY DYING TRAJECTORIES
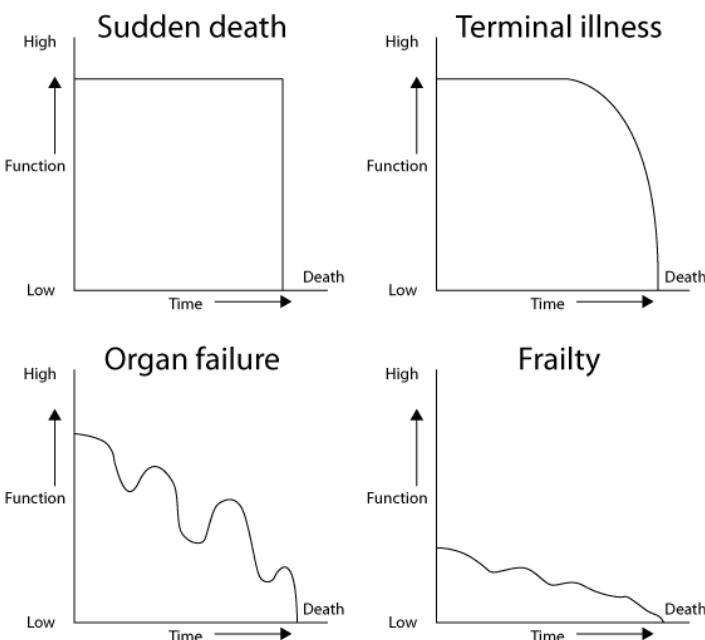
Royal College of Nursing (2015)

Many older peoples' deaths, although not all, are preceded by a period of frailty which can be considered part of the process leading to dying and death. That is, the dying process is in effect prolonged. A particularly vivid memory of mine involved an indirect patient care experience, but is derived from an internal review into aspects of the care and management of an individual patient. This particular patient had an implanted cardiac defibrillator (ICD). He had been treated for end-stage cardiac failure but was also suffering debilitating mental health problems. Despite interventions by geriatricians, cardiologists, old-age psychiatrists and specialist palliative care, his physical and mental distress was not readily alleviated. He transitioned into last days

of life and into unconsciousness. His ICD was deactivated following discussions between specialists and the expressed wishes of his family. He died about seven days later. Sadly the family were ill-prepared and were particularly distressed as they had anticipated ICD deactivation would be associated with immediate death. The prior and ensuing distress for the family was tangible from just the reading of his clinical notes. Nursing staff remained the constant conduit for contact, care and support. This clinical scenario demonstrates an aspect of the complexity of managing and delivering end-of-life care for people with treated multi-morbidity in contemporary healthcare services. There is also recognition that end-of-life care will involve more people with multi-morbidity and frailty (WG, 2017a). This group of people are less likely to follow a predictable dying trajectory and therefore present with a complexity which can be difficult to navigate.

Glaser and Strauss (1968) also considered lingering trajectories at home. They identified three salient features. The first being the desire of the family or the patient to shape the dying trajectory, the second involves relationships between the nurse and responsible carers and how together they handle care of the dying, and thirdly the importance of the mode of dying in determining whether the family can sustain care until the very end. Notably since this date there have been societal changes with an increase in institutional deaths reiterating the suggestion of a separation, a sequestration, apartheid of vulnerable older adults, particularly those nearing end-of-life. As such, Gawande (2015) highlights the medicalisation of old age particularly at end-of-life and the rise of the nursing home, predominantly occupied by older people with frailty. The majority of older people die in an institution in the UK; the oldest of the old are most likely to die in hospital (ONS, 2015b) and as 75% of people who die need palliative end-of-life care (WG, 2017b), the role and involvement of the nurse in any of these environments of care is self-evident.

6.3 CONCLUSION

This chapter has explored social changes, the medicalisation of old age and dying, and trajectories of death and dying. The arguments that highlight the medicalisation of old age and dying are compelling. Improvements in medical treatments and understanding of disease processes have added years to life, but the contribution of scientific medicine reducing premature human mortality in the 19th-century UK has been

contested. Demographic changes have illustrated that death in old age is a phenomenon of modernity, and additionally in contemporary society the majority of older people die in an institution with many requiring nursing care.

Sequestration of death as a concept is also compelling. There is the rise of the nursing home, predominantly occupied by older people with frailty. Social changes and hiddenness have been observed in the gradual sequestration of death whereby physical contact with death has become remote from ordinary day-to-day experience. Perhaps this underpins the view that contemporary society maintains an illusion that death does not exist. By placing dying people in institutional settings they are kept away from the public gaze, but in the full view of nursing and care staff. It has also been argued that sequestration is associated with the body and the processes taking place within it. This could be symbolic of two levels of sequestration; the hiding death within an institution and the further concealment within cubicles or less visible areas. The latter could also be motivated by a contemporary desire to provide privacy and maintain dignity. The rhetoric of invisibility could also be linked to the medicalisation of the human body rather than dying per se.

The themes of social change, the medicalisation of old age and dying, and trajectories of death and dying factors can be seen to shape the context of nursing practice. The role and involvement of the nurse in vulnerable older adults end-of-life care in all environments of care is self-evident. The suggested apartheid of vulnerable older adults with frailty, particularly those nearing end-of-life could possibly render a lowered perceived societal value of nurses working in these environments, a concept highlighted by Nolan and Tolson (2000). This further justifies the exploration of the experiences of RN's with regard to achieving a good enough death for vulnerable older adults with frailty.

6.4 CONCLUSION TO PART 1

Part 1 has introduced a focus on RN's experiences of delivering end-of-life care for vulnerable older adults with frailty. It has provided a justification for this study, presented key relevant definitions and the research question, aims and objectives.

It has set the scene by exploring the historical context of dying and death, end-of-life care policy, and introduced healthcare policy in Wales and the UK. Part of setting the

scene explored demographic changes and the concepts of vulnerability and frailty. The 'good enough', or 'not good enough' dying and death was also introduced, and given the widespread reportage of poor care the concept of poor care was also explored. As intended, comfort theory was also explored. The final chapter in part 1 continued to set the scene by exploring the structural influences of social change and the medicalisation of old age, death and dying that will have influenced the context within which RN's practice.

Part 2 of this thesis will discuss the research design, and a review of the choice of methods, procedures and decisions. Part 3 will present the data analysis and findings whilst part 4 will locate this thesis in the wider context.

PART 2

CHAPTER 7 - THE RESEARCH DESIGN-METHODS AND PROCEDURES

7.1 INTRODUCTION

Part 2 of this thesis presents the study design and outlines the various decisions that have needed consideration. It then provides an overview of the important underpinning theoretical concerns informing IPA before describing the research process involving ethical approval, data generation and the interview process.

7.2 THE RESEARCH DESIGN, METHODS AND PROCEDURES

Motivated by the aim of facilitating a good enough death for vulnerable older adults the central research question was developed and asks "what are the experiences of RN's with regard to achieving a good enough death for vulnerable older adults with frailty who require end-of-life care?"; the sub questions ask about the RN's experiences in delivering end-of-life care for older adults, and whether they have a shared understanding of the meaning of a good enough death. The research aims are to critically explore the RN's experiences, their understanding and meaning of the good enough death in practice with vulnerable older adults with frailty, and to make explicit similarities and differences with regard to their experiences. The research objectives are to identify and make explicit the determinants that facilitate or pose barriers to the delivery of the good enough death.

7.1.2 DESIGN AND METHODS

There are various options for the collection of data. These include questionnaires, written reflections, participant observation, or interviews with individuals or focus groups. Questionnaires could be structured and provide data which is qualitative, quantitative or a combination of both. The research question focuses on RN's experiences and understanding which may be difficult to effectively capture within a questionnaire. Qualitative research has been described as being "orientated towards analysing concrete cases in their temporal and local particularity" (Flick, 2009: p.21) which aligns with analysing particular experiences of delivering end-of-life care and recognises the particular context in which these experiences were developed. The intent is to explore the RN's experiences rather than to try to explain them. An

inductive method requires that the data is approached without a theoretically informed coding frame so that the themes that emerge are firmly grounded in the data (Willig, 2013). Using an iterative approach, which is an interplay between data generation and analysis, the researcher moves back and forth between data generation and analysis during the research process (Flick, 2017). The phenomenon of RN's experiences of delivering end-of-life care for vulnerable older adults with frailty appeared to fit with a qualitative, exploratory, inductive research design.

I considered the critical incident technique (CIT), which is a qualitative research method first described by Flanagan (1954) over 60 years ago. He described it as:

> "a set of procedures for collecting direct observations of human behavior in such a way as to facilitate their potential usefulness in solving practical problems"
>
> (Flanagan, 1954: p.237)

As the experiences of RN's were concerned with achieving a good enough death this also felt congruent with the research question and aims. In addition the CIT has been employed in research by a wide range of disciplines and is recognised as a useful method to examine issues pertinent to nursing (Byrne, 2001; Keatinge, 2002; Kemppainen, 2000; Norman et al., 1992; Schluter et al., 2008). It has been described as an effective exploratory, investigative tool (Butterfield et al., 2005; Chell, 2004; Woolsey, 1986), and has been developed from within an interpretative paradigm (Butterfield et al., 2005; Chell, 2004; Chell and Pittaway, 1998; Woolsey, 1986).

The CIT commonly elicits very effective or very ineffective practices (Byrne, 2001; Flanagan, 1954; Schluter et al., 2008). This is perceived as advantageous as it can ask participants to recall descriptions of real events, grounded in practice, rather than descriptions of how things should be (Bradbury-Jones and Tranter, 2008; Redfern and Norman, 1999). CIT has been described as "a qualitative interview procedure, which facilitates the investigation of significant occurrences (events, incidents, processes or issues), identified by the respondent, the way they are managed, and the outcomes in terms of perceived effects. The objective is to gain an understanding of the instance from the perspective of the individual" (Chell, 2004: p.48). As such, the CIT would likely offer insight and enhance understanding grounded in actual clinical practice associated with the good enough, or the not good enough death.

The term critical incident has been highlighted as problematic within healthcare (Schluter et al., 2008) as incident reporting focuses on unintended or unexpected incidents which could have or did lead to harm; this includes adverse events, actions and omissions. Schluter et al. (2008) suggests adopting the term 'significant event' to reduce the potential for confusion with clinical incident reporting, whereas Norman et al. (1992) propose the term 'critical happenings' which are identified by the participant as 'meaningful' and are important to meet the general aims of the study. After considering these issues I adopted the term 'memorable clinical case' to reduce potential confusion with reportable clinical incidents and to assist the participant to focus on experiences in clinical practice.

The use of open ended questionnaires or written reflections was considered but these approaches would reduce the opportunity to explore in-depth the RN's experiences. Interviews can be structured as in a survey, semi-structured or unstructured. Unstructured or semi-structured interviews are more likely provide the opportunity for interviewees to convey their experiences in their own way, where the interviewer can probe and follow up topics that arise that may be of interest. Face to face interviews also provide the opportunity for the interviewer to read non-verbal communication signs. Interviews can be undertaken with individuals or groups. Focus group interviews have a particular interest on the interaction between research participants (Kitzinger, 1994) whereas one-to-one interviews can provide a context rich, retrospective account of a memorable clinical case as perceived by the participant. For these reasons, individual face to face interviews is the preferred method of data generation in order to meet the aims of this study. The CIT is suitable for using a semi-structured approach for interviews, and has been described as providing the opportunity of undertaking an interactive interview whilst also enabling a focused approach (Norman et al., 1992). As the study aims are concerned with RNs understanding and experiences of the good enough death, a focused approach using semi-structured interviews is anticipated as being helpful in meeting the aims of this study.

Exploratory studies have been described as providing an in-depth exploration of a single process, variable, or concept (Banerjee et al., 2006) to gain familiarity with the phenomenon or to gain new ideas or insights into it (Kothari, 2004). Chell (2004) also suggested that CIT can be used with a phenomenological, an interpretivist or a

grounded theory approach. Similarly Interpretive Phenomenological Analysis (IPA) is a qualitative research approach that enables the examination of how people make sense of their major life experiences (Smith et al., 2009). Like CIT, IPA also provides a framework for the research process. As a novice researcher, a set of flexible procedures to aid the research and analysis process were felt to be advantageous. The next section will provide an overview of the important theoretical considerations that inform IPA and how it provides a better match for this thesis.

7.2 INTERPRETIVE PHENOMENOLOGICAL ANALYSIS

Interpretive phenomenological analysis (IPA) is a qualitative inquiry. It is recent in its development (Smith et al., 2009) founded in psychology but increasingly used in social and health sciences. It is influenced by the theoretical traditions of phenomenology, hermeneutics and idiography. IPA is interested in how people understand and make sense of their experiences (Larkin and Thompson, 2011) "in terms of their relatedness to, and their engagement with, those phenomena" (Larkin et al., 2006: p.109). The research aims to capture an account that is rich, detailed and reflective (Larkin and Thompson, 2011). Sense making draws upon interpretation grounded in the participants' accounts, to make visible what is normally hidden (Shinebourne, 2011), which enables the researcher to look for meanings embedded in human experience (Wagstaff et al., 2014). IPA seeks to understand people's experiences at a particular time, in a particular context.

IPA is a critical realist method (Shaw, 2010), adopting a critical realist form of social construction which accommodates "both the socially constructed nature of the world and its material reality" (Sullivan, 2010: p.29). This also resonates with my personal and professional values reflecting my ontological perspective and philosophical paradigm that 'the world' and knowledge are socially constructed and require contextual understanding. I also hold the view that the beliefs, rituals and knowledge surrounding death and dying are socially constructed whilst recognising that dying and death are obviously factual occurrences. Hence there is a fit between IPA and my values and understanding.

In IPA participants' accounts are viewed as a window into their inner state, whilst acknowledging that access to experience is imperfect, indirect, partial and complex.

IPA pursues 'experience close' (Smith et al., 2009; Smith, 2011), it is an empathic method that aims to understand experience from someone else's, the participants' experiences (Shaw, 2010), to understand what it is like "to stand in the shoes" of others (Pietkiewicz and Smith, 2014: p.8) whilst recognising that this is not truly possible. IPA is not without its critics with a number of publications evidencing this (Giorgi, 2011; Paley, 2016; van Manen, 2017; Smith, 2018). This contemporary diversity and disagreement is reflected within Bakewell's (2016) descriptions of phenomenology's historical developments; these are steeped in diversity and disagreement. This challenge seemingly stems from phenomenology being both a philosophy and a method.

Method wise respondents were asked to tell their stories of a memorable clinical case; something that matters to them. Using an IPA lens to facilitate data analysis appeared to fit with the data generation method and the aims of the study. IPA is suitable for, and aligns with nursing values. Pringle et al. (2011) stated:

> "It is an approach that emphasises the importance of individual accounts, so has much in common with nurses' desire to offer holistic care. Just as nursing seeks to deliver care that is evidence-based, the findings of IPA studies are firmly rooted in the 'evidence' of the words of participants"

> (Pringle et al., 2011: p.24)

The following section will present an overview of the theoretical foundations of IPA.

7.2.1 PHENOMENOLOGY

As stated above, phenomenology is both a philosophy and method. It is the study of 'being' (Larkin and Thompson, 2011). Phenomenology studies conscious experience as experienced from the subjective or first person point of view (Smith, 2013). Smith et al. (2009) explain that we take for granted our experiences of the world but once we stop to self-consciously reflect, that is on seeing, thinking, remembering or wishing "we are being phenomenological" (p.13). There are different traditions in phenomenology and various methods applied within these traditions. Historically there are two major phenomenological traditions; descriptive emanating from the philosophical traditions of Edmund Husserl and interpretive from the philosophical traditions of Martin Heidegger (Reiners, 2012).

Husserl's phenomenology is a 'descriptive enterprise', which aims at gaining clarification rather than explanation. Descriptive phenomenology aims to identify structure "the essential components of phenomena or experiences which makes them unique or distinguishable from others" (Pietkiewicz and Smith, 2014: p.8). It has historically relied upon phenomenological or eidetic reduction in attempting to be freed from presupposition and preconceptions. This requires the analyst to practice a number of techniques involving 'bracketing' or 'bridling' their preconceptions, and using 'free imaginative variation' to consider different possible instances of the phenomena in order to determine the essential constituents of the experience. Bracketing has also been associated with objectivity stemming from a positivist paradigm (Dowling, 2004), understood to have been derived from the field of mathematics.

The other major phenomenological tradition is hermeneutics or interpretive phenomenology. This aims to interpret phenomena to uncover hidden meanings. Heidegger's perspective features worldliness; human existence involves being-in-the-world. The German word Dasein can be understood fundamentally as being, particularly being-in-the-world. Being-in-the-world integrates the interaction of the individual self with things. As such, Dasein cannot be separated from the world, and the world cannot be separated from Dasein (Delancey, 2006). As Larkin et al. state (2006) we are "always somewhere, always located and always amidst and involved with some kind of meaningful context" (p.106).

The work of Merleau-Ponty, particularly around embodiment has also influenced IPA. Embodiment, living, sensing and understanding the world through our body shapes our knowing about the world; "the body not only connects us to the world, but also offers us the way to be in that world and to understand it" (Finlay, 2011: p.55). This is explored further in the lifeworld.

7.2.2 LIFEWORLD

The lifeworld helps us to understand our lived world. It embodies the "intentional relationship between conscious, meaning-making human subjects and the external taken-for-granted, meaning-giving world" (Finlay 2011: p.125). Ashworth (2003) refers to seven fragments of the lifeworld: selfhood, sociality, embodiment, temporality, spatiality, project and discourse. Temporality asks how one's sense of time, biography

or duration is affected. Bakewell (2016) asserts that we are temporal beings by our very nature. She explains that Heidegger's 'authentic existence' means accepting that we are finite and mortal; we will die. She explains that this realisation is what Heidegger calls authentic, 'Being-towards-Death' (Bakewell, 2016: p.88).

In Ashworth's (2003) lifeworld selfhood is part of sociality and refers to understanding what the situation means for one's sense of self, one's identity and agency and how this affects relations with others, whereas project considers how the things which are central to one's life are affected. Spatiality considers the understanding of place and space. Embodiment relates to feelings about one's own body including emotions, and discourse relates to the sort of terms used to describe and understand the situation. Ashworth (2003) warns that these fragments of the lifeworld are heuristic, they are "perspectives or analytical moments of a larger whole which is the situated embodiment of the human individual" (p.151). We are persons in context, in a "shared, overlapping and relational" existence (Smith et al., 2009: p.17). Participants are embodied, meaning-making beings, who are always-already immersed in a linguistic, cultural and physical world. Their experiences are interpreted in the context of ongoing personal and social relationships, of which the researcher forms a part. The relational context can be expanded further and Finlay (2009) explains that data is co-created out of the researcher and participant relationship. This recognises the role the researcher plays in generating the data, the analysis and 'meaning making'. In IPA the research process and outcomes are co-produced.

7.2.3 HERMENEUTICS

Hermeneutics can be described as the art of interpretation. Its history lies with the interpretation of biblical and other historical texts (Smith et al., 2009) and is now embedded in many schools of qualitative research. More generally Kinsella (2006) argues that hermeneutic thought informs qualitative research as it emphasises understanding and interpretation, rather than explanation and verification. She also explains that hermeneutics acknowledges the situated location of interpretation, "a view from somewhere" (Kinsella, 2006: unpaginated) and recognises the role of language and historicity in interpretation. Historicity assumes that all efforts to understand take place within some background for example historical traditions, web of belief or practice. History (or tradition) is not something external to us, objective or

past but is integral to our efforts to achieve understanding (Schwandt, 2015). Quite simply, we do not exist in a vacuum.

IPA attends to the hermeneutic circle which is concerned with the dynamic relationship between the part and the whole. The hermeneutic circle requires that "to understand any given part, you look to the whole; to understand the whole, you look to the parts" (Smith et al., 2009: p.28). Analysis requires the dismantling of the experience in several ways in order to make sense of and rebuild the experience. The part and the whole can describe a number of relationships.

FIGURE 8: THE RELATIONSHIPS BETWEEN THE PART AND THE WHOLE

The part	The whole
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete oeuvre
The interview	The research project
The single episode	The complete life

Reproduced from Smith et al. (2009: p.28)

The process of engaging the part and the whole is iterative, a method to develop understanding. Understanding the part and the whole are interdependent activities. As Schwandt (2015) explains, to understand the meaning in first the few lines of a poem, one needs to have a grasp of the meaning of the overall poem.

Ontologically the hermeneutic circle presents interpretation as "ubiquitous and inescapable" (Schwandt, 2015: unpaginated) when striving to gain understanding. Hence the inevitability of interpretation (Eatough, 2015). IPA encourages participants to describe and reflect on their experiences. They are interpreting, making sense of their experiences and the researcher is also carrying out an interpretive activity in trying to make sense of what the participants tell the researcher. This is known as the double hermeneutic (Shaw, 2010; Smith et al., 2009). The researcher only has access to the participants experience through what the participant says. The researcher is also seeing this through their own experientially informed lens (Smith et al., 2009). Eatough (2015) emphasises that whilst we cannot escape interpretation, we can reflect upon

our role in producing them, and we can maintain a commitment to ground them always in our participants' claims and concerns. This is a requirement of IPA.

7.2.4 IDIOGRAPHY

Idiography is concerned with a focus on the particular. The idiographic sensibility of IPA is revealed in researchers' commitment to understanding experiential phenomena from the perspective of particular individuals in particular contexts. It is also shown by the depth and detail of the micro-level analysis (Finlay, 2011). IPA does provide analytical procedures that enable the movement from single cases to more general statements but remains traceable to the particular claims of any of the individuals involved. This tension between idiography and shared meaning is different to a nomothetic approach which aims to generalise. The phenomenological view of experience incorporates both a uniquely embodied, situated experience, but it is also a worldly and relational phenomenon (Smith et al., 2009). IPA "is concerned with the micro analysis of individual experience with the texture and nuance arising from the detailed exploration and presentation of actual slices of human life" (Smith et al., 2009: p.202). From a nursing perspective, the participants' individual experience aligns with clinical practice in that the emphasis is on the individual patient, recognising that patients and carers may have shared health related conditions and experiences.

7.2.5 CONCLUSION

IPA is a relatively new approach to qualitative inquiry. Phenomenology, hermeneutics and idiography are not unique to IPA, but the way in which they have been combined and the specific emphasis and techniques used within the method identify IPA as an affiliated but distinct approach in the field of phenomenological inquiry (Cassidy et al., 2011). IPA originated from psychology but it is increasingly being used within health sciences and is appropriate to nursing. It enables the researcher to "understand and 'give voice' to the concerns" of these RN's involved in delivering end-of-life care and "to contextualize and 'make sense' of these claims and concerns" (Larkin et al., 2006: p.102). It also aligns to clinical practice whereby interactions with the individual patient or carer is initially taken at face value, but meaning is sought by listening to what and how things are communicated, and subsequently 'making sense' of what the individual 'means'.

IPA provides an integrative approach to the two arguably polarised traditions of descriptive and interpretive phenomenology. It recognises the inescapability of interpretation and does not rely on eidetic reduction in an attempt to be freed from presupposition or preconceptions. IPA recognises participants as embodied, meaning-making beings, who are always-already immersed in a linguistic, cultural and physical world. These were particularly important concepts for me as a researcher and nurse as I was unable to conceive how I could 'bracket' 30 years of life and professional experience. IPA adopts a critical realist form of social construction which fits with my personal ontological perspective and is compatible with my view that the beliefs, rituals and knowledge surrounding death and dying are socially constructed whilst recognising that dying and death are factual occurrences. Lastly IPA's idiographic focus enables a more personal exploration of each RN's perspective. It supports understanding and communication of the experiences of my participants. The research question also asked whether the RN's have a shared understanding of the meaning of a good enough death. IPA involves a detailed analysis of each case followed by the search for patterns across cases (Smith, 2011) but the focused use of idiography locates these patterns in the particular. The use of IPA can be seen to be a good fit to facilitate exploration, and assist in answering the research questions at the core of this thesis.

7.3 ETHICAL APPROVAL

The next section provides an account of the specific research governance and ethical review processes within which this study was undertaken.

Initially the research proposal involved recruiting members of staff from within my local University Health Board (UHB). The proposal was submitted to the Cardiff University School of Nursing and Midwifery Studies (SONMS) for scientific and ethical screening. It was then, following some clarifications, awarded a favourable science review by the Cardiff and Vale Research review services (CaRRS, appendix 2). Subsequently the proposal was submitted to SONMS research ethics committee (REC) where it received ethical approval with conditions (appendix 3). One of the conditions included consideration of the concept of the 'good' rather than 'healthy' death. Another was in reference to the recruitment of (junior) colleagues from within my own NHS organisation. The REC proposed that an option would be to generate data from

within a different NHS organisation than the one I worked in. With support from my supervisors we explored options and the potential for accessing post registration nurse students was considered. In principle this was supported by SONMS REC. A covering letter provided additional clarifications and justification (appendix 4) and the research proposal was revised and re-submitted to SONMS. Ethical approval was subsequently granted (appendix 5).

7.4 DATA GENERATION

7.4.1 INTRODUCTION

IPA embraces an idiographic, phenomenological and empathetic interpretative approach to data analysis (Larkin et al., 2006). IPA interviews seek to gain rich data. In relation to this thesis, interviews can provide a context rich, retrospective account of a memorable clinical case as perceived by the participant. This provided the participants with the opportunity "to tell their own stories" (Smith et al., 2009: p.57). IPA's use of the double hermeneutic circle requires that the participants make sense their experience before the researcher can make sense of their sense making. Shaw (2018) emphasises that in IPA data is not collected but it is generated during the interaction between the participant the interviewer. IPA requires in-depth interviews in order for the data to be suitable for analysis.

Smith et al. (2009) emphasise this in stating:

> "a good interview is essential to IPA analysis. Unless one has engaged deeply with participants and their concerns, unless one has listened attentively and probed in order to learn more about their lifeworld, then the data will be too thin for analysis"

(Smith et al., 2009: p.58)

7.4.2 RECRUITING PARTICIPANTS

Following confirmation of ethical approval (appendix 5), I was granted permission to introduce myself and my research proposal to newly enrolled post registration students who were undertaking a palliative care module. People were provided with a participant information sheet (appendix 6) with an open invitation to contact myself for further information. I was able to talk about my research in a face-to-face setting. At the end of this first meeting, six people provided contact details as potential

participants; five subsequently provided written consent and participated. I was also granted permission to approach the next cohort of students where a further six people provided contact details and two subsequently participated.

In IPA we are aiming to produce an analysis about 'these' people who will share 'this' relationship to 'this' phenomena in 'this' context. Purposive sampling finds a more closely defined group for whom the research question will be significant (Smith and Osborn, 2008) therefore IPA studies are conducted on a relatively small sample size with a reasonably homogenous sample. This homogeneity also helps to facilitate the examination of patterns of convergence and divergence between participants experiences based upon a detailed account of individual experiences (Smith et al., 2009; Smith and Osborn, 2008). The original proposal suggested a sample size of ten participants. Smith et al. (2009) suggest that the number of interviews undertaken as part of a doctoral study range between four and ten. The self-selected, non-probability purposeful sample of seven RN's is therefore appropriate for an IPA study.

7.4.3 INTERVIEWS

Individual face-to-face interviews were undertaken with the participants. Private interview space was made available in the University building where I had initially met potential participants. Four participants elected to be interviewed at the University, two in their place of work and one in their own home. The University was the noisiest environment with students mulling around the corridors. There were two transient interruptions in both of the participants' work places, neither of which appeared to faze the participants. The participant who chose to be interviewed in her own home with her dog present, likely put her at ease. I was made very welcome, but being in her personal space initially felt slightly intrusive for me as a researcher.

7.4.4 THE INTERVIEW PROCESS

The seven female RN's who agreed to participate in the research were enrolled on a palliative care module and were all employed as RN's within various environments of care within South Wales. Each participant was allocated a pseudonym to preserve their anonymity and any individual or place named during the interview was also given a pseudonym.

Participants were invited to tell 'their' story and were asked to focus on a memorable clinical case(s) involving the dying and death of an older vulnerable adult. This approach was designed to elicit their experiences grounded in clinical practice. It focused on the person-in-context and their relatedness to the 'phenomena at hand' which is their experience of delivering memorable end-of-life care (Larkin et al., 2006). They were also asked more generally about the concept of a good death.

The decision had been taken to use minimally structured interviews. Smith and Osborn (2008) emphasise the advantages of the semi-structured interview in IPA. These advantages involve facilitating rapport and empathy, and provide a greater flexibility of topic coverage allowing the interview to go into different areas. This inductive approach using open-ended questions sought to gain rich and detailed descriptions of the phenomenon being studied. The interview attempted to elicit and explore the RN's experiences of delivering end-of-life care, with a desired focus on the care of vulnerable older adults with frailty.

The participants were greeted and thanked for their participation, whilst this is arguably general politeness, it also helped develop a rapport which was built on the initial meeting and subsequent contact to arrange and confirm the interviews. The interview and consent process was talked through verbally and then the participant was asked to sign the written consent form (appendix 7). With consent, the interviews were digitally recorded to be subsequently transcribed verbatim. Participants were also provided with a copy of the signed consent form. The interviews were undertaken between October 2013 and May 2014.

7.4.5 THE INTERVIEW SCHEDULE

Developing a schedule in preparation for the interview also necessitated that I explicitly thought about what I hoped the interview might cover and the prompts and probes that might help to answer the research question and to meet the aims and objectives outlined in section 1.5 of this thesis. Smith and Osborn (2008) explained that this encourages the researcher to consider difficulties that might be encountered, for example question wording or sensitive areas, and to give some thought to how these difficulties might be handled. I found this beneficial as part of the preparation for the interviews. As suggested by Smith et al. (2009) I undertook a 'practice run' with a family member on a number of occasions and recorded a mock interview which also

helped develop confidence with the recording equipment. This preparation and practice helped me as the researcher to better concentrate on what the respondent was actually saying during the interview.

The interview began with an introductory question which intended to put the participant at ease. This was followed by focussing the interview topic by asking "When I spoke with you previously I asked you to think about a memorable clinical case, involving end-of-life care of a frail older person. Have you been able to identify a memorable case study?"

Table 6 below outlines the suggested interview questions from within the interview schedule (appendix 8) which were used as a guide for the interviews.

TABLE 6: SUGGESTED INTERVIEW QUESTIONS

<div style="border:1px solid black; padding:10px;">

Questions taken from interview schedule (appendix 8)

Greyed out text was not used.

- Can you tell me a bit about your role and how long you have been working with older people?
- When I spoke with you previously I asked you to think about a memorable clinical case, involving end-of-life care of a frail older person. Have you been able to identify a memorable case study?
- Would you tell me about this memorable case?
- For [this memorable case]
    - What do you feel went well?
    - What went not so well?
- Do you feel overall that [memorable clinical case] received good, bad or unremarkable end-of-life [care]?
- How would you describe [memorable clinical case] death?
- Can you tell me what you consider is a good death?
- Can you tell me what you consider is good end-of-life care dying?
- Can you tell me what you consider is a bad death?
- Can you tell me what you consider is bad end-of-life care dying?
- I'd like to ask you to think about an 'ideal world'- in which we could have/ ensure a 'perfect death' – what would that look like?
- What do you think 'we' could do that would/could make this happen?

</div>

- Is there anything else you would like to tell me about that I haven't asked or that you have not had the opportunity to say?

The questions became potential prompts rather than questions per se. When I felt the interview was coming to a natural close, I then asked the individual participants if they minded if I checked my schedule to see if there was anything in particular the interview had not covered. I did not ask about the 'perfect death' as I had intended, instead I asked a variant of "is good dying the same as good death or is it different?" This was asked in the context of the stories the participants had told me, which I felt was more appropriate.

7.4.6 RESEARCHER INVOLVEMENT

IPA relies on the double hermeneutic, that is the researcher is trying to make sense of the participant trying to make sense of their world (Smith and Osborn, 2008). Being a RN and interviewing RN's potentially provides opportunities and constraints. Clancy (2013) proposed that the main problem for nurse researchers' is 'role confusion'. This was highlighted as a concern in the ethical scrutiny processes and is considered in chapter 13 as part of reflexivity.

7.4.7 PRACTICALITIES

The interviews were recorded using an MP3 digital recorder. Audio recording is recognised as a prerequisite for IPA interviewing (Smith and Osborn, 2008). The recorded interviews were directly downloaded to a password protected computer hard drive for listening and verbatim transcribing. Field or reflective notes were made immediately after each interview and added to during the transcription process. The interviews were recorded and transcribed in sequence. They were transcribed by listening to short segments which were dictated into a Microsoft Word document using Dragon NaturallySpeaking11.5 software. The interviews were undertaken between October 2013 and May 2014. The length of the interviews ranged from 34.31 minutes (1st interview) to 67 minutes (7th interview) with the intervening five interviews being between 38.5 and 41.5 minutes in length.

7.5 CONCLUSION

IPA requires that the interview includes sufficient depth of description and narration, particularly in terms of experiential, embodied, sensory or emotional content. This depth involved the participants' articulation of their beliefs, understanding reasoning and interpretation. That is the explicit meaning making of the participant. In practice, the minimally-structured interview approach helped to focus the interview on the phenomenon of the RN's experiences of delivering end-of-life care in order to explore and achieve the good enough death with a particular focus on the care of older people with frailty. However a definition of 'frail older people' was not specified which may have created a mismatch between my expectations and those of my participants.

Part 3 will engage with the processes for data management and analysis and presents the findings of this research study.

CHAPTER 8 - DATA MANAGEMENT AND ANALYSIS

8.1 INTRODUCTION

This section of this thesis describes the processes for data management and analysis and will present the findings. The participants', who are RN's, provided the data in the telling of their stories. In IPA the first aim is to try to understand the participants' world, and to describe 'what it is like' by producing a coherent, third-person account, which tries to get as close as possible to the participants' experience (Larkin et al., 2006). This chapter presents the descriptive analysis process along with the findings of the RN's case by case idiographic descriptive analysis. This analysis is enriched in chapter 9 with a further layer of understanding derived from exploring the language the RN's used, specifically linguistic devices such as metaphor, analogy, simile, binary opposites and symbolism. In chapter 10 the analysis will carefully proceed looking for patterns of convergence and divergence in the RN's experiences and meaning making and will present the RN's shared experiences. Finally chapter 11 will integrate the findings of a systematic search of the literature with the RN's experiences.

8.2 DESCRIPTIVE ANALYSIS THE PROCESS

The first aim of IPA is to produce a coherent description which tries to get as close to the participants views, claims and concerns as is possible, whilst recognising that being a 'person in context' we cannot escape preconceptions (Larkin et al 2006). Smith et al. (2009) explain that analysis aims to interpret the meaning of the content of the participants' accounts and does not require an overly detailed approach to transcription. I modified Silverman's (2006) simplified transcription symbols to provide a framework transcription (figure 9).

[	Left brackets indicate the point which the current speaker's talk is overlapped by another's talk
(.)	A dot in parentheses indicates a tiny pause
(..)	short untimed pause
(....)	long untimed pause
--	false start/sharp cut off
_____	Under scoring indicate some form of stress, by a pitch and or amplitude
(.hh)	a row of h's prefixed by a dot indicates an in breath, without a dot (hh) an outbreath The length of the row of h's indicate the length of the inbreath or outbreath
( )	empty parentheses indicate the transcriber's inability to hear what was said
(( ))	double parentheses contain author's descriptions rather than transcriptions
~	pseudonym
°°	whisper or very quietly spoken
><	faster, condensed speech

Adapted from Silverman (2006).

After listening to the interviews to gain an overview I undertook verbatim transcriptions of the individual interviews. The transcriptions were undertaken in the order the interviews were carried out. Each participant was provided with a pseudonym allocated in the alphabetical order the interviews were undertaken beginning with A through to G. Any individual or place named during the interview was also given a pseudonym.

The text of each transcript was converted into a table, double spaced and separated by paragraphs which were numbered. These numbers were used to identify sections within the transcripts which enabled me to easily revisit the RN's words to check the context of emerging claims and concerns. Intermittent timings taken from the recordings were also inserted into the transcripts which facilitated easy access to

sections of the recordings for focused re-listening purposes. Additional columns were inserted left and right of the original transcript for annotating. The transcripts and annotations were subsequently printed which enabled me to work with hard copies of the interview transcripts. I subsequently used Microsoft Word documents containing the individuals' interview transcripts which were set up with individual line numbers to label the participants' spoken experiences for quotation purposes. An extract is shown in figure 10.

FIGURE 10: AN EXTRACT OF A TRANSCRIPT WITH LINE NUMBERS (ALICE)

	Alice
103	and I could sort of (.) I could understand his reasoning for thinking he didn't want that
104	tube (..) the NG tube ((participant remained tearful)) and think oh God you know I've
105	gone through enough I don't want to prolong my life now. What for? To just die anyway
106	in a couple of weeks (.hh) (….).Um ((tearfulness stopped)) (..)
107	he had (..) two daughters in their sort of thirties somewhere around there I would say ()
108	um both of them (..) had children (…) um and they were just (.) they were just lovely.
109	They were (.) they were so level headed they were just obviously (.) you know devoted
110	to their father ((participant tearful)). They wanted just to support him in whatever he
111	decided ((sniff)).
112	(…..) um (…..) what's my point (.) I think yeah, I think so (.) I think for me that may be
113	that's why because it (..) ((participant tearful)) to see to see the outcome of that when
114	he came in and I could really empathise with the fact that he didn't want to go on and
115	what was the point? (…) To him then—
116	and I did explain to him that it was (..) I felt like he was being sort of (.) roller-coastered
117	(.) into making the decision to have the NG tube fitted
118	D right
119	ALICE So I felt like it was my responsibility (.) to explain to him look you don't have to
120	(.) you can't ask for treatment but you can say no (.) if you want to do that you can say
121	no.(.hh) ((sniff)) and then I think he had a chat with our doctors who (…) um (..) who
122	kind of (..) talked about the fact that it may just--not to prolong his life but it could help

I undertook a case-by-case idiographic approach to analysis. I re-read the first transcript in tandem with re-listening to the digital audio recording of the interview. Close line-by-line analysis was commenced, the transcript was annotated initially by hand and then word processed which facilitated some refinement of hand written notes. An extract of an annotated transcript is shown in figure 11.

	22. D right	
Cure versus care • wanted to treat • wanted to do this • Wanted do that • saw our interventions as giving up • comfort versus discomfort • two different stances but together • different visions, goals and processes	23. P 2 so that (.) that just always sticks with me. Just everything about it was done badly. But I do remember that one particular doctor (..) being (.) so (..) I guess he didn't think he was being negative I think he thought he wanted to treat (.) he wanted to do this (.) he wanted to do that. Why put her on a syringe driver. I guess he saw our interventions as (..) giving up.	Sticks everything done badly want to treat negative
	24. D right	
	25. P 2 but I think as nursing staff we recognised that this lady was deteriorating and that we should be making her comfortable (...) and what he was doing was not making her comfortable and you know it's just a different mind-set really I don't think he was cruel or unprofessional or anything like that but it was two very different stances butting together like that (..) and (.) I think sometimes that (.) happens in nursing you know the nurses have input (.) but they are sometimes overridden by doctors who are tunnel visioned into (..) treating and (.) doing surgery or withdrawal of treatment seems to them to be like giving up (...) and sometimes it's just the best thing to do (...)	Frustrated different stances butting together-hitting, wrestling, jostling, fighting, forces different goals difference assessments of poor outcome overridden lost battle, hierarchy tunnel visioned particular view, partially sighted, blind, not holistic or person centred withdrawal = giving up that it is
8	P a g e B e t h P . 2		
		the best (and right) thing to do

The recordings were subsequently listened to in their entirety several times, and specific passages were re-visited on numerous occasions to check understanding.

TABLE 7: ANNOTATION KEY

Annotations	Hand annotated key	Word processed key
Initial impressions	yellow marker (on text)	light grey (on text)
Summary descriptions	pencil (left-hand column)	black text (left-hand column)
Words or descriptions of potential interest	underlined in red	underlined in red
Exploratory notes	blue biro (written in the text)	black text (right-hand column)
Descriptive comments/ participant's word(ing)	black biro (left-hand column)	black text (left-hand column)

Annotations	Hand annotated key	Word processed key
Linguistic comments tone metaphor or juxtaposition	pink biro (left-hand column) red biro (left-hand column)	pink or red text (right-hand column
Interpretive comments	black (right-hand column)	black italic text (right-hand column)
Emergent topics	blue marker (left-hand column)	blue text (left-hand column)
Interview technique	green biro (written in text)	green text (middle and left-hand column)

This process was repeated for each of the RN's interview transcripts.

To begin with individual interview transcripts were analysed descriptively, that is to describe content. Issues that mattered to the RN were outlined, initially accepted at 'face value' without interpretation. Descriptive exploratory comments included keywords, in vivo codes and phrases used by the individual. A descriptive summary of each of the RN's experiences was produced.

Shaw (2010) emphasises that themes "are not waiting to emerge but are borne out of close readings, careful consideration and systematic interpretation" (p.196). Initially I used a longer version of the RN's descriptive summaries and physically cut each into coded sections for each individual. I commenced by grouping descriptive sections on flip chart sheets and iteratively 'themed' these. I repeated this for each RN. Following supervision and using reflexivity I recognised that as a novice IPA researcher I had assigned 'my' themes rather than those purely described and embedded within the RN's stories. I returned to the annotated transcripts.

Word processing facilitated the copying and pasting of descriptive exploratory comments and codes, and their associated text into separate word documents. This is congruent with working primarily with the initial notes rather than the transcript itself (Smith et al., 2009). To understand the individual experience, the descriptive analysis involved identifying key words, phrases and stories that appeared to matter to each of the RN's. These initial emergent themes were presented next to the supportive interview segment to ensure that the themes were data-driven (Shaw, 2010). My initial

attempt produced a list of potential topics which emerged chronologically in order of appearance in the transcripts.

As Smith et al. (2009) explain, the process of identifying emergent themes involves breaking up the narrative flow of the interview. This did feel uncomfortable as I was fragmenting the RN's descriptions of their experiences. For each individual participant the emergent labels, descriptive comments and selected quotes were printed, cut and arranged on a flipchart. These small sections of text were reorganised, regrouped and assigned tentative, emergent themes using post-it notes: see figure 12.

FIGURE 12: AN EXAMPLE OF DEVELOPING EMERGENT THEMES (GWEN)
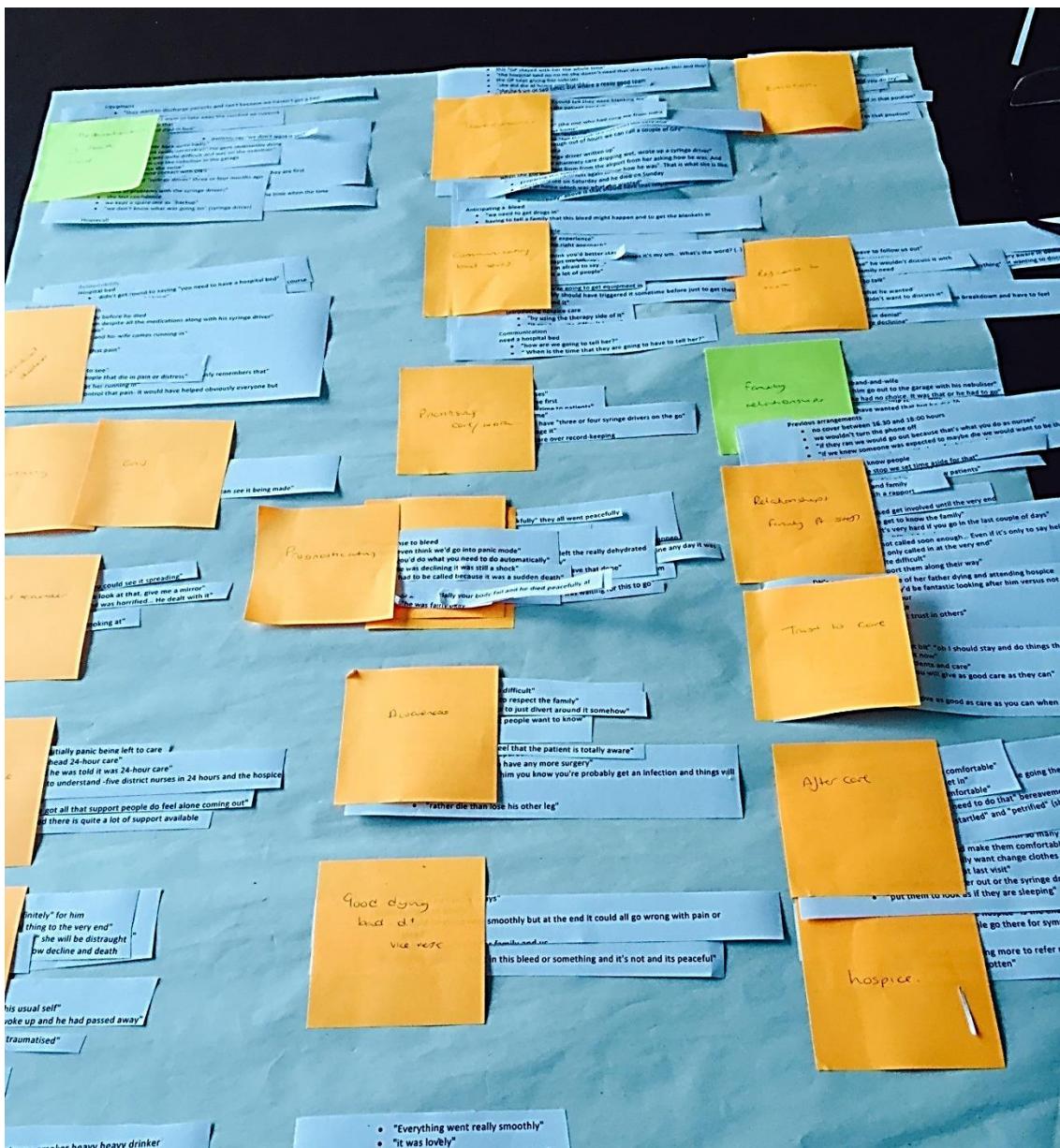
Some of the emergent themes were discarded or amended as part of the analytic process in order to focus on illustrating the most interesting and important aspects of the participant's account (Smith et al., 2009). I began with Alice, the first participant and repeated this process for each of the participants in the order that the interviews were undertaken. The themes were then tentatively grouped for each individual. The emergent themes were further explored by processes outlined by Smith et al. (2009) which include abstraction, putting like with like and developing a new name for the theme, or subsumption where an emergent theme itself is used to bring together a series of related themes.

This following section presents the descriptive analysis and findings of this study. As stated, each RN was allocated a pseudonym to preserve their anonymity. Names of patients, places or relatives or other staff were also anonymised. A brief biography, and descriptions of the unique context of each of the RN's is presented, followed by a concise descriptive summary of their idiographic experiences. The analysis and findings derived from their stories are supported by relevant quotes to support the emergent themes. This provides a layer of understanding of the RN's idiographic experiences of patients' 'good enough' or 'not good enough' dying and death.

8.3 ALICE

Alice is a RN who has been qualified for six years. She now works three days a week at a hospice where she has worked for a couple of years. Alice chose to talk about one memorable patient. She talked in a spiritual, personal, intimate, affectionate manner rather than using a professional vocabulary and tone.

8.3.1 ALICE'S DESCRIPTIVE SUMMARY

Alice talked about Iain who was in the hospice for "*for quite a long time".* She felt that she knew and had a sense of him as a person. Iain had been given an unexpected diagnosis of throat cancer with a poor prognosis following what was understood to be a routine procedure.

Alice described her lack of experience in tracheostomy care and was "*upfront*" about this to Iain describing that she thought that being transparent with him "*might be comfort in itself*"; other members of the team were perceived as not being supportive of this approach.

The night Iain died Alice experienced a vivid dream of an orca whale leaping out of the sea. She shared her experience of the dream with his daughter to whom she also sent an orca whale bookmark and a letter. She did become tearful at times during the interview.

Alice also discussed her personal values and beliefs about pain, symptom management and truth. Alice described caring for dying people and their family as "*an honour*". After the recording device was turned off Alice introduced the need for debriefing for staff in the hospice environment.

8.3.2 ALICE'S EXPERIENCES AND EMERGENT THEMES

Alice was explicit in articulating a unique perspective relating to inevitability which involved some personal convictions surrounding the cause-and-effect of particular symptoms.

> "*for every mental thing it creates a physical thing ((sniff)) so in a way even things like pain that you might initially think oh I don't want that um I kind of feel it's got a reason for being there*" (L 352-353)

She voiced "*everything is for a reason and has its timing as well*" (L 387) which emphasised a further sense of causality. Some aspects of Iain's dying and anticipated death that were arguably not good enough involved 'being at risk'. This was accompanied by a lack of control and a presumed certainty:

> "*It was only a matter of time that this tracheostomy was going to get blocked basically and you know he was assuming that was the way he was going to go, he was going to have to suffocate to death*" (L 71-74)

This certain inevitability was also wrapped up with expectations of discomfort and suffering, a death which arguably would not be good enough. Alice's description of Iain's dying trajectory arguably emphasised that his experiences were difficult, despite this, he reportedly had a peaceful, a good enough death. These supportive quotes underpin the emergent theme 'inevitability'.

Alice portrayed Iain's dying trajectory as difficult and uncomfortable. She described difficult decision-making and perceived futility in relation to the insertion of a Nasogastric tube [NGT]. "*I've gone through enough I don't want to prolong my life now. What for? To just die anyway in a couple of weeks*" (L 104-106). Alice also referred to Iain "*feeling safe*" although he was dying. Alice's account of being a nurse dealing with sensitive issues associated with end-of-life management was encapsulated within the theme 'emotional work'.

Iain's not good enough experiences were arguably compounded by her and others perceived lack of competence and "*rusty*" (L 90) skills in tracheostomy care. "*I feel it would be obvious in when it comes to the practical that they didn't really know what they were doing*" (L 150-151). Knowing, or in this instance not knowing how was an emergent theme which also involved the personal knowing of patients and families "*I just felt like that I kind of had an understanding of what sort of person he was*" (L 155-156). Knowing 'things' also featured; Alice referred to his daughter knowing "*all the gossip about the ward*" (L. 427). The emergent theme 'knowing' is demonstrated from within Alice's experiences.

Whilst knowing Iain and his family appeared to be particularly important for Alice, this personal knowing did lead to a blurring of professional boundaries with Iain's bereaved daughter. Her personal values "*be truthful to myself and everyone else*" (L 395) also encroached into her professional practice. Alice referred to discomfort within the

nursing team "*as a manager it was a bit of a power trip almost that that um making staff feel uncomfortable and everything was quite aggressive in her manner*" (L 210-212). This trait in her managers' behaviour reportedly affected Alice's experiences. These experiences are captured in the theme 'the personal affecting the professional'.

8.3.3 SUMMARY

The clustering of subordinate themes and the development of Alice's superordinate themes are illustrated in table 8.

TABLE 8: ALICE'S IDIOGRAPHIC THEMES

Subordinate themes	Superordinate themes
Causality	Inevitability
Certainty	
End-of-life management	Emotional work
Doing	
Being a nurse delivering end-of-life care	
Communicating sensitive issues	
Getting to know people	Knowing
Knowing things	
Practice knowledge and skills	
Blurred professional boundaries	The personal affecting the professional
Personal values and behaviours	

The table above illustrates that the related subordinate themes of certainty and causality were brought together using abstraction into the superordinate theme of inevitability. End-of-life management, doing, communicating sensitive issues and being a nurse delivering end-of-life care were brought together using abstraction into the superordinate theme of emotional work. Getting to know people, practice knowledge and skills and knowing things were incorporated into the superordinate theme of knowing. The personal affecting the professional is Alice's remaining superordinate theme.

8.4 BETH

Beth is a RN who has been qualified for four years. She has surgical experience and now works in surgical gynaecological oncology at a district general hospital. Beth described herself as "*not backward in coming forward*" and presented herself in a confident manner.

8.4.1 BETH'S DESCRIPTIVE SUMMARY

When I asked Beth if she had been able to think of a memorable clinical case, a memorable patient concerning end-of-life care, she responded "*I can think of lots to be honest, and I've been racking my brains as to which, to tell you, which would be the best because I've got an example of a good one and a bad one really*". We agreed she would tell me about both.

Beth described the care of two female patients. The first patient 'a lady' died in pain, her symptoms were not controlled effectively and there was a lack of dignity and team working. She explained she used this experience constructively. She is now able to challenge decision-making and prioritises a care and quality of life model within the active dying trajectory.

Beth's second story of Mary's dying and death was described as "*as good as it could be*". Beth described having an "*almost overwhelming sense that I'm glad it's me*" in being present and providing care for Mary at this time.

Beth explained that she finds it easier to deal with patients who know that they are dying and who share goals of comfort care. She also emphasised the need for personalised care. She described herself as being "*passionate about death and making it as good as possible*" but acknowledged deficits in her own knowledge and practice.

8.4.2 BETH'S DESCRIPTIVE EXPERIENCES AND EMERGENT THEMES

Beth made reference to professional hierarchies, team dynamics, discord, not being listened to and poor ward morale. An example of this is demonstrated in:

> "*the nurses have input, but they are sometimes overridden by doctors*" (L 102)

A positive aspect of professional culture included Beth's "*honour*" (L 243) and pride in being a nurse and having been involved in providing end-of-life care for Mary.

Within this professional culture and practice, the subordinate theme of doing or not doing was present. There was a sense of "*too little too late*" (L 73) but also doing too much:

> "*doctors who are tunnel visioned into treating and doing surgery or withdrawal of treatment seems to them to be like giving up and sometimes it's just the best thing to do*" (L 101-104)

The practice of 'doing' could contribute to the 'good enough' death in providing comfort care but equally it could contribute to the 'not good enough' death. The subthemes of team working, being a nurse and doing are encapsulated in the theme 'professional culture and practice'.

Beth described feelings of vulnerability and helpless; an emotional self doing an emotional 'job'.

> "*it's part of the job and we know that. We know that before we go into the job don't we, that you know the kind of emotional side is a huge part of our job*" (L 511-513)

She also experienced leaked emotional responses "*I obviously feel but I didn't expect to cry*" (L 269-270). Emotional work also incorporated the communication of sensitive issues and the effort of relationship building with patients:

> "*yet I couldn't click with her for some awful reason […] I could care for her and I could be really compassionate and do my job but I just, I didn't feel a bond with her*" (L 261-263)

These experiences underpin the emergent theme 'emotional work'.

Knowledge and skills, when present and when felt to be lacking were incorporated into 'knowing'.

> "*there's stuff that we can do to improve our practice on the frontline that's why I want to do this. I think I know I know a bit and I know more than some but I don't know enough*" (L 377- 379)

Beth also used clinical reasoning to explain decisions. Knowing also involved 'being aware' of dying by either the patient or the family. This 'open' awareness, which was Beth's preference, was accompanied by the knowledge of the inevitability of death. 'Knowing' emerged as a superordinate theme.

The care setting involved the environment of care with implications for both dignity and autonomy. Two examples were provided by Beth "*she should have been in a side room*" (L 79-80) and "*we moved her to a cubicle when she wanted to go*" (L 209-210). Beth's view is that although progress has been made, it remains difficult to achieve a good (enough) death in hospital every time. These experiences have been used to illustrate the theme 'care setting'.

8.4.3 SUMMARY

The development of Beth's superordinate themes by the clustering of subordinate themes is illustrated in the table 9 below.

TABLE 9: BETH'S IDIOGRAPHIC THEMES

Subordinate themes	Superordinate themes
Team working	Professional culture and practice
Being a nurse	
Doing	
Emotional self	Emotional work
Communicating sensitive issues	
Developing relationships	
Learning	Knowing
Knowledge	
Being aware	
Environment of care	Care setting

As illustrated in the table above, the subordinate themes of team working, doing and being a nurse involved abstracting them into the superordinate theme of professional culture and practice. The emotional self, communicating sensitive issues and developing relationships were combined into the theme of emotional work. Learning, knowledge and awareness have been brought together into the theme of knowing. The environment of care was renamed care setting.

8.5 CARA

Cara is a RN who has been qualified for 12 years. She has worked in a number of hospitals, predominantly on specialist medical wards. Cara was working as a ward sister on this ward for the last 18 months. She described this ward as "*more focused towards palliative care*" than any of the other wards she has worked on.

Cara talked about two patients dying and deaths; she did not name either. Cara talked in a manner that suggested she had rehearsed these stories many times and whilst talking about personal, emotional and sensitive information maintained a professional, composed tone and persona. Cara chose to be interviewed in her ward office, dressed in uniform.

8.5.1 CARA'S DESCRIPTIVE SUMMARY

Cara described the use of personal coping mechanisms. Her first patient story involved the patient being awake, looking physically uncomfortable, frightened, "*lucid*" and aware of what was happening around her. She was also having difficulty talking because of "*the constant bleeding*". The patient had an underlying clotting deficiency but essentially died from a nosebleed.

Cara described a lack of proficiency coupled with a lack of professionalism displayed by junior doctors resulting in poor patient experience. She described this death as undignified and uncontrolled.

The second patient's dying and death that Cara described involved an older male who had known cancer of the lung. He and his family were Arabic. The family were very capable in managing their father's symptom of breathlessness but his family did not accept their father's imminent dying and became extremely distressed. Cara reflected that a referral to the palliative care team was overlooked in part because the family was so capable in dealing with the physical aspects of their father's care.

8.5.2 CARA'S EXPERIENCES AND EMERGENT THEMES

Cara described emotionally challenging work. She referred to her professional identity as a nurse, particularly the use of a uniform as part of a strategy for protecting herself: "*I think that's a coping mechanism in itself is the uniform you just kind of you know got a job to do*"(L 261-262).

She described the experience of leaked emotional responses "*there's some really sad situations you get a lump in your throat*" (L 197) but was troubled by the necessity, and her ability to function in these emotional situations.

> "*you question yourself to the point where you kind of think, you know you're dealing with this these really really tragic sad situations where relatives are really upset and everything*" (L 69-71)

Cara was in effect describing her role in the circumstances of the just good enough and not good enough dying and death. She described a family's particular emotional distress which resulted in the patient's son being removed by security staff, and a story about 'the lady' whose death was "*so uncontrolled*" (L 179). These experiences were used to develop the theme 'emotionally challenging work'.

Cara described comforting patients by talking and 'doing' "*I can do the patient care I can do the directive kind of care and everything like that and symptom management*" (L 42-43). She also described patients as feeling "*safe*" (L 457, 467). However providing comfort care requires knowledge and experience. This was demonstrated in the quote below: If

> "*you had support maybe from one of the consultants or something […] there would have been maybe, you know more care and consideration given to the patient's experience if there was nothing they could do*" (L 187-190)

Lack of knowledge and skill impacted on a 'not good enough' death in the case of the female patient where "*no one was really clear on how to insert them* [nasal tamponades] *or use them*" (L 220). In reference to a not good enough death Cara referred to staff being aware that the patient was dying but the family "*were completely in denial*" (L 326). This contributed to the family who had been very attentive, not being present at the time their father died. These experiences have been captured into the theme 'knowing and doing'

Cara described unprofessional behaviours both in a generalised context and specifically related to the female patient's experiences.

> "*you can be in a situation where actually, it's really really traumatic but you know, something's said that's a bit light-hearted that actually kind of lifts it, but this was just completely inappropriate*" (L 114-116)

She also described a discord between medical and nursing staff which was balanced with a reference to the day team who were "*really nice*" (L 232-233). Cara also expressed pride in the team "*we provide excellent care*" (L 467-468). These experiences are encapsulated in the theme 'professional culture and behaviour'.

8.5.3 SUMMARY

The two 'not good enough' deaths that Cara described were different. The female patient's death was uncontrolled, unanticipated and uncomfortable; the male patient's story focused more on relationship building, family interactions and family distress.

The development of Cara's superordinate themes by the clustering of subordinate themes is illustrated in table 10 below.

TABLE 10: CARA'S IDIOGRAPHIC THEMES

Subordinate themes	Superordinate themes
Self-care	Emotionally challenging work
Vulnerable self	
Uncontrolled dying	
Knowledge and skills	Knowing and doing
Doing	
Knowing the patient and family	
Being aware	
Professional culture and behaviour	Professional culture and behaviour

As shown above the subordinate themes of self-care, vulnerable self, and uncontrolled dying were abstracted into the theme of emotionally challenging work. The subordinate themes knowledge and skills, doing, knowing the patient and family, and being aware were subsumed into the theme knowing and doing. Professional culture and behaviour was adopted as a superordinate theme.

8.6 DAWN

Dawn is a RN who has been qualified for nine years. She described herself as coming into nursing "*late*". After gaining wider experience Dawn chose to work in a medical day unit which provides care for people with haematological malignancies, breast and lung oncology, and delivers chemotherapy and supportive treatments. She emphasised that within the day unit she does see some patients "*extremely unwell*" towards the end-of-life who require admission to hospital, but she is not usually involved in "*seeing*" end-of-life care.

Dawn talked about two patient deaths that occurred in the same week within the preceding year. She also talked about a patient who had attended the day unit "*a few years earlier. We gave one lady a blood transfusion, she wasn't particularly unwell but she wasn't the same as she had been, we'd noticed a difference and unfortunately she died 24 hours later*" (L 222-225). Dawn communicated using a calm, consistent and at times exacting but hesitant professional tone. She did not name any of her patients.

8.6.1 DAWN'S DESCRIPTIVE SUMMARY

An older "*gentleman*" with an inoperable diagnosis of lung cancer attended the day unit for the first time for palliative chemotherapy. He was particularly breathless on arrival so Dawn checked whether she should initiate the treatment. The treatment was administered and approximately 30 minutes later the patient suffered a sudden deterioration and became unresponsive; he died a few hours later. A subsequent post-mortem examination confirmed the tumour as cause of death but a formal concern was raised by the family suggesting that he had choked.

The second patient was an older female who attended for an initial consultation appointment. She collapsed in the corridor. Following a successful cardiac defibrillation, she died an hour later. The patient's daughter, a fellow professional (police officer) remained present throughout all interventions and treatment.

8.6.2 DAWN'S EXPERIENCES AND EMERGENT THEMES

Dawn described her emotional self in terms of vulnerability, responsibility and doubt particularly in relation to these unanticipated deaths. The male patient's unanticipated death was perceived as 'not good enough' by the family who became angry and subsequently formalised a concern. Dawn's vulnerability in relation to this experience is captured in the quote below:

> "*I don't ask any more now because it's sort of seven months down the line and all it does is churn things up again*" (L 526-527*)*

In contrast, the female patient's family who also died unexpectedly "*just accepted that it was it what it was*" (L 392-393), that is, a 'good enough death' despite the uncertainty in her physiological response to resuscitation as *"it could have happened* […] *at home"* (L 393). The superordinate theme of emotional work incorporated sensitive communication, and the uncertainty of, and the inevitability of death "*when your time's up your time is up regardless of what you try and do to prevent it or prolong it*" (L 442-443). These experiences illustrate the theme 'emotional work'.

Addressing patient's comfort, providing treatments and organising the environment care as best as possible involved 'doing'. It also involved the need to provide dignity and privacy for both the dying person and other patients.

> "*because it [curtain] doesn't block sound out but it does at least provide a little bit of dignity and, and shield the people that-- because we couldn't clear the unit we were in the middle of blood transfusions and chemotherapies and everything else so you couldn't just herd people out*"
> (L 421-424)

These experiences are captured in the theme 'doing'.

Knowing involved relationships that develop between staff and patients as well as the "*camaraderie*" (L 621) that builds up between patients. Knowing was also captured in the not knowing how to "*I don't really know how you would manage that* [bleeding out] *sort of death*" (L 293). 'Knowing' is an emergent theme.

Team support involved seeking reassurance about the commencement of the chemotherapy treatment, and the involvement of external teams such as the 'CRASH' team, but ultimately it captures Dawn feeling supported by her manager in the wake

of the unanticipated male patient's deterioration, dying and death: "*the sister of the unit said I was the one checked it with you, it could have been any one of us*" (L 492-495). These experiences underpin the theme 'team support'.

8.6.3 SUMMARY

The development of Dawn's superordinate themes by the clustering of subordinate themes is illustrated in table 11 below.

TABLE 11: DAWN'S IDIOGRAPHIC THEMES

Subordinate themes	Superordinate themes
Emotional self	Emotional work
Sensitive communication	
Inevitability	
Doing	Doing
Dignity and privacy	
Developing relationships	Knowing
Getting to know people	
Not knowing how	
Team support	Team support

Table 11 shows that the subordinate themes of emotional self, sensitive communication and inevitability have been abstracted into the theme emotional work. Doing and working towards providing dignity and privacy have been subsumed into the superordinate theme doing. The themes of getting to know people and developing relationships, as well as not knowing 'how to' have been combined into the superordinate theme knowing. Team support has become a superordinate theme.

8.7 ELSA

Elsa is a RN and works as a ward sister in a hospice. Elsa originally registered as a nurse 31 years ago but after a career break returned to nursing several years ago. She has a variety of recent nursing experience and feels she is in a position to contrast hospice care with hospital care.

Elsa predominantly described one older patient's death which she communicated in a calm, reflective and professional tone. She did not use his name.

8.7.1 ELSA'S DESCRIPTIVE SUMMARY

Elsa described her memorable patient as a male in his late 80s. He was particularly anxious and required copious reassurance. He was also a Welsh speaker. He was admitted for symptom management of breathlessness, pain and worsening haematuria. The team had difficulty in effectively controlling his symptoms which were exacerbated by his anxiety.

Elsa talked about this patient's wife, who initially was very quiet and unable to express her needs. Elsa arranged for her to bring their dog into the hospice which transformed the husband-and-wife's experience. His wife and dog stayed with him during the final days of his life.

Elsa had given thought into providing the story of a memorable older patient's death. She explained that she could think of lots of younger people and found it more difficult to think of older people's deaths.

8.7.2 ELSA'S EXPERIENCES AND EMERGENT THEMES

In terms of self-care, Elsa referred to the benefits of counselling but also observed "*I think people* [staff in hospital] *feel guilty and so they, they withdraw, because they can't give the time*" (L 146-147). She also talked about nurses' use of a "*brutal*" (L 295) sense of humour. Elsa acknowledged that doctors at the hospice alleviate a lot of "*the strain*" (L 134) of communicating with relatives. Some of the other struggles in delivering end-of-life care involved uncertainty:

> "*the times we've put down end of life care and the next week oh stable again and then the next week oh going down again and it's just you know sometimes you just can't tell*" (L 209- 211)

The theme 'emotional work' included self-care, professional issues, the communication of sensitive issues and similar difficulties involved in end-of-life care.

Managing symptoms and discomfort, and individualising the environment involved doing. Doing also involved the use of clinical assessment and skills which could be experienced as problematic:

> "*the other thing that I find difficult sort of clinically, is if somebody's starting to get agitated you think is that just because, you know if they are not communicating very well and you think is that agitation, should I give them?-- If they haven't had midazolam first, and then you give you're starting off the whole process*" (L 404-408)

'Doing' emerged as a theme.

Knowing how is illustrated in the use of clinical skills. Patient's familiarity with general routines is knowing what, and knowledge of the individual patient and their loved ones is arguably knowing who. In contrast, not knowing was associated with uncertainty.

> "*once we'd control that, it would be something else, because of the anxiety it clouds quite a lot of stuff that we weren't sure whether-- not that he was lying by any means but whether the symptoms weren't getting better or being better controlled or-- I mean you could tell with haematuria, but with breathlessness it's really subjective a lot of the time*" (L 354-358)

Knowing how, what and who is illustrated in the theme 'knowing'.

Elsa also made reference to ethical practice particularly for the care of older people:

> "*You know I was saying that um, they are not memorable the elderly people but I don't think that we would change the medication stuff because somebody's old*" (L 458-460)

Elsa described 'a little gem'; she uniquely described old people's dying and death as "*more run-of-the-mill*" (L 10) which being largely unmemorable has implications for a 'good enough death'. Elsa's experiences that 'older peoples' deaths are more run of the mill' is an emergent theme.

8.7.3 SUMMARY

The development of Elsa's superordinate themes by the clustering of subordinate themes is illustrated in table 12.

Subordinate themes	Superordinate themes
Self-care	Emotional work
Professional issues	
Communicating sensitive issues	
Uncertainty	
Managing discomfort	Doing
Individualising the environment	
Clinical skills	Knowing
Routines	
Knowing the individual	
Older people's end-of-life care is more run-of-the-mill	Older people's end-of-life care is more run-of-the-mill

The table above shows that the subordinate themes of self-care, professional issues, communicating sensitive issues and uncertainty have been clustered, and using abstraction are embodied within superordinate theme of emotional work. Managing discomfort and individualising the environment have been abstracted into the theme doing. The subordinate themes of clinical skills, routines, and knowing the individual have been brought together under the superordinate theme knowing. Older people's end-of-life care is more run-of-the-mill is Elsa's final superordinate theme.

8.8 FFION

Ffion is a RN who has been qualified for six years. She has worked as a staff nurse for five years in a community hospital and for the past year has been working as a community nurse as part of the district nursing team. She lives at home with her husband and son.

Ffion talked in an excitable manner and spoke in a very direct, 'say it as it is' style. She betrayed an overarching sense of the importance of humour and kindness but also disclosed critical judgements. Ffion recalled a number of memorable patients in hospital and community comprising of both good enough and not good enough death experiences.

8.8.1 FFION'S DESCRIPTIVE SUMMARY

The first male patient named 'John' had been "*fast tracked*" out of hospital but lived independently for a further three months. He died at home but was preparing to go into the hospice the following day. Ffion described this as "*a nice comfortable death*" but "*a shock*".

The second male patient 'Jack' was in hospital with arrangements to transfer to a nursing home. His unanticipated death occurred during a nightshift and was also the first death experience for the student nurse on duty. The need to inform his wife of his unanticipated death created uncertainty for Ffion. Ffion referred to this patient's after-care as being "*quite fab*" but she focused on the deficits in care of his wife, which occurred after Ffion had left the ward.

The third male patient died in hospital and experienced a lingering dying trajectory which was permeated with anger, frustration, blame and suffering. However she also described a care scenario in which she experienced a sense of achievement. Ffion also talked about a bariatric patient who became very anxious about being moved to a care environment where staff would not know her. Due to her complex needs, the plan was for her to be cared for in the community hospital which reassured the patient. Nonetheless she died in the district general hospital whilst being treated for a non-resolving chest infection.

8.8.2 FFION'S EXPERIENCES AND EMERGENT THEMES

Working with dying and death involved emotionally challenging work, the self, the communication of sensitive issues, and dealing with death and dying. An aspect of this can be seen in "*he knew he was going to die so that was just horrible, horrible*" (L 484), which created feelings of helplessness; "*there was nothing we could do*" (L 482). The uncertainty of when individual patients might die, along with the inevitability of death created challenges in practice. In describing her experiences of reassuring a student nurse following Jack's unexpected death, Ffion recounted saying:

> "*you did the last thing on this earth which was an act of kindness, and you did it for him*" (L 389-390)

In general, the communication of sensitive issues as apart of patient care was presented differently for hospital and community. In the hospital "*the doctor's there, and the doctor can take that responsibility, and that burden of bad news is on the doctor*" (L 583-584). In contrast "*out in the community we do more of that kind of talk to patients*" (L 575). Working with dying and death although emotionally challenging, also created experiences of role satisfaction:

> "*I managed to persuade him to cut his beard. But I said once I start I can't stop ((laugh)) but if you say yes and there is a razor touching your face I said I've got to carry on. You know, so I thought that was quite nice, to do that*" (L 494-498)

These experiences underpin the emergent theme 'emotionally challenging work'.

The care setting involved the physical place of care and also anticipating place of death; "*if they know, where they are going to die, it could ease it a bit*" (L 623). Within the hospital environment a cubicle was the preferable place of care. However in the home environment equipment supplied by the district nurses was not always welcomed which led to compliance issues; "*he's on a primo mattress. He turned it off in the night because he couldn't stand the noise*" (L 142-143). Ffion also explained that John subsequently "*had a nice comfortable death*" (L 31) in his own home. The 'care environment' emerged as a theme.

Interpersonal relations incorporated professional behaviours and hierarchies, discord and relationships. In the hospital there was discord between doctors and nursing staff and also between certain members of the hospital nursing team. Ffion also described a

tension between hospital and community nursing staff. A professional hierarchy can be seen in the hospital in "*I think if they had their* [doctor's] *own view on something, that was their view, it seems hard to change around to our view*" (L 218-219). However in contrast she explained that in the community the GP's rely on the district nurses assessment. Ffion was able to contrast practice between the care environments of community and hospital care. She portrayed working as part of a team in hospital as challenging.

The 'good enough' death was also associated interpersonal relations for both staff and family "*it's the relationship that the staff and the family build up that helps them* [staff and family] *get through it*" (L 455-457) but Ffion also talked about "*fractured*" (L 526) families which can be difficult for the staff, the family and the patient. These 'interpersonal relations' emerged as a theme.

8.8.3 SUMMARY

The development of Ffion's superordinate themes by the clustering of subordinate themes is illustrated in table 13.

TABLE 13: FFION'S IDIOGRAPHIC THEMES

Subordinate themes	Superordinate themes
Emotionally challenging work	Emotionally challenging work
The self	
Communicating sensitive issues	
Dealing with death and dying	
Care interventions	Doing
Care environment	Care environment
Professional behaviours and hierarchies	Interpersonal relations
Team working	
Relationships: personal or work place	

The subordinate themes emotionally challenging work, the self, communicating sensitive issues and dealing with death and dying were subsumed into the superordinate theme emotionally challenging work. Care interventions have been renamed doing and the care environment has been adopted as a subordinate theme.

The theme 'interpersonal relations' incorporates the subordinate themes of professional behaviours and hierarchies, team working and personal or workplace relationships.

8.9 GWEN

Gwen is a RN who initially qualified as a mental health nurse and registered as a general nurse 24 years ago. She has worked as a district nurse for 16 years. Gwen chose to participate in the interview at the health centre where she is based. She talked in a confident, natural tone.

8.9.1 GWEN'S DESCRIPTIVE SUMMARY

Gwen had been involved with a patient death that morning. Gwen chose to begin with "*her lady*", who was not an older person but had pancreatic cancer and lived with her husband and children. The need for a hospital bed was identified by the team but they did not get around to having this difficult conversation; she died at home in her own bed, which was problematic for the district nurses.

The "*gentleman*" who had died that morning had known chronic myeloid leukaemia. The evening before he died he was "*his usual self*". He was found to have died by his wife. As it was a sudden death which necessitated the involvement of the police, Gwen anticipated his wife would be "*quite traumatised*".

Another "*gentleman*" described as temperamentally "*quite difficult*", progressively became bedbound and died peacefully at home with his family. She related to another patient who required the use of a nebuliser but his wife did not like the noise of it; eventually he died peacefully at home. Another "*gentleman*" died during the district nurses' first visit to initiate a syringe driver, and another suffered significant pain but had refused further surgery. Gwen also discussed concerns about a colleague's care and management in hospital. Gwen described a number of deaths at home. For most the actual death was peaceful but their dying was problematic.

8.9.2 GWEN'S EXPERIENCES AND EMERGENT THEMES

The emotional self can be seen in the following quote:

> "*although you get emotional, there's a level, there's a fine, a fine level and you know you do get upset and you do cry*" (L 328-329)

She described her work as having "*a lot of sad times but we are a really good team*" (L 938).

The communication of sensitive issues was focused on examples in practice that Gwen had found particularly difficult, but it also involved a lack of communication as Gwen

referred to a patient who "*you couldn't talk to him about his illness at all*" (L 303). The sensitive and difficult issues focused on anticipation of symptoms or interventions. Care was provided in people's own home which created some challenges, an example being 'her lady' and the need for equipment; "*how are we going to tell her she needs to have a hospital bed*" (L 84-85), as "*often patients say we don't want it yet because it gives you that clinical environment*" (L 127-129).

Unpredictability created a capriciousness in that the 'good enough' dying and death do not necessarily go hand-in-hand:

> "*care could be going very smoothly, but then at the end, it could all go wrong with pain or bleed or, and then that stays there doesn't it it's that's their last memory then for the family, and us*" (L 514-518)

The theme emotional work involved the emotional self, team support, the communication of sensitive issues, anticipation and unpredictability.

Providing clinical or comfort care, peri-death care and bereavement calls to family and managing the workload involved doing. In relation to peri-death care Gwen explained that the district nurses "*do like to go and make them comfortable as best you can*" [after death] (L 194). Gwen also recounted experiences when 'the doing' was ineffective "*I don't know what else we could have done*" (L 523-524) or becomes stretched in practice "*we can have maybe three or four syringe drivers on the go but I think you learn to manage it*" (L 357-358). 'Doing' emerged as a theme.

Gwen emphasised the importance of getting to know the patient and family when delivering end-of-life care. Not knowing the patient or the family was deemed difficult for the Gwen. She referred to a patient who died during their first visit in terms of "*worst*" (L 836)

> "*none of us ever-- one of the girls met him about five months previously to do a continence assessment, but that was the one visit, and nobody'd ever been. But for him that was probably great because he only had intervention at the very end, um and the family for that one visit were forever grateful*" (L 842-846)

This was likely to have been a good enough death for him and his family, but not in terms of the Gwen's or her colleagues' experiences.

In the community Gwen felt that individuals are usually aware of their terminal status or that 'things' are declining. However, one male patient was described being "*very, very aware, but in denial*" (L 286-287). The emergent theme 'knowing' involved clinical knowledge, interpersonal knowing, awareness and denial.

8.9.3 SUMMARY

The development of Gwen's superordinate themes by the clustering of subordinate themes is illustrated in table 14 below.

TABLE 14: GWEN'S IDIOGRAPHIC THEMES

Subordinate themes	Superordinate themes
Emotional self	Emotional work
Communicating sensitive issues	
Team support	
Anticipation	
Unpredictability	
Doing	Doing
Workload	
Clinical knowledge	Knowing
Interpersonal knowing	
Awareness and denial	

The subordinate themes emotional self, communicating sensitive issues, teamwork, anticipation and unpredictability were abstracted into the superordinate theme of emotional work. End-of-life care involved 'doing', proving comfort care and pain relief, the provision of clinical equipment and managing the workload were subsumed into the superordinate theme of doing. Clinical knowledge, interpersonal knowing, awareness and denial were abstracted into the superordinate theme of knowing.

8.10 CONCLUSION

This section has presented the participants' idiographic descriptive accounts, using the participants own words taken at face value. The themes have been developed conceptually by engaging with the data. Using careful consideration and initial

interpretations, connections across emergent themes for each individual RN have been presented.

A table summarising the RN's idiographic superordinate themes is presented below.

TABLE 15: RN'S IDIOGRAPHIC SUPERORDINATE THEMES

Participants' idiographic superordinate themes			
Alice	Inevitability	Emotional work	Knowing	The personal affecting the professional
Beth	Professional culture and practice	Emotional work	Knowing	Care setting
Cara	Emotionally challenging work	Knowing and doing	Professional culture and behaviours	
Dawn	Emotional work	Doing	Knowing	Team support
Elsa	Emotional work	Doing	Knowing	Older people's end of life care is run-of-the-mill
Ffion	Emotionally challenging work	Doing	Care environment	Interpersonal relations
Gwen	Emotional work	Doing	Knowing	

The next chapter will take the analysis deeper by exploring the RN's use of language and linguistic devices to aid communication and understanding.

9.1 INTRODUCTION

IPA attempts to explore, understand and make sense of the subjective meanings of events and experiences of the individual participants. Although the framework for this study is hermeneutic and interpretive rather than linguistic, in IPA the researcher is concerned with trying to find out what the participant thinks and feels about what they are talking about. It is concerned with cognition, with understanding what the particular respondent thinks or believes about the topic under discussion (Smith et al., 1997). IPA recognises the person as a cognitive, linguistic, affective and physical being and assumes a connection between people's talk, their thinking, and their emotional state (Smith and Osborn, 2008). For this thesis, the purpose of exploring the use of language and linguistic devices employed by the RN's is to supplement their descriptive and interpretive accounts; as Eatough (2015: unpaginated) states "words are not lifeless entities".

9.2 THE USE OF LANGUAGE

In considering the use of language I reflected on my personal experience of my dad's intracerebral haemorrhage and subsequent death. The registrar had explained the imminent medical management plan but I struggled to understand what he was saying; there was mention of potential intensive care, to enable the CT scan he had been intubated but now he "had a machine to breathe". The use of euphemisms and lay language obscured my understanding. I explained I was a stroke nurse and asked him to explain my dad's condition 'medically'. The crucial things I remember hearing after "bless you" (which gave me a sense of incongruence) followed by a deep sigh was "both cerebrum", "bled into both ventricles" and "extubate". The use of medical terminology was a shared language which provided me with a clear understanding of the gravity of the situation and the ensuing management plan.

This personal example helped me to understand that in day-to-day life the use of language is taken for granted and liable to uncritical interpretation. It can add clarity but presumes a shared understanding and undisclosed presumptions can also obscure meaning and hide detail. It is anticipated that focusing on elements of language found

in the participants' stories will produce a richer picture of the participants' experience (Shinebourne and Smith, 2010).

9.3 LINGUISTIC ANALYSIS

The following section examines the use of linguistic devices such as metaphor, analogy, simile, binary opposites and symbolism within the RN's stories. It is understood that this will influence 'meaning making' and facilitate the development of a further layer of interpretive understanding of the RN's experiences.

Metaphors have been described as powerful tools for communicating and sharing experience using richly textured communication (Shinebourne and Smith, 2010). Metaphor can be defined as "seeing, experiencing, or talking about something in terms of something else" (Ritchie, 2013: p.8). Metaphors are often used to express emotions (Ritchie, 2013) or complex, subjective, intangible, abstract, or sensitive experiences. They can be used as a 'safe bridge' to communicate and indirectly express experiences and emotions, particularly negative ones (Shinebourne and Smith, 2010).

Lakoff and Johnson (1980) argue that spatial orientation is fundamental to our culture. They explain that common orientational metaphors organise the whole system of concepts with respect to another. These largely involve spatial orientations of up-down, front-back and central-peripheral. These spatial orientations stem from the reality that we have physical bodies that function in our physical environment. Likewise Finlay (2011) states "the body not only connects us to the world, but also offers us the way to be in that world and to understand it" (p.55). A few common examples are 'up' is associated with good, more, health, life, and happiness whereas 'down' is associated with bad, less, sickness, death, and sadness. In the social and spatial orientation dimension 'up' is positive, 'down' is undesirable (Lakoff and Johnson, 1980; Shinebourne and Smith, 2010). Binary opposites can help articulate experience and provide rich ways of illuminating people's stories.

The following examples are used to illustrate a presumed shared understanding between myself and the individual RN's. Beth described a ward as "*heavy*" (L 27). My assumptions were that the ward was busy and the patients were particularly physically dependent on staff for care needs. My assumptions involved moving and handling

patients' bodies and limbs which can entail weight, hence physically heavy, hard work. However I didn't check this understanding with Beth. Gwen told me "*she was starting to mark*" (L 139) which provided an invalidated shared understanding indicative of compromised tissue viability. These examples illustrate a presumed and shared understanding within the language of nursing jargon. Slightly differently Ffion explained that "*families were all fractured*" (L 525-526). In clinical terms fracture usually refers to a broken bone. Using the term "*fractured*" families provided a shared, pseudo clinical understanding of damaged or broken, unrepaired family relationships.

Alice used metaphors to describe a number of things. In reference to symptom management Alice used the metaphor "*let's nip it in the bud*" (L 374). The de-budding of plants halts the development of the flower or fruit hence it puts a stop to something before it develops. In this case it prevents a potential problematic symptom before it develops or escalates. Alice explored her personal beliefs regarding symptoms; "*let's nip it in the bud*" appeared to be at odds with her personal beliefs, and may suggest that the use of metaphor enabled Alice to convey a personally complex aspect of practice. In a different vein Alice also described Iain being "*roller-coastered*" (L 116) into a decision making; a metaphor, a concrete experience that we can comprehend to describe his ups and downs, highs and lows. The roller-coaster can include bumps and uncertainty; "just when you think you're in a good place, the bottom drops out and your stomach goes with it" (Penson et al., 2004: p.712). The roller-coaster metaphor may also convey momentum, speed and lack of control. It conveyed a sense of unpleasantness.

Beth described doctors as being "*tunnel visioned*" (L 102). Clinically tunnel vision describes a lack of peripheral vision but being able to see what you are directly looking at. Used metaphorically it conveys a narrow, prejudiced outlook. Tunnel vision is also an orientational metaphor associated with binary opposites wide and narrow, coherent with more is better versus less is bad (Lakoff and Johnson, 1980). Tunnel visioned is also perhaps conveying a perceived negative attribute of doctors' ways of seeing the world. Other binary opposites included Ffion's reference to a gentleman being "*really perky*" (L 38) and "*he just died*" (L 39), and less obviously Elsa's reference to the gentleman as the "*patriarch*" (L 26), the boss who was in reality was relatively powerless in this situation.

Analogy can be used as a comparison between one thing and another. In describing nurse and doctor relations, Beth described "*two very different stances butting together*" (L 100). Stance could be interpreted as the attitude or position of a standing person whereas butting may suggest ramming or pushing. The relational aspects between doctors and nurses are described in physical terms, which provides a sense of spatiality and embodiment. The use of combative analogy culminated in Beth feeling "*better armed*" (L 147), better prepared, better equipped to enable her to manage these tensions in practice.

Simile compares one thing with another thing of a different kind, used to make a description more emphatic or vivid. Cara described her patient, "*her eyes were like rabbits in the headlights*" (L 167-168) which seemed to emphasise that her eyes were vividly noticeable and expressed a sense of tangible fear. Ffion described a gentleman who seemed to "*tick along for a bit*" (L 27), hence like a clock. A clock is used to measure and display time. Time can be seen as a moving object in "*tick along*" but "*for a bit*" suggests that 'the journey' (moving along, life as a journey) will end.

Dawn referred to a patient who died within the "s*pace*" (L 104) of one hour. Time is often considered a valuable commodity, although at times it can be limited. The analogy 'space' conjures up images of a gap, of emptiness, in a sense incompatible with time as measured as seconds, minutes, hours, days, weeks etc. Temporality is further illustrated in "*when your time's up your time is up*" (L 442). Time here is used to depict duration and end of human life, and conveys a sense of resignation and inevitability. When referring to another patient the contrary was espoused as Dawn described her "*time cut short*" (L 467). This suggests this was not inevitable or perhaps more accurately, was not expected, not anticipated at this particular point in time.

Symbolism may use images to express ideas and emotions. Cara's words "*you could literally see her slowly starting to kind of fade away*" (L 106) portrays a vivid image of a growing paleness, perhaps due to physiological shock, but the "*fade away*" also portrays a sense of disappearance. This aided my understanding of her patient physiologically dying. Alice's most vivid imagery involved her dream of an orca whale. Lakoff (1993) proposes that our unconscious metaphor system structures dreams, connecting the hidden meanings of dreams to their overt meanings and images in a systematic way that makes use of what is important in the everyday life of the

dreamer. He argues that dreaming is a mechanism for relating concrete images to abstract meanings, which provides conditions that can be seen and heard, hence understood. Alice appeared to have made sense of her dream by explaining it as symbolic of Iain's diagnosis, living, dying and death. Dawn in describing her patient said "*his heart was still going but the lights were out*" (L 106). Physiologically he was still alive but "*the lights were out*", he wasn't home, arguably 'he', the essence of the individual, had left his body. The use of symbolism conveyed an understanding of him being unresponsive and dying.

Elsa described older people's dying as more "*run-of-the-mill*" (L 10) a commonly used phrase that depicts ordinariness with no particular special attributes. This may explain that Elsa found older peoples' deaths generally unmemorable. Binary opposites were used to help differentiated between "*on the surface*" and "*underneath*".

> "*I don't know if age is (pause) and I think it's tempting (pause) underneath, I don't do it on the surface but I think underneath I probably think oh well they have had a good life that (sigh) you have to die in some way*" (Elsa, L 194-196)

Underneath could relate to subconscious thought but it could be interpreted as suggesting that this thought needs to remain hidden, buried, unspoken as it is taboo. There is also a suggestion of light and shade. The shade, the underneath is associated with the spatial orientation of down. The surface is opposite to underneath. The surface is accessible, visible, observable and public.

Cara described the gentleman's family as "*up in arms*" (L 326), depicting anger and conflict which resulted in the son being "*removed*" (L 339), taken out of the area by security. This was accompanied by a nervous laugh, and an incomplete sentence "*you just think*" (L 291) which was not clarified but conveyed a sense of incredulity and sadness.

When talking more generally about providing support for carers Gwen alluded to finding a common, shared language that is acceptable to both her and the patient and their family to discuss the need for hospice care; "*I do use perhaps the therapy side, perhaps it's my um-- what's the word? -- not because I am afraid to say*" (L 467-468) but "*it can be quite difficult to say*" (L 455-456). Within this context of 'difficult' sensitive communication, Gwen appears to be framing a conversation using carefully

chosen words but at the same time creating some avoidance of specific information; the unsaid.

9.4 CONCLUSION

This section of analysis has engaged with language, metaphor and imagery. The RN's use of language and linguistic devices appeared to communicate and indirectly express experiences and emotions, as Shinebourne and Smith (2010) state, particularly negative ones. Metaphor and binary opposites specifically helped the participants articulate their experience and provided rich ways of illuminating their stories.

Within the interviews there was a presumption of shared understanding. Some of this arose from the fact that myself as the researcher and the participants are RN's and have commonality within our experiences and roles. Language can be seen to foreground and background aspects of the RN's stories. Their use of language did not just reflect their experience; it was used to shape their stories, in which they made sense of their own experiences. The way in which they communicated these experiences was an attempt to share understandings.

The layered activity of identifying, exploring and developing an understanding the RN's use of language reflects the double hermeneutic activity appreciated in IPA. I recognise that as the analyst, I have only access to the RN's experiences through their own account of it, and that I have interpreted what they have told me.

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CHAPTER 10 - SEARCHING FOR PATTERNS ACROSS CASES: CONVERGENCE AND DIVERGENCE

This chapter highlights major themes that appear in all, or most of the cases in an attempt to understand what is shared across the RN's reflections of their experiences. The shared experiences remain firmly rooted in the individual's understandings which is a continued attempt to achieve an empathic analysis of the participants' experiences (Shaw, 2010), to attempt to understand what it is like "*to stand in the shoes*" of others (Pietkiewicz and Smith, 2014: p.8). IPA involves a detailed analysis of each case followed by the search for patterns across cases and also explores convergence and divergence of experiences (Smith, 2011). This aims to help answer the research sub question 'do registered nurses have a shared understanding of the meaning of a good enough death?' and to make explicit the similarities and differences of the RN's experiences with regard to the understanding of the 'good enough' death.

The RN's generalised descriptions and opinions of what makes dying and death good enough or not are presented below (table 16) using verbatim quotes for each participant. Arguably these understandings have been developed experientially, and in Beth and Cara's descriptions can be seen to be directly related to one of each of their memorable cases.

TABLE 16: PARTICIPANTS' STORIES OF THE GOOD ENOUGH OR NOT GOOD ENOUGH DYING AND DEATH

Participant	'good enough' dying	'good enough death'	'not good enough death'
Alice		"*trying to put in place what the patient wants to happen at their death*" (L 267-268) "*You wouldn't want them to be in lot of pain*" (L 291)	
Beth	"*put their affairs in order* " (L 461)	"*comfortable*" (L 452) "*think everybody would prefer to die in their sleep and not know anything about I*"(L 399-400) "*control*" (L 317), "*autonomy*" (L 318)	"*falling on deaf ears*" (L 164) "*uncomfortable*" (L 454) "*in pain and not in privacy there was no real dignity* " (L 74-75)

Participant	'good enough' dying	'good enough death'	'not good enough death'
		"*listen to what people want and respect it*" (L 357)	
Cara	"*time to come to terms with it*" (L 481) "*to have said what they have got to say to the people that they want to say it to* " (L 437) "*when somebody is ready, when they acknowledge that they are ready and they can, they can kind of you know be at peace with themselves and kind of dot the i's and cross the t's for them*" (L 440-442)	"*to be comfortable, be sleeping, to not have any pain, […] them to not be on their own*" (L 436-438)	"*Sudden, unplanned, chaotic, undignified, traumatic for family*" (L 484-485) "*not comfortable*" (L485) "*unexpected*" (L 487)
Dawn		"*respect the person's wishes*" (L 275) "*comfortable, pain control, privacy, dignity*" (L 276) " *relaxed*" (L 286)	"*complete opposite when you don't get there in time, where they're in pain, they're distressed and maybe the family members aren't there with them*" (L 288-289) "*bleed out*" (L 290)
Elsa		"*with people that people want to have around to be around* " (L 389-390) "*not in pain, to be sedated enough so that they are just comfortable and peaceful*" (L 391-392) [Elsa's Mum] "*I didn't see her as dying until she was dead, or in the final stages which would meant it was a good death […] because the dying process is the death*"(L 382-387)	"*Agitation and excruciating pain. and I think people who see people you know who see their mothers, sometimes it can be 'oh mum I want to come to you' type thing but other times it can just be horrendous for people seeing*" (L 395-397)

Participant	'good enough' dying	'good enough death'	'not good enough death'
Ffion	"*getting your affairs in order*" (L 654)	"*pain free*" (L 421) "*Their family there if that's what they want*" (L 423-424) "*peaceful*" (L 593) "*He* [John] *had a nice comfortable death*" (L 31)	"*pain not controlled*" (L 557) "*denial*" (L 558)
Gwen	"*everything was planned she'd planned her funeral. She'd done boxes for the boys and with-- she was having little blankets made so if they had children as soon as they, they could wrap them in*" (L 71-73)	"*for us doing the best we can for a patient, and hopefully that they are comfortable when they die and they go peacefully*" (L 404-405) "*the family to be at peace*" (L 408)	"*in pain or distress*" (L 409) " *or bleed*" (L 517)

The RN's differentiated dying as a process, and death as the end point. Beth, Cara and Ffion identified preparation as part of the dying process. Gwen had described 'her lady's' preparation in her example of the 'good enough' death but did not refer to this more generally. Being comfortable or avoiding discomfort was specifically cited in six of the RN's descriptions, and pain control was mentioned by all.

10.1 SHARED THEMES: CONVERGENCE AND DIVERGENCE OF PARTICIPANTS' SUPERORDINATE THEMES

Having considered the descriptive findings of each individual RN, and patterns within each of their individual accounts, the analysis then moved to looking for patterns across cases. The development of shared themes arguably encompasses a type of generalisation, but IPA focuses on the lived experience of particular individuals, and the use of an idiographic focus locates these themes in the particular. The shared themes are evident within each of the RN's interviews. Table 17 presents the superordinate themes from the idiographic descriptive analyses of each participant to illustrate patterns of shared themes. The themes by each participant are indicated using ☑.

Emotional work: the experiences of registered nurses in delivering end-of-life care for older adults										
Participants	Emotional work	Knowing	Doing	The personal affecting the professional	Professional culture and practice/ or behaviour	Care setting	Inevitability	Individual and team support	More run-of-the-mill	Interpersonal relations
Alice	☑	☑		☑			☑			
Beth	☑	☑			☑ practice	☑				
Cara	☑ challenging	☑ & doing	☑ & knowing		☑ behaviour					
Dawn	☑	☑	☑					☑		
Elsa	☑	☑	☑						☑	
Ffion	☑ challenging		☑			☑				☑
Gwen	☑	☑	☑							

The major shared theme was emotional work. All participants shared this superordinate theme with two participants emphasising the emotionally 'challenging' aspects of working with dying people and death. Two other superordinate themes shared by most of the participants included 'knowing' and 'doing'. Knowing can be understood to be knowing who (personal knowing), knowing how (practical knowledge) and knowing what for example familiarisation with routines. Whilst knowing was not a subordinate or superordinate theme for Ffion, practice knowledge did feature in her stories for example she said "*because they sent you home with these I'll just explain*" (L 132) as did personal knowing for example Jack and his wife, and the hospitalised male patient's family dynamics. The knowing of patients and families' circumstances was implicit and encapsulated within the theme 'relationships'. However knowing did not emerge as a theme within Ffion's narrative.

Doing involved caring acts some of which are subtle for example drawing a curtain. Doing also involved doing too much or too little. Doing was not a superordinate theme for either Alice or Beth but it featured as a subordinate theme. For Alice it was

associated with futility and symptom control, and for Beth doing was associated with treating, futility, inadequacy, and providing comfort. For Alice the subordinate theme 'doing' was subsumed into the superordinate theme 'emotional work' and for Beth it was subsumed onto the superordinate theme of 'professional culture and practice'.

Considering divergence, inevitability was a superordinate theme only in Alice's experiences, and was a subordinate theme of Dawn's experiences. Ffion's focus on interpersonal relations included the subordinate theme of professional behaviours and hierarchies, (not dissimilar to Beth's and Cara's superordinate themes of professional culture and practice or behaviour) but also teamwork and relations. The relations involved staff, staff and patients, staff and relatives, patients and relatives, and the wider family. Dawn's experience of support in the workplace was in contrast to other RN's memorable events. Alice's and Elsa's unique superordinate themes are discussed in section 10.2.

SUMMARY

In summary, the overarching shared experience is that memorable clinical dying and death experiences are imbued with 'emotional work'**.** This is underpinned by the common themes of 'knowing' and 'doing'. Pain control was cited as an important general component of end-of-life care and providing comfort care can be understood as 'doing'. This descriptive analysis has demonstrated that the participants have shared experiences and that working with dying and death, perhaps unsurprisingly, involves emotional work.

Beth described Mary's death was "*as good as it could be*" (L 236). Beth categorised this as a '*good death'*. Beth ended our interview with these reflections:

> "*Yes I can come and talk to Denise about my experiences and I'll be fine. And then you re-live it, and it still gets you. How, how, how can it still get me? And it does. Yeah but I think she'll get me forever she will. I just think about her and you do don't you in nursing you think of some people just stay with you forever. I don't know why all, the ones, you know I've seen some horrible things I've seen some great things, but a lot of them go by the wayside and it's just the odd one that really stick with you. It's very strange. I don't know why*" (Beth, L 538 -547)

A quote that sums up a residual impression of emotional work associated with delivering end-of-life care.

10.2 PARTICIPANTS' UNIQUE EXPERIENCES

This section considers the unique experiences that have been described. Alice was unique in describing and explaining her personal values and beliefs, particularly that there is no such thing as a bad death. Her experience of dreaming of an orca whale she understood as symbolic of a particular dying trajectory (Iain). This appeared to be particularly important to Alice and culminated in a description of the blurring of professional boundaries; the personal affecting the professional.

Smith (2011) emphasised the use of 'the gem' which stems from the words of a particular participant but adds value to the analysis as a whole. He argues that 'the gem' helps shine light on the phenomenon. One particularly unique 'shining gem' was Elsa's observation that older people are "*more run-of-the-mill*". Smith (2011) explained that the shining gem becomes apparent with limited effort on the part of the researcher. The participant is also aware of the meaning of what they are saying and is able to articulate it. Elsa had explained she had found it difficult to think of a memorable older person's dying and death because they are "*more run-of-the-mill*". She started to explore the meaning and ethical implications of this:

> "*I don't know if age is (pause) and I think it's tempting (pause) underneath, I don't do it on the surface but I think underneath I probably think oh well they have had a good life that (sigh) you have to die in some way*" (Elsa, L 194-196)

This extract was specifically explored within the linguistic analysis (section 9.3). This also demonstrates working with the part and the whole as part of the hermeneutic circle. The implications of this 'shining gem' for the wider study are twofold. The first observation is that participants did not specifically explore older people who have frailty in the sense that I had anticipated. The second observation is that perhaps 'run-of-the-mill' deaths are 'good enough' deaths. They are not particularly memorable, but to become memorable would have likely involved good, effective or bad, ineffective care outcomes.

10.3 CONCLUSION

This chapter has presented the findings of the descriptive and conceptual analysis of RN's shared themes and unique experiences. Whilst IPA is concerned with the particular, analytical procedures enable the movement from single cases to more general statements. However these general statements remain traceable to the particular claims of any of the individuals' involved. This chapter has attempted to make explicit the similarities and differences of experiences by looking for and presenting patterns across cases with regard to the understanding experiences of the good enough, and not good enough death. The overarching shared experience is that memorable clinical dying and death experiences are imbued with emotional work. This is underpinned by the common themes of 'knowing' and 'doing'.

Conversely the 'run-of-the-mill' deaths in old age are non-memorable, but it is not possible to conclude that these deaths do not, or did not involve emotional work. However there is potential that 'run-of-the-mill' deaths are, by virtue of being non-memorable, may be 'good enough' deaths. However for me, 'run of the mill' particularly associated with older adults with frailty created a sense of invisibility.

The next section will integrate findings of the literature review with exemplars of the RN's experiences to explore examples of convergence and divergence between the extant literature and this study's findings.

11.1 INTRODUCTION

This thesis critically explores the experiences of RN's in delivering end-of-life care for older adults with frailty. IPA prioritises the participants claims "on their own terms" (Smith et al., 2009: p.42) but as Smith et al. (2009) state "it doesn't hurt to have some idea" (p.42) what these claims are likely to be by engaging with the literature. In IPA, an initial scoping of the literature is undertaken, as such the literature search and filtration process was commenced prior to undertaking the interviews. A key aim of IPA is to make a contribution through interrogating or illuminating existing research (Smith, 2004). The researchers themselves also have a responsibility to discuss findings through interrogation of the extant literature and to point out and debate the connections as well as the dissonance between the findings of the study and the prevailing discourse and or evidence (Smith, 2004). The purpose of this second literature review is to support the RN's understanding of their experiences by integrating them with existing literature.

IPA is committed to giving voice to the participants' experiences and emphasises this as a priority. The themes derived from this literature review were developed following analysis of the RN's experiences. The RN's shared superordinate theme is that working with dying and death is 'emotional work' underpinned by 'knowing' and 'doing'.

The literature review was undertaken to cover the 13 year period between January 2005 and December 2017 to reflect contemporary healthcare. Although this study is focused on RN's experiences, older adults' care most often involves multiple professionals and at times multi-agency co-operation. For this reason other professionals were included within the search strategy. The literature was systematically searched using AMED (Allied and Complementary Medicine), EMBASE, Ovid MEDLINE(R) databases originally for the period 2005-2015. The searches were re-run for the years 2016 and 2017. To keep up to date with the literature, an auto alert service (Selected Dissemination of Information: SDI) was set up and subsequently three further papers were included. The search strategy is detailed in appendix 9.

To be considered for inclusion the abstract was available and reported in English. The inclusion criteria required the abstract to indicate that the paper was concerned with

end-of-life care and staff experiences, attitudes, views or perspectives. If this was unclear the full paper was retrieved. Specific exclusion criteria included child, infant, adolescent or maternal death, voluntary euthanasia, physician assisted euthanasia or suicide, and life limiting illness not end-of-life care. Figure 13 depicts the literature selection process. The decision to include or exclude each search item was recorded in an Excel spreadsheet. A section of the spreadsheet is shown in figure 14.

FIGURE 13: LITERATURE REVIEW PROCESS

	A	B	C	D	E unclear	F end-of-life care	G staff experiences, attitudes, views, perspectives	H child or maternal death	I euthanasia, physician assisted and or suicide	J lifelimiting illness not EOLC	K patients or relatives experiences	L EOLC discussions	M specifically older adults	N exclude abstract screen	O include	P paper retrieved	Q subsequently excluded	R Comments
266	Noome	2016	Exploring family experiences nursing aspects of end of life care in the ICU	Netherlands		1	0	0	0	0	1	0	0	0	1	1	1	relatives experiences
267	Phongtankuel et	2016	Why do home hospice patients returned to the hospital	USA		1	1	0	0					0	1	1		
268	Shaw et al.	2016	Living well to the end the phenomenological analysis of life in extra care housing	UK		0	0	0	0	1	1	0	1	1	0		
269	Thoresen et al	2016	Advance care planning Norwegian nursing homes- who is it for	Norway		1	1	0	0	0	1	1	1	0	1	1	
270	volandes	2016	use of video decision aids months ACP in Hawaii	USA	1	0	unclear	0	0	0	0	1	0	0	1	1	1	
271	Vrijmoeth	2016	Physicians identification of the need for palliative care for the intellectual disabilities	Netherlands		0	1	0	0	0	0	0	0	0	1	1		
272	Wholihan	2016	Seeing the lights-end of life experiences visions, energy surges in a good death bed phenomena		1	1	unclear							0	1	ILL	1	energy surges
273	Wilcock	2016	Lung cancer diagnosed following an emergency admission	UK		0	0	0	0	1	1	0	0	1	0	0		
274	Wion	2016	EOLC behind bars	USA & UK		1	0	0	0	0	0	0	0	0	1	1	1	Not clearly health staff
	Zimmermann	2016	Perceptions of palliative care amongst patients with	Canada	1	1	unclear	0	0	0	1	0	0	0	1	1	1	caregivers were family

hand search | 2006-2016 | 2016 | **2005-2017** | 2017 | alerts 2017

The overarching themes identified from within this literature review included care delivery (care actions, ethical issues and communication), the self (emotional self and knowing) and the dying trajectory. Although presented as discrete overarching and subthemes, the reality is that many examples of the themes overlap other categories. The overarching themes and subthemes are presented in figure 15.

Care delivery

Care actions
- care actions
- dignity
- cultural sensitivities

Ethical issues
- missed care actions
- futility
- decision-making

Communication
- anticipatory care/place of death
- good/quality
- limited/missed/difficult/avoided

The self

Emotional self
- feelings of burden/uncertainty
- coping resources
- grief and loss

Knowing
- interpersonal relationships
- knowledge, skills or training
- use of different types of knowledge i.e tacit/ reflection

The dying trajectory

Dying trajectory
- recognition/prognostication/uncertainty
- models

The studies were undertaken in a variety of settings with various healthcare professionals, care assistants, family members, patients, residents and managers. The studies predominantly used qualitative methods with six utilising a mixed methods approach.

A critical grid (see appendix 10) contains details of setting, data collection method, and participants. It also maps the overarching themes that were present in all the publications, however the sub themes did vary.

 An overview of the findings of the literature review are presented in table 18.

Overarching themes	Care delivery									The self						The dying trajectory	
Sub themes	Care action			Ethical issues			Communication			Knowing			Emotional self			Dying trajectory	
	Care actions	Dignity	Cultural sensitivities	Missed / unachievable care	Futility	Decision-making	Anticipatory care/ place the of death	Good / quality	Limited / missed/ difficult	Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/ reflection	Burden/ vulnerability	Coping resources	Grief and loss	Recognition/ prognostication uncertainty	Model
Number of times included	21	11	6	11	9	19	21	14	26	30	23	10	24	13	13	27	11

The next section will integrate findings of the literature review with exemplars of the RN's experiences to explore examples of convergence and divergence between the extant literature, the experiences of the RN's and the overarching findings of this study.

11.2 CARE DELIVERY

11.2.1 CARE ACTIONS

The overarching themes derived from the literature review included care delivery, the self and the dying trajectory. Care delivery aligns with the findings of this study in 'doing'. Care delivery is underpinned by care actions, ethical issues and communication. Care actions include day-to-day care along with the utilisation of specialist roles and skills (Cartwright et al., 2009; Kaasalainen et al., 2013). Some care actions are specifically associated with patient dignity and cultural sensitivities (Johnstone et al., 2016). Dawn described organising the environment of care and using curtains to provide "*a little bit of dignity*" (L 421-422) whilst Ffion explained that in the case of an unanticipated patient death "*we had to put the curtain round, which wasn't very nice, like the other patients sort of guessed what had happened*" (L 359-360). Care actions incorporate physical and emotional care (Goodridge et al., 2005; Van Humbeeck et al., 2016) and surveillance (Bacon, 2017). Whilst care actions are not exclusively concerned with meeting physical need, interpersonal relationships,

communication and ethical issues emerged as discreet themes within the literature. Cara also described clear delineations between interpersonal relationships, practical care actions and patient and staff communication. She observed "*the rapport that that the nurses strike up with the families, from a very palliative care kind of focus, whereas actually I'm not very good at doing that. I can do the patient care, I can do the directive kind of care and everything like that and symptom management*" (L 40-43), which illustrates a congruence between her experiences of 'doing' and the overarching themes of 'care actions' and 'communication'.

Hirano et al. (2011) identified key care actions and responsibilities of home care nurses. These involve estimating the possibility of dying at home, visualising what is coming and what can be done, enabling family to be able to say goodbye, building family consensus, coordinating resources, and offering psychological support for bereavement. These six care actions are undertaken continuously from the onset of illness through to death illustrating the breadth of care delivery. Beth's involvement with her patient Mary, Gwen with 'her lady', and Ffion's patient John, all of whose deaths were 'good enough' can be aligned with these care actions and responsibilities. However the 'not good enough' dying and death's relating to Cara's experiences and Beth's 'lady's' story do not align with these, nor does Ffion's experiences with Jack's unanticipated death. These four deaths took place in the hospital rather than the home environment but arguably these are transferable actions and responsibilities.

Brown et al. (2011) studied care actions with an interest in conserving dignity in end-of-life, and similarly Periyakoil et al. (2013) and Saevareid and Balandin (2011) were concerned with the intensity of treatment in terminally ill people and resuscitation decisions. End-of-life was not necessarily defined as imminent dying but could involve the preceding months. Conversely Cable-Williams and Wilson (2017) found that palliative care is not recognised as an intervention in long term care facilities until the residents are recognised as imminently dying; that is the last few hours or days before death. They also observed an intensification of care actions for the dying person. In a different vein McClement et al. (2010) found healthcare support workers re-did aspects of patient care to redress aspects of observed perfunctory care. Not dissimilarly Hov et al. (2009) discovered that if and when nurses disagree with decisions made by others, they do not necessarily convey their opinions or have

discussions with those responsible; their response is to give the patients intensified care as compensation for the 'wrong' decision. At times nurses also revoke physicians' orders and covertly adapt the care and treatment delivery (Hov et al., 2009). Beth's prior experiences as a student nurse help illustrate this; "*we kind of went around him* [Dr] *and spoke to the palliative nurse which I know we're not really meant to do*" (L 55-56), exemplifying an aspect of the phenomenon of 'redoing' (following the medical ward round) and 'adapting' as an attempt to compensate for perceived ineffectual care decisions.

Bailey et al., (2011) identified emergency care actions within the spectacular trajectory of end-of-life care in the EU which were associated with good quality, attentive responsive care. In contrast, the absence of crucial care actions in the subtacular trajectory resulted in poor care and was described as neglect. Depersonalisation was generally used as a coping strategy in the EU. In a different context Elsa felt that hospital staff "*feel guilty and so they, they withdraw because they can't give the time*" (L 146-147). Here the links between care actions and ethical concerns are made explicit. Missed care actions were also evident and tolerated in one US nursing home (Forbes-Thompson and Gessert, 2005); here psychosocial care was not addressed. Forbes-Thompson and Gessert (2005) present several exemplars of poor care emanating from poor leadership and the attitudes associated with the delivery of perfunctory care. They found that as the home was assessed as meeting federal and state standards, the administration interpreted this as evidence that they were providing good (or perhaps just good enough) standards of care. One of the leaders is quoted in stating that "the state is paying for a resident to be fed, bathed, turned; they are not paying for someone to sit down and talk" (p.548), a strikingly uncompassionate philosophy. They use a different care home to provide exemplars of good care. Good care is attributed to 'caring' personalised interactions. The authors determined that compliance in order to meet monitored standards is not good enough and it negatively impacted on the individual residents' quality of life. However the monitoring of these standards imply that they are 'just' good enough. Forbes-Thompson and Gessert (2005) conclude that "it is not necessary to think of good end-of-life care as conceptually different from good care in general" (p.554), a poignant observation, the difference of course is that there is arguably only one chance to get end-of-life care right.

Healthcare provision varies across the world and perceptions of quality of care do vary. These perceptions are likely influenced by cultural beliefs and practice. Aita et al. (2007) explored why Japanese medical staff feel bound to provide artificial nutrition and hydration through the use of percutaneous endoscopic gastrostomy (PEG) tubes in older patients with severe, irreversible cognitive impairment. They identified legal issues such as lack of proxy decision-making laws, the long held medical primacy of prolonging and saving life, and cultural values which place significant importance on continuing the life of the patient for the family. Additionally medical reimbursement is a related factor for undertaking the PEG procedure. Beth described subtle aspects of differences in professional culture and practice between doctors and nurses, whereby doctors were perceived to be "*treating and doing*" (L 101) in a futile sense. Conversely Gwen recounted how the community team urgently arranged for their district nurse colleague to be transferred from hospital to home to die in response to perceived poor assessment and hospital care; "*we got her home and she was peaceful yeah. On a Friday afternoon*" (L 1055).

Regarding her male patient, Cara referred to his family's Middle Eastern culture: *"he had really dedicated, two daughters and a son, and he was an older man, they had done everything for him you know a proper Arabic family*" (L 295-296). This appeared to be said in a warm and approving sense. Cultural sensitivities and language barriers can create difficulties in practice (Chan and Kayser-Jones, 2005; Kramer and Auer, 2005; Periyakoil et al., 2013) and Cara's experiences of her patient's family values and intense focus on their father did create some significant tensions in practice. Livingston et al. (2011) also found that care home nurses from overseas feel that they are perceived as less professional by relatives, and as a result feel vulnerable in a foreign country. It is apparent that cultural sensitivity in healthcare is interwoven with opaque ethical issues which may affect both those receiving care and those delivering it.

11.2.2 ETHICAL ISSUES

Ethics "is a generic term for various ways of understanding and examining the moral life" (Beauchamp and Childress, 2001: p.1). It is concerned with the moral principles of right and wrong human conduct (p.2). 'Professional morality' (Beauchamp and Childress, 2001: p.5) is concerned with standards of conduct that are generally acknowledged by those in the profession. In the UK, RN's adherence to 'the Code'

(NMC, 2015a) enacts the 'the professional morality'; the professional standards that RN's and midwives must uphold. Issues concerning problematic professional ethics can arise from conflicts over professional standards (Beauchamp and Childress, 2001). Cara's reference to the junior doctors' conversation and behaviours which were, on one occasion "*just completely inappropriate*" (L 116) illustrates this. The three sub-themes concerning ethical issues emerging from the literature explore missed care actions, futility and decision-making. Missed nursing care represents care being left undone (Ball et al., 2014a). Considering futility, Beauchamp and Childress (2001) explain that decisions about beginning or ending treatment should be based on considerations of the benefits and burdens of the treatment as judged by the patient or a Lasting Power of Attorney where possible. Periyakoil et al. (2013) question why doctors continue to provide high intensity care for terminally ill patients but personally would opt out of such care for themselves at end-of-life. Ethical issues can be difficult to tease out and resolve.

Healthcare support workers in a nursing home hold a moral sense of obligation and duty in delivering end-of-life care (McClement et al., 2010). The experiences that they find ethically problematic include inadequate pain control, the provision of perfunctory care (going through the motions), inadequate resources, and a perceived disregard of residents wishes regarding end-of-life care preferences by the residents' family members. This experience is described as a 'broken covenant' (McClement et al., 2010). Ffion's story of the male patient who had mental capacity but 'ripped out' his PEG and refused analgesia created ethical concerns in practice. Ethical concerns are also evident in the use of 'perfunctory' care in a compliance centred, rather than person centred philosophy (Forbes-Thompson and Gessert 2005). In a UK study, Livingston et al. (2011) found that staff often transfer residents with dementia into hospital despite the wishes of the family, and despite the fact they feel they can recognise when their residents are near death. These actions are rooted in concerns about blame, potential litigation and the view that life should be prolonged as much as possible.

Nurses' perceptions and experiences of attempting cardiopulmonary resuscitation on the oldest of the old is also occupied with ethical concerns (Saevareid and Balandin, 2011). Poor communication and perceived poor decision-making creates ethical

dilemmas in practice. Do not attempt resuscitation orders are associated with avoiding futile treatments (Saevareid and Balandin, 2011) but the concept of futility was surprisingly sparse in the literature. That said, oncologists associate futility with the treatment of older adults including a belief that they are less likely to want or tolerate treatment (Bluhm et al., 2017). The effect of incorporating specialist palliative care into the critical care environment facilitated a change from intensive burdensome treatments at end-of-life towards higher rates of advance decision making and use of hospice, and a reduction in use of certain non-beneficial treatments (O'Mahony et al. 2010). Conversely, in the ED it was found that when the patient is hovering 'on the edge of clinical and social death', resuscitative efforts may be pursued even when unlikely to be effective (Chan, 2011). Within the EU overall care was found to be poor for patients within the subtacular trajectory (Bailey et al., 2011). These patients are frequently older adults, often with complex needs associated with chronic disease or terminal illness. This illustrates the dependency and vulnerability of people who are situated along the chronic disease or frailty trajectory of dying, and especially those who do not have the mental capacity to make or communicate their needs, or make highly individualised decisions.

Significant ethical concerns surrounding decision-making are evident, particularly concerning the initiation and administration of anticipatory medication (Wilson et al., 2015), the use of continuous sedation (Anquinet et al., 2014; Douglas et al., 2013; Robijn et al., 2017) and palliative chemotherapy (Näppä et al., 2014). Likewise Elsa discussed the felt responsibility of "*starting off the whole process*" (L 408) of administration of breakthrough drugs as she explained "*they might have had a bit of lorazepam before and then you're the one who sticks the needle in with midazolam*" (L 417-418). In the literature various end-of-life decisions brought with them feelings of significant responsibility (Hov et al., 2009; Ruopp et al., 2005; Saevareid and Balandin, 2011; Touhy et al., 2005; West et al., 2005) demonstrating a felt burden in weighing up ethical dilemmas. Ffion's experience and actions "*don't tell her he's died*" (L 276-277) is also arguably an ethical issue.

Bluhm et al. (2017) found that oncologists report that they treat younger patients near death but not older patients with similar clinical presentations. They describe these

decisions at either end of the age spectrum as 'easy'. Interestingly Brummell et al. (2016) who studied decision-making in commencing, continuing or stopping cardiopulmonary resuscitation, observes a heuristic distinction between 'old age' and 'elderly'; the latter being associated with illness or 'extreme frailty' which is incorporated into the decision-making in the context of 'biological data'. Elsa was the only participant who explored differences in decision making in the case of older adults. She concluded "*I don't think that we would change the medication stuff because somebody's old. You know I don't think we 'oh they've had a good life' we better* […] *you know we'll sedate them quicker or anything*" (L 458-463).

Older adults' dying is permeated with ethical concerns. In Bailey's et al. study (2011) the subtacular trajectory is most relevant for older adults, often involving poor care. Aase et al. (2008) found for physicians, older adults' death is usually perceived as unproblematic and natural, as are conversations with older patients about death and dying; potentially "*more run-of-the-mill*" (Elsa, L 10). However in a study of medical students' first experiences of a patients' death, the authors conclude that "old deaths were frequently experienced as so routine as to be dehumanizing" (Kelly and Nisker, 2010: p.424). McClement et al. (2010) found the 'routinised, mechanical interactions' associated with 'perfunctory' care as ethically problematic for their participants. The need to protect the individuality and dignity of older adults is clear. If older adults' deaths are viewed as routine, this may contribute to de-sensitised, undignified care, which arguably is 'not good enough'. This routinisation also draws attention to the question of how nurses in the acute setting particularly become familiar with frail older adults' values and wishes, particularly as Browall et al. (2014) found that nurses experience existential dilemmas when they had cared for a person over a long period of time but had not known their wishes surrounding end-of-life care.

11.2.3 COMMUNICATION

Effective and sensitive communication is crucial to achieving satisfaction with quality of care (Granek et al., 2013; Seccareccia et al., 2015; Thoresen et al., 2016), yet communication can be problematic (Ball et al., 2014b; Bélanger et al., 2014; Browall et al., 2014; Casey et al., 2011; Chan and Kayser-Jones, 2005; Goddard et al., 2013; Hockley, 2014; Livingston et al., 2011; McVey et al., 2014; Munn et al., 2008; Ostertag and Forman, 2008; Tan et al., 2013; Towsley et al., 2015). Communication surrounding

end-of-life care in care homes is described as 'largely taboo' (Livingston et al., 2011). Cable-Williams and Wilson (2017) found that the culture in Canadian long-term care facilities emphasised messages about living to the exclusion of dying, even though one in three of their residents would die each year. Staff need training and support to deliver explicit, sensitive information (Cable-Williams and Wilson, 2017; Livingston et al., 2011), with staff feeling emotionally unsupported in communicating with relatives about their loved ones end-of-life care (Livingston et al., 2011). Gwen, an experienced nurse, talked about feeling unsupported in her own practice surrounding the preparation of patients and families for a potential 'bleed'; "*we've always felt that perhaps it's not a district nurse's role, because there is somebody above us that should have that responsibility*" (L 664-665). This demonstrates that explicit, sensitive information giving can be delivered at multiple levels, by people with different experience and responsibilities.

In care homes it is reported that staff rarely provide other residents with clear information about fellow residents deaths, and frequently conceal death information which co-residents perceive as disrespectful (Ball et al., 2014b; Tan et al., 2013). Dawn also highlighted this as a dilemma in practice when other patients ask "*oh, how, when*?" (L 619) about fellow patients. She explained "*if somebody is unwell or has died it's sometimes hard to not disclose things that you shouldn't disclose*" (L 614-615) which could in turn be perceived as concealment.

The quality of anticipatory care and for anticipating place of death are largely reliant on effective communication (Bélanger et al., 2014; Cartwright et al., 2009; De Korte-Verhoef et al., 2015; Denvir et al., 2014; Handley et al., 2014; Munn et al., 2008; Periyakoil et al., 2013; Slort et al., 2011; Thoresen et al., 2016; Verhoeven et al., 2011). Ffion contrasted the responsibilities of communicating sensitive issues within the hospital and in the community, the onus in the hospital being with the doctors, and in the community it requires more involvement by the district nurses. However both Ffion and Gwen perceived that there is more open awareness of terminal illness in the community.

Whilst in an attempt to protect the patients, a system of closed awareness in a care home was found to dominate whereby staff keep people 'in the dark' regarding their terminal status (Casey et al., 2011). Beth discussed this in the hospital context

"*sometimes we know before they do that their prognosis isn't good and you'll get handover 'this patient doesn't know'. When are we going to tell them? Are we going to tell them? They need to know, they have a right to know*" (L 456-458). Indeed, Browall et al. (2014) found that open awareness between nurses, the patient and their family are experienced as feelings of 'relief'. To the contrary, Livingstone et al (2011) found that staff avoid conversations about people with dementia being at the end-of-life. They feel this is protecting 'everyone' from upset. Whilst palliative care staff feel it is important to communicate directly about impending death, Seccareccia et al. (2015) found that there are mixed responses from family caregivers about staff being direct with their loved ones. In terms of information giving, Elsa talked about protecting family members during the last days of life "*so the idea is just-- we can tell them that they are dying, but you don't need to go through all the things about the issues, the priorities and stuff because it just causes so much disruption for people and so much anxiety*" (L 485-487). Bélanger et al. (2014) also found that discussions about symptom management in end-of-life care is part of healthcare professionals anticipated role, but the decision to initiate conversations regarding preparation for death remains under the patient's control. Gwen provided an example of this "*he knew what was wrong with him. Very, very aware but in denial. Totally not wanting to discuss anything*" (L 286-288). This demonstrates the complexity of information giving in content and timing as well as individual sensitivities.

In a slightly different vein, Back et al. (2009) focus on the non-abandonment of critically ill dying patients and their families, and the communication strategies employed to facilitate this. In a related way Cara observed that as her patient "*started to get poorlier, the family became more demanding*" (L 302-303) and that she needed to "*kind of deal with them a bit differently*" (L 323-324). Slort et al. (2011) explored the facilitators and barriers in palliative care communication between GP's, consultants and patients. They found that for patients as well as GP's, essential enablers include accessibility, taking time, showing commitment, and listening carefully. Major barriers reported by GPs and end-of-life consultants differed slightly and include difficulty in dealing with former doctor's delay, strong demand from patient relatives, difficulty in dealing with strong emotions, troublesome patient problems and concerns, promises that could not be met, helplessness, insufficient anticipation and too close involvement in the part the GP (Slort et al., 2011). Dawn had experienced difficulty in

dealing with the strong emotions of a bereaved patient's relative who "*was very angry, and she accused us of choking him, she accused us of killing him*" (L 121) which arguably impact on the quality and effectiveness of communication.

Hockley (2014) observed that the use of euphemisms give mixed messages to staff and relatives, whilst Livingston et al. (2011) found that staff use euphemisms as a tactic to avoid being held to account in terms of information giving. Conversely Cara recounted the strong demands, expectations and "*distress*" of a patient's relatives who were "*in denial*" and demanding that the medical team revoked a do not attempt resuscitation order on their actively dying father. This illustrates that direct communication can, as Beth described, fall "*on deaf ears*" (L 164), although there is potential that language and cultural differences compounded these uncomfortable experiences.

11.3 SELF

11.3.1 EMOTIONAL SELF

Dealing with dying patients and death is an emotionally demanding role (Centofanti et al., 2016; Goddard et al., 2013; Rejno et al., 2012). This thesis has presented 'emotional work' as its superordinate theme. Similarly Van Humbeeck et al. (2016) argue that 'keeping an appropriate distance' and withdrawal are self-care coping strategies used by staff. Elsa also described staff 'withdrawing'. Personal discomfort with death and dying has been recognised in oncologists (Granek et al., 2013) along with the potential to bring back memories of other loved ones who have died (Ní Chróinín et al., 2011). Indeed Elsa referred to her mother's dying and death and Gwen talked about caring for her dying father. Interestingly, Gwen focused on trusting others "*you knew that they'd be fantastic looking after him, but it's like that trust. You didn't trust them for you know, maybe only an hour*" (L 919-921). She did subsequently entrust the day care unit with his care for short periods. Ffion was the only participant who explicitly referred to her own 'potential' death in terms of place of death. Delivering end-of-life care is complicated by the need to continue to provide care to others (Ní Chróinín et al., 2011) whether that is in a hospice, hospital, care home or their own home. Similar experiences were discussed by Ffion and Dawn.

The emotional vulnerability of staff can be seen with six papers explicitly exploring the existential experiences of healthcare staff (Aase et al., 2008; Browall et al., 2014; Jansen et al., 2016; Kelly and Nisker, 2010; McClement et al., 2010; Ruopp et al., 2005). Beth, Cara and Gwen described how they had experienced leaked emotions and became tearful in practice. Cara talked about her coping strategies with terms such as "*boundaries*", "*shield*" (L 196) and "*uniform*" (L 260). Elsa referred to the use of counselling and debriefing. Ffion did not describe personal coping mechanisms but difficult scenarios were accompanied by laughter, arguably a coping mechanisms in itself. However she also described feelings of helpless "*there was nothing we could do*" (L 482). Contrary to the literature and to other participants' experiences, Alice described her coping in terms of "*I don't really ever go home and think, oh that was terrible today. I just feel like well I did my best and that was all I could do*" (L 310-311). Nevertheless both Alice and Beth became tearful during the interviews when recounting their stories.

Nurses have emphasised concerns about their accountability (Bacon, 2017; Livingston et al., 2011). A mismatch between what participants believe is best practice and the reality of care delivery can create internal turmoil (Casey et al., 2011; Sims-Gould et al., 2010) which along with a sense of powerlessness (Browall et al., 2014; Jansen et al., 2016; Touhy et al., 2005) could lead to emotional distress. Cara described a memorable death using the term "*we really failed her*" (L 148) and she recalled that at the time she felt very "*upset*" (L 80). Kelly and Nisker (2010) exploring the experiences of medical students found a tension between emotional concern and professional detachment, likewise Jansen et al. (2016) found that care home doctors feel challenged in balancing personal commitment and protective disengagement of the dying patient, whilst Bekkema et al. (2015) describe that the interweaving of emotional and professional involvement becomes a struggle. However, Brummell et al. (2016) conclude that experienced practitioners develop strategies to cope with the moral uncertainties of balancing intervention and withdrawal of treatment in critical life-and-death situations. Beth's experience of refusing to initiate a sliding scale insulin infusion on a dying patient is an example; "*I'm not doing a sliding scale insulin, it's cruel*" (L 178). Physicians also expressed feelings of sadness and guilt, but developed individualised coping strategies in order to provide end-of-life care (Aase et al., 2008; Back et al., 2009; Kelly and Nisker, 2010; Ruopp et al., 2005; Slort et al., 2011).

Interpersonal relationships between staff are also associated with satisfaction levels. Livingston et al. (2011) identified poor interpersonal/ interprofessional relationships whereby the nurses, care workers and doctors do not see themselves as team. Hov et al. (2009) also found a hierarchy between doctors and nurses but also between nurses working different shift patterns, between newly qualified and experienced staff and between care home and hospital staff. This can be seen in Ffion's narration of hospital experiences; "*she's not very compassionate anyway. So I we used to call her doctor because she used to think she was a doctor*" (L 326-327). On the other hand, Hov et al. (2009) found that care home nurses often feel that they have been unfairly criticised especially by the hospital, but often they say nothing even when they disagree with a decision made by a colleague. This is in an attempt to remain loyal to their co-workers.

Grief and loss experienced by nurses did feature in some of the papers. Goddard et al. (2013) conclude that there is a need to improve support networks to help staff to deal with their grief. The stresses of providing end-of-life care are often referred to but the only papers that focused exclusively on the nurses' existential encounters were Browall et al. (2014) and Bacon (2017). Browall et al. (2014) found that nurses' accounts of critical incidents in end-of-life care exposed feelings of anxiety, insecurity, loss of control, guilt, punishment, powerlessness, insufficiency and uncertainty. Similarly Bacon (2017) examined nurses' experiences with patients who died from failure to rescue after surgery. Their memories were recounted in vivid detail years later and they expressed feelings of shock, loss, disbelief and some guilt. This reflects one of Cara's experiences. Bacon (2017) describes these deaths as unexpected but not necessarily preventable. This also aligns with Ffion's experience of Jack's unanticipated death "*he just died. He was going to be discharged*" (L 606-607), and Cara's female patient who died.

Tan et al. (2013) explored residents' grief, whilst Ní Chróinín et al. (2011) found that both residents and staff experience grief following the death of a resident. They proposed a four stage model that describes grief reaction following a fellow resident's death. However, Livingston et al. (2012) and Van Humbeeck et al., (2016) conclude that staff feel that their grief is inappropriate, and that there is not time to express grief. Beth's experience was slightly different in that with Mary's relatives "*I did let a tear slip but I think they, they respected that because they knew that we cared*" (L 274-

275). However Beth cried and "*really couldn't get it together and when the family came in I just thought I need to get it together. I can't be like this*" (L 272-274). There is also a residual emotional response as Beth also became tearful during the interview.

These findings highlight the complexity of the emotional self in delivering and being surrounded by end-of-life care. Not dissimilarly Granek et al. (2012) explored oncologists perceived support needs to help them cope with patient loss, and Hockley (2014) identified the benefits of facilitated debriefing for staff following the death of a resident; both Alice and Elsa spoke of the need for staff debriefing when working with dying and death. Amidst the 'emotional self', a sense of privilege and being special in sharing patients' life stories was revealed (Browall et al., 2014). Both Beth (L 243) and Alice (L 322) referred to the 'honour' of being involved in specific patients' dying and deaths.

11.3.2 KNOWING

Arguably a generalised theme of knowledge and knowing was present within all papers involving all participants which enabled the investigators to answer their research questions. The theme 'knowing' in the literature relates to three sub themes: interpersonal relationships, knowledge, skill or training use or need, and the use of different types of knowledge including tacit knowledge and reflection in and on practice.

Livingston et al. (2011) and Sims-Gould et al. (2010) examined enablers and barriers associated with improving end-of-life care for people with dementia. Enablers related to the warm, family like bonds and relationships between staff and residents, and enhanced and frequent communication. Getting to know patients and their families was important to all the participants in this study. Even though Cara described being uncomfortable and avoiding "*the interaction with relatives*" (L 36), her reality was "*you can't help but get to know the families and you know you have that kind of deeper compassion for the families so in a way it's kind of unavoidable*" (L 278-280).

Vrijmoeth et al. (2016) found that doctors caring for people with a learning disability rely on multiple sources of information and signals to alert them to the need for palliative care referral, incorporating their knowledge and experience with knowing the individual and their carers. As Gwen said "*I think it's nice to get to know the family.*

I think for them it's very hard if you go in the last couple of days. And they know nothing about you they don't know anything. I find that's really dif can be very difficult" (L 330-332).

Bekkema et al. (2015) identified an intensified caring relationship between families, relatives and care home staff associated with end-of-life care. Casey et al. (2011) identified three enablers that govern the provision of good end-of-life care: the philosophy, culture and organisation of care, knowing the person, and the physical environment and resources. Knowing the person was felt to be a crucial enabler in developing relationships, interpreting treatment and care wishes when communication was no longer possible, and being able to distinguish between normal behaviour patterns and episodes of distress. However knowing the person makes little difference where there is a philosophy of closed awareness and closed communication regarding dying and death (Casey et al. 2011).

The use of tacit and experiential knowledge was emphasised by Brummell et al. (2016). In describing four resuscitation categories, they conclude that these categories are constructed quickly for each individual patient using "fast and frugal heuristic decision-making approaches" (p.54) combining technical and bodily information whilst considering the social context. Bacon (2017) quoted nurses using tacit knowledge such as "keep an eye" and "something doesn't feel right". Whereas Centofanti et al. (2016) and Ruopp et al. (2005) observe that the research interview process assisted junior doctors to reflect on their experiences, and to identify how their care may have benefited both patients and families.

A number of papers focused on identifying training or service development need (Borgsteede et al., 2006; Centofanti et al., 2016; De Korte-Verhoef et al., 2015; Denvir et al., 2014; Granek et al., 2013; Granek et al., 2012; Hockley, 2014; Horey et al., 2012; O'Mahony et al., 2010; Ostertag and Forman, 2008; Seccareccia et al., 2015; Slort et al., 2011; Verhoeven et al., 2011). Others recognised the importance of skilled, knowledgeable staff (Goddard et al., 2013; Kaasalainen et al., 2013). Both Alice, and Cara referred to lack of knowledge in the practical skills of tracheostomy care and use of nasal tamponades respectively, whereas Beth spoke in a more generalised way about palliative care "*I think I know I know a bit, and I know more than some but I*

don't know enough" (L 379-380). Knowledge, knowing or not knowing was unsurprisingly threaded throughout the literature and the participants' experiences.

11.4 THE DYING TRAJECTORY

The dying trajectory featured in 34 of the 68 included papers. In some cases it was associated with prognostication of dying which necessitates recognition of dying and often features some uncertainty. As such, a core enabler or barrier of the good enough death is recognition of the dying process (O'Mahony et al., 2010; Phongtankuel et al., 2016; Verhoeven et al., 2011; Welch et al., 2008) which can be challenging with chronic progressive disease in advanced old age as there are few prognostic markers (Cable-Williams and Wilson, 2014). Ffion's experiences of Jack's unanticipated death in hospital demonstrated this.

Livingston et al. (2011) interviewed nursing and care staff working in a care home for older adults and found that although care staff are experienced in delivering end-of-life care, and recognising when people were nearing death, they do not use this knowledge to deliver good end-of-life care. Conversely Welch et al. (2008) found that nursing staff working in nursing homes believe that the opportunity to accurately recognise terminal decline in residents is very limited. Hov et al. (2009) refer to vulnerable residents being 'on the edge of life', a transition between living and dying, with uncertainty as to whether the outcome of illness or crisis will result in recovery or death. This suggests that the chronic disease trajectory of dying can obscure the more subtle signs of the dying process and has a component of uncertainty. A study of respondent pairs of bereaved family members and staff found that the majority of staff and family described the trajectory of the illness as a slow steady decline rather than stable or as a series of health ups and downs (Rich et al., 2010). However around a third of the family staff pairs disagreed about whether the death was expected, whether the symptom burden was low or high and the type trajectory the decedent experienced. Dawn's experiences of both patients' deaths were permeated with uncertainty. The story of the female patient collapse/fall who they "*defibbed her and brought her back*" (L 447) but subsequently died is an exemplar. The male patient Dawn treated with palliative chemotherapy may have had an anticipated dying trajectory, however his dying and death did not follow this.

A study of the care of critically ill patients at end-of-life and found that the concept of terminally ill and dying lack precision (O'Mahony et al., 2010). One third of patients who both intensivists and palliative care teams expected to die actually survived to hospital discharge (data was not presented to support this finding), on the other hand Kramer and Auer (2005) found a third of deaths in patients with multi-morbidity and chronic conditions were unexpected by the team. There are clear challenges associated with prognostication and recognition of dying.

Nine papers explored patterns in the dying trajectories. Ball et al. (2014b) identified three dying trajectories of people living in assisted living facilities: a gradual decline, a steeper decline and a sudden death. Barclay et al. (2014) identified four trajectories during care home residents' final weeks of life: anticipated dying, uncertain dying, unexpected dying and unpredicted dying. Ffion's experience of Jack's death likely aligns with unpredicted dying as it was planned for him to transfer to a care home. A study of medical students' first experiences of the death of a patient (Kelly and Nisker, 2010) categorised the death event by referring to young, old or unexpected. Young deaths are perceived as tragedies provoking emotional responses. Older adults' deaths are frequently experienced but considered routine. The unexpected trajectory raised the issue of control for the professional role of the doctor. In delivering end-of-life care Hirano et al. (2011) identified distinct stages of care need. They describe care roles associated with the onset, the maintenance, the worsening and the dying period. The onset and progression towards death is described as a marked deterioration in physical function. The maintenance period is between onset and worsening. The worsening period refers to an expectation of living for a few more weeks, whereas the dying period is categorised as the last few days of life. Similarly Bekkema et al. (2015) described a shift in approach to provide comfort care, symptom relief and physical care when the involved people recognise that the individual is approaching end-of-life. The RN's experiences too predominantly focussed on the active dying period rather than the last year of life.

Bailey et al. (2011) and Chan (2011) both considered trajectories of end-of-life in the EU. Bailey et al. (2011) identified two trajectories: the spectacular and the subtacular. The spectacular involved certain, often traumatic loss of life and care is prioritised for these patients. They argue that the needs of the patients in the subtacular trajectory

are often neglected when the spectacular death is occurring concurrently. These are often older adults who have complex needs associated with chronic disease, multi-morbidity or terminal illness. They observe that the EU is focused on life-saving and suggest that there is an embedded reluctance to accept that patients within the subtacular trajectory constitute a large part of emergency work. Chan's (2011) study revealed 108 'stories'. He identified seven trajectories of dying and death: dead on arrival, pre-hospital resuscitation with subsequent EU death, pre-hospital resuscitation with survival until admission, terminally ill and comes to the EU, frail and hovering near death, alive and interactive on arrival but arrests in EU, and lastly a potentially preventable death by omission or commission. Brummell et al. (2016) also developed a typology of cardiac arrest categories. With the exception of the themes 'dead on arrival' and 'frail and hovering near death' the illustrations of Chan's (2011) remaining five trajectories involved aggressive, invasive treatment, even when prognosis was deemed poor. Frailty is often associated with older adults, but this 'hovering' trajectory was illustrated by describing the care a young adult with cerebral palsy who had lived his whole life bedbound in a long-term care facility.

11.5 CONCLUSION

A systematic search of the literature provided an integration of contemporary qualitative research findings of healthcare staff experiences of delivering end-of-life care for older adults across diverse environments with the experiences of the RN's who participated in this study. The review identified three overarching themes: 'care delivery',' the self', and 'dying trajectories'. The themes of care delivery included care actions, ethical issues and communication. The self involved the sub-themes of the emotional self and knowing. The dying trajectory as a theme is concerned with various patterns of functional decline leading up to death. Whilst older adults may experience any of the dying trajectories, frailty may be associated with the 'subtacular' or as Elsa described the 'run-of-the mill' dying trajectory.

Arguably staff require a supportive culture to care for their emotional selves, and to be knowledgeable about their patients' wishes and care needs in order to deliver truly person centred care. The divergence between the literature and the findings of this study are that Alice's experiences map to the extant literature and the other participants' experiences only in a limited way. There is evidence of convergence

between the extant literature within this review and the generally shared findings of this study which has explored the experiences of RN's with regard to achieving a good enough death for vulnerable older adults with frailty, requiring end-of-life care. The major shared theme in this study was 'emotional work' which maps across to 'the self', particularly the sub theme of 'emotional self' but also, knowing. The literatures theme of care delivery natural aligns with this study's theme of 'doing'.

CHAPTER 12 - LOCATING THE REGISTERED NURSES EXPERIENCES IN THE WIDER CONTEXT

12.1 INTRODUCTION

This section of the thesis, consistent with the requirements of IPA, considers the data in a more 'speculative fashion' (Larkin et al., 2006) but this interpretive analysis remains data driven (Shaw, 2010), firmly rooted in the words of participants (Pringle et al., 2011). The first section locates the RN's experience within the theoretical constructs of comfort theory (Kolcaba, 1994) which I had anticipated would be central to this thesis. Although comfort did not emerge as a theme, comfort and discomfort were identified as determinants in the realisation of the 'good enough' or 'not good enough' death. For these reasons I have included a section on comfort theory to help explain and develop a layered understanding of the RN's experiences. To cultivate further understanding and sense of making of the RN's experiences, this chapter also considers awareness and temporal aspects of dying (Glaser and Strauss, 1965a; 1965b; 1968) and knowledge-in-practice-in-context (Gabbay and Le May, 2011) to take the analysis deeper (Smith et al., 2009).

21.2 COMFORT

I initially chose comfort theory as the anticipated framework to support an understanding of the RN's experiences of the good enough death as I thought that comfort care would facilitate the articulation of nursing interventions. I had anticipated that symptom management, and physical and psychological care would be designed and implemented to meet the comfort needs of patients. According to comfort theory, patients experience a need for comfort in stressful healthcare situations (Kolcaba, 1995a) including end-of-life care (Kolcaba, 1996; Vendlinski and Kolcaba, 1997). Comfort is described as a process and product which is merged in holistic nursing art (Kolcaba, 1995b). Holistic comfort is a whole person response, in which the state of being strengthened is enabled by having needs for relief, ease, and transcendence addressed physically, psychospiritually, environmentally, and socioculturally (Kolcaba, 1991; 2010b). Relief is the state of having a specific comfort need met, ease is the state of calm or contentment and transcendence is the state in

which one can rise above problems or pain (Kolcaba, 1991). Although presented as discreet circumstances, they are of course intra-dependent occurring within whole persons (Kolcaba, 1994: p.1179).

TABLE 19: COMFORT GRID (CG)

	Relief (1)	Ease (2)	Transcendence (3)
Physical (1)	CG reference 1 1	CG reference 1 2	CG reference 1 3
Psychospiritual (2)	CG reference 2 1	CG reference 2 2	CG reference 2 3
Environmental (3)	CG reference 3 1	CG reference 3 2	CG reference 3 3
Sociocultural (4)	CG reference 4 1	CG reference 4 2	CG reference 4 3

The RN's experiences were initially explored using the theory of comfort and will begin with the physical context which is understood as pertaining to bodily sensations, (Kolcaba 1991, 1994) such as pain or breathlessness and changes in homeostasis. All participants referred to the physical context of care and in describing 'good enough' dying, pain and other symptoms were managed. However not all symptoms were managed; discomfort was associated with a 'bad' dying and death for example Ffion's experience of the male patient who refused interventions and was "*in agony*" (L 475), "*well that was a bad one*" (L 555). This 'not good enough' death was not associated with neglect but arguably could relate to the concept of self neglect.

The psychospiritual context involves the internal awareness of self-esteem, identity, sexuality, meaning in one's life, and can be one's understood relationship to a higher-order or being. Beth's story about a patient named Mary, who "*we moved her to a cubicle when she wanted to go*" (L 209-210) might be suggestive of a state of psychospiritual comfort.

Environmental context involves the external background of human experience including temperature, light, sound, odour and provision of privacy and dignity (Kolcaba, 1991; 1994). The participants worked within different environments of care including hospice, general hospital wards, a community hospital, a day unit and people's own homes. Within these different environments, references to noise were highlighted by several participants. Ffion explained that a male patient John, turned the pressure relieving mattress pump off in the night "*because he couldn't stand the*

noise" (L 143). Gwen described a male patient where "*his wife made him use the nebuliser in the garage because she didn't like the noise of it*" (L 779-779), and Dawn referred to a patient fall where "*everybody heard it*" (L 432). Noise in these contexts was considered unpleasant.

Sociocultural involves interpersonal, family and societal relationships (finances, teaching, healthcare personnel etc.) and also family traditions, rituals or religious practices (Kolcaba, 1991; 1994). Interpersonal relationships were evident with examples of patients' family described as '*devoted*' (Alice, L 109), '*dedicated*' (Cara, L 294), '*amazing*' (Gwen, L 83) and '*supportive*' (Beth, L 294), alternatively '*fractured*' (Ffion, L 526), '*politely controlling*' (Dawn, L 66) and '*patriarch*' (Elsa, L 26).

As a novice researcher I had anticipated that comfort was an appropriate nursing theory that would help articulate the RN's memorable experiences and perceptions of delivering end-of-life care. In addition, tools had been developed to evaluate nurses' comfort both around end-of-life care (Novak et al., 2001) and general satisfaction with the workplace (Kolcaba, 2010c; Kolcaba et al., 2006). Interestingly the nurses comfort questionnaires resonated with the NHS staff survey (WG, 2016a). However neither tool was particularly helpful for developing an understanding of the RN's experiences for the purpose of this study.

Comfort theory and its conceptual framework has been used to explore end-of-life care (Kolcaba, 1996; Vendlinski and Kolcaba, 1997); but when I used the comfort grid to map participants' stories, I found that it was better suited to considering the understanding and meaning making of the patient's experiences as viewed by the RN rather than the RN's experiences per se. As such this theory limited my exploration of the RN's experiences so I needed to reconsider the use of different theoretical frameworks.

12.3 AWARENESS AND TEMPORAL ASPECTS OF THE DYING TRAJECTORY

The seminal works *Awareness of Dying* and *Time for Dying* (Glaser and Strauss, 1965a; 1968) appeared to resonate with many of the difficulties the RN's experienced. Glaser and Strauss (1965a) focus on the management of information for terminal patients or their family members. Open awareness of dying, the most prevalent contemporary awareness context, enables people to plan their 'dying careers' (Seale et al.,1997).

However Bélanger et al. (2014) found that the decision to initiate conversations regarding preparation for death remains firmly under the patient's control.

Timmermans (1994) critique of *Awareness of Dying* argues that the "interactional drama" (p. 324) presented in Glaser and Strauss's theory (1965a), downplays the emotional dimension of having a terminal diagnosis. Timmermans (1994) explored this emotional dimension using his own experience as a relative of a person who was given a terminal diagnosis. He extends the awareness context into three different interpretations of the situation: the context of 'suspended open awareness' refers to the family disregarding explicit clinical information; the context of 'uncertain awareness' exists when people do not dismiss the possibility of a fatal outcome, but they prefer the uncertainty of not exactly understanding as this may help to preserve hope; and the context of 'active open awareness' is when the patient and family except the full implications of the information and try to come to terms with it. Copp and Field (2002) studied hospice patients and found that acceptance and denial fluctuated for individuals. They recommend that these should be viewed as interdependent and fluctuating coping strategies used by dying patients. This understanding is likely to be transferable for carers and family members.

Gwen described a male patient as being "*in denial*" (L 287) which appears to correspond with the context of suspended open awareness. Arguably the male patient's family that Cara referred to as not being in "*that zone*" (L 431) could be suggestive of suspended open awareness, but given the family members' skilful symptom management this may relate to a context of uncertain awareness. They also may have been experiencing and using vacillating awareness and denial tactics as coping mechanisms. Alice's story of Iain and his family, and Beth's representation of Mary and her family are suggestive of a context of active open awareness. Cara also referred to a female patient who died "*from a nose bleed essentially*" (L 84) but in this context it is uncovers the doctors' uncertainty. They had "*put her NFR*" (L 132) which indicates that they had considered the possibility that she may be at risk of a cardiac or respiratory arrest for which cardiopulmonary resuscitation would not be clinically effective. However Cara intimated that the doctor seemed shocked when she told her of the patient's death. This scenario highlights a level of uncertainty when dealing with

critically ill people. It has also shown that awareness of dying may be accompanied by differing expectations for the different individuals involved with the dying person.

Glaser and Strauss (1965a; 1968) found that patients with a known terminal diagnosis create uncertainty because although it is understood that the individual will die, the when and where this will happen is not known. They describe this as a non-scheduled 'status passage' as the dying person is passing between statuses of living and death with some uncertainties (Glaser and Strauss, 1965b). There is a relative 'certainty' of death, but the 'time' when the certain death will occur remains unknown. They propose that this combination of certainty and time yield four types of death expectations for people with potential terminal diagnoses:

- Certain death at a known time.
- Certain death at an unknown time.
- Uncertain death but a known time when certainty will be established.
- Uncertain death and an unknown time when the question will be resolved.

Glaser and Strauss (1965a; 1968) refer to the doctor as the gatekeeper to the confirmation of certain death, but in contemporary UK healthcare this will extend to some RN's with advanced roles. They describe the 'relative certainty' of death being the degree to which the individual is convinced that the patient will die. Sullivan et al. (2007) undertook a secondary exploratory analysis of interviews with physicians who had cared for patients who had died in hospital. In relation to patient deaths, 38% of physicians were unsure on admission that the patient would die, but over the course of hospitalisation 86% reported knowing that death was imminent. Arguably certain death at a known time relates to recognition of imminent dying, but this can be problematic and is reflected in the RN's experiences. Examples such as withdrawal of life-support may meet this descriptor, or it could relate to assisted suicide; remaining mindful that this remains illegal in the UK (Criminal Justice Act (Northern Ireland) 1966; Noel Douglas Conway v The Secretary of State for Justice, 2017 ; Scottish Parliamentary Corporate Body, 2013; Suicide Act 1961).

Certain death at an unknown time correlates with having a terminal disease. It also reflects human mortality. Beth summed it up:

> *"you've got the sort of diagnosis hanging over you that you know your life expectancy could be years. You know, but you have got that knowledge down there, actually yeah I'm probably going to die quicker than if I didn't have that disease"* (L 410-411)

Time also appeared to be of concern for Dawn who described that "*within three hours of him stepping on the department, he was not dead but he was unresponsive*" (L 174-175). Although two patients she talked about collapsed in the department, and both had terminal diagnoses, Dawn's expectations did not involve sudden deterioration and imminent dying. This initially reflects 'uncertain death', but following urgent interventions the question was resolved and 'certainty of death' was established in an anticipated (known) time frame. Glaser and Strauss (1968) explain that staff are continually redefining these death expectations. When a patient's (perceived) status moves from an expectation of certain death at an unknown time to a known time, this change in expectation can trigger specific care actions. Ffion described that in the hospital when they have recognised that a patient has started to deteriorate, that is the assessment that the death will be soon, they move the patient into a cubicle. Likewise the use of the 'fast-track' service to support people out of hospital into their own home to die is triggered by this change in expectation of status passage.

The circumstances of uncertain death, and an unknown time when this question will be resolved could be associated with waiting to receive a medical diagnosis and ongoing treatment options. Beth described a scenario where a patient has "*just come from clinic who knows they've got a mass, is probably not a great prognosis but it's all very uncertain*" (L 426-427). She also described the uncertainty as 'terrifying'. What appears particularly relevant in the RN's experiences is that their expectations of the patients' expected dying trajectory was subject to change, with uncertainty featuring strongly.

An attempt to plot the RN's descriptions of death expectations made the open ended process of redefining these expectations more tangible. I have subjectively identified predominant descriptions of expectations for each RN's story which are presented in table 20.

Participant's story	Described prominent death expectation experiences			
	certain death at a known time	certain death at an unknown time (arguably all human beings)	uncertain death but a known time when certainty will be established	uncertain death and an unknown time when the question will be resolved
Alice		☑ (Iain: palliative care)		
Beth	☑ (Mary [patient]: peaceful death)	☑ (In general)	☑ (general: awaiting diagnosis and prognosis)	☑ (unnamed female: student experience)
Cara	☑ (male patient)			☑(female patient)
Dawn		☑ (palliative care patients)	☑ (male & female: uncertain imminent death post collapse)	☑ (haematological malignancies)
Elsa	☑ (male eventual peaceful death with wife and dog present)	☑ (palliative care patients)		
Ffion		☑ (male 1 [John] at home) (male 3 [unnamed] in hospital)		☑ (male 2 [Jack] unpredicted: planning for care home)
Gwen	☑ (general imminent end-of-life care at home)	☑ (palliative care) ☑ (risk of bleeds) ☑ (male patient who died 'there and then')		

The scenarios recounted by the RN's may also be viewed from different perspectives at different times as the dying person often passes between more than one of the four death expectations; for example the male patient Elsa refers to will have passed between certain death at an unknown time, to a known time during his time at the hospice.

Having the knowledge and expectation for certain death of a patient did appear to be associated with better caring experiences for the RN's. The organisation of work,

comfort care, and routine are described as being complemented by a 'sentimental order', the "intangible but very real patterning of mood and sentiment that characteristically exists on each ward" (Glaser and Strauss, 1968: p.14). In describing the lingering trajectory of dying, predominantly of older people with frailty, Glaser and Strauss (1968) state that the sentimental order integrates patience and inevitability, but they also describe the disruption of this order. Within Cara's experience of the death of a male patient with cancer of the lung, although a lingering trajectory, his relatives' non-acceptance of his imminent dying disrupted the organisation of work and impacted on the 'sentimental order' of the environment of care. An associated component of maintaining the sentimental order is the nurses' composure (Glaser and Strauss, 1965a). Both Cara and Beth described instances of their leaked emotions surrounding the deaths of two patients. Cara was particularly aware of a detrimental impact this could have had on her team, whereas Beth concentrated more on the potential impact for the family.

Time for dying focuses on the temporal aspects of dying; Glaser and Strauss (1968) theorised that regardless of the particular attributes of a specific patient's dying trajectory, there are certain events which appear along the trajectory and are managed by the temporal organisation of work. They term these care events "*critical junctures*" (p.7) of which there are seven. Glaser and Strauss (1968) observe that the patient trajectory ends with death, however the hospital's work continues after the death. Ffion and Gwen discussed the importance of after death care and Beth referred to making Mary "*comfortable and presentable*" (L 237). In a later publication Strauss et al. (1982), expanded the use of the term trajectory to include the total organisation of work over the course of the patient's illness, including the impact on those involved with the work. I have added 'after death' as an eighth critical juncture as it forms an important part of the nursing care of the individual and the family. The eight care events along the dying trajectory are listed below:

- The patient is defined as dying.
- Staff and family (and potentially the patient) make preparations for the death.
- There is nothing anyone can do to prevent death.
- The final descent of the dying trajectory may take weeks, days or hours.
- The last hours.

- The death watch.
- The death itself.
- After death.

Glaser and Strauss (1968) argue that when these critical junctures occur as expected and on schedule, those involved are prepared and the staff are able to incorporate this into the temporal order of work. For example, Beth was able to anticipate and recognise when Mary was near death. In moving from the certain death at an unknown time, to a certain time expectation meant she was ready for 'the death watch' and 'the death'. However in the case of the lady who died unexpectedly in Cara's narrative, the critical junctures of the patient being defined as dying, the last hours, the death watch and the death itself were 'off schedule'. This appeared to result in a difficult experience for the patient, her daughter and the staff involved. It is an example of the 'not good enough' death.

Glaser and Strauss (1965a; 1968) also focus on the temporal organisational of nurses behaviour towards dying patients. They (Glaser and Strauss, 1965a) propose that in order for the nurses to keep composure in the face of difficult deaths they employ a 'general defence strategy'; this incorporates the organisation of their work and their interactions, which together serves to reduce involvement with the dying patient. Similarly Elsa described her observations of nurses' behaviours of withdrawing from interaction with dying patients on the general hospital wards. She suggested this may be a potential coping mechanism "*it's easier to withdraw than than realise how much your, you know, you haven't got time for people*" (L 149-150). This appears to resonate with this 'general defence strategy'.

In the context of delivering end-of-life care, expectations of an impending patient death appeared to be associated with a better experience for the RN's. This suggests that following a changing but anticipated dying trajectory is, for the RN's, relevant to achieving a good enough death. Policy wise only one participant referred to the then Integrated Care Priorities for the last days of life document (Palliative Care Matters, 2012), but this was not used to structure her experiences of a memorable clinical case of dying and death.

Whilst Glaser and Strauss's (1965a; 1968) theories resonated with me and the RN's experiences they appeared to limit the exploration of the RN's experiences by virtue of the timeframe, cultural differences, developments in contemporary nursing practice, and the development and mainstreaming of palliative care approaches. Glaser and Strauss (1965a) also suggested that due to ambiguity between doctors and nurses communication in the 'nothing more to do' phase, in trying to achieve patient comfort, nurses would undertake "invisible acts" (p. 209) of administering increased doses of analgesics; if not prescribed or indicated this would clearly be in breach of NMC standards (2015a), if not a criminal offence. Much of the nurses comfort work in the 'nothing more to do' phase of the patients' dying has significantly changed in the UK, for example the use of syringe drivers for pain and other symptom control. These considerations and the relative absence of reference to decision support tools in end-of-life care led me to consider the use of clinical guidelines and evidence-based practice. The following section considers the participants' experiences in the context of practice-based evidence, specifically considering the persuasive work of Gabbay and Le May (2011).

12.4 "KNOWLEDGE-IN-PRACTICE-IN-CONTEXT"

(Gabbay and Le May, 2011)

There is ongoing concern about the gap between the evidence-base and implementation into practice (Haines et al., 2004). Gabbay and Le May (2011) examined how clinicians develop and use clinical knowledge in day-to-day practice. In contrast to the traditional evidence-based practice movement, they propose that clinicians use mindlines which are multifaceted mental resources that aid clinical decision making. Mindlines embody not just formal knowledge but also a lifetime of social, organisational, professional, economic, ethical and cultural considerations. Mindlines present an alternative understanding of clinical decision-making. This contrasts with the dominant hierarchy of evidence (Porta and Last, 2018). Conceptually, clinical mindlines are made up of blended knowledge that has been absorbed from numerous sources including formal education and other influences. Formal education such as nurse training is not value free, it "also carries with it a large penumbra of the professional mind set conveyed by teachers, other established

professionals and learning from each other as students" (Gabbay and Le May, 2011: p.77).

Mindlines are described as consisting of an 'encapsulated' multi-layered complexity of deeply ingrained, embedded knowledge-in-practice-in-context (Gabbay and Le May, 2011: p.72). They argue that we draw on these mindlines and integrate them with professional and personal values, emotional intelligence and the working culture in order to make decisions about care actions for the individual person we are engaging with. It is recognised that many roles particularly in healthcare require soft skills of which emotional interpretation and display are central components (Heery and Noon, 2018).

Gabbay and Le May (2011) concur with Benner (2001) and Dreyfus (2004) that experts acquire transcendent knowledge-in-practice, in that there is some structure to the chronological growth of clinicians practice; that is novice, advanced beginner, competent, proficient and expert. They have supplemented this chronology by adding an additional category of 'contextually adroit'. They emphasise that formal knowledge is inextricably melded with a wide range of experiential and tacit knowledge and behavioural norms.

There are two dimensions of tacit knowledge, the informal personal skills or crafts referred to as know-how, and the second is the cognitive dimension that uses values, beliefs and schemata (Nonaka & Konno, 1998). Gabbay and Le May (2011) argue that practical experiential knowledge is implicit and inexpressible; it is intangible (Nonaka and Konno, 1998). Nonaka and Konno (1998) explain that explicit knowledge can be expressed in words and numbers, and can be shared. They state that the interaction between tacit and explicit knowledge leads to the creation of new knowledge. Gabbay and Le May (2011) emphasise that all new information, whether tacit or explicit becomes transformed by the complex social processes described in the SECI (socialisation, externalisation, combination, internalisation) spiral shown in figure 16.

FIGURE 16: THE SECI CYCLE
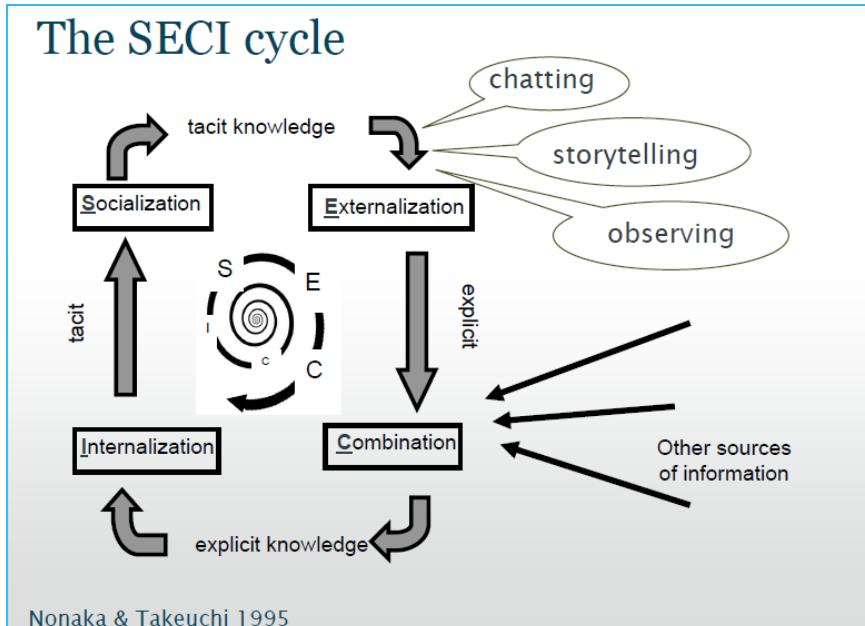
The SECI cycle Nonaka & Takeuchi 1995 displayed in Gabbay and May (2010: unpaginated)

They suggest clinicians amalgamate knowledge with other relevant knowledge before using and applying it. Information from research, educational and other formal sources becomes practical knowledge only after social processing. Clinicians use this knowledge within illness scripts, heuristics and rules of thumb. These tried and tested thought patterns are drawn upon in circumstances where fully rational decisions are not possible because of lack of time or lack of information. One example of this could be Dawn's experiences in dealing with the patient's sudden deterioration. Without full information and during a crisis, it seemed that there was an assumption, a heuristic that the patient had choked. Although subsequently this was disproved, this heuristic provided a working hypothesis that may have helped inform Dawn regarding the course of care actions that ensued.

Socialisation is understood to involve the sharing of tacit knowledge, where people share feelings, emotions, experiences and mental models (Nonaka and Konno, 1998). Ffion's experiences of not knowing how best to communicate with Jack's wife following his unanticipated death was discussed with her colleague. This socialisation process would have drawn on Ffion's professional and personal values, and the working culture. Nonaka and Konno (1998) philosophically refer to this in terms of Heidegger's being-in-the-world. Externalisation involves dialogue and involves reflection and analysis (Nonaka and Konno, 1998) of her own and her colleagues

expressed thoughts in order to make the tacit knowledge explicit. Arguably externalisation engages the emotional intelligence Gabbay and Le May (2011) refer to. This involves having an awareness of the reactions and emotions of others in order to gauge the effective communication needed to transform this tacit knowledge into explicit knowledge. The combination phase involves the melding of a wide range of experiential, tacit knowledge and behavioural norms with the newly developed explicit knowledge which then informed Ffion's actions. This new knowledge theoretically is then internalised and transformed into internal tacit knowledge, which was later externalised to me during her interview. Engagement with the theory of practice-based evidence to explore the RN's experiences will be undertaken to develop another layer of analysis in order to help advance my sense making of the participants making sense of their experiences.

The RN's were asked to tell their stories of a memorable clinical case. Gabbay and Le May (2011) emphasise that stories, which they describe as anecdotal evidence, have both knowledge transmission roles and social roles, and lead to transformation of knowledge. This is particularly relevant in IPA as the participants are interpreting and making sense of their experiences, and as the researcher, I am also carrying out an interpretive activity in trying to make sense of what the participants have told me.

FIGURE 17: AN IMAGE DEPICTING AN EXEMPLAR OF THE DEVELOPMENT OF CLINICAL MINDLINES
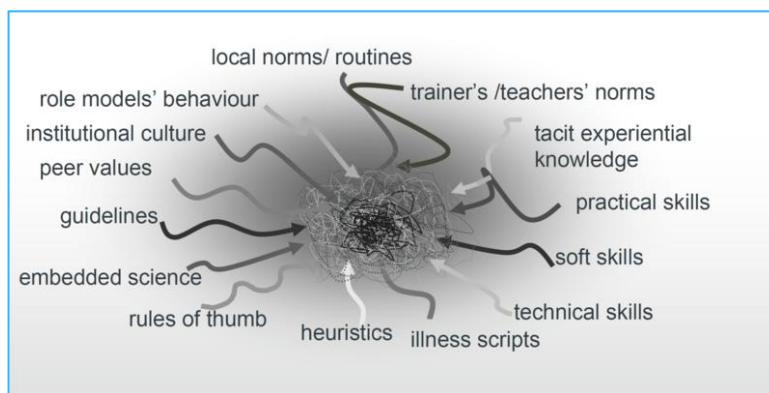
A schematic representation of some accumulated contents of mindlines (Gabbay and Le May, 2011: figure 4.2 p.73).

In the next section, the participants' individual stories are examined using the framework of knowledge-in-practice-in-context; 'clinical mindlines'. The participants' experiences are presented in the order that the interviews and analysis took place.

Alice predominantly described her experiences of caring for one male patient named Iain. Alice described a lack of practical and technical skills associated with Iain's tracheostomy care which appeared to lead to conflict within the team. There was reference to the ward sister who should have been one of her role models, but her involvement was interpreted as adding "*fuel to the fire*" (L 217) which may have contributed to a perceived sense of insecurity. There was no reference to guidelines or a clear plan of care but this could be that the SECI spiral of socialisation, externalisation, combination and internalisation was in its infancy at the time she experienced this. This may be reflected in Alice saying "*each shift we were passing on information to each other about how to care for this thing*" (L 94-95) suggesting a tacit knowledge which is being externalised but has yet to become explicit, combined and internalised. As stated, practical knowledge is obtained only after social processing (Gabbay and Le May, 2011).

Alice did make use of illness scripts for example "*it was only a matter of time that this tracheostomy was going to get blocked basically, and you know, he was assuming that was the way he was going to go, he was going to have to suffocate to death*" (L 71-74). Her knowledge of the increasing size of the tumour which had begun to dislodge the tracheostomy tube, will have added to her understanding and according to Gabbay and Le May (2011) even faded biomedical knowledge from her nurse training will have laid the foundations of her clinical mindlines. However the narration of Iain's information was presented predominantly using lay terminology rather than an exchange of clinical information between practitioners. An example of this involved a description of Iain's breathing being compromised and the need to get a balance of "*trying to loosen the fluids, that he could breathe through the tube, but not sort of feeling like he was drowning*" (L 239-241).

Alice described that through her own practice of meditation particularly through childbirth, she has validated her belief that body and mind are linked. This suggests that her personalised tacit and experiential knowledge has become internalised. She also described a number of beliefs such as "*everything is for a reason and has its timing*" (L 386-387) and "*the truth is the truth*" (L 391). Socialisation of where and when these beliefs, a type of personal knowing have originated, is likely to be from

outside of clinical practice. It is acknowledged that nurse's reactions to specific dilemmas are based on their individual values and beliefs, among other principles such as professional codes and the culture of care (Cohen and Erickson, 2006), which presents a further melding of knowledge types.

Alice's values, and the institutional culture of delivering individualised person centred care could be understood to incorporate relationships with individual patients and their family and carers. The importance Alice appeared to have levied in relation to her interactions with Iain and his family, together with her values and beliefs seem to suggest that the 'soft' skills including communication, professionalism and emotional intelligence were arguably imbalanced which led to a situation involving a blurring of professional boundaries.

12.4.2 BETH

Beth predominantly talked about two different patients she had been involved with in delivering end-of-life care. The first patient story was used to describe her experiences as a student nurse. Beth's experiences were that this lady's symptoms were not adequately controlled. In part, the institutional culture, peer values, role models, behaviours and local norms and routines were described as detrimental attributes. Her observations were that ward morale and team dynamics were poor. The soft skills of communication, and emotional intelligence appeared to be lacking in comparison to her description of a palliative care consultant who she described as "*excellent at breaking news*" (L 477)*.

More generally Beth described that the medical teams, at times appeared to be relating to illness scripts that were different to her script. She described this in saying "*doctors who are tunnel visioned into treating and doing surgery or withdrawal of treatment seems to them to be like giving up, and sometimes it's just the best thing to do*" (L 102-104). In the early stage of her career, tacit and experiential knowledge, soft skills, practical and technical skills were underdeveloped and she didn't "*have the tools to know what to do*" (L 145). She has stated that she has used this experience as a learning opportunity to inform her subsequent practice in a positive way.

Development and use of Beth's practice-based evidence can be captured in the second patient story she described. There is clear reference to embedded biomedical science

presented heuristically "*yes her blood sugars are high and yes her tissue viability is going to be affected*" (L 174-175) as Beth was drawing on an illness script that the patient was dying. The accumulated content of experiential knowledge, formal education, national guidelines and critical reflection (Beth completed her dissertation on the concept of the good death), skills of communication and emotional intelligence, and practical and technical skills appear to have become melded in her maturing clinical mindlines. Beth appears to demonstrate this by articulating her judgement and behaviour in challenging a medical decision, whereby she refused to initiate sliding scale insulin. This is an example of knowledge-in-practice-in-context. Beth's story seems to portray growth; as a nurse, her stories appear to have described her development from a novice practitioner to a 'contextually adroit expert'.

12.4.3 CARA

Cara predominantly described two patient's dying and deaths. In telling the story of one patient's dying and death where the bleeding "*just wouldn't stop*" (L 101), she referred to the practical and technical skills that she perceived were missing in the use of the nasal tamponades. The lady had an underlying clotting deficiency although Cara mentioned this almost in passing and only once, but this does imply embedded biomedical science. In this situation the illness scripts that the medical and nursing teams were using appeared underdeveloped; "*nobody realised that she was going to die because of this nose bleed*" (L 85). Cara described the doctors as junior with limited knowledge. This could indicate a novice or advanced beginner within this particular context. There is a suggestion that Cara had tacit and experiential knowledge, and heuristically she recognised the lady was dying but she appeared unable to communicate this effectively to the doctors. This is suggested in "*I said to this registrar you know, she's just died. 'She died?' And I'm like yeah I told you she was dying*" (L 146-147). Cara suggested that if a consultant had been present, more care and consideration could have been given to the patient's experience. In saying this Cara seems to be recognising the experience and knowledge-in-practice-in-context a consultant would bring as a 'contextually adroit expert'.

Cara was aware of her own responsibilities as a ward sister as a role model for others particularly when she had become visibly upset; staff "*look up to the sister*" (L 243). In her own practice she talked about having practical and technical skills; "*everything has*

to be on a practical level" (L 393). She also described the family of a patient who "*from a symptom point of view they were very capable*" (L 430) but when their father was dying they "*weren't in that zone*" (L 431) despite his multi-organ failure. The clinical teams were using collective mindlines, a shared illness script, which seemed to be at odds with the family's view of their father's illness and dying trajectory.

Cara also alluded to her own lack of experiential knowledge in having limited exposure with sudden death compared with colleagues who work in the EU. This also resonates with the importance of practice-in-context. Cara may be a contextually adroit expert within her own clinical environment, but if she was to work elsewhere, she may not function as an expert in that new context. Interestingly Cara said, "*from a senior nurse point of view I feel that I'm-- you know I can, I can help the patients and make sure that they've kind of got dignity and that they are pain-free, but actually the interaction with relatives, I personally take a real step back and I just-- I can't-- that's my kind of weakness really*" (L 44-47) which serves to illustrate the importance and potential complexity of 'context'. It could also reflect the view of Tomkins and Eatough (2013) that nurses tend to see patients primarily within the terms of their current needs and vulnerabilities; in the present and with consideration for the future whereas families hold a combination of past and present knowing of the individual. Cara's 'stepping back' may be associated with distancing herself from the individuals' prior life by concentrating on the patient who is now in front of her. That is, concentrating on 'doing'.

12.4.4 DAWN

Dawn predominantly talked about two memorable clinical cases but also described some generalisations. One male patient presented as very breathless on attending the day unit for palliative chemotherapy. Dawn appeared to draw on tacit experiential knowledge when having concerns about initiating the prescribed treatment and she asked for advice from senior colleagues. Dawn used practical and technical skills to administer the chemotherapy. Sadly this male patient became very breathless; it was assessed that this was not an adverse drug reaction but he subsequently died. Dawn explained he "*sort of stumbled on, on, not choked*" (L 80) his lunch. Dawn appeared to be using a rule of thumb in that if somebody starts coughing while eating, it is likely to be a choking episode. Dawn drew on embedded anatomy and physiology to explain

cause of death; the post-mortem examination confirmed the tumour as the cause of death, there was no food present in his airway and there was no adverse drug reaction. However there is a risk that this experience, this unusual case, could distort Dawn's clinical mindline development.

In trying to make sense of two unexpected deaths Dawn drew on the temporal course of illness scripts "*I think that like they say when your time's up your time is up, regardless of what you try and do to prevent it or prolong it*" (L 442-443). This pattern recognition of a "*disease just takes over and does what it's, it does*" (L 342) holds a sense of the inevitability of death with terminal disease, but also appears to reflect observed patterns within the dying trajectory. Dawn also talked about a lady who had been receiving supportive treatment for an extended period of time; she recognised a deterioration, provided treatment but the lady died at home the following day. She described this lady's death as "*an inevitable outcome but the timing was different*" (L 225) suggesting that the temporal course of this illness script was on schedule; the patient was in the penumbra of death. The sudden and unanticipated deterioration and deaths of the other two patients appeared to be 'off schedule' compared with Dawn's perceived illness script.

Further pattern recognition was illustrated using haematological malignancies which can cause people to "*bleed out*" (L 290). Dawn drew on embedded biomedical science to explain this illness script "*because of lack of platelets etc.*"(L 292). However she explained she was uncertain in how best to manage the situation, particularly in the context of being with and for family members. To address this lack of expertise, discussing this potential scenario with colleagues who have encountered or deliberated this would potentially help inform her clinical mindline development.

Dawn's experiences provided a sense of capricious inevitability, encapsulating uncertainty relating to the temporal course, symptoms and treatments of disease. She also discussed multiple personas; the professional and the layperson reflecting that as individuals and communities we acquire knowledge through socialisation, passing on beliefs values and attitudes through generations as well as via religious and cultural heritage. As health professionals we are subjected to a secondary socialisation which incorporates a specialised view of health and healthcare, gained through professional

training (Naidoo and Wills, 2000), thus reflecting the complex social construction of clinical mindlines (Gabbay and Le May, 2011).

12.4.5 ELSA

Elsa tended to generalise about the care of older people. Older people are much more "*run-of-the-mill*". Dying and death are commonplace in the hospice, as are older people's deaths but older people's deaths did not seem generally, particularly memorable. This may reflect institutional cultures, or rules of thumb that suggest that more often than not, older people who attend hospice, will or do die. It could encompass an arguably ageist practice that "*oh well they have had a good life*" (L 195) or represent the 'good enough' death.

Elsa also talked about pain management and terminal agitation being generally more straightforward in the care of older people. She was not able to clearly articulate the rationale for more effective palliation and related it to body size, lack of fight, reduced physical strength and a weaker heart compared with younger people. There seemed to be a faded embedded bioscience within her explanations. In terms of illness scripts, Elsa articulated that younger people are able to tolerate large doses of opiates and still experience really complex pain. This may suggest that older people tend to have different patterns of clinical and symptom presentation. Conversely older people often require more complex discharge planning which she described as being convoluted and protracted which seems to illustrate a different type of pattern recognition.

Elsa described her memorable patient as a male in his late 80s. He had been admitted for symptom control. The team appeared to be questioning their tacit experiential knowledge as they "*weren't sure whether-- not that he was lying by any means but whether the symptoms weren't getting better or being better controlled*" (L 355-357). The usual approaches and treatments appeared to be ineffective necessitating different ways thinking about symptom control; the familiar, contextually adroit expertise may have been temporarily lost.

Elsa's practical and technical skills appeared to be evident in being "*the one*" (L 417) to initiate the administration of sedative medication. She described difficulty in getting the balance right and referred to dilemmas in practice when people become hypoxic or confused with "*paranoia*" (L 451) thinking that staff are trying to poison them. The

patients are then often administered midazolam "*which in effect is what they are worrying about*" (L 453-454). She appeared to be drawing on experiential knowledge, embedded biomedical science, along with pattern recognition which developed an illness script of the dying trajectory. She talked about a role model, a sister in the hospice during the time she was developing her competencies. The sister administered prescribed anticipatory drugs and the individual patient died a few minutes later. This concrete example of unpredictability and responsibility may augment her residual concerns regarding initiation of sedative drugs. It is a possibility that this relatively unusual experience may have unduly influenced her tacit experiential knowledge.

Elsa also talked about her mum and explained that she knew her mum was ill and heading towards death, but did not correlate this with seeing her as dying until she was dead or in the final stages of dying. Although she has internalised practice-based evidence in end-of-life care, it seems that she may have inhabited the role of layperson and daughter rather than healthcare professional with different sources of knowledge and understanding coming to the fore in this particular context.

12.4.6 FFION

Ffion predominantly talked about three male patients. The first male patient had been fast-tracked home from hospital. Rule of thumb for fast-tracked end-of-life care suggests one or two weeks of remaining life. They (the hospital) "*said he only had I don't know, a week or so but he went on for about three months*" (L 9). Here the illness script provided by the hospital, although correct in diagnosis, seemed inaccurate in terms of the temporal course. When he did die, Ffion described being "*shocked*" (L 49) as whilst it was known that he was dying, neither he nor the staff knew he was going to die the day he died. She explained "*he just died*" (L 606), seemingly without signs of imminent dying, which appeared to be off schedule in terms of his anticipated dying trajectory, but considered by Ffion as a nice death.

The second male patient Ffion discussed experienced a sudden and unanticipated death. Ffion emphasised "*the worst part*" (L 272) of this experience was that she had to contact his wife, reflecting the soft skills of communication and emotional intelligence. She took advice from a colleague "*I said oh my god what am I going to do? She said ring his wife she said but don't tell her he's died* [...] *just say he's taken a turn for the worse he's poorly*" (L 275-277). The 'worst part' appears to relate to not

knowing how she is expected to deal with this unexpected situation. Neither Ffion nor her colleague appeared to be relying on formal guidelines but seemed to be externalising tacit knowledge by conversing and developing a solution for an unfamiliar experience through the mode of externalisation.

Ffion described another male patient's lingering dying trajectory. He had been diagnosed with mouth and throat cancer. Ffion integrated temporal perspectives of past, present and future in telling this male patient's story. Lifestyle choices appeared to be afforded the attribute of prior causation (risks), present symptoms (disease process) and future trajectory (dying and death). She described him unhappily being PEG fed and resistive to interventions. Following his violent removal of the PEG he subsequently refused analgesia and subcutaneous fluids, "*and there was nothing we could do because he still had capacity apparently*" (L 482). Here, guidelines, or more accurately the Mental Capacity Act 2005 as current law in England and Wales is inferred as the driver. Ffion and colleagues interventions or perhaps more pertinently lack of practical and technical interventions, appear to be in contrast to the usual norms and routines.

In exploring Ffion's views of what helps towards achieving a good death she explained that "*if you know where you're going to be at the end it eases it a bit*" (L 651). This conclusion was explored using experiential knowledge of a specific patient who became very distressed "*because she didn't know where she was going to be and she didn't want to go somewhere where nobody knew her*" (L 629-630). Ffion concluded; "*It's like getting your affairs in-order isn't it really* [...] *because they've got to get their affairs in-order. So that would come under that getting the death in-order*" (L 654-657) which appears to illustrate that some of her experiences have informed her current mindlines.

12.4.7 GWEN

Syringe driver care featured frequently within Gwen's stories about her experiences. The purpose, practical, technical and experiential skills of managing a syringe driver appeared to be taken for granted and received little attention except for when it was problematical. Describing the care of 'her lady' she explained they experienced a lot of problems with her syringe drivers which were failing; "*we had problems with the batteries and various things and we don't know what was going on*" (L 61-62). Despite

their experiences and discussions within the team, their co-constructed collective mindline drew no clear explanation, so they provided a spare syringe driver for 'backup'. Gwen also gave an example of a male patient 'someone' who died during their first visit. They were initiating a syringe driver, "*and he died, there and then*" (L 838). For the nurses this was off schedule, the temporal course of his illness script did not match their expectations and arguably their clinical mindlines.

A few days before 'her lady' died, Gwen's explained she "*was starting to mark a little bit*" (L 139-140). Starting to mark is arguably a shared, tacit, internalised knowledge which draws on embedded physiology concerning tissue viability and organ failure. It also seems to be a precursor to an illness script; "*it could have come to the point where we would have had to care for her*" (L 140-141). She appeared to be entering a different phase of her dying which may have required further interventions from the district nursing team.

Gwen discussed the peri-death care of a particular patient; "*rigor mortis had set in and it was very difficult to, to get her comfortable*" (L 94). Rigor mortis is clearly associated with bodily changes after death which likely draws on some faded embedded biomedical science, but in this instance it seemed to be presented heuristically. The attempt to get her to look comfortable uses experiential practical skills; it is the norm for the district nurses to undertake this task as "*we do like to do that last visit*" (L 197) which may also facilitate a sense of closure for the RN's.

12.5 SHARED EXPERIENCES

This section has explored the RN's experiences in the context of 'knowledge-in-practice-in-context'. Table 21 presents an overview of the tentative sources of knowledge present within this section of the interpretive analysis.

TABLE 21: SOURCES OF KNOWLEDGE BY PARTICIPANTS' STORY

Participant's story	Sources of knowledge									
	Role models/ behaviour/ peer values	Local norms/ routines	Illness scripts	Biomedical knowledge	Guidelines	Practical/ clinical skills	Personal beliefs values	Emotional intelligence	Experience	Heuristics
Alice	☑		☑	☑		☑	☑			
Beth	☑	☑	☑	☑	☑	☑		☑	☑	☑
Cara	☑		☑	☑		☑			☑	☑
Dawn			☑	☑		☑	☑			☑
Elsa	☑		☑	☑		☑			☑	☑
Ffion	☑	☑	☑		☑	☑		☑	☑	☑
Gwen		☑	☑	☑		☑			☑	☑

The RN's told stories of their experiences in delivering end-of-life care which appeared to link to tacit, internalised knowledge, skills and attitudes. In describing memorable clinical cases, there were experiences within their stories that were particularly notable for them and caused them to search for explanations, meanings and solutions. The use of 'clinical mindlines', the theory of practice-based evidence as part of the interpretive analysis enabled another layer of analysis which helped develop a different understanding of the RN's experiences. Gabbay and Le May (2011) theorise that we draw on these mindlines and integrate them with professional and personal values, emotional intelligence and the working culture in order to make decisions about care actions for the individual person we are engaging with. This appeared to fit with, and help explain the RN's experiences.

12.6 CONCLUSION

IPA is an empathetic method that aims to understand experience from someone else's experience. The narration of experience was that of the participants as RN's. The interpretive nature of IPA recognises the double hermeneutic: "the researcher is making sense of the participant, who is making sense of X" (Smith et al., 2009: p.35). I have attempted to make sense of the RN's, making sense of their experiences of delivering end-of-life care. As the researcher, I only have partial access to their

experiences through what they have told me. I have also viewed this through my experiential-informed lens and with IPA I too recognise that I have co-produced these research findings.

It is possible that regardless of the framing of the research question, the RN's would have talked about end-of-life care experiences which were memorable ones because their experiences did not follow their perhaps tacit expectations. The RN's inhabited the role of layperson and healthcare professional and perhaps unsurprisingly drew on different sources of knowledge and understanding in particular contexts. The RN's experiences also appear to have demonstrated the argument that comfort is best recognised when the patient leaves the state of discomfort.

Importantly awareness of dying may be accompanied by differing expectations for all who are involved with the dying individual. What appeared most relevant to the RN's experiences was that their expectations of the patients' expected dying trajectory is subject to change, creating uncertainty. Conversely, when 'certain death' is recognised, that is the person is diagnosed as dying, this did appear to be associated with a better caring experience for the RN's.

Using the theories of comfort, awareness of and temporal aspects of dying, and knowledge-in-practice-in-context has enabled a critical exploration of the understanding and meaning of the good enough death and dying. It has made explicit similarities and differences within and between the RN's experiences in delivering care to vulnerable older adults (with frailty) at end-of-life. In the RN's experiences, the determinants that facilitated the good enough death involved awareness of dying, recognising imminent dying and being able to provide comfort to the patient and their loved ones. Patients' who had been diagnosed as dying, and who died suddenly was considered a good enough death. The RN's experiences that posed barriers to the delivery of the good enough death involved futile treatments, staff and family's unpreparedness, and inability to provide sustained comfort for the patient and their loved ones.

The next section explores reflective practice as during the interviews, whilst the RN's were recounting their experiences, at times they were actively seeking to make sense

of and develop a new understanding that helped explain their experiences. This will be followed by succinct examples using the RN's stories.

12.7 EPISTEMOLOGY OF REFLECTIVE PRACTICE

This discussion section begins by exploring reflective practice. IPA embodies being phenomenological, consciously thinking about experience. During the interviews the RN's drew on their practice and experiences, trying to make sense of them and developing new knowledge and understanding for themselves, which they were then telling me. Reflection is described as a process of turning experience into learning (Boud, 2001), to gain *"new understandings and appreciations"* (Boud et al., 1985: cited in Boud 2001: p.10). As Eraut (1994) states "professional knowledge is constructed through experience and its nature depends on the cumulative acquisition, selection and interpretation of that experience" (p.20) reflecting a fit with hermeneutics and phenomenology.

Benner (2001), who is commonly referred to in nursing, used reflection to make clinical knowledge derived from within narratives of experiential learning public and accessible. The influential work of Schön (1988) based on the seminal work of Dewey (1910) describe reflective inquiry. Schön (1988) conceives that when an individual reflects-in-action, that individual becomes a researcher in the practice context. This suggests reflective practice as a vehicle to deliver evidence based practice; however Eraut (2004) warns that the term reflection is so commonly used that there is danger of it being taken for granted, and as such may have limitations for exploration and learning.

Mantzoukas (2007), Rolfe (1999) and Gabbay and Le May (2011) argue that the use of a hierarchical structure of evidence (random controlled trials [RCT] as gold standard) may prevent the use of the most effective treatments. During recent personal experience as part of a multi-agency clinical framework development group, the type of evidence that should be incorporated was strongly contended. The clinicians in the group were open to the inclusion of practice-based evidence, but public health colleagues with a background in epidemiology were not. Hence this resonated with my experiences where "daily practice, in contrast to well-designed and executed RCT's, is complex and uncertain" (Mantzoukas, 2007: p.215). Findings of clinical research trials

are not usually directly transferable, particularly for older adults with frailty, because the multiple and diverse characteristics of each patient does not mirror the participants that responded positively in the trial (Gabbay and Le May, 2011; Mantzoukas, 2007). This is important for practitioners faced with specific clinical decisions about unique individuals (Rolfe, 1999) in their specific context, whereby the clinical aims and goals will also be individual and unique. As Rolfe (1999) states "statistical data can provide us with useful information on the macro level of whole populations, but not on the micro level of individual patients" (p.19).

Rolfe (2002) challenges the hierarchy of evidence on which to base practice, and argues that reflection-on-action has become a tool which has been absorbed into a technical rationality paradigm. He argues that the reflective practitioner uses reflection-in-action through on-the-spot experimentation and hypothesis testing; complex problems usually have to be worked out on the spot (Rolfe, 2014). His argument is interesting as the NMC (2017a) requires that registrants' provide written reflective accounts *on* practice. Rolfe's (2014) argument that nursing has almost completely ignored reflection-in-practice in favour of reflection-on-action appears to ring true. Although one could reflect on experiences of reflecting-in-practice, the NMC do not make reference to this, whilst the RCN (2017) state that practitioners rarely do this. Reflection-in-action is bounded by the 'action-present' in the time frame that action can still make a difference to the situation (Yanow and Tsoukas, 2009). Eraut (1994) proposes that reflection-in-action is only relevant when the action is fairly rapid because when the pace becomes slower, he argues that there can be no clear distinction between when the reflection is in, or on action.

Mantzoukas (2007) conclude that reflection is viewed as a process of transforming unconscious types of knowledge or practices into conscious, explicit and logically articulated knowledge-of-practice which enables transparent and justifiable clinical decision-making. Yanow and Tsoukas (2009) argue that reflection-in-action has a cognitive bias (reflection as thinking) which demonstrates linkage to Dewey's (1910) original work, *How We Think*. Eraut's (1994) critique of Schön's work *the Reflective Practitioner* implies that Schön searched out examples of professional work to demonstrate professional artistry in order to refute the technical rationality model. Eraut (1994) argues that Schön was concerned with developing an epistemology of

'professional creativity' (p.143) rather than every day professional practice. Eraut (2000) emphasises the importance of non-formal learning for professional practice, he distinguishes between implicit learning, reactive on-the-spot learning and deliberative learning. He also argues that there are three types of tacit knowledge; understanding of people and situations, routinised actions, and tacit rules that underpin intuitive decision making. He proposes that these are combined "when professional performance involves sequences of routinised actions, punctuated by rapid initiative decisions based on tacit understanding of the situation" (p. 113); arguably reflection-in-action.

Dewey (1910) proposed that an element of reflective thinking stems from the state of perplexity, hesitation or doubt as something was unexpected, a shock or an interruption. He problematised the focus of the reflection. In his work on reflection, Schön (1988) also proposes that surprise or divergence triggers certain thoughts back on-action, and on-knowing which is implicit in action. Yanow and Tsoukas (2009) sought to further develop the concept of reflection-in-action using a Heideggerian phenomenological perspective. They emphasise the embedded (social), engaged (practice), and embodied (material) aspects of reflection. They argue that within social practices, reflection-in-action is triggered by 'backtalk' from the 'materials' of the practice. 'Surprise' as part of this backtalk results in the individual improvising a reaction or response (Yanow and Tsoukas, 2009). Dreyfus and Wrathall (2005) explain that besides Dasein, Heidegger's other modes of being include 'availableness' and 'occurrentness'. Availableness can be understood in terms of a piece of equipment that we know how to use and transparently lends itself to that use. Occurrentness is explained as 'presence-at-hand', things constituted by properties they possess in themselves rather than through their relations to use (Dreyfus and Wrathall, 2005). They explain that in breakdown situations the occurrentness of an available object will obtrude. As Bakewell (2016) explains, when a computer freezes we "stare angrily at the contraption and jab at its keys. What had been ready-to-hand flips into being present-at-hand: an inert object to be glared at" (p.69).

Utilising Heideggerian principles, Yanow and Tsoukas (2009) distinguish different kinds of surprise and awareness which enables them to articulate how improvisational responses emerge in the midst of action.

Table 22 adapted from types of surprise and responses they generate (Yanow and Tsoukas, 2009: p.1354).

TABLE 22: CHARACTER OF THE TASK AND INTERUPTED ACTIVITY

Character of the task					
	Ongoing routine activity	Interrupted activity through backtalk/surprise/disturbance			
		malfunction	temporary breakdown		total breakdown
			mild	persistent	
Type of intentionality or awareness	absorbed coping transparency	reconstituted absorbed coping shift to a new way of absorbed coping	deliberate coping attention to the task	involved deliberation reflective planning	thematic awareness analytical/theoretical reflections
Mode of being entities in the world (e.g. tools, actors)	availableness	momentary unavailableness	unavailableness	unavailableness	occurrentness

They argue that improvisation requires preparation and all improvisation draws on collectively established distinctions and standards of excellence factors. They contend that health practitioners who 'seemingly' act on their own, improvise in the context of collectively constructed 'genre', codes of practice and professional norms (Yanow and Tsoukas, 2009); arguably involving tacit understanding of people and situations, routinised actions, and tacit rules which underpin intuitive decision making (Eraut, 2000).

Phipps and Ozanne (2017) extended the concept of ontological security by outlining five ontological states in reference to stable and unstable practices. They propose that discursive consciousness is the ability to give conscious, rational accounts for one's actions, whereas practical consciousness is understood as tacit knowledge (Nonaka and Toyama, 2003; Phipps and Ozanne, 2017). In the stable state practices are performed effortlessly, "producing feelings of ease and trust in a predictable world" (p. 1), hence embedded security. They emphasise that people are often unaware of their embodied competencies, but that practical understandings become apparent when elements of practices are misaligned. Following from misalignment or as Yanow and Tsoukas (2009) describe an interruption, re-stabilisation requires 'discursive

understanding' involving reflection on new practices. Phipps and Ozanne (2017) termed this acclimating security which leads to availableness and automaticity, leading to a new embedded security. When considering discursive insecurity they used examples of stage of life transitions; that is becoming older and frailer and requiring care, or the introduction of a new baby into a family. These life transitions lead to a change in routines and they propose lead to feelings of insecurity. Embedded insecurity is associated with 'obdurate' blocked practices in which they discussed in terms of medical practice where they argue that the use of technology embeds insecurity in practice. An example being the NHS cyber-attack (NHS digital, 2017).

Whilst Phipps and Ozanne (2017) focus is on consumerism, the ontological states of security and insecurity resonate with the RN's experiences. Gwen's embodied skills of using syringe drivers in palliative care could sit under the ontological state of embedded security. 'Her lady's' experience of malfunctioning syringe drivers could be incorporated into discursive insecurity where the realignment of practice was fragile and unstable. Her concerns about the one male patient's intractable pain, or the need to identify who is responsible for discussing potential catastrophic bleeds could be captured under embedded insecurity. In Phipps and Ozanne's (2017) model, the practical and discursive understandings in the wake of disturbance were re-worked which reflects Eraut's (1994) point that the distinction between whether the reflection was in, or on action can be unclear. The experience of the reflective process is prompted by backtalk, surprise, disturbance or interruption (Dewey, 1910; Schön, 1988; Yanow and Tsoukas, 2009) which needs critical examination or as Eraut (2000) describe 'on the spot or deliberative learning' to develop new knowledge and understanding. These disturbances are arguably reflected within the memorable happenings of the RN's experiences that they chose to describe.

12.7.1 THE REGISTERED NURSES REFLECTIVE ACCOUNTS 'ON' PRACTICE

The original plan to focus on a memorable clinical case anticipated that this would reveal stories of very good or very poor experiences; generally this was the case. The 'backtalk' associated with awareness and temporal aspects of the dying arguably made the experience memorable for the participants. Predominantly the 'off schedule critical junctures' contained elements of surprise, disturbance or interruption. These disturbances may have triggered the reflective account on or in practice. Smith et al.

(2009) explain that in IPA "the interviewer is facilitating some self-conscious phenomenological reflection by the participant" (p.190). The purpose of phenomenological reflection is to try to grasp the meaning of something (Van Manen, 2011) as Smith et al. (2009) state "being phenomenological involves taking a quality which occurs in everyday life, honing it, stretching it, and employing it with a particular degree of determination and rigour" (p.189). There has also been criticism that ordinary reflection has been equated with phenomenological reflection (Giorgi, 2011). The point here is that the interview process facilitated the participants' reflective understandings.

Within the RN's experiences, there is a blurring of reflection in-action and on-action. The RN's were recounting past experiences during the interview but were also reflecting on-practice that at times appeared to have been related to practice-in-action. Beth appeared to be reflecting-on-practice-in-action when recounting her decision not to set up a sliding scale insulin infusion for a dying lady, whilst Cara may have been reflecting-on-practice-in-action in saying "*we've got to do something*". Dawn appeared to be reflecting-on-practice-in-action in her experience with the male patient who presented as particularly breathless. As does Ffion in saying "*what am I going to do*?" (L 275), and Gwen, in saying "*we didn't really want her husband to see her*" (L 552-553) in relation to a patient who had died. Elsa arguably reflected-on-practice-in-action in suggesting to the patient's wife that she bring the dog into the care environment, but predominantly Elsa reflected-on-practice, and actively appeared to be trying to make new sense of her experiences during the interview.

12.8 CONCLUSION

Reflective practice is an expectation and requirement for RN's in the UK (NMC, 2015b; 2017a). Smith et al. (2009) explain that in IPA the interviewer facilitates some self-conscious reflection by the participant. The participants can be seen to have reflected on and in practice in order to further develop meaning making and understanding. As reflections are triggered by disturbances, the request to focus on a memorable clinical case may also have contributed to generating their reflective practice accounts.

Reflexivity requires that the researcher makes visible their individuality and the effects on the research process (Gough, 2003). A researcher's background will affect what they choose to investigate, the angle of investigation, methods, the findings considered most appropriate, and the framing and communication of conclusions (Malterud, 2001). Whilst being mindful that researchers faced with the same qualitative task will produce different accounts due to their individual philosophies and theoretical commitments (Sandelowski, 1993), IPA also emphasises that research is a dynamic process with an active role for the researcher within that process (Smith and Osborn, 2008). The research findings are co-produced, or 'co-constituted' (Finlay, 2002) between the participants and the researcher.

Likewise, Finlay (2002) advises that being reflexive requires the examination of the impact of the position, perspective, and presence of the researcher. Being a RN and interviewing RN's has advantages and disadvantages (Finlay, 2002). Both relate to perceived shared 'professional' understandings but it remains difficult to unravel what is truly shared.

I will now try to capture my reflections of my research journey.

My interest in exploring RN's experiences of delivering end-of-life care for older people with frailty is relevant to my role working 'with older vulnerable adults'. This interest seems to have been derived from my professional experiences, triggered particularly when I was working in acute stroke care (my prior role) but embedded further during my current role as a consultant nurse working with vulnerable older adults. However my personal and student nurse experiences will have undoubtedly also contributed to this interest.

When developing the research proposal I made a conscious decision not to define the term older, but I also did not define vulnerable or frailty which suggests I had not fully considered my assumptions and preconceptions. I was however encouraged to consider my own ontological perspective. I came to the conclusion that 'the world' and knowledge are socially constructed and require contextual understanding. I also concluded that the beliefs, rituals and knowledge surrounding death and dying are

socially constructed whilst dying and death are factual occurrences. This seemed to be a peculiar perspective to describe. At the time that I was exploring my way of seeing the world I was not cognisant of IPA being a critical realist method which Sullivan (2010) described as accommodating "both the socially constructed nature of the world and its material reality" (p.29). This made sense to me but also justified my 'peculiar perspective'.

The interviews were held at mutually convenient times and places agreed with the participants. A room to undertake the interviews was provided in Cardiff University. Four interviews were held at the University, one participant chose to be interviewed at home and two chose their place of work. During the first interview I felt particularly nervous in this different role, accompanied by some excitement that I was actually embarking upon data collection. The first two interviews were conducted on the same day. Ideally I would not have undertaken two interviews in the same half day but nevertheless the second interview felt as if it went more smoothly than the first but that may well have been associated with the personalities of the participants.

This study used a qualitative exploratory inductive research design, but was initially considered from a CIT perspective. When using IPA the interview approach recommends funnelling down into topics, from the general to the specific. The schedule did start with a generalised question 'can you tell me a bit about your role and how long you have been working with older people?' This was intended as an introductory question to open the interview and put the participant at ease. In the re-reading and analysis of the first interview transcript I recognised that Alice had very early in the interview began talking quite specifically about a particular individual, Iain which was in response to my asking her 'when I spoke with you previously I asked you to think about a memorable clinical case, involving end-of-life care of a frail older person. Have you been able to identify a memorable case study?' The middle part of the interview was more generalised, and the generalisations helped to better understand her experiences and how they linked with her personal values and beliefs. This helps explain these differences in the interview structure and perhaps how I may have added in a more generalised question e.g. can you tell me generally about your involvement in delivering end-of-life care? However I do not believe the approach was

detrimental to the interview process and I did not change my approach in subsequent interviews.

As a relatively senior nurse I have experience in interviewing staff but predominantly in recent years these interviews have been associated with concerns relating to aspects of patient care. As part of the ethical approval process the potential blurring of my clinical and research role was raised. I remained mindful of this particularly during the interviews and during the transcription process but I have since recognised that this requires an ongoing awareness. Of the seven participants Cara was a member of staff that I intermittently engaged with clinically and within leadership roles. On reflection, this appeared to facilitate a comfortable interaction with only one discernible occasion that may have related to my professional role. This was when Cara, after describing an aspect of poor practice followed up with "*so I obviously I kind of just acted on it straight away ((laugh)) and pulled one of the doctors out and just told him that it was unacceptable*" (L 116-117). I do recall 'feeing relieved' that she had offered this explanation; whether my non-verbal communication influenced this or whether Cara would have told me this anyway remains unclear. Another occasion I felt a tension between my role as researcher compared with my 'day job' was when Alice stated "*she wrote me back a lovely letter back, to the hospice, and um, just saying about how she was getting on and whatever for everybody to read*" (L 414-415). In my mind I questioned the relevance of 'to the hospice' and 'everybody' and wondered whether she had provided her personal contact details to the family; I would have asked this as part of my role as an investigating officer but did not in my role as a researcher. Weighing it up on my feet so to speak (reflection in practice), whilst I recognised probing and exploring is a part of the qualitative interview I considered my role as a researcher rather than an investigating officer and decided this was not related to the study's question. During Dawn's interview I slipped into my professional role and offered organisational explanations surrounding the complaint (concerns) process. Recognising this enabled me to ensure that the remainder of this interview and subsequent interviews remained focused on the participants' experiences. I have subsequently encountered three of the participants as part of my professional practice. I have remained mindful of the need to maintain confidentiality and likewise none of the RN's made reference to the research. These experiences have

demonstrated to me that separating the professional and researcher role requires conscious effort.

Had I not been a RN or perhaps another healthcare professional, I have wondered whether I would have asked for clarification of particular points; e.g. Gwen talked about her lady starting to mark. I presumed we both understood that this related to tissue viability whereas a different researcher may have followed this up. Another instance involved Alice talking about Iain needing to go to the hospital to have a NGT fitted; I assumed she meant a PEG but on reflection it is quite possible that it was a NGT. The type of feeding tube was not particularly important, what seemed important was the need to make a medical decision and Alice's communication with and assessment of Iain's predicament. This demonstrates that my preconceptions and experiences did influence the interview questions. The RN's did not focus particularly on older people with frailty in the sense that I had expected, but they also focussed not on the last year of life (definition of end-of-life) but on the very end-of-life, the dying process. This may have been influenced by the research aims focussing on the good enough death.

Having considered that the participants told me quite emotive stories, and at times talked about their emotional responses, I do not recall feeling uncomfortable. I did feel a sense of being privileged in that they were sharing their experiences, perhaps this outweighed any feelings of sadness, or perhaps again this reflects my professional role. I imagine that some people would find this is a difficult subject to explore. I believe that thinking about my experiences and perspectives beforehand probably helped prepare me to deal with this potentially very sensitive subject.

The patients I engage with have some degree of frailty and many have a cognitive impairment. My perceptions of 'vulnerable older adults' involve people with moderate to very severe frailty accompanied by some degree of cognitive impairment. I assumed, wrongly, that my participants would share this understanding, but only Ffion chose to tell one story of a patient's death that aligned with my preconceptions of a 'vulnerable older adult'. This perplexed me and likely directed my interest in Elsa's reflection that older people's deaths are 'more run of the mill'. I tend to work with the older of the old, and perhaps I did take for granted that the clinical syndrome of frailty along with multi-morbidity would culminate in dying. With the exception of one of

Ffion's stories, specific diseases (predominantly cancer) tended to prevail. This has served to substantiate my feelings that older vulnerable adults with frailty may die 'invisible deaths'. This conclusion is arguably the opposite of my initial interest in exploring the concept of the healthy death.

This personal 'revelation' that I see frailty through a different lens to that of my participants has prompted me to re-consider my perceptions of my own and others' practice. I need to make my perspectives more explicit (both for myself and for others). This new knowledge has filtered into personal reflections about practice. I have come to believe that many staff working with older people with frailty hold an implicit rather than explicit understanding of frailty syndrome.

As I have explained, much of my professional work is associated with complexity, difficult decision-making, and can and does involve the scrutiny of poor practice with associated consequences for patients, their loved ones, and staff members. Not unsurprisingly the participants' stories did not reach 'my interpretation of' safeguarding thresholds. This had been reiterated verbally and in writing as part of the consent process: "I understand that information will be kept confidential with the exceptions of new disclosures of criminal offences, people identified as at risk of harm or abuse, or breaches of professional codes of practice" (consent form v.2 appendix 7).

I have recognised that part of my research journey has taught me the importance, and perhaps the skill of keeping an audit trail during complex investigation processes, and indeed practice and policy development, and most importantly in this case during a research project. The new ability to assimilate large amounts of evidence based information into a critical grid has been particularly useful. Naturally within my role there are exemplars of excellent patient outcomes in difficult situations; some of this is attributed to use of the Mental Capacity Act 2005, or 'thinking outside the box', or as I often describe it 'grasping at straws' (externalising tacit knowledge perhaps). I now feel more aware of the benefits of being a reflective practitioner. The writing of this thesis has demanded careful thought and explanation. The research process has required me to develop different ways of thinking and seeing, which no doubt will develop further. Part of my learning in undertaking this study are being translated and incorporated into my professional working practices.

I had not previously appreciated the level of the general public's lack of familiarity with dying and death; knowledge I have drawn from the literature. I have used this increased awareness with family, friends and patients' loved ones. One example is an opportunist encounter with a friend in a hospital corridor. She explained that her mum was dying but then offered that she didn't know what to expect. I was able to ask further questions and provide clear concise information. In a later discussion about her mum's death, aspects of my information giving appeared to have been retained. Another instance involved my family where I was again able to provide clear, concise, and perhaps 'blunt' information and explanations whist remaining mindful that the literature confirms that the use of euphemisms can impede understanding. I was also able to steer some misconceptions and this helped to prepare my family for witnessing the dying process and death. I received feedback later that my (virtual) assessment and information was helpful.

The writing of this chapter has demanded that I reflected on the research journey from a personal and professional stance. It also involved instances of reflection in and on practice; concepts that have helped me to examine my professional practice.

CHAPTER 14 - LIMITATIONS OF THIS RESEARCH

This is a small qualitative study that explores the experiences of seven RN's in delivering end-of life care. It is not designed to provide generalisable findings although it does carefully explore patterns across cases and presents some shared experiences which may have relevance for others.

The RN's were a purposeful sample who volunteered to take part in this study. Their reasons for taking part were not explored but may contain some unspecified bias. They were also undertaking a palliative care module which may also have influenced their thinking.

Personal and professional knowledge and experience will influence the observations and conclusions related to this thesis. IPA is an interpretive method and as such this thesis presents my interpretation of the RN's meaning making of their experiences; other researchers may have developed different interpretations. However I have made explicit that the findings remain grounded in the RN's experiences and can be traced back to their own words. Finally, this research has been undertaken as part of a Professional Doctorate programme and as such has also been shaped by university requirements.

I set out to explore the experiences of seven RN's with regard to achieving a good enough death for vulnerable older adults with frailty. Arguably people are frail at the end-of-life as they have limited functional reserve (Cornwell, 2012). With the exception of Ffion's experiences with Jack in hospital, the RN's did not focus particularly on older people with frailty in the sense that I had expected. And whilst end-of-life care is understood as the last year of life, the RN's focused on people at the very end of life, the actual dying process and death. This may represent their understanding of end-of-life care.

Much of the participants' experiences were not novel. Indeed the overarching shared experience that memorable clinical dying and death experiences are imbued with 'emotional work', underpinned by 'knowing' and 'doing' is arguably unsurprising. Their experiences also aligned with the contemporary literature described in chapter 11. That said their experiences also resonated with the seminal works of Glaser and Strauss; *Awareness of Dying* (1955) and *Time for Dying* (1968) demonstrating that Glaser and Strauss's work remains covertly relevant in contemporary practice which in itself is an important finding.

The focus of end-of-life care publications tend to prioritise strategic development, including a welcomed movement towards palliative care for all. The intricacies of end-of-life care practice tend to focus on deficits in end-of-life care, fundamentally attributed to a lack of respect leading to poor experiences. The original concepts that older people's deaths are more run-of-the mill, the question of a good enough death for whom and the use of IPA as a vehicle for reflective practice are discussed below.

15.1 OLDER PEOPLE'S DEATHS ARE MORE RUN-OF-THE-MILL

One of this study's findings is that older people's death is considered 'run-of-the-mill' and that the RN's did not always choose to tell their stories about older people with frailty. This could reflect Glaser and Strauss's (1966) observations that older people are considered a lower social loss. Alternatively the 'emotional work' of nursing older people who are dying and die may have become routine. Staff may have become desensitised to what may be classed as routine care. Concurringly Kelly and Nisker

(2010) found that "old deaths were frequently experienced as so routine as to be dehumanizing" (p.424). Of particular concern is the potential that this desensitisation has led to end-of-life care for older people not being seen as 'real nursing' as it can, as much physical care is in contemporary practice, be largely delivered by healthcare support workers. If older people's deaths are viewed as routine, this may create risks for delivering de-sensitised, undignified care. Hence routinisation, which may be a coping strategy for staff may lead to 'poor care'.

A different interpretation may be that 'run-of-the-mill' deaths take place for the RN's without backtalk, surprise, disturbance or interruption (Dewey, 1910; Schön, 1988; Yanow and Tsoukas, 2009). Phipps and Ozanne (2017) emphasise that people are often unaware of their embodied competencies, but that practical understandings become apparent when elements of practices are misaligned. This raises an alternative interpretation; perhaps the RN's possess embodied competencies and use them to deliver care culminating in 'the good enough' death. A further potential interpretation is that 'run-of-the-mill' may allude to a slow and steady decline, perhaps depicted in contemporary dying trajectory of frailty (RCN, 2015). If these are the cases a 'run-of-the-mill' death could be understood as a 'good enough death'. However, for me, 'run of the mill' particularly with older adults with frailty creates a sense of invisibility.

15.2 A GOOD ENOUGH DEATH FOR WHOM?

This thesis began with a concept of exploring the achievement of a healthy death for older people, which was then modified to a good death, which subsequently became a 'good enough' death. During the writing of this thesis the question arose 'a good enough death for whom?'

The RN's experiences of good enough death were concerned with open awareness, and having the knowledge that death was a certainty which appeared to positively influence their experiences. The findings suggested that following a changing but anticipated schedule, is for the nurses connected to achieving a good enough death. If the RN's are prepared, arguably they can support and comfort the dying patient and their loved ones which may provide a sense of purpose and achievement.

The RN's had similarities in their expectations of a 'good enough death' which included symptom control and providing comfort care, respecting the individual's wishes, being

peaceful, with people they want to be present and preparedness. In the hospital setting privacy and dignity also featured, more so by being compromised in practice. However the RN's mainly described experiences where there were significant aspects in the patient's condition where these expectations for the 'good enough' death were not achieved.

Lack of the RN's preparedness was a factor for them that impacted this on their experiences, but they were able to recognise that times this resulted in a 'good enough death' for the patient. Paradoxically this contributed to a difficult experience for the patient's loved ones, associated with misaligned expectations. Gwen provided the example of a dying male patient who unexpectedly died during the night. This resulted in the police being called to the property which added distress for his wife. Conversely this was considered a good death for the patient. This appeared to be associated with maintaining some quality of life, and the actual death perceived as a quick process with little if any physical suffering. Within these three perspectives the conundrum of the 'good enough death for whom' is made explicit.

The 'good enough death for whom' could be explored further within multidisciplinary teams. Given some of the team working tensions experienced by the RN's which may have been associated with disparate goals and stemming from seemingly different beliefs, values, and assumptions particularly between doctors and nurses, a potential way forward in practice could be multi-disciplinary simulation training. A focus is also required to understand how RN's and other practitioners become familiar with frail older people's values and wishes, which perhaps may be more challenging particularly in the acute setting. This 'personalised' knowing could potentially help tackle the concept of desensitisation.

15.3 REFLECTIVE PRACTICE

The RN's were asked to think about a memorable clinical case rather than use the original planned terminology of a critical incident or critical happening. However they described 'critical incidents' some of which were positive but there was an emphasis on incidents where care did not go as planned or appeared to be particularly demanding.

The use of IPA encouraged the participants to describe and reflect on their experiences and can be seen to produce new knowledge which can be useful not just to the individual; perhaps justifying reflection as an essential component for nurses continued registration and practice. It also appeared that the RN's used the research interview at times as a mechanism for self-led de-briefing. The need for emotional support in terms of debriefing or counselling was mentioned by some of the RN's. However the 'run of-the-mill', 'good enough' deaths, are unlikely to trigger a formalised debriefing or reflective session and by virtue remain an unseen, or an undisruptive aspect of RN's cumulative 'emotional work'.

In my professional work, the requirement to produce five written reflective accounts and five pieces of practice feedback in order to revalidate with the NMC does appear to have engaged an increase in reflective activity; group discussions, requesting and providing practice feedback, and actively seeking opportunities to 'talk through' experiences with colleagues. Like my participants, my reflective practice has been triggered by critical incidents, backtalk, surprise, disturbance or interruption, leading to critical reflection. This interrupts the natural attitude, the uncritical, every day, ordinary way of being-in-the world. As Dahlberg et al. (2008) explain "the meaning of the experience being verbalised is that the speaker or writer is distancing her or himself from the natural attitude" (P.162), it is being externalised so that meaning and knowledge is consciously derived.

The use of IPA as a research methodology does resonate with nursing's requirement for reflective practice. A contemporary interesting topic would be to explore RN's experiences of preparing their reflective accounts, particularly the accounts they share for revalidation purposes.

15.4 IMPLICATIONS FOR PRACTICE

This study considered a number of associated topics which may have implications for practice. These include:

- Understanding frailty, particularly at end-of-life.

- The RN's role in patient advocacy.

- Familiarisation with older adults' values and wishes; particularly within and between different settings of care.

- The concept of the 'good enough death for whom'.

- RN's experiences of preparing their reflective accounts, particularly the accounts they share for revalidation purposes.

It is important to create awareness and promote critical discussion surrounding these practice implications which have relevance for RN's delivering care for older vulnerable adults with frailty but also more generally. Two implications that potentially have multi-agency implications for practice and programmes of research include:

- The recognition of differing thresholds and implications for the appropriate reporting of poor care.

- The 'zone of tolerance' and expectations in the delivery and receipt of interpersonal care and attention.

As a final point, the findings of this study and the implications for practice will be shared. The intentions for sharing include clinical meetings within my Health Board, and externally at conferences and via publications in a bid to improve an awareness of RN's and older adult's vulnerabilities associated with end-of-life care. Sharing the findings will also provide an opportunity to discuss the significance of RN's role in delivering end-of-life care, and to promote a better understanding of the needs of vulnerable older adults with frailty. There is also a need to better understand the 'zone of tolerance' which seems particularly important when considering the vulnerability of people requiring care and the reported poor care and abuse.

EPILOGUE

The planning of this study began by considering the concept of the healthy death, which changed to the good death and subsequently became the good enough death. The plan was to conduct an exploratory inductive study of RN's experiences of delivering end-of-life care for frail vulnerable older adults by using the Critical Incident Technique (CIT).

Identifying a research sample was not straightforward due to organisational constraints at the time, but with my supervisors support I was able to approach two cohorts of RN's undertaking a palliative care module. I gained a 'fairly homogenous' purposeful sample of seven RN's. During my reading it became apparent that whilst many documents used the term 'frail', as an older people's nurse and in attempting to be respectful I chose to use the term 'vulnerable older adults with frailty'.

Following data generation using minimally structured interviews and following transcription whilst initially attempting to analyse the data using CIT I attended a masterclass in IPA. This encouraged me to explore the methods and philosophy of IPA. I found the idiographic sensibilities of IPA intriguing; IPA gives the participants' 'voice'. It recognises people as interpretive meaning making beings and in doing so recognises the contribution the researcher brings to the process. It embraces the double hermeneutic circle. It also has a clear set of processes that new researchers are encouraged to follow, although in practice they weren't so clear. Overall it felt like a better fit for my research.

I proceeded to analyse the data using IPA using the individual printed transcripts descriptively, conceptually and linguistically. Then I carefully looked for patterns across cases to elicit some shared experiences and themes. Their experiences were then explored in the wider context using Kolcaba's comfort theory, Glaser and Strauss's *Time for dying,* reflective practice and *Practice-based evidence for healthcare: clinical mindlines*.

I adopted an exploration of the concept of the 'good enough death' but in reality the deaths were 'just good enough' if good enough at all. A question that emerged for me during this study persists. That is 'a good enough death for whom?' which may have varying angles and perspectives depending on one's position. However I am left with

an overarching sense of invisibility surrounding the dying and deaths of vulnerable frail older adults, resonating with my experiences of acute stroke care where the need for improvement in end-of-life care for this group of people became particularly visible to me. These experiences encapsulate me as an interpretive meaning making being.

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APPENDICES

APPENDIX 1 - CONCEPT ANALYSIS LITERATURE SEARCH STRATEGY 2007-2017:
POOR CARE

Search strategy- concept analysis of poor care
1. quality of healthcare/
2. poor.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
3. suboptim$.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
4. standard$ of care.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
5. good enough.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
6. bad.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
7. unsatisfactory.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
8. substandard.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
9. ineffective$.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
10. unsuccessful.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
11. unmet need.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
12. wrong.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
13. deficient.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
14. mediocre.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
15. inappropriat$.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
16. unacceptable.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
17. deficient.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
18. defective.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
19. faulty.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
20. imperfect.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
21. inferior.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
22. neglect.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
23. inadequate.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
24. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25. limit 5 to "all adult (19 plus years)"
26. limit 25 to abstracts
27. limit 26 to english language
28. patient$ care.mp. [mp=ab, hw, ti, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, px, rx, ui, sy]
29. 27 and 28
30. limit 29 to yr="2010 - 2017"
31. remove duplicates from 30

I

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

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From: Professor JI Bisson
R&D Director
R&D Office, 2nd floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

18 January 2013

Miss Denise Shanahan
180, The Barry Hospital,
Colcot Road,
Barry
CF62 8HE

Dear Miss Shanahan

Cardiff and Vale UHB Ref: 11/CLC5255 : A Good And Healthy Death: A Critical Exploration Of Health Care Staff Knowledge And Attitudes Into Best Practice In End Of Life Care

Thank you for your recent correspondence addressing the reviewers' comments on the above project. Your response and revised documents were reviewed by the Chair of the Cardiff and Vale Research Review Service (CaRRS).

The Panel is now satisfied with the scientific quality of your proposal., and I can confirm that the following documents have received favourable scientific review:

Document	Version	Date
Protocol	-	October 2012

As this is an unfunded study, you must ensure that you have Directorate support for involvement of NHS staff participants during working hours before you can proceed to apply for NHS R&D governance review. Once you have obtained this confirmation, please follow the application instructions below:

For ethical review:
Please contact your sponsor, Cardiff University RACD for further advice about requirements for University ethical review.

Page 1 of 2

Version 1.0. 09.06.10

Bwrdd Iechyd Prifysgol Caerdydd a'r Fro yw enw gweithredol Bwrdd Iechyd Lleol Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board is the operational name of Cardiff and Vale University Local Health Board

UHW129X

II

For NHS R&D governance review:

- Contact Cardiff University RACD to obtain the sponsor's representative signature needed on the IRAS NHS R&D form prior to your submission to the National Institute for Social Care and Health Research – Permissions Coordinating Unit (NISCHR PCU).
- The following signatures/authorisations must be obtained in Q23 the SSI form prior to submission to NISCHR PCU: Dr Sinead O'Mahony, Directorate R&D Lead. An email of support forwarded to the R&D Office is an acceptable alternative to an 'ink' signature.
- Once the above signatures/authorisations are in place you should submit the IRAS NHS R&D form and Site Specific Information (SSI) form and all supporting study documentation to NISCHR PCU who will coordinate completion of governance checks prior to R&D permission being granted.

Final R&D permission to begin your study in Cardiff & Vale UHB will be issued following completion of the governance review by Cardiff and Vale UHB and NISCHR PCU.

<u>YOU SHOULD NOT BEGIN YOUR PROJECT BEFORE RECEIVING WRITTEN CONFIRMATION OF NHS R&D PERMISSION TO BEGIN.</u>

If you require any further information or assistance, please do not hesitate to contact the staff in the R&D Office.

Yours sincerely,

Professor Jonathan I Bisson
Chair of the Cardiff and Vale Research Review Service (CaRRS)

CC   R&D Lead, Dr Helen Houston
CC   Sponsor contact Chris Shaw RACD Cardiff University

Link: 'Gaining NHS research permission from Cardiff and Vale UHB – Guidance for researchers' http://www.cardiffandvaleuhb.wales.nhs.uk/opendoc/180875

III

Cardiff School of Nursing and Midwifery Studies
Head of School and Dean Professor Sheila Hunt
Ysgol Astudiaethau Nyrsio a Bydwreigiaeth Caerdydd
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Our Ref:

21 June 2013

Denise Shanahan
SONMS

Cardiff University
Eastgate House
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Dear Denise

APPROVAL WITH CONDITIONS

Your project entitled "Achieving a good, healthy death for older, frail, vulnerable adults at the end-of-life: the perceptions and attitudes of health care professionals and health care support workers" has been approved by the School of Nursing and Midwifery Studies Research Ethics Committee of Cardiff University subject to the following:

The REC appreciates the care taken in the preparation of this proposal, which has been developed against a background of heightened public, policy and professional interest (nationally and locally) in the care of people at the end of life. Before the REC is able to approve the study it requests responses to the following:

1. The REC is unsure what is meant by the idea of a 'healthy' as opposed to a 'good' death, and from where this idea arises. In the proposal the two terms are sometimes used in an interchangeable way (for example, participants will be asked to talk about 'good' rather than 'healthy' death in their interviews). The REC suspects that these ideas may actually be rather different, with the 'healthy' idea having largely dropped out of use. With all this in mind the REC invites the research team to consider if there is a case for greater conceptual clarity in the study.
2. The REC sees that only relatively recent literature will be reviewed (post-2006), and invites the team to consider if this strategy will inhibit the potential the study has to make a contribution to knowledge.
3. The REC requests that more detailed plans be given for the identification and recruitment of potential participants. This is needed not least as the researcher works as a senior nurse in the same organisation as the intended sample. Studies involving the recruitment of colleagues (particularly junior ones) always raise ethical issues, which in this case have not been fully addressed. The REC also notes that an option would be to generate data in a different NHS organisation than the one the researcher works in. Regarding participants and their wellbeing, the REC notes the plan of alerting them to the existence of the Employee Wellbeing Service, and considers that members of the palliative care team in the UHB may also be in a position to offer support and/or supervision to participants (and indeed the researcher, if necessary).
4. Approval processes are given on page 16 of the submitted document, where it is stated that 'Ethical approval will be sought prior to commencement of the study via Cardiff University, and Cardiff and Vale UHB research ethics committees'. Greater accuracy is needed here, and the REC asks that the correct titles are used in the naming of all committees (in both the University and the NHS) involved in the study's approval.
5. On page 13 of the main document it is stated that in studies of this kind it is recommended that data be gathered on 50-100 critical incidents. Here the proposed sample is 10 members of staff, each talking about 2 or 3 incidents (see page 23). This gives a maximum of only 30 incidents in the study as a whole, and the REC asks how the information in these two sections can be reconciled.
6. The 'covering letter' mentioned first on page 16, and then given in detail as appendix 3 (pages 25-26), needs to be referred to and laid out as a version-numbered-and-dated participant information sheet. Additional information is needed here: including that confidentiality will be broken if poor practice is discovered (this is mentioned in the consent form, but not the info sheet), and that participants have access to the Employee Wellbeing Service (as is mentioned on pages 16 and 17). REC Supervisor contact details need adding, along with details of the relevant committees/organisations which have approved the study.

Dr Ben Hannigan
Chair of the School of Nursing and Midwifery Studies Research Ethics Committee
Cardiff University,
Eastgate house, 7th floor,
35-43 Newport Road,
Cardiff.
CF24 0AB

Dear Dr Hannigan,

Thank you for your letter outlining approval with conditions of my project entitled "Achieving a good, healthy death for older, frail, vulnerable adults at the end-of-life: the perceptions and attitudes of health care professionals and health care support workers".

I have had the opportunity to review and respond to the recommendations made by the School of Nursing and Midwifery Studies Research Ethics Committee of Cardiff University. I have attached a track changed version of my research proposal and a clean updated version and have provided responses below to the conditions raised in the letter dated 21st of June 2013.

1. The REC is unsure what is meant by the idea of a healthy as opposed to a good death.
   - Following discussion with my research supervisors and with reflection, the project will focus on the good death. The REC request also drew attention to the potential for confusion for potential participants. The concepts of 'healthy' and 'unhealthy' have been removed from the proposal.
2. The REC sees that only relatively recent literature will be reviewed (post-2006).
   - In 2003 the DH reported on the 'choice, responsiveness and equity consultation' care at the end-of-life featured as a major theme. In 2004 the NHS End-of-life Care Programme was launched but the strategy for NHS England was not launched until 2008. The Strategy for Palliative Care Services in Wales was published in 2005 (WAG, 2005). Since 2007 a number of publications and reports have been released identifying best practice care standards for the delivery of end-of-life care. The initial search timeframe will be extended to 2004 to coincide with the introduction of the NHS end-of-life care programme. Backward chaining has and will continue to be used to identify earlier seminal literature. The time frame will be re-reviewed as the research progresses.
3. The REC requests that more detail plans be given in relation to the identification and recruitment of potential participants.
   - Further to the REC observations involving the recruitment of colleagues (particularly junior ones) the sampling decision has been revised. Participants (registered nurses) will be sought from enrolled Cardiff University students commencing study of palliative and end of life care.
4. The incorrect reference to the School of Nursing and Midwifery Studies Research Ethics Committee of Cardiff University has been corrected.
5. The REC asked how the information in the sections concerning potential number of participants and critical incidents can be reconciled.
   - Participants will be asked to recall and discuss a clinical case study. Within this individual case study a number of critical incidents will be identified during analysis. The critical incidents will be the units of analysis.
6. The 'covering letter' needs to be referred to as laid out as version numbered and dated participant information sheet. Additional information regarding confidentiality is required. Supervisor contact details need adding.

   - The participant information sheet and consent form is now version-numbered-and-dated. Supervisor contact details and confidentiality information have also been added.

Project is now titled "Achieving a good death for older, frail, vulnerable adults at the end-of-life: the perceptions and attitudes of registered nurses".

Thank you for considering these responses. I look forward to receiving further correspondence.

Yours sincerely,

Denise Shanahan

Cardiff School of Nursing and Midwifery Studies
Head of School and Dean Professor Sheila C Hunt

Ysgol Astudiaethau Nyrsio a Bydwreigiaeth Caerdydd
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila C Hunt

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01 August 2013

Denise Shanahan

Dear Denise

Application for School Research Ethics Committee approval
Reference: 2013/05/03

Thank you for your email dated 31 July 2013 requesting approval of amendments to the above project entitled "Achieving a good, healthy death for older, frail, vulnerable adults at the end-of-life: the perceptions and attitudes of registered nurses". The application has been approved subject to the following:

The SONMS REC notes the changes which have been made to this proposal, and that these changes comprehensively respond to each of the REC's comments. The REC now requests that the full proposal document, information sheet and consent form (all dated 31.07.13 and labelled as version 1) be re-labelled as version 2, to distinguish them from the original documents submitted for review. The REC also requests that the opportunity be taken, during this re-labelling of documents, to make a final amendment to the information sheet which currently states that interviews will last both for 45 minutes and for one hour. The REC suggests that 'one hour' be given consistently.

Please could you send a final, version 2, set of documents as now approved by the REC for record-keeping purposes.

As you now plan to access students for the purposes of data generation you will also need to approach RRESC for this approval. You may wish to include with your re-labelled documents a RRESC front sheet to begin this process.

If you make any substantial changes with ethical implications to the project as it progresses you need to inform the SREC about the nature of these changes. Such changes could be: 1) changes in the type of participants recruited (e.g. inclusion of a group potentially vulnerable participants), 2) changes to questionnaires, interview guides etc. (e.g. including new questions on sensitive issues), 3) changes to the way data are handled (e.g. sharing of non-anonymised data with other researchers).

All ongoing projects will be monitored every 12 months and it is a condition of continued approval that you complete the monitoring form. Please inform the SONMS REC when the project has ended.

Please use the SONMS REC project reference number above in any future correspondence.

R C Williams

pp
Dr Ben Hannigan
Chair of the School of Nursing and Midwifery Studies Research Ethics Committee

Version 2: date 31.07.13

Achieving a good death for older, frail, vulnerable adults at the end-of-life: the perceptions and attitudes of registered nurses

Dear [Insert name],

My name is Denise Shanahan. I am currently studying for a Professional Doctorate (Advanced Healthcare Practice) at Cardiff University. Part of my study involves undertaking a research project which is why I'm contacting you.

What is the purpose of the study?

This study is about finding out about staff experiences and what influences the quality of end-of-life care.

What are the possible benefits of taking part?

The study may not help you personally, but the information may be used to inform recommendations for best practice, practice development and for education and training.

Why have I been invited to take part?

You are enrolled on a Cardiff University module studying palliative and end-of-life care and have valuable experience of caring for older people at the end of their lives.

Do I have to take part?

It is entirely up to you whether or not to take part. If you decide to take part but change your mind at any time, you are entirely free to do so without having to give reasons or speak to me.

What will happen if I take part?

If you agree to take part I will ask you to agree to an interview. I anticipate that the interview will take up to one hour.

Before the interview I will make sure you have understood the information about the study, given you the opportunity to ask any questions and ask you to sign a consent form. I will ask you to think of a memorable clinical case of an older patient that involves end-of-life care to discuss during the interview. I will also ask you for your opinions about what you consider to be good or bad end-of-life care and a good or bad death. With your permission I would like to audio record what you say, so that I can make sure I have captured all the information. I may ask you to take part in a further interview.

All information collected will be kept strictly confidential. You will not be identifiable.

As part of this you will be given the opportunity to request more information about the study. If you agree to participate the interview will take place between you and me. I will arrange for the interview to be undertaken in private in a place and at a time that is most convenient to you.

Your name and any other information which could identify you will not be associated with anything you say. Once the interview is over I will type out what you have said word

for word but your name or the name of anyone else you refer to will not be used. You or anyone you refer to will not be identifiable in any written report.

When I have typed what you have told me I will analyse what you have said and compare this with what other people tell me. The typed information will then be kept in a locked filing cabinet accessible only to me for a period of five years. The computer on which the typed information is stored will be password protected and only accessible by me.

Confidentiality will only be broken if information is disclosed that breaches professional codes of practice, is criminal or exposes people at risk of harm or abuse.

What are the possible disadvantages and risks of taking part?

The interview will take approximately 1 hour of your time and will inevitably involve you discussing your experiences of end-of-life care which can be upsetting. You will not have to answer any questions that make you feel uncomfortable and you can end the interview at any time without giving me any explanation. If you remain upset, the palliative care educators will be available to provide support and signpost to other services.

Further information and contact details

If you would like some more information about the study or there is anything that is not clear, please do not hesitate to contact me.

What should I do now?

If you would like to take part please contact me via email or leave message and your contact details on either 029 20556037, Cardiff and Vale UHB Internal line 46037, mobile telephone 07791 195278 or via email Denise.Shanahan@wales.nhs.uk. If leaving a message please provide your contact details, I will then contact you and discuss any questions you may have.

You may also contact my academic supervisor, Dr Jane Harden, Director of postgraduate studies (Taught) at Cardiff School of Nursing and Midwifery Studies, and can be contacted by telephone 029 2917 725, mobile 07736933547 or via e-mail hardenj@cardiff.ac.uk.

Ethical approval has been received from the School of Nursing and Midwifery Studies Research Ethics Committee of Cardiff University dated 01.08.13.

Thank you for taking the time to read this information.

Yours sincerely,

Denise Shanahan

VIII

Consent Form

Achieving a good, healthy death for older, frail, vulnerable adults at the end-of-life: the perceptions and attitudes of health care professionals and health care support workers

Name of Researcher: Denise Shanahan

Please initial each box

I have read the information presented in the participant information sheet version 2 dated 31.07.13 about the end-of-life care study.

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason.

I understand that my participation in this project will involve discussing experiences about the quality of end-of-life care.

I understand that information will be kept confidential with the exceptions of new disclosures of criminal offences, people identified as at risk of harm or abuse, or breaches of professional codes of practice.

I understand that the information provided by me will be held confidentially, such that only the researcher, Denise Shanahan can trace this information back to me individually. I understand that my data will be anonymised. I am also aware that excerpts from the interview may be included in the reporting of this research but that all quotations will be kept anonymous.

I agree to the interview being audio recorded.

I agree to participate in this study.

Participant Name: _____

Participant Signature: _____ Date:_____

Researcher Name: _____

Researcher Signature: _____ Date:_____

Consent form. Version 2 (31.07.13)

I copy for participant, 1 copy for researcher

Interview Guide

Focus interview topic-

When I spoke with you previously I asked you to think about a memorable clinical case, involving end-of-life care of a frail older person. Have you been able to identify a memorable case study?

If NO interviewer to ask participant to discuss a recent experience involving the end-of-life care of an older frail person with the intent of drawing out whether, in the experience of the participant it was a 'good' or 'bad' or 'unremarkable' end-of-life care (using prompts below).

If YES elicit, further recall about memorable case.

Suggested question:

Would you tell me about this memorable case?

Suggested question:

Introduce concepts of good, bad, unremarkable end-of-life [care]-

For [this memorable case]

What do you feel went well?

What went not so well?

Do you feel overall that [memorable clinical case] received, good, bad or unremarkable end-of-life [care]?

How would you describe [memorable clinical case] death? [good, bad or unremarkable death]

Prompts for researcher to consider:

Who, what, when, where, how and why?

How were you involved?

What happened?

What happened next?

Why did it / did not happen?

Who else was involved?

Interview guide. Version 2 (31.07.13)

X

Who else was involved?

How did you or the people involved feel?

What were the consequences-   immediately?

In the long term?

What policies, procedures or practices were used or considered?

Who used/ initiated these policies, procedures or practices?

Is there a different approach/ policies, procedures or practices that could have been used?

What, if anything would/ can/ has been done differently or similarly?

Education and training?

Ask participant-

Can you tell me what you consider is a good death? (Consider participants' terminology).

Can you tell me what you consider is good end-of-life care? (Consider participants' terminology).

Can you tell me what you consider is a bad death? (Consider participants' terminology).

Can you tell me what you consider is bad end-of-life care? (Consider participants' terminology).

Ask participant-

I'd like to ask you to think about an 'ideal world'- in which we could have/ ensure a 'perfect death' – what would that look like?

Ask participant-

(building on response) **What do you think 'we' could do that would/could make this happen?**

Ask participant-

Is there anything else you would like to tell me about that I haven't asked or that you have not had the opportunity to say?

Close the interview by thanking the participant for their openness/ co-operation/ valuable contribution.

This interview guide, questions and prompts will be reviewed and built upon as the research & interviews progress.

XI

APPENDIX 9 - LITERATURE SEARCH STRATEGY

1. Nursing Staff, Hospital/ or Dental Staff, Hospital/ or Dental Staff/ or Medical Staff, Hospital/ or Medical Staff/ or Nursing Staff/
2. Physical Therapists/ or Occupational Therapy/
3. nurse$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
4. nurse$ aid$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
5. Nurse$ assist$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
6. health care support work$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
7. nurs$ aux$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
8. multidisciplinary.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
9. interdisciplinary.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
10. doctor$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
11. therapist.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
12. staff.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
13. physician$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
14. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15. Hospitalization/
16. Terminal care/
17. Palliative care/
18. Hospice care/
19. home hospitali?ation.tw.

20. (hospice* adj2 home).tw.

21. ((terminal or palliative or hospice* or respite) adj2 (care or support)).mp. and home.tw. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

22. (end adj2 life).mp. and home.tw. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

23. communit$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

24. home$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

25. nursing home$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

26. care home$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

27. (home$ adj1 nurs$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

28. residential home$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

29. hospice$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

30. hospital ward.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

31. hospital$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

32. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31

33. Death/

34. death.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

35. (death not trauma$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

XIII

36. (digni$ adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

37. (digni$ adj1 dying).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

38. (dying adj1 well).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

39. (bad adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

40. (good adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

41. (heal$ adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

42. (heal$ adj1 dying).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

43. (unheal$ adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

44. (passive euthanasia not voluntary euthanasia).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

45. allow to die.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

46. right to die.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

47. (pain$ adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

48. (pain$ adj1 dying).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

49. (peace$ adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

50. (peace$ adj1 dying).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

51. (comfort$ adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

52. (comfort$ adj1 dying).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

53. (digni$ adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

54. (undigni$ adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

55. (digni$ adj1 dying).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

56. (undigni$ adj1 dying).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

57. (uncomfort$ adj1 death).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

58. (uncomfort$ adj1 dying).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

59. 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58

60. Attitude of Health Personnel/

61. Attitude to Death/

62. perspective$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

63. experience$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

64. feel$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

65. emotion$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

66. wish$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

67. belief$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

68. trust$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

69. want$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

70. prefer$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

71. opinion$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

72. attitude$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

73. inform$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

74. view$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

75. concern$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

76. satisfaction$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

77. thought$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

78. expectation$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

79. accept$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

80. 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79

81. exp Nursing Methodology Research/

82. (qualitative or ethno$ or emic or etic or phenomenolog$).mp.

83. (hermeneutic$ or heidegger$ or husserl$ or colaizzi$ or giorgi$ or glaser or strauss).mp.

84. (van kaam$ or van manen or constant compar$).mp.

85. (focus group$ or grounded theory or narrative analysis or lived experience$ or life experience$).mp.

86. (theoretical sampl$ or purposive sampl$ or ricoeur or spiegelberg$ or merleau).mp.

87. (metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$).mp.

88. (maximum variation or snowball).mp.

89. (field stud$ or field note$ or fieldnote$ or field record$).mp.

90. (thematic$ adj3 analys$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

91. (content analy$ or unstructured categor$ or structured categor$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

92. (participant$ adj3 observ$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

93. (nonparticipant$ adj3 observ$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

94. (non participant$ adj3 observ$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

95. action research.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

96. exp tape recording/

97. (audiorecord$ or taperecord$ or videorecord$ or videotap$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

98. ((audio or tape or video$) adj5 record$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

99. ((audio$ or tape$ or video$) adj5 interview$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

100. 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89 or 90 or 91 or 92 or 93 or 94 or 95 or 96 or 97 or 98 or 99

101. 14 and 32 and 59 and 80 and 100

102. aged/

103. "Aged, 80 and over"/

104. Frail Elderly/

105. 102 or 103 or 104

106. 101 and 105

107. limit 106 to abstracts

108. limit 107 to english language

109. limit 108 to human

110. limit 109 to "aged (80 and over)"

111. limit 110 to "qualitative (best balance of sensitivity and specificity)"

APPENDIX 10 - LITERATURE REVIEW PART 2: CRITICAL GRID

Author, date and country where research was undertaken	STUDY INFORMATION — SETTING					DATA COLLECTION METHOD						PARTICIPANTS							THEMES — CARE DELIVERY — CARE ACTION			ETHICAL ISSUES			COMMUNICATION			THE SELF — EMOTIONAL SELF			KNOWING			DYING TRAJECTORY	
	Emergency or critical Care units	General hospital	Home/community	Residential Care Facility or Nursing	Hospice/palliative care	Observation	Focus group	Semi structured interviews	instrument/survey	Notes review	Other	Registered/licensed nurses	Hospital/specialist doctors	General/community doctors/Practitioners	Care assistants (various)	Family/carers	Patients/residents	Other MDT/managers	Care actions	Dignity	Cultural sensitivities	Missed/unachievable care	Futility	Decision-making	Anticipatory care/place of death	Good/quality	Limited/missed/difficult	Burden/vulnerability	Coping resources	Grief and loss	Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/reflection	Recognition/prognostication	Model
Bacon (2017) USA	☑	☑						14				14							☑			☑						☑	☑	☑		☑	☑	☑	
Bluhm et al., (2017) USA								17					17									☑	☑	☑			☑					☑		☑	
Robijn et al., (2017) Belgium		☑	☑		☑			50				22	28					RIP 27	☑	☑				☑	☑	☑		☑	☑		☑			☑	
Brummell et al., (2016) UK	☑					☑		37				19	16					2	☑				☑	☑					☑		☑	☑		☑	☑
Cable-Williams & Wilson (2016) Canada one			N					50				10			8	12	9	11	☑								☑							☑	
Centofanti et al., (2016) Canada	☑							33				33																☑	☑		☑	☑	☑		

Key: ☑ is used to correlate research and components as per table headings; * indicates referred to but not expanded in publication; F represents care facility e.g. residential care home whereas N represents care home with registered nursing facilities. Numbers are used to present numbers of interviews etc. and participant where information is available. RIP represents decedents.

Literature review part 2: critical grid

Author, date and country where research was undertaken	Emergency or critical Care units	General hospital	Home/ community	Residential Care Facility or Nursing	Hospice/ palliative care	Observation	Focus group	Semi structured interviews	instrument / survey	Notes review	Other	Registered / licensed nurses	Hospital/ specialist doctors	General/ community doctors /Practitioners	Care assistants (various)	Family/ carers	Patients/ residents	Other MDT/ managers	Care actions	Dignity	Cultural sensitivities	Missed / unachievable care	Futility	Decision-making	Anticipatory care/ place of death	Good / quality	Limited / missed/ difficult	Burden/ vulnerability	Coping resources	Grief and loss	Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/ reflection	Recognition/ prognostication	Model
STUDY INFORMATION — SETTING →						**DATA COLLECTION METHOD**						**PARTICIPANTS**							**THEMES — CARE DELIVERY: CARE ACTION**			**ETHICAL ISSUES**			**COMMUNICATION**			**THE SELF: EMOTIONAL SELF**			**KNOWING**			**DYING TRAJECTORY**	
Jansen et al., (2016) Norway				N			3							17					☑					☑	☑		☑	☑	☑					☑	
Johnstone et al., (2016) Australia		☑						☑				22							☑		☑				☑		☑	☑			☑				
Van Humbeeck et al.(2016)				N				14				9			5				☑			☑				☑	☑	☑	☑	☑	☑	☑			
Phongtankuel et al., (2016) USA			☑				7					26	4	2				41																☑	
Thoresen et al., (2016) Norway				N		☑						10		7	2			1						☑	☑		☑	☑			☑		☑	☑	
Vrijmoeth et al., (2016) Netherlands			☑					10						10										☑							☑			☑	
Bekkema et al., (2015) Netherlands	☑	☑	☑	F	☑			45				6	7	3		16	RIP 12	13	☑					☑				☑			☑		☑	☑	☑

XX

Key: ☑ is used to correlate research and components as per table headings; * indicates referred to but not expanded in publication; F represents care facility e.g. residential care home whereas N represents care home with registered nursing facilities. Numbers are used to present numbers of interviews etc. and participant where information is available. RIP represents decedents.

Literature review part 2: critical grid

Author, date and country where research was undertaken	STUDY INFORMATION — SETTING					DATA COLLECTION METHOD						PARTICIPANTS							THEMES — CARE DELIVERY — CARE ACTION			ETHICAL ISSUES			COMMUNICATION			THE SELF — EMOTIONAL SELF			KNOWING			DYING TRAJECTORY	
	Emergency or critical Care units	General hospital	Home/community	Residential Care Facility or Nursing	Hospice/palliative care	Observation	Focus group	Semi structured interviews	instrument/survey	Notes review	Other	Registered/licensed nurses	Hospital/specialist doctors	General/community doctors/Practitioners	Cere assistants (various)	Family/carers	Patients/residents	Other MDT/managers	Care actions	Dignity	Cultural sensitivities	Missed/unachievable care	Futility	Decision-making	Anticipatory care/place of death	Good/quality	Limited/missed/difficult	Burden/vulnerability	Coping resources	Grief and loss	Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/reflection	Recognition/prognostication	Model
De Korte-Verhoef et al., (2015) Netherlands			☑					59				15		26		18	RIP 30								☑		☑					☑		☑	
Seccareccia et al.,(2015) Canada					☑		X 8 (39)	46				11		4		23	23	24								☑	☑				☑	☑			
Towsley et al., (2015) UK				N				38								12	16	10									☑								
Wilson (2015) UK			☑	N		83		61				16							☑					☑				☑						☑	
Anquinet et al., (2014) Canada		☑	☑		☑			35					23	12			RIP 39							☑											
Ball et al., (2014) USA				F		☑		63	178						4		51 *178	8									☑								☑
Barclay et al., (2014) UK				F				*		☑							RIP 23	NS																☑	☑

XXI

Key: ☑ is used to correlate research and components as per table headings; * indicates referred to but not expanded in publication; F represents care facility e.g. residential care home whereas N represents care home with registered nursing facilities. Numbers are used to present numbers of interviews etc. and participant where information is available. RIP represents decedents.

Literature review part 2: critical grid

Author, date and country where research was undertaken	STUDY INFORMATION — SETTING					DATA COLLECTION METHOD						PARTICIPANTS							THEMES — CARE DELIVERY: CARE ACTION			ETHICAL ISSUES			COMMUNICATION			THE SELF — EMOTIONAL SELF			KNOWING			DYING TRAJECTORY	
	Emergency or critical Care units	General hospital	Home/community	Residential Care Facility or Nursing	Hospice/palliative care	Observation	Focus group	Semi structured interviews	instrument/survey	Notes review	Other	Registered/licensed nurses	Hospital/specialist doctors	General/community doctors/Practitioners	Cere assistants (various)	Family/carers	Patients/residents	Other MDT/managers	Care actions	Dignity	Cultural sensitivities	Missed/unachievable care	Futility	Decision-making	Anticipatory care/place of death	Good/quality	Limited/missed/difficult	Burden/vulnerability	Coping resources	Grief and loss	Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/reflection	Recognition/prognostication	Model
Bélanger et al., (2014) Canada		☑	☑			101						2		6				18							☑		☑							☑	
Browall et al., (2014) Sweden			☑		☑						88 CI's	83															☑	☑		☑				☑	
Cable-Williams & Wilson (2014) Canada				F N		*	1	50		182	☑	10			8	12	9	11														☑		☑	
Denvir et al., (2014) UK			☑				X 2 (15)	11				3	7	1	☑	☑								☑	☑		☑					☑		☑	
Handley et al., (2014) UK				F				54		121		16		3		19	*63	16							☑									☑	
Hockley et al., (2014) UK				N							X 10	17		29				6									☑				☑	☑		☑	
McVey et al., (2014) Australia				F				93 (+7)			X ? 8 (23)				23	21	72	7							☑							☑	☑	☑	

XXII

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Author, date and country where research was undertaken	Emergency or critical Care units	General hospital	Home/community	Residential Care Facility or Nursing	Hospice/palliative care	Observation	Focus group	Semi structured interviews	instrument/survey	Notes review	Other	Registered/licensed nurses	Hospital/specialist doctors	General/community doctors/Practitioners	Care assistants (various)	Family/carers	Patients/residents	Other MDT/managers	Care actions	Dignity	Cultural sensitivities	Missed/unachievable care	Futility	Decision-making	Anticipatory care/place of death	Good/quality	Limited/missed/difficult	Burden/vulnerability	Coping resources	Grief and loss	Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/reflection	Recognition/prognostication	Model
Näppä et al., (2014)					☑			17				17											☑	☑								☑			
Douglas et al., (2013) Australia					☑			17			X 1 (2)	17	1						☑					☑				☑							
Granek et al., (2013) Canada		☑						20				20														☑	☑	☑	☑	☑		☑			
Goddard et al., (2013) UK				F N				90				28			29			33											☑	☑	☑	☑	☑	☑	
Kaasalainen et al., (2013) Canada				N			X 35	25				34	9		15	21	14	50	☑								☑					☑	☑		
Periyakoil (2013) USA				N							45	45			*26					☑	☑				☑										
Tan et al., (2013) Australia				F				48				16			4		23	5											☑			☑			
Granek et al., (2012) Canada		☑						20				20																				☑		☑	

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Literature review part 2: critical grid

Author, date and country where research was undertaken	STUDY INFORMATION — SETTING: Emergency or critical Care units	General hospital	Home/ community	Residential Care Facility or Nursing	Hospice/ palliative care	DATA COLLECTION METHOD: Observation	Focus group	Semi structured interviews	instrument / survey	Notes review	Other	PARTICIPANTS: Registered / licensed nurses	Hospital/ specialist doctors	General/ community doctors /Practitioners	Cere assistants (various)	Family/ carers	Patients/ residents	Other MDT/ managers	THEMES — CARE DELIVERY — CARE ACTION: Care actions	Dignity	Cultural sensitivities	ETHICAL ISSUES: Missed / unachievable care	Futility	Decision-making	Anticipatory care/ place of death	COMMUNICATION: Good / quality	Limited / missed/ difficult	THE SELF — EMOTIONAL SELF: Burden/ vulnerability	Coping resources	Grief and loss	KNOWING: Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/ reflection	DYING TRAJECTORY: Recognition/ prognostication	Model
Horey et al., (2012) Australia				N				50	14	63		24		28	14			18							☑							☑			
Livingston et al., (2011) UK				N				58				20			38						☑						☑	☑		☑	☑			☑	
Rejnö et al., (2012) Sweden		☑						10				10										☑					☑	☑			☑			☑	
Bailey (2011) UK	☑					100		28				10	2			6	7	3	☑			☑													☑
Brown (2011) UK (Scotland)			☑				X 6					4		3		5	8		☑	☑											☑				
Casey et al., (2011) Ireland		☑		N				33				20		2	11				☑	☑		☑					☑			☑	☑			
Chan (2011) USA	☑					10		11			8	5	3					3					☑												☑

XXIV

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Author, date and country where research was undertaken	STUDY INFORMATION — SETTING: Emergency or critical Care units	General hospital	Home/ community	Residential Care Facility or Nursing	Hospice/ palliative care	DATA COLLECTION METHOD: Observation	Focus group	Semi structured interviews	instrument / survey	Notes review	Other	PARTICIPANTS: Registered / licensed nurses	Hospital/ specialist doctors	General/ community doctors /Practitioners	Care assistants (various)	Family/ carers	Patients/ residents	Other MDT/ managers	THEMES — CARE DELIVERY — CARE ACTION: Care actions	Dignity	Cultural sensitivities	ETHICAL ISSUES: Missed / unachievable care	Futility	Decision-making	COMMUNICATION: Anticipatory care/ place of death	Good / quality	Limited / missed/ difficult	THE SELF — EMOTIONAL SELF: Burden/ vulnerability	Coping resources	Grief and loss	KNOWING: Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/ reflection	DYING TRAJECTORY: Recognition/ prognostication	Model
Hirano et al., (2011) Japan			☑					31				31							☑						☑										☑
Ni Chróinín et al., (2011) Ireland				F				10				3						7													☑	☑	☑		
Saevareid and Balandin (2011) Norway		☑						16				10							☑	☑			☑	☑	☑	☑		☑			☑				
Slort et al., (2011) Netherlands			☑				X 2 (20)	6	22				22	20				6							☑	☑	☑	☑	☑		☑	☑			
Verhoeven et al., (2011) Netherlands			☑				X 1 (9)	9						18												☑		☑			☑	☑	☑		☑
Kelly and Nisker (2010) Canada		☑					X 1 (5)	20			4							29		☑					☑			☑	☑				☑		☑
McClement et al., (2010) Canada				F				12									12		☑			☑	☑					☑							

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Author, date and country where research was undertaken	Emergency or critical Care units	General hospital	Home/ community	Residential Care Facility or Nursing	Hospice/ palliative care	Observation	Focus group	Semi structured interviews	instrument / survey	Notes review	Other	Registered / licensed nurses	Hospital/ specialist doctors	General/ community doctors /Practitioners	Cere assistants (various)	Family/ carers	Patients/ residents	Other MDT/ managers	Care actions	Dignity	Cultural sensitivities	Missed / unachievable care	Futility	Decision-making	Anticipatory care/ place of death	Good / quality	Limited / missed/ difficult	Burden/ vulnerability	Coping resources	Grief and loss	Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/ reflection	Recognition/ prognostication	Model
O'Mahony et al., (2010) USA	☑						X 1 (3)		157 19	157		9				10							☑	☑	☑	☑						☑			☑
Rich et al., (2010) USA				F N					664			112			63	332		40									☑							☑	
Sims-Gould et al., (2010) Canada				N		☑		17								44		4		☑						☑		☑				☑	☑		
Back et al., (2009) USA			☑					☑				25		31		36	55									☑					☑	☑	☑		
Cartwright et al., (2009) USA				F				38				24			14				☑						☑	☑						☑			☑
Hov et al., (2009) Norway				N				28				14 (x 2)							☑					☑				☑	☑			☑			☑
Aase et al., (2008) Norway		☑						13				10 (2x2)	1												☑			☑	☑			☑			
Munn (2008)				N			X10 (65)					15			20	19	11											☑		☑		☑		☑	

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Literature review part 2: critical grid

Author, date and country where research was undertaken	STUDY INFORMATION — SETTING					DATA COLLECTION METHOD						PARTICIPANTS							THEMES — CARE DELIVERY: CARE ACTION			ETHICAL ISSUES			COMMUNICATION			THE SELF: EMOTIONAL SELF			KNOWING			DYING TRAJECTORY	
	Emergency or critical Care units	General hospital	Home/ community	Residential Care Facility or Nursing	Hospice/ palliative care	Observation	Focus group	Semi structured interviews	instrument / survey	Notes review	Other	Registered / licensed nurses	Hospital/ specialist doctors	General / community doctors /Practitioners	Care assistants (various)	Family/ carers	Patients/ residents	Other MDT/ managers	Care actions	Dignity	Cultural sensitivities	Missed / unachievable care	Futility	Decision-making	Anticipatory care/ place of death	Good / quality	Limited / missed/ difficult	Burden/ vulnerability	Coping resources	Grief and loss	Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/ reflection	Recognition/ prognostication	Model
USA																																			
Ostertag and Forman (2008) USA			☑		☑		(81)	7				(4)	(3)	14	18	19		37		☑							☑					☑		☑	
Welch et al., (2008) USA				•	☑			88				51 (7)		30				7						☑								☑		☑	
Aita et al., (2007) Japan		☑						30							30				☑		☑			☑		☑					☑				
Borgsteede et al., (2006) Netherlands			☑					50							20			30										☑	☑		☑	☑			
Chan & Kayser-Jones (2005) USA			N			☑		☑			☑	☑		☑	☑	☑	34	☑			☑											☑			
Forbes-Thompson & Gessert (2005) USA			N			☑		☑		☑	☑						56	☑	☑	☑					☑									☑	
Goodridge et al., (2005) Canada			N					26				14			8	4		RIP 15	☑															☑	

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Literature review part 2: critical grid

Author, date and country where research was undertaken	Emergency or critical Care units	General hospital	Home/community	Residential Care Facility or Nursing	Hospice/palliative care	Observation	Focus group	Semi structured interviews	instrument/survey	Notes review	Other	Registered/licensed nurses	Hospital/specialist doctors	General/community doctors/Practitioners	Cere assistants (various)	Family/carers	Patients/residents	Other MDT/managers	Care actions	Dignity	Cultural sensitivities	Missed/unachievable care	Futility	Decision-making	Anticipatory care/place of death	Good/quality	Limited/missed/difficult	Burden/vulnerability	Coping resources	Grief and loss	Interpersonal relationships	Knowledge, skill or training use or need	Use of different types of knowledge tacit/reflection	Recognition/prognostication	Model
Kramer & Auer (2005) USA				N			X 5 (38)	2	9			31					RIP 120	3			☑				☑									☑	☑
Ruopp et al., (2005) USA	☑	☑						75	75			75												☑			☑	☑							
Touhy et al., (2005) USA				N				25				15			4	6				☑		☑	☑	☑							☑				
West et al., (2005) USA	☑					51					51	35					169	51						☑	☑						☑				

XXVIII

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