Uncovering the Lived Experience of Hospital Nurses Providing End-of-Life Care

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ABSTRACT

TITLE: Uncovering the Lived Experience of Hospital Nurses Providing End-of-Life Care

BACKGROUND: In end-of-life care there is one chance to get it right. Policy and drivers that aim to achieve this are founded on sound palliative care principles. How these principles effect the care in a treatment orientated hospital environment is not clearly understood. Current evidence suggests hospital nurses end-of-life care is complex due to the conflicting tasks of treatment focused care against palliation which needs further exploration.

AIM: To understand hospital nurses' experiences of end-of-life care.
METHOD Interpretive phenomenology was used to explore 10 hospital nurses' experiences. Visual images created by the nurses as metaphors of their experiences were explored in an elicitation interview. Transcriptions were analysed using Ricoeur's approach to hermeneutic analysis.

FINDINGS AND IMPLICATIONS The hospital nurses lived experience is represented as The Harbour. In The Harbour it will be calm, informed by the nurses' ideas of a good death, transitioning from the storm of treatment to the calm of dying, human contact and practical care. This may differ to the palliative principles that inform current practice, indicating an emergent field of knowledge. Protection is needed in The Harbour to maintain the calm. The nurses protect their authentic-self to maintain end-of-life care, but this creates emotional dissonance and vulnerability, with potential physical and psychological consequences. Nurse managers recognition of the emotional burden and vulnerability of their nurses providing end-of-life care is needed. The nurses' actions suggest their end-of-life practice may be principled by love; a desire to create calm, grounded by the virtue of natural goodness and a willingness to focus on the individual and their family, making the most of whatever time they have left. In The Harbour, nurses work collaboratively to enable the calm. Recognition of this form of collaborative power may help with nurses' management of end-of-life care. Appropriate knowledge is needed in The Harbour to manage the transition to calm, but the unpredictable nature of end-of-life care required them to operate outside their objective knowledge base, suggesting end-of-life education should combine objective, technical rational education with more principled, less task based, professional artistry. Not all the nurses reported being changed existentially by their end-of-life care experience. Those that did reported living for the moment, being more appreciative of life with the suggestion of not being self-absorbed with unimportant activities.

CONCLUSION Hospital nurses are motivated by love to provide end-of-life care that is guided by their attitude to death, principally to transition the storm of treatment to calm.

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CONTENTS

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CHAPTER 7: CONCLUSIONS

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

Practicing as a specialist nurse in palliative and end-of-life care I encountered patients who were coming to terms with their death. They often discussed their hopes, what they were losing by facing death in relation to those unmet dreams as well as the ending of relationships and events that were incomplete or had not yet happened. My role was sometimes just to listen, sometimes to realign expectations. In doing so I became aware of my own mortality. I learnt to live in the moment to reduce the existential threat. I cannot stop death.

Patients who are told they have a life limiting illness are faced with the fear of death and suffering, ending of hopes and relationships (Saunders, 2003). I tried helping patients to identify what was important to them, what had meaning and what was achievable within the limitations of their physical and temporal ability. As one patient put it "to have one last summer"; to enjoy what they had left of their life, to drink the best wine; eat the best food; have high tea at Claridge's. The focus of end-of-life care is not on dying, but on living, on quality of life, not quantity (Saunders, 1976). Re-evaluating the life of another caused me to do the same, but I maintained a professional position, focusing on the need of the other person and the professional relationship. As a nurse practicing in end-of-life care, I had chosen to work in this field.

Embedded in my role were the skills, experience and expertise to support the patient in their wish to have 'one last summer'. This approach to care has been the foundation of palliative care provided by hospices and made available predominantly to patients with cancer. Recently this has changed to encompass all life-limiting illnesses in all settings. In contrast to hospices, hospitals are curative focused environments and this study aims to explore the experience of hospital nurses of providing end-of-life care in treatment intended units and their experiences of patient's "greatest sorrow… the ending of relationships, the ending of plans and to face the physical, and deeply emotional pain of death" (Saunders, 2003, p. 23).

Palliative care foundations are built on the ideas of Dame Cicely Saunders' simple statement of "You matter because you are you and you matter to the last moment of your life. We will do all we can not only to help you die peacefully, but to live until you die" (Saunders, 1976, p. 1003). Current policy and strategy documents set out priorities for palliative and end-of-life care in all health care settings, based on Saunders's principles of palliative care. Although there are variations among the documents as to what those priorities are, common to all of them are honest informed communication, integrated care, an expectation that all staff will be prepared to care confidently, competently and compassionately (NICE 2017; Health Education England, Skills for Health & Skills for Care., 2017; National Palliative and End of Life Care Partnership, 2015; Leadership Alliance for the Care of Dying People, 2014). There is 'one chance to get it right' (Leadership Alliance for the Care of Dying People, 2014).

Such an approach is also indicative of a 'revivalist good death' (Walter 1994). Practised within hospices where the person is aware of their death, personal conflict and unfinished business is resolved, it is a peaceful death, free of pain and suffering and follows the persons preferences (Cotterell, Duggleby 2016; Gott, Small et al. 2008; Walter 1994). Embedded within this approach assessing and managing pain and other symptoms are recognised as important skills 'to get it right' with the understanding the nurse should know and respect the individual's preferences and priorities of care and offering timely, personalised support for the required emotional, social and practical needs, which are appropriate to their preferences and maximises their engagement for as long as possible (NICE, 2017). Alleviating suffering, distress and being comfortable are also part of these priorities, with nurses being there to continually assess and manage end-of-life symptoms.

This encompasses recognising the person may be entering the last days of their life and, following assessment, manage symptoms accordingly, utilising specialist services when symptoms are not well managed. There should also be good communication as shared decision making, including discussing their current understanding that they may be nearing death and subsequent decisions. Nurses practicing end-of-life care in any setting are expected to provide care that is compassionate, individualised, using effective communication with the dying person and their family (Leadership Alliance for the Care of Dying People, 2014; NHS England, 2014). Nurses should provide end-of-life care that is tailored to the individual, delivered to a high professional standard and possess the relevant skills and knowledge, "nothing less will do" (Leadership Alliance for the Care of Dying People, 2014; NHS England, 2014).

These priorities and policies set out the standards of care that all palliative and end-of-life patients should expect. They are founded on sound palliative care principles originating from the work of Saunders, and revivalist ideas of a good death. The treatment focused nature of the hospital setting may challenge the principles of palliative and end-of-life care and ideas of a good death, making hospital end-of-life care worthy of wider study.

There are also emerging difficulties differentiating between generalist and specialist palliative care. The UK End-of-Life Strategy (2008) identified an expectation that generalist practitioners would provide generalist palliative care and the type of care once seen as unique to cancer patients would be routinely provided for all patients at the end of their lives (Gott et al., 2011). The use of the term 'end-of-life' has led to some confusion with some practitioners being unclear what is palliative care, specialist or generalist end-of-life, with the delineation between generalist and specialist palliative care remaining confusing (Gott et al., 2011). The Leadership Alliance for the Care of Dying People (2014) define end-of-life to mean patients are likely to die in the next 12 months including those whose death may be imminent. Palliative care is accepted to be an approach that improves the quality of life of patients and their families (WHO, 1990).

Specialist Palliative Care is generally understood to be the management of complex cases of end-of-life by teams of health care staff whose main activity is palliative care with recognised training (Bergenholtz, Jarlbaek & Hølge-Hazelton, 2016; Leadership Alliance for the Care of Dying People 2014; Gardiner, Gott & Ingleton, 2012; Gott et al., 2011). The separation between generalist palliative care and specialist palliative care has moved the palliative care provision to a much wider remit of patients (Gott et al., 2011). With an increase in an ageing population and a reduction in the provision of specialist palliative care services generalist practitioners are now seeing a request to further upskill their palliative and end-of-life practice (The Democratic Society, 2015).

Most end-of-life care that patients receive may be provided by generalist health practitioners, not by specialist practitioners (Bergenholtz, Jarlbaek & Hølge-Hazelton 2015; National Institute for Health Research, 2007) particularly within the hospital setting (Bergenholtz, Jarlbaek & Hølge-Hazelton 2016). A small proportion of patients are seen by SPC teams, which are reducing against increasing demand (The Democratic Society, 2015). Gott et al., (2011) revealed a perceived lack of responsibility for palliative care amongst practitioners within the hospital setting. Nurses viewed their core task as treatment and not generalist palliative care. Hospital nurses report ambiguity regarding the priority end-of-life care patients received over curative routines, as well as a lack of understanding as to the nature of end-of-life care and the nurses' role (Bergenholtz, Jarlbaek & Hølge-Hazelton, 2016; Gott et al., 2011; Dahlborg-Lyckhage, Lidén, 2010; Willard & Luker, 2006). Willard (2006) found nurses reported a treatment orientated culture and a prioritization for "fast and efficient treatment ". Dahlborg-Lyckhage, Lidén, (2010) found hospital ward organisation did not facilitate good palliative care, as the care was focused on a curative routine based on clinicians' routines, and tasks associated with medical science. Even where end-of-life care was practiced the medical approach was dominant with a focus on symptom management and prescriptions. Staff in general can be reluctant to give up on treatment, seeing palliation as a failure and difficulty with staff agreeing that the patient may be dying (Willard, Luker, 2006).

These studies begin to indicate hospital nurses' end-of-life care is a complex phenomenon needing further exploration. Although limited, these studies imply an imbalance between the care set out by palliative and end-of-life care priorities that requires greater clarity. In particular, the nurse's experience of caring for end-of-life patients in the hospital setting was not the main focus of the studies, this identifies a need to build awareness of hospital nurses' unique experiences of providing palliative and end-of-life care in a curative focused setting. Such an awareness of hospital nurses experience of providing end-of-life care in such a complex care environment would deepen awareness of the nurses needs to facilitate care in response to this increasing service demand.

When providing end-of-life care, nurses often bear witness to patient's existential anguish, consequently, nurses are faced with the reminder of their own mortality bringing into awareness their personal existentialism (Strang et al

2014; Vachon, Fillion et al. 2012; Boston et al 2011; Mok et al 2010; Lavoie et al 2008 Arman 2007; Houtepen and Hendrikx 2003). Nurses in the palliative care setting described re-evaluating their lives and being forced to reconsider their lives from an existential point of view, as well as a shattering of their basic life and death assumptions, such as kind patients suffering great pain, patient's unable to achieve a life without regrets (Chan et al 2016; Strang et al 2014). These studies suggest some evidence of nurses re-evaluating their own lives as a consequence of existential experience of end-of-life care, as well as the witnessing of existential suffering to be painful and require energy and time. There is very limited understanding of the existential experience of the hospital nurse providing end-of-life care and if the focus on acute treatment and intent has any difference on the existential experience. Consequently, how the hospital nurses' exposure to death in relation to existential experience may influence end-of-life patient care demands further enquiry.

Nurses with a positive attitude towards death are more likely to have a positive attitude towards providing end-of-life care (Peters et al 2013). However, the emotional work can come at a cost, with a high risk of stress and burnout (Liu, Chiang 2017; Nyatanga 2013; Erickson and Grove 2008; Mc Queen, 2004). While some nurses provide end-of-life care to a high standard, others practice death avoidance and block the emotional burden of end-of-life care (Griffiths 2016; Haroldstodottir 2011; Holman 2008; Smith 1998). Nurses' emotional labour of caring for the dying can be demanding and exhausting as well as intensely emotional (James 1989; Holman 2008). Nurses sometimes separate or distance themselves from the emotional labour of caring for the dying (Haroldsdottir 2011; Holman 2008; Smith 1998; Savage 1995). In certain contexts, the physical aspects of care can become the focus of nurses' caring tasks and the emotional care avoided as a form of emotional protection (Haraldsdottir 2011). This evidence considers the experiences of nurses working in palliative care settings. A more detailed awareness is required of the influence of emotional labour on how nurses providing general end-of-life care in the hospital setting provide end-of-life care.

Avoiding caring for end-of-life care patients could be attributed to death anxiety. High levels of death anxiety among nurses has been equated to grieving, leading nurses with high death anxiety to shield themselves from the emotional work of end-of-life care by developing death avoidance behaviours (Kondo and Nagata 2015; Dunn 2005 ;Peters et al 1998). The current body of evidence focuses on the palliative care setting with some studies considering nurses in the hospital environment (Decker, Lee et al 2014; Kondo, Nagata 2015; Peters, Cant et al. 2013; Gama, Barbosa et al. 2012; Braun, Gordon et al. 2010; Dunn, Otten et al. 2005; Carr, Merriman 1995). All of these studies provide valuable insights into nurses' thoughts of death anxiety, but all use psychometric tools which can inhibit understanding of individual human experience (Mercer and Feeney 2009). Alternative research approaches are needed to understand individual nurses experience of death anxiety and how this could influence patient care.

This introductory chapter has established end-of-life care to be founded on palliative care and the ideas of Saunders and revivalist ideas of a good death. The focus being on the person, helping them to make the most of their life until the very end, an aware death and one that follows personal preference, is peaceful and free from suffering. Current policy and priorities for palliative and end-of-life care establish the expectations that generalist nurses' practice should built on Saunders ideas and principles of palliative care. The evidence questions if there is a difference between these principles of palliative and end-of-life care and hospital setting. The emergent suggestion is that hospital nurses end-of-life practice may be governed by a completing set of standards between treatment and palliation.

By questioning what is the experience of hospital nurses providing end-of-life care to patients this study aims to understand the lived experience of hospital nurses end-of-life care. The findings of this study will contribute to emergent knowledge and future research regarding end-of-life nursing care in the hospital setting. The findings will also contribute to the development of hospital nurses' education, policy and practice.

The following chapters detail the development of the study with chapter 2 contextualising the study in relation to the relevant literature. Chapter 3 provides a detailed account of the research methodology and process. Chapters 4,5 and 6 detail and discuss the study findings. Finally, Chapter 7 concludes the study by considering the study strengths and limitations and then the implications for clinical practice, policy, education and future research.

CHAPTER 2
LITERATURE REVIEW

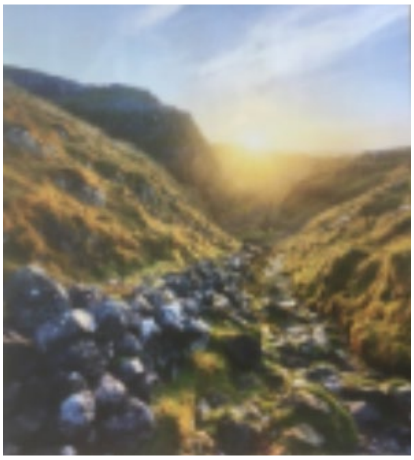


Figure 1 Reflexive Self Portrait 1 (Peter)

To locate relevant research-based literature an established systematic search strategy advocated by Polit and Beck (2010) was utilised. This involved searching databases that were nursing focused; Science Direct, Taylor Francis, Sage, PMC, Medline, Internurse, Ingenta, Cinal, Amed. Polit and Beck (2010) also suggest tracking studies that cite the original item, but this approach proved to be unsuccessful. Limitations were placed on the search with a date restriction of studies published in the last 10 years, aimed to include only current literature, but this yielded few results. To widen the scope of the search the date limit of publication limitation was removed. A limitation of UK based research for relevance to practice was also made, but again this yielded few results. This limitation was modified to English language and extended to international papers. The focus of the review was on hospital nurses' experiences and consequently this informed the inclusion criteria, however some studies crossed between both the hospital and specialist palliative care setting. For this reason, studies that included, but not exclusively, hospital nurses' experiences were considered as eligible (see appendix 1 for further details).

The search was conducted from Feb 2017 to Aug 2017 and repeated July 2019. Each of the core themes identified in the introduction required a separate search using the parameters described, with individual search terms. The details of the search terms with truncation, phrases and fields used can be found in appendix 1. The outcome was a limited range of research-based literature specific to hospital nurses' experience. What follows is a detailed review of the studies located and explored in the context of the wider literature.

Nurses’ Existential Experience of End-of-Life Care

In facing death, we are faced with many losses; but to face death is also to face the loss of meaning we have in our lives (Saunders, 2003). Nurses caring for end-of-life patients in the hospital setting may not be any different. The following review aims to establish what existential means, followed by an exploration of the current understanding of hospital nurses’ experiences of the existential aspects of the end-of-life care encounter.

Existential Conceptions of End-of-life

Nurses providing end-of-life can witnesses a person’s struggle to redefine themselves as they live through the final phase of their life (Strang et al. 2013; Fillion & Achille 2012; Boston, Bruce & Schreiber 2011; Mok et al. 2010; Vachon, Arman 2007; Houtepen, Hendrikx 2003). Consequently, nurses as human beings possessing emotional and spiritual capacity to question a sense of life and death, are faced with the reminder of their own imminent death, the limitations of their own existence (Boston, Bruce & Schreiber 2011; Mok et al. 2010; Lavoie, Blondeau & Koninck 2008; Arman 2007). Much of the current end-of-life literature focuses on patients’ existential concerns, with limited attention on the effect existentially on nurses caring for the dying. Of those studies that do concentrate on nurses’ experience, many centre on nurses working in end-of-life care settings, and not hospitals.

The term “existential” is used inconsistently. Boston et al (2011) identified 56 different definitions of existentialism in the nursing research, suggesting an inconsistent approach to how nurses, and researchers, understand and manage existential concerns in end-of-life care. A vocabulary such as “existential distress”, “existential anguish”, “existential suffering” being used without distinguishing between the difference in meanings. This presents ‘existential’ as a confusing term. Udo (2014) stresses the importance of separating “existential” from its neighbouring concept, such as existential *suffering* or existential *distress*, when looking for explanation as binding the two can cause confusion.

The work of existential philosophers may help define existential as an individual term. Born from a realisation that the objectivity of the natural sciences could not fully explain the human experience of the world, existentialism was developed as a philosophy of self-understanding (Crowell, 2012a). Central to the existential philosophy is 'being', a verb, which Heidegger explains as *Dasein 'being there'* or *being in the world* (Reynolds, 2014). Heidegger makes the point that we spend most of our lives in a state of forgetfulness of being, in which we move through the day unaware of the choices and decisions we make about our daily lives (inauthenticity). Occasionally we have cause to be mindful of being (to be authentic) which is to be aware of the ability to make decisions about one's life (Reynolds 2014; Blattner 2012; Yalom 1981). Significantly, Heidegger suggests that the knowledge that one day we will die means that we do not live our life frivolously, or inauthentically, but the recognition of death means we "are compelled to act now… and act with resoluteness to transform the way we view and experience life" (Reynolds, 2014, p. 43). For Heidegger, death is of the utmost importance in enabling the person to discover their own *authentic* being and their relation to death defines their meaning of being or self-hood (Cohen, 2006).

Sartre presents the view that, unlike Heidegger who believes the knowledge that one day we will die means death is expected, death cannot be expected (Schumacher, 2010). Sartre uses the comparison of waiting for Peter at the station and waiting for death, there could be various factors that cause delays to Peter's train, the same goes for "my death". For this reason, although we know one day we will die, we do not live every day expecting our death (Schumacher, 2010). Death is not expected every day, we only experience death through others, such as grief, which leads to recognition of our own mortality. Central to Sartre's concept of existentialism is the idea that "existence precedes essence" (Sartre, 2007). This expresses the idea that the person exists first as a biological body without a soul, they simply are, it is only later through consciousness and freedom that they possess essence (Sartre, 2007). Freedom provides the essence of consciousness and self-hood, as "projects" in which the person makes choices, actions, commitments and roles about their life. Existentialism recognises the *self* as something that is made through those individual choices and commitments, and by making choices the person takes on whatever meaning and value it has for them, and a meaningful world appears (Reynolds, 2014; Crowell, 2012b; Crowell, 2012a;). Consequently, death is an evil as it deprives us of the freedom to plan for the future (Schumacher, 2010).

When we approach the end-of-life, we see life's goals achieved or not achieved, and projects fulfilled or left incomplete (Blattner, 2012). In acknowledging death, a person looks at the existential fulfilment of their life; their projects made from a freedom which has given their life meaning and value. In Heidegger's view, if they have been *authentic* they have been conscious of their ability to be free to make life choices. Conversely if they have moved through the day to day existence of life unaware of their freedom to make decisions, they have been *inauthentic*. In being *authentic,* we are presented with a problem of what decisions to make, how to fill life with meaning. If we make the wrong decision, we risk feelings of despair and angst (Reynolds, 2014). Sartre focuses more on this choice, referring to 'bad faith' decisions which is the fear of making the wrong decisions, commitments and the potential consequence of making a choice. De-Beauvoir questions Sartre's bad faith idea by suggesting we need a willingness and ability to be free, not everyone is free, particularly women (Reynolds, 2014; Arp, 2012; Deutscher, 2003). De Beauvoir also criticises Sartre's concept of existential freedom by examining through old age the disassociation between physical freedom emotional/mental freedom and the restrictions of choice old age places upon our world (Deutscher,2003).

Levinas questioned both Heidegger and Sartre's ideas and proposed a deeper existential understanding of death by considering an ethical approach as opposed to Heidegger and Sartre's ontological views. Levinas sees death not from the perspective of the person but from the 'Other', the Other being another person (Cohen, 2006). Levinas reflects on the death of the Other, and how in caring for that person, the human subject achieves true humanity (Cohen, 2006). Levinas suggests that suffering and death bring with them relationships with Other and as a result face-to-face is essential in our lives, this is our interpersonal existence that defines our authentic-self, formed by the rules, culture, expectations, manners that directs behaviour and social engagement (Morgan, 2007). Levinas argues that each of us is fundamentally unique and a person distinguishes themselves by making choices and decisions regarding their existence, which Levinas refers to as existential freedom (Morgan, 2007). In

Levinas view, through suffering, such as ill health, our own or others, we are reminded of our mortality which inhibits our existential freedom.

As Saunders (2003) identified, when faced with death we are often faced with the loss of meaning in our lives. This can now be understood as an existential threat, depending on the extent we have lived our lives free to make choices, fulfil our projects and give life meaning. Although there are many other texts and ideas of existentialism available, this short review is aimed at providing clarification of the concept. Common to these concepts, and the definition that will be used for this study existentialism is the freedom to make choices and from these choices we give our life meaning. Having broadly understood what may be meant by the term existential, hospital nurses' experiences of existential issues in providing end-of-life care can be explored.

Existential understandings of nurses' experience

Existentialism, as being free to give meaning to life, will be explored in the context of hospital nurses' experiences of end-of life care. Nurses caring for patients in the hospital may focus on curative treatment decisions (Bergenholtz, Jarlbaek & Hølge-Hazelton 2016; Gott et al. 2011; Dahlborg-Lyckhage, Lidén 2010; Willard, Luker 2006). As a consequence, the impact of providing end-of-life care to dying patients could existentially affect the nurses' lives.

There is very limited literature exploring hospital nurses meaning of life and exposure to end-of-life care. Most of the literature explores nurses' reactions to existential encounters with patients and does not describe the nurses' own existential experience. What literature there is, describes nurses' exposure to end-of-life situations in palliative care environments. Some nurses re-evaluate life, engaging in activities and living a more meaningful life (Chan et al. 2016; Karlsson et al. 2016; Strang et al 2014; Vachon et al 2012). Some nurses felt forced to re-evaluate their lives (Strang et al 2014). Others found the experience validated their existential meaning (Chan et al 2016). Death confrontation challenged the beliefs of some nurses particularly those with no beliefs or meaning they could utilise at difficult times (Vachon et al 2012). Whereas nurses with a higher level of religiosity were found to be more confident with engaging in existential issues (Bjarnason et al 2010).

Summary

In end-of-life care, nurses are reminded of the existential threat of death. Reviewed from an existential philosophy this is the freedom to make choices, fulfil our life and give life meaning. The close encounters with death that nurses face in providing end-of-life care has been explored to gain an appreciation of the existential effect on nurses in the hospital setting. Due to the very limited evidence it is difficult to present a distinct understanding. The literature from studies conducted in the palliative care setting suggest end-of-life care can lead to nurses revaluating their lives and giving life more meaning. It can also challenge the beliefs and question those that have no existential beliefs or meaning. Further inquiry is needed to appreciate the existential experience of hospital nurses providing end-of-life care and the relevance to patient care.

Nurses Experience of Death Anxiety in the Hospital Setting

Nurses who work in the hospital setting choose an environment of care which is treatment orientated where curative procedures are prioritised over end-of-life care (Bergenholtz, Jarlbaek et al. 2016; Bloomer, Moss et al. 2011; Dahlborg-Lyckhage, Lidén 2010; Willard, Luker 2006). In such environments, conflicts between curative intentions and end-of-life care may potentially pose a problem for the hospital nurse. Additionally, exposure to death can be a difficult reminder of the nurses' own mortality, (Browall, Henoch et al. 2014; Vachon, Fillion et al. 2012) and such reminders of death may be something nurses seek to avoid if they do not have the appropriate defences to manage the fear and anxieties exposure to death presents (Haraldsdottir 2011; Holman 2008; Smith 1998).

Nurses' practicing in hospitals are often exposed to difficult caring situations including death and are known to experience anxiety (Menzies-Lyth 1960). The more difficult the situation, the more concentrated the relationship, the more likely the nurse is to experience anxiety (Menzies-Lyth 1960). High levels of anxiety linked to exposure to death among nurses has been equated to grieving, leading nurses with high death anxiety to shield themselves from the emotional work of end-of-life care by developing feelings of death avoidance (Kondo, Nagata 2015; Peters, Cant et al. 2013a; Dunn, Otten et al. 2005). Death avoidance behaviour can also be described as not discussing death or not telling the patient the honest truth (Peters, Cant et al. 2013a). Depersonalisation, which is to put a distance between work and the employee, possibly as a psychological coping mechanism, could also be a form of death avoidance behaviour (Nyatanga 2013). The following provides an overview of concepts of death anxiety, proceeded by an application of this understanding to hospital nurses' experiences.

Death Anxiety Conceptions

Death anxiety can be the dread of non-being, the awareness of the fragility of being and the understanding of the "impossibility of further possibility" (Yalom 1998 p. 192). Anxiety and fear can be linked and by transforming anxiety into fear it can be confronted, and by doing so "we can create a self-protective campaign to either avoid the thing we fear or find ways to overcome it" (Yalom 1998, p. 194). Death anxiety is so intimately woven to existence it is different to other forms of anxiety, and that life cannot be lived without death anxiety, as the anxiety gives us an authentic existence (Yalom 1998).

Nyatanga, de Vocht (2006) question if death anxiety is caused by thoughts of death that are ontologically focused, or theologically based. The difference being ontological anxiety is how we preserve our 'being' with the constant state of our non-being, and theological anxiety is based on a belief in life after death. The strength of this belief acts as a buffer against death anxiety. Lehto, Stein (2009) distinguish between death anxiety and death fear making the distinction that death anxiety refers to the dread of complete annihilation and is more spiritually focused on the loss of existence, in contrast to a fear of death which is more of a belief that death itself is frightening and is related to a physical awareness of death. Simplified further; fear of death is fear of the dying process whereas death anxiety is regarding spiritual and existential concerns (Strang, Henoch et al. 2013).

Kastenbaum (2009, p. 282) distinguishes between death anxiety and the terror of death. The terror of death is not the "garden variety fear of anxiety… terror is a heart-stopping or hammer-pounding holistic response to what is perceived as an overwhelming threat". As salient beings we should be constantly terrorised by the fear of dying in everything we do, and this is combined with the need for preserving our existence and survival (Landau, John et al. 2004). This is the premise for terror management theory (TMT) which aims to investigate how humans manage the fear of annihilation (Kastenbaum 2009; Pyszczynski, Greenberg et al. 2006; Landau, John et al. 2004). TMT mitigates against this terror of death by developing and creating our own *cultural worldviews* which serves to protect us by giving us a life full of meaning, function, order, stability and permanence (Pyszczynski, Greenberg et al. 2006; Landau, John et al. 2004,). These are benign concepts that help to explain and organize our world and are supported by our daily schedules, social groups, faith and belief systems (Pyszczynski, Greenberg et al. 2006; Landau, John et al. 2004,). Increases in reminders of death, such as in end-of-life nursing care, increase positive reaction with those who support our cultural worldview and negative reactions to those who threaten it (Pyszczynski, Greenberg et al. 2006).

Death anxiety is presented as the focus of anxiety on the spiritual and existential aspects of death; the threat of the loss of an existence and a wavering of faith. Tillich (1967) summarises this as anxiety caused by the realisation of non-being, non-being meaning cessation of life. Fear of death is consistently reported as the focus on anxiety caused by the fear of the process of dying. Terror management theory argues for a system of defence to buffer against these anxieties. When the buffer does not work for nurses, due to exposure to mortality reminders, and the anxiety becomes overwhelming, symptoms of fatigue, numbness, avoidance, detachment and a lack of interest become apparent (Trifiletti, Pedrazza et al. 2017). Death is avoided in modern culture (Walters 1994; Aries 1974). Yalom 1998) suggests we can choose to avoid the thing we fear and, as the following suggests, this can sometimes happen in nursing.

Hospital Nurses Experiences of Death Anxiety

The following discussion uses the term 'death avoidance' which has two different meanings relevant to nursing. Death avoidance as a category of questions used by some of the psychometric scores relevant to death anxiety, such as the Death

Attitude Profile tool which has “I avoid death thoughts at all costs” as a scale statement. Death avoidance can also be a deliberate behaviour by nurses to avoid, or reduce the time, caring for someone who is dying.

Nurses in the hospital setting may spend less time with patients as they are dying, due to a higher death anxiety/fear of death, are less likely to show positive attitudes to death and more likely to report feelings of death avoidance (Braun, Gordon et al. 2010). Nurses working in hospital areas with low death exposure (0-5 death per month) were more likely to experience feelings of death avoidance than those practicing in areas with higher exposure, which is attributed to a higher fear of death (Braun, Gordon et al. 2010). Nurses’ who experience death avoidance held less positive attitudes towards caring for dying patients, with some (54%) of hospital nurses reporting they would sometimes, or almost always, avoid being with a dying patient if it could be arranged (Carr, Merriman 1995). Nurses working in the hospital setting reported uncertainty and difficulty dealing with death and dying, describing the uncertainty of caring for the dying and the emotional experience as an exhausting, leading some nurses to become desensitised to death to protect themselves (Kondo, Nagata 2015).

The emergency department is an example of where nurses report feeling uncomfortable when dealing with death and dying (Decker, Lee et al 2014; Peters, Cant et al. 2013). Emergency department nurses, despite the exposure to death, had high scores for death avoidance (Peters et al 2013). They also reported significantly lower coping skills, were less comfortable when dealing with death and dying compared to the same results among palliative care nurses. This indicates a contrast in attitude towards death and dying between the nurse who has chosen to work in a treatment focused area and nurses who have chosen to work in a dying focused area. Emergency department nurses, although frequently exposed to death and dying, implied a need or desire to avoid death (Decker 2014).

These studies suggest a link between death anxiety and death avoidance. In hospitals where nurses are confronted with death in their daily practice, this can cause increased death anxiety leading to the avoidance of death. This supports Yalom’s idea, where death anxiety is increased, the nurses seek to reduce the anxiety by self-protection campaigns to avoid death encounters. The difficulty with this interpretation is other studies using death anxiety tools do not support these findings and present a conflicting explanation of nurses' experiences of death anxiety in end-of-life care. Nurses' uncertainty around death encounters is not supported by Dunn et al (2005) who found nurses felt death was part of life and did not avoid thinking about it. The nurses felt strongly that caring and interacting with dying patients and their families was worthwhile and important. Religiosity was an influencing factor to the nurses' response to death anxiety with 83% of the nurses reporting a place of worship. Religiosity and acceptancy of death has been shown to be associated with reduced death anxiety among nurses (Braun et al 2010; Carr and Merriman 1996).

Age is reported to be an influencing factor on nurses (working in the hospital environment) ability to accept death, with older nurses reporting higher level of death acceptance (Gama, Barbosa et al. 2012; Dunn, Otten et al. 2005). Older nurses and nurses with more work experience had more developed strategies for dealing with emotional response to death and dying (Gama, Barbosa et al. 2012). Older nurses also hold the view that death can be an opportunity for escape, as a relief from suffering, and accepted death as a 'neutral way' more often than the younger nurses (Dunn et al 2005). It should be noted that idea of 'older' is not explicitly explained by the studies, but a mean of 30 years (Gama, Barbosa et al 2012) and 40 years (Dunn, Otten et al 2005) among the study participants is used to describe this category. This suggests older is defined as years lived as a categorical data.

What is presented are a number of factors that mitigate against the anxiety of death, these vary between studies but consistently reported are religiosity, experience and age. These could be considered cultural world views from a TMT perspective to buffer against the terror of death but are not explored in this context. Several of the studies used psychometric tools to measure death anxiety. Such tools are valuable for objective measurement of the psychological state of death anxiety and, if desirable, correlation of death anxiety with other variables (Lonetto, Templer 1970). Such psychometric tools can struggle to understand the cultural context of death and predominantly explain death and dying from a biomedical mainstream psychological perspective, with the preoccupation on anxiety negating many of the other ranges of attitudes to death that may exist (Mercer and Feeney 2009). Mercer and Feeney (2009) claim the use of psychometric analysis inhibits sufficient depth of detail, context or range of human experience to understand the complexity of how death is experienced. Using Interpretive Phenomenological Analysis (IPA) as an example they investigate Filipino nurses practicing in a hospice and white nurses practicing in the same hospice. The white British nurse's emotional response to death allowed them to be 'good hospice nurses', creating care that is holistic. For the Filipino nurses, death was identified as a biological process to be stopped, avoidable, leading to disengagement and avoidance behavioural towards caring for what they regarded as already dead. The study emphasises the depth and variety of emotional response to death elicited by qualitative methodology.

Summary

This review has described a distinction between death anxiety and death fear, with death anxiety being identified as anxiety of non-being (Yalom 1988; Tillich 1967) and death its self as frightening (Strang, Henoch et al. 2013; Lehto, Stein 2009). Religiosity and age are influencing factors regarding death anxiety with older nurses and those with a stronger faith having less death anxiety and more likely to engage with dying patients. Nurses working where death was less common are more likely to experience death anxiety and feelings of death avoidance. There are instances where hospital nurses report trying to avoid being with dying patients or their families.

The literature reviewed predominantly uses psychometric tools to measure nurse's reaction to the exposure to death. Such methods have been useful in exploring nurses' ability to cope with death anxiety and fear. Death systems, changes in legislation and social opinion form a strong association between our connection between our constructions of self, society and world and our constructs of death (Kastenbaum 1996). Using death anxiety tools is helpful to understand variants between groups and death anxiety, where an understanding of the results can be clearly interpreted but limits our appreciation of the individual experience and the influence of culture on the expression of death feelings. A patient's attitude to death is personal, bound by their culture, family, history, personality as well as their social values and spirituality. This does not change for the nurse as a person, supporting Kastenbaum's and Mercer and

Feeney's analysis that death anxiety is not easily measurable by psychometric tools.

Understanding hospital nurses' personal attitudes towards death, how they make connections with existential meaning and death is needed to help define more clearly how they experience the repeated exposure to death. Carefully considered research methods that facilitate this are needed and the increased understanding would help inform targeted end-of-life priorities for hospital nurses.

Nurses Emotional Labour and Management Relevant to End-of-Life

Emotional engagement is an essential component of nursing care (Henderson 2001). Containing and managing emotions in end-of-life care can be difficult and current literature will be reviewed to help understand this. Emotional labour describes the emotional work that nurses provide as part of their care but the difference between emotional labour and nurses emotions at work needs some clarity regarding the specific issues relevant to emotional labour of end-of-life care in the hospital environment which will also be reviewed.

Emotional Labour in Nursing

Hochschild first identified the concept of emotional labour and defined it as "inducing or suppressing feelings in order to sustain the outward countenance that produces the proper state of mind in others" (Hochschild, 1983; p. 7). Hochschild's work identified occupations required employees to engage with the public in defined ways, with value-based emotion being seen as an extension of a company's commodity. By exploring flight attendant's stories, Hochschild found air hostesses had to mentally detach themselves from their own feelings. A significant point for Hochschild's concept of emotional labour is the understanding that the employee must repress their own feelings to present a required emotional state or response, to create an emotional reaction in others. Steinberg and Figart (1999,p. 9) give a detailed description of this occurring in a coffee company mission statement; “under no circumstances should the customer ever wonder if you are having a bad day, your troubles should be masked with a smile” and “if you are not having fun those around you won’t be smiling either”. The significance is not just the explicit emotional labour but that these profitable dimensions of job content are often not remunerated.

Nursing skills of countering other people’s emotions, but not being credited or remunerated for this was a finding of James (1989). James’s study in a UK hospice identified emotional labour to be “the labour involved with other people’s feelings, a core component is the *regulation* of emotions”. James identified that core to the nurses’ management of dealing with other people’s feelings is a social process in that she found emotional labour is part of the nurses, as women, caring process. At the time caring as ‘women work’ was seen as natural, unskilled and invisible. James describes this as a contradiction where women may be employed due to their skills of dealing with other people’s emotions yet are given no credit for this. James argues emotional labour in nursing was unrecognised as a form of labour, and consequently not valued.

Nurses ability to cope with the emotional demands of nursing was a focus of Smith’s ethnographic study originally conducted in the 1980, repeated 20 years later (Smith, 2012). Smith’s work found an expectation for nurses to cope with upsetting situations. For this reason, Smith defines caring for the dying as the ultimate emotional labour. When undertaking such care nurses’ feelings were rarely acknowledged in the open arena of the ward, and staff were likely to develop ways to distance themselves which kept them from getting personally involved with their patents (Smith, 2012). Busy clinical environments, require the nurse to focus on the technical and practical aspects of care, to get the work done, which may act as a device to contain their feelings and reduce their direct engagement with patients (Smith, 2012). This defers the emotional labour of nurses to other care workers. Smith’s seminal work from 1980, repeated in 2012, provides important insight into emotional labour but the hidden feelings and motivations of the nurses are not made visible. These need exploring further to understand what determines the emotional behaviour of the nurse when providing end-of-life care leading to their emotional labour.

The professional caring image of the nurse enables vulnerable patients to trust the nurse caring for them (Theodosius 2008). The role of emotional labour in nursing is therefore an essential element of the caring relationship, with the nurse responding to moral rules which enables the patient to allow the nurse to access their body, emotions and private information and life (Theodosius 2008). Theodosius argues that this makes nurses' emotional labour different from flight attendants; it is private emotion work, the balance of power is more complex. Theodosius differs to Hochschild by the way she views emotional labour not as a commodity but considers patients, unlike customers, are vulnerable individuals who have no choice but to trust in the care they are offered. Theodosious (2009) identifies that emotional labour should not involve the simple suppression of the nurses' emotions in order to facilitate the right emotions, but in recognising one's own emotions, the emotions of others, one is central to recognising and assisting others with their difficulties and how they might manage them. Theodosious's provides a valuable development of emotional labour in nursing. When considering some of the nurses' personal anxiety and experiences of caring for the dying in hospital more evidence is needed to understand how Theodosious's idea could apply to end-of-life care.

The work of Hochschild, James, Smith and Theodosious identify emotional labour as the nurse suppressing or modifying their emotions in any situation in order to facilitate a required interaction or response with that person. Emotional labour is also the nurse conveying an emotion they may not feel, but are required to have, in order to facilitate an expected interaction with a person. Further understanding is needed as to what determines hospital nurses' emotional behaviour, engagement and labour in end-of-life care situations.

Nurses Emotional Behaviour in end-of-life situations

The emotional aspect of nursing is viewed as an essential component of nursing care (Henderson, 2001). However, there is a correlation between nurses' denial of their true feelings which results in feelings of agitation and frustration leading to stress and occupational burnout (Erickson, Grove, 2007). Nurses who pretend to have the expected feeling but don't experience similar reactions and burnout (Erickson, Grove, 2007). This identifies a cost involved with the emotional management on the nurse providing further evidence of nursing being more than physical care (Henderson, 2001; Gray, Smith 2009).

Nurses make emotional connection with dying patients through personal choice (Roche-Fahy, Dowling 2009; McMillen 2008; Henderson, 2001; Froggatt 1998). The consequence of this connection can affect personal vulnerability by getting too attached, leading to personal emotional cost (Roche-Fahy, Dowling 2009). The behavioural management strategy developed among some nurses is a 'switching-on switch-off', strategy (Hayward, Tuckey 2011; Froggatt 1998). Nurses develop this strategy to mentally distance themselves from the emotional threats that engendered their work (Froggatt 1998). The switching-off presents a hardening to the situation, through a process of rational control. The switch acknowledges the presence of different aspects of their lives which the nurse could choose to protect or open in different settings, as regulation.

The manipulation of the emotional boundaries is also proposed by Hayward, Tuckey (2011) is a way for the nurse to maintain authentic-self by the nurse choosing to engage or distance their emotional self from the work-related emotions, giving the nurse emotional control over the situation. Hayward and Tuckey make a distinction between the cognitive and the affective emotional engagement of nurses with their clients. Viewing empathy as *cognitive* by seeing, communication and understanding the other's feelings, additionally *affective* is engaging with and experiencing the feelings of the other person. Emotional connection requires both the *cognitive* and *affective* elements, distancing can be *cognitive* or *affective*. Nurses demonstrated flexibility with the emotional boundaries in response to their own and other's needs, acknowledging demands from home, and work interlaced with what they were prepared to give.

The behaviour of switching on and off emotions implies a regulation of emotions. The regulation of emotions as emotional work identifies a relationship between the nurses' practice and their emotions (Gray, Smith 2009; Henderson 2001). Nurses anger and frustration with clinical decisions, and resources are often suppressed in front of families and patients, resulting in a dissonance between the genuine feeling and those being displayed (Gray, Smith 2008). Nurses also suppress their physical health to care for patients, such as running a clinic, smiling, attending the patient, with a headache (Gray, Smith 2008). Although emotional engagement is valued as essential in nursing, emotional connection can reside in the individual nurse (Henderson 2001; Froggatt 1998).

Suppressing emotions by the regulation of emotions can lead to emotional distancing. Emotional distancing may be used in end-of-life care as a form of protection against death awareness and this form of protection can be integrated into nursing systems of care (Haraldsdottir 2011, Holman 2008). Social systems can be used as a defence against anxiety caused by caring for the dying, and avoidance integrated into the systems of caring (Haraldsdottir 2011; Holman 2008; Menzies Lyth 1960). Holman (2008) identified care work is intensely emotional with some health-workers displaying grief reactions following the death of patients. Haraldsdottir (2011) found among hospice nurses the physical aspects of care were the focus of nurses caring tasks and emotional avoidance by preserving an upbeat atmosphere was a form of emotional protection. The routinisation of hospice care and the focus on high quality physical care prevented nurses from emotional engagement (Haraldsdottir 2011).

Summary

The experience of being moved by another's distress exposes one's own potential for vulnerability (Davenport, Hall 2011). Hospital nurses have the choice to engage emotionally with dying patients. The emotional strategy employed has been described as an on-off switch with the nurse using the emotional switch depending on their emotional boundary, which they manipulate, depending on the situation and their personal circumstances. The suppression of emotions, through emotional regulation, may lead to emotional distancing which can act as a form of protection. Such emotional behaviour works against an emotional labour that requires an understanding of the dependence, trust and vulnerability of the patient advocated by Theodosious. Further understanding of the nurses' emotional behaviour in end-of-life care regarding emotional distancing is needed as well how hospital nurses manage their anxiety while being emotionally authentic in the end-of-life caring encounter. From this awareness, there is potential to develop targeted supportive strategies for hospital nurses providing end-of-life care.

DISCIPLINARY POWER AND POWER OF BEING

Nurses providing end-of-life care are doing so in a healthcare system in the UK that is more service user driven, following audits and national targets and regular inspections providing patient with choice and importantly empowerment (Armstrong, Rustin, 2015). This form of increasing surveillance may affect how nurses experience end-of-life care in the hospital setting, with inspection and governance influencing control on nurses' professional practice and care management (Armstrong, Rustin, 2015; Allen, 2014).

Disciplinary Power

To appreciate this perspective of nursing practice Foucault 's concept of disciplinary power will be used to explore nurses experience of power and knowledge in relation to end-of-life care in the hospital setting. Foucault presents disciplinary power as a conditioning power that is asserted by detailed control of the body through hierarchical observation, normalising judgement and examination (Foucault, 1975). *Hierarchical observation* is the mechanism by which the individual is surveyed, or 'gazed upon'. It is a network of surveillance relations, from the top down, laterally and bottom up, so that the power becomes indiscreet "it is everywhere and always alert constantly supervising" (Foucault, 1975 p. 177). In nursing, disciplinary power can be evident through nurses' fitness to practise process, nurses reporting concerns regarding professional conduct, a duty of candour, and not only responding to concerns about their own practice but also for that of others (Bradbury-Jones, Sambrook & Irvine, 2007). *Normalising judgements* are the set of laws, judgments, rules that the individual must remember and be classified against. These define what is permitted and what is forbidden (Foucault, 1975). Nurses' normalising judgement is evident through self-monitoring and policing themselves with professional integrity; exhibiting expected ideal behaviours of being caring; compassionate and self-sacrificing (Bradbury-Jones, et al 2007; Henderson, 1994). *Hierarchical observation* and *normalising judgement* are combined in the disciplinary power of *examination* which seeks to qualify, classify and punish (Foucault, 1975). As a result, Foucault proposes the examination is highly ritualised and is at the heart of the procedures of the discipline. The practice of nursing is measured and examined by competency standards to gain, and maintain, registration, with the recognised ‘examiner’ and institutions being gatekeepers to the qualification of nurse (Bradbury-Jones, et al, 2007).

A hospital is an example of institutional disciplinary power. The doctors create a well-disciplined hospital with the medical discipline becoming a hierarchical group using a correlation of associated knowledge and examinations to gain control and subordinate other groups (Foucault, 1975, 2003). Disciplinary knowledge becomes the objective and specific corpus of knowledge and associated attributes that help define that discipline, identified through normalising judgments and the systems of examination (Foucault, 1975, 2003). It is from this analysis Foucault forms his premise that there is a “correlative element of power and knowledge” (Foucault, 1975 p. 194). The conformity and restriction of the hospital ‘gaze’ observed in clinical practice informs these knowledges, and because of their existence, shapes health care (Henderson, 1994). Foucault’s foundation for disciplinary power is the understanding that the body can be “manipulated, shaped, trained to obey, respond and becomes skilful”, and the body is docile in that it can be subjected, used and transformed as a “docile body” (Foucault, 1975 p. 136). It is through disciplinary power that the docile body is shaped into the organism that is required, such as the hospital requiring doctors and nurses to perform certain tasks. This establishes the norms that are the foundations of the discipline and determines what is acceptable behaviour, dissuading those who transgress (Perron et.al. 2005). The result is the normalising nature of disciplinary power serves as an instrument of social control (Perron, et.al. 2005).

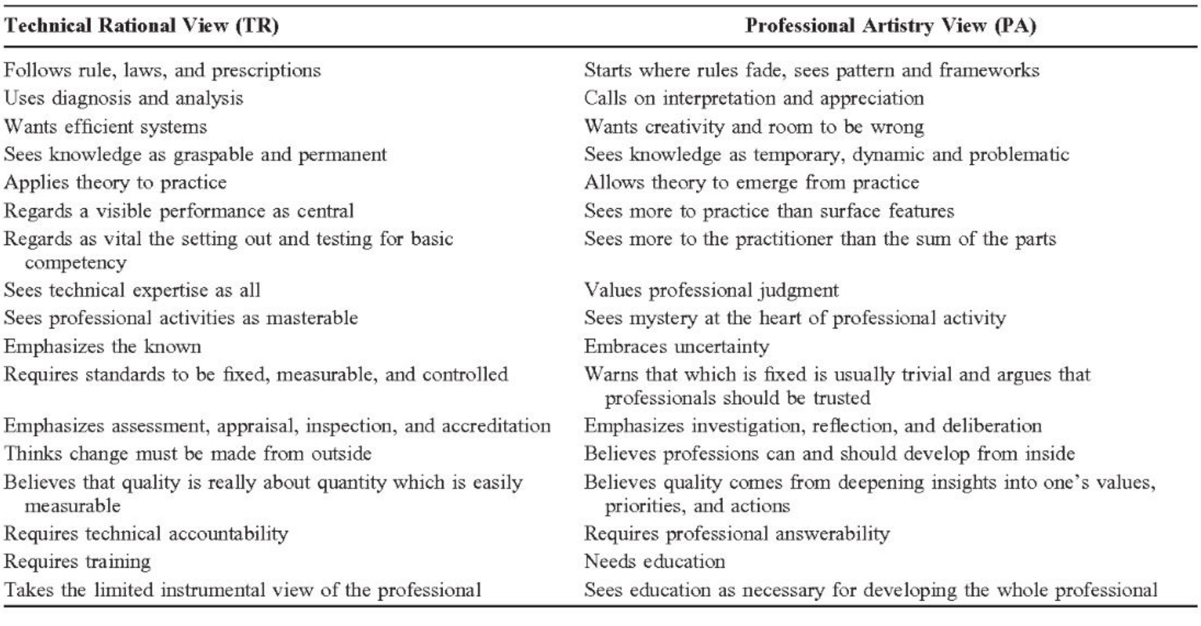
A different perspective of power is offered by Tillich (1954). Foucault’s view of power is correlated to knowledge whereas Tillich argues everybody has power. Tillich defines the ontology of power as “the *power-of-being*”, the possibility of self-affirmation (Tillich, 1954 p. 40). With *power-of-being*, everyone has opportunities for self-affirmation, but must take risks to actualise their *power-of-being,* otherwise it remains hidden (Tillich, 1954). The alternative to the *power-of-being* is ‘non-being’; a finite being where ones’ destiny is not to ‘be’ or to no-longer exist, which is death (Tillich, 1954). Similar to existential philosophy awareness of non-being, as finite, creates an ultimatum with death and ‘to be’ becomes a process of becoming through self-affirmation. Individuals have a power of universal participation and it is from this power that comes the power-of-being; the power within of selfhood, ‘becoming’, dynamisms and freedom (Tillich, 1954). The *power-of-being* comes from this drive within the individual and is dynamic to mitigate against non-being. In conquering non-being, courage is needed to overcome the significant theme of angst, or anxiety, that is ever present as a result of the anticipation of death (Tillich, 1954).

Tillich describes the greatest *power-of-being* is the one who is completely self-centred, self-related and self-aware “his centeredness makes him the master of his world, and where there is centeredness there is a hierarchical structure to power” (Tillich, 1954 p. 44). But individuals are not isolated, they do not exist “in an empty space” they are part of a social structure where there is social *power-of-being* of the group, this has a hierarchical power structure due to the centeredness of social power (Tillich, 1954 p. 91). Socialisation means life is a continuous process of decisions involving encounters with others who represent a power-of-being, resulting in a decision about the amount of power-of-being embodied within each of them. The decisions are always made around those different dynamics of the *power-of-being.* There are injustices that can occur as a result of the struggle between the *powers-of-being*, the most frequent are those which occur within the frame of an institutional structure (Tillich, 1954). Individuals can exercise power by the place they hold in the institution by their use of authority, which is an ‘authority-in-principal’ is a repressive authority and therefore unjust. This contrasts with ‘authority-in-fact’ which is the mutual dependence of all of us on each other of our power to stand by our selves, and for this reason is a just authority.

Tillich presents a differing view of power to Foucault. There are other philosophical perspectives that could be considered but the purpose here is to establish a baseline for analysis of hospital nurses’ experiences of end-of-life care, which Tillich and Foucault conceptual views offer. What Tillich lacks is an explanation for knowledge in the analysis of power, which is the premise for Foucault’s theory. For this reason, the following section adds to this analysis.

Discipline Knowledge

Discipline-based professional knowledge is derived from coherent and systematic knowledge (Eraut, 2003; Foucault,1975). In contrast professional knowledge that is gained and validated in practice is subjected to debate as to its scope, generalisability, and value compared to discipline-based knowledge (Eraut, 2003; Schön, 1983). Schön (1983) refers to professional knowledge that is specialised, standardised, evidence-based, utilising a problem-solving approach of a logical selection of the best suited option as technical rational (TR). This differs to professional artistry (PA) which utilises reflection-in action to deal with the uncertainty, uniqueness and conflict of the practice situation. A TR approach views professional practice as delivering a service as a predetermined set of routines and behaviours, whereas, PA is the application of principles with practitioners having the autonomy to apply those principles (*fig2*) (Fish, Coles 1998). For this reason, professional artistry sees practice as complex, requiring an understanding of the component parts, as opposed to the individual tasks (Fish, Coles 1998). Eraut (2003) suggests TR approach ignores the alternative of PA, describing PA as emphasis on responsiveness, invention and a quick reading of situations.



Technical Rational View (TR)	Professional Artistry View (PA)
Follows rule, laws, and prescriptions	Starts where rules fade, sees pattern and frameworks
Uses diagnosis and analysis	Calls on interpretation and appreciation
Wants efficient systems	Wants creativity and room to be wrong
Sees knowledge as graspable and permanent	Sees knowledge as temporary, dynamic and problematic
Applies theory to practice	Allows theory to emerge from practice
Regards a visible performance as central	Sees more to practice than surface features
Regards as vital the setting out and testing for basic competency	Sees more to the practitioner than the sum of the parts
Sees technical expertise as all	Values professional judgment
Sees professional activities as masterable	Sees mystery at the heart of professional activity
Emphasizes the known	Embraces uncertainty
Requires standards to be fixed, measurable, and controlled	Warns that which is fixed is usually trivial and argues that professionals should be trusted
Emphasizes assessment, appraisal, inspection, and accreditation	Emphasizes investigation, reflection, and deliberation
Thinks change must be made from outside	Believes professions can and should develop from inside
Believes that quality is really about quantity which is easily measurable	Believes quality comes from deepening insights into one's values, priorities, and actions
Requires technical accountability	Requires professional answerability
Requires training	Needs education
Takes the limited instrumental view of the professional	Sees education as necessary for developing the whole professional

Figure 2 Fish Coles 1998 p. 41

Nursing knowledge can be located from a professional artistry position (Sadler-Smith, Smith 2006). This draws on Aristotle's' concept of practical wisdom (*phronesis*) and political wisdom (Natali, 2014). Aristotle defines practical wisdom as knowledge concerned with human actions and "true reasoning concerned what is good and bad for a human being" (Natali, 2014 p. 188). This cannot operate alone, and wisdom comes from joining with political or philosophical wisdom which is to be wise in human affairs and deliberations. To be wise is to have the ability to "deliberate well about the right thing, the right way at the right time" (Natali, 2014 p. 1994). McKie et al (2012) suggest phronesis, as practical wisdom, acknowledges both the emotional and cognitive aspects of the practice situation as well as the uncertainty. Understanding nursing knowledge as wisdom, combining practical knowledge with professional artistry, the complexities and challenges of everyday practice can be viewed differently, to just the scientific technical rational approach of disciplinary power (McKie et al., 2012; Sadler-Smith, Smith, 2006; Fish, Coles 1998; Schön, 1983). Consequently, further exploration of the experiences of the hospital nurses understanding in relation to end-of-life care and their knowledge is needed.

Summary

Foucault's concept of disciplinary power and the observational gaze serves to help understand the power context which hospital nurses experience when delivering end-of-life care. Tillich's power of being provides a contrasting approach, focusing power not within the organisation but within the individual. Foucault's disciplinary power also examines the authority of nurses' knowledge in end-of-life care and this has been explored as a technical rational approach which is more focused on the tasks, diagnosis and analysis, whereas, professional artistry aims to understand principles, is subjective and interpretation of events. What is not present in the literature is an understanding of hospital nurses' experiences of power and knowledge in the context of end-of-life care situations.

REVIEW SUMMARY

Existentialism has been explored in the context of some existential philosophers and defined as the freedom to make choices, fulfilling our projects to give life meaning. There is currently very little literature directly exploring hospital nurses existential meaning and awareness attributed to their exposure to end-of-life care. Further evidence is needed to understand the nature of hospital nurses existential experience providing end-of-life care.

An awareness of the threat of death can lead to death anxiety or the dread of no-longer existing. This review suggests hospital nurses' experience of death anxiety was varied with some nurses reporting when they were confronted with death it could cause increased death anxiety, contradictory evidence reports nurses viewed caring for the dying as worthwhile and important. Nurses defence of death anxiety is attributed to religiosity, older age and experience. Recognising individual nurses' attitudes to death beyond death anxiety scales may develop wider appreciation of this issue. Additionally, understanding hospital nurses' personal construction of authentic-self and how they make connections with existential meaning and death is needed to help define more clearly how they assimilate the repeated exposure to death.

Emotional labour has been explored with a further need for appreciating nurses' management of their emotions in 'emotional boundaries', which links to empathy and feelings, reactions to situations and anticipation of events and emotional distancing. Further exploration is needed of nurses' emotional labour in end-of-life care and how hospital nurses manage their anxiety and existential distress while being emotionally authentic in the end-of-life caring encounter to better inform supportive strategies.

Foucault's' disciplinary power as power derived from coherent and systematic knowledge has been broadly explored and contrasted with Tillich's power-of-being where everyone has the opportunity for power as self-affirmation. Disciplinary power has been explored in the context of technical rational and professional artistry knowledge. Wider understanding is needed of hospital nurses experience of the utilisation of power in relation to their knowledge in the context of end-of-life situations.

This review indicates hospital end-of-life care is not a single experience but composed of multiple meaningful insights. Uncovering and explaining these insights of the hospital nurse's lived experiences may be useful in describing overall the phenomena of providing end-of-life care. Such knowledge could be influential in informing the development of focused nursing education, practice and future policy as well as helping inform the development of research for this potentially emerging field of knowledge. Combined, the understanding will inform how end-of-life patients care is, and could be, delivered in the hospital. This is reflected in the following research question, aim and objectives:

Research question What is the lived experience of hospital nurses providing end-of-life care?

Research Aim: To understand hospital nurses' experiences of end-of-life care

Objectives:

1. To explain hospital nurses' existential experience of providing end-of-life care
2. To understand hospital nurses' attitudes towards death
3. To explain how hospital nurses' authentic-self is negotiated when providing end-of-life care
4. To identify how hospital nurses use power and knowledge in end-of-life care situations.

CHAPTER 3:

RESEARCH METHODOLOGY, METHOD, ETHICS AND REFLEXIVITY

Practicing as a male nurse in the acute setting, gave me some insight of what it is like to provide end-of-life nursing care in the hospital environment. As a researcher, this gave me an awareness of the participants world that could offer co-construction of knowledge, rather than personal experience to be isolated and removed from the research. To understanding the hospital nurses experience required an exploration of the contextual features of nurses' individual experience of the phenomenon of end-of-life care. For this reason, I wanted to understand not the clinical tasks but the personal feelings and meanings that can give insight and deep understanding beyond the tasks of the caring event. My choice of interpretive phenomenology as a research approach reflects this rationale. The choice of visual methods as a data collection method also reflected this rationale for uncovering personal feelings and meanings of a sensitive topic.

RESEARCH DESIGN

Nurses caring for patients who are dying are exposed to reminders of the fragility of life and their own mortality. How such exposure is regulated and experienced is unique to the individual nurse suggesting each nurse holds a different version the real world, placing emphasis on the existence of multiple realities and insights of the experience (Kant 1998). Ontologically this conveys a world of appearances independent of each other. To understand these worlds Kant determined that "the sensible world is nothing but a chain of appearances…and therefore has no existence for itself…" (Kant 2004 p.105). It is only through human cognition can those appearances be cognised as things in themselves and be complete. Kant combined sensory, or sensible, understanding of the word of appearances with the intuitive understanding of the human mind as thing-in-itself. In doing so Kant combined reasoning with sensory perception to understand the real world (Moses and Knutsen 2012 p. 177). In this way Kant delineates between human understanding as sensibility, as objects that appear to our senses as appearances and things-in-themselves. The 'thing-in-itself' can appear different to every eye, and are formed by intuition, appearing in the mind as *a priori* knowledge. The thing-in-itself causes ‘appearance’ which is *a posteriori* knowledge (Kant 1998). Kant distinguishes between appearance and thing-in-itself by arguing appearance is the representation, such as a rainbow. The rainbow contains all the necessary sensory conditions for us the apprehend the rainbow. Kant states that the rainbow appears to our senses as a rainbow. Our cognitive apprehension of the rainbow would be to understand the thing-in-itself is the rain, without this empirical intuition from human cognition, the rainbow is a mere appearance in a sunshower (Kant 1998). Kant’s argument is knowledge is the combination of ‘sensibility’ as *a posteriori* knowledge and ’empirical intuition’ as *a priori* knowledge.

Critics of Kant have commented on his combining of a priori and a posteriori knowledge, arguing that this relies on experience and causality to know reality, therefore the mysterious and unknown will not and cannot appear and become known to us (Rockmore 2016). In particular Maimon is critical of Kant’s duality, reasoning that Kant’s idea of cognitive understanding that makes sense of the appearance is flawed, arguing that empirical intuition as *a priori* in the form of thing-in-itself is not possible (Maimon 2010). Maimon argues for the universality forms of thought in general and our sensibility. Intuition is a modification of human cognition, both active and passive, with appearance being undetermined intuition (Maimon 2010). In this way Maimon argues for plurality with the real world being known by intuitive knowledge.

Despite criticism, Kant’s philosophy founded the ontological view that there is a world real world (noumena) and that our perception (phenoumena) of that world is linked. Kant’s reasoning leads to the ontological view that real world can be understood by using human reasoning and sensory perception (Moses and Knutsen 2012). This follows a constructivist view by cognitively constructing what is known (Rockmore 2016).

The ontology for this study is therefore relativist, with each nurse holding mental constructions of the *phenomenon*, which can be socially and experientially based and sometimes conflicting (Guba, Lincoln, 1984). Following Kant’s philosophy the ontological perspective is represented in *fig 3*, where the *thing-in-itself* is the individual nurse's experience of the reality of providing end of life care, *appearance* is the end-of-life caring encounter(s).

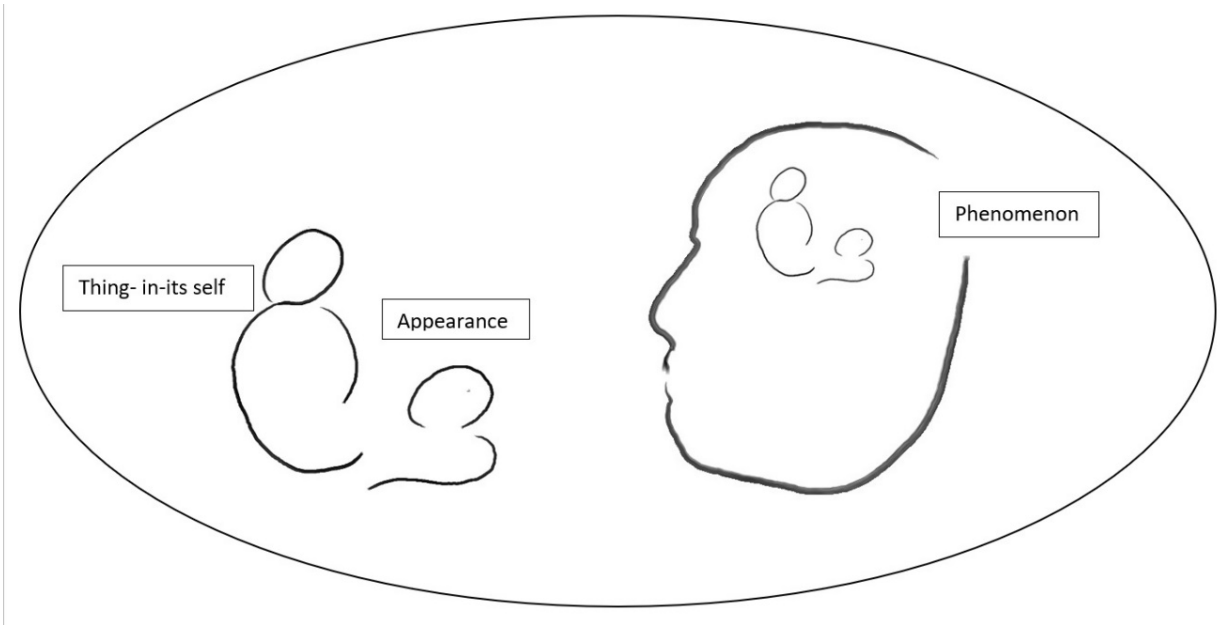


Figure 3 Ontology (adapted from Pernecky 2017)

Epistemological Framework

Epistemology is concerned with how the researcher can empirically access the phenomenon to be understood (Giacomini, 2010). Knowledge about the nurses' experience of end-of-life care should be determined by the ontological outcomes (Guba, Lincoln, 1994). Nurses working in the hospital setting are not a homogenous group, with many different divisions, specialties and departments, each one their own hierarchies of care and different organisations and disciplinary cultures. Consequently, the epistemological approach recognised the multiple constructions of nurses' realities by acknowledging the relative value of each nurse's construction of the truth about their experiences of the phenomenon of end-of-life care (Giacomini, 2010).

Although several methodologies are available to appreciate the essence of hospital nurses' experience of the phenomena, Ontologically what is most real is the essence of the nurses' experience of providing end-of-life care and the epistemological methodology of interpretative phenomenology is the best fit to explore the phenomenon, with the following justification.

Within phenomenology several approaches exist. Husserl's approach to phenomenology follows a tradition of enquiry, which is a science-based description of conscious experience, devoid of presuppositions (Parahoo 2014; Lopez, Willis 2004). Husserl's aim of understanding strips back to the things in themselves without interpretation, to reveal the essence of the phenomena. To do this requires a state without prior knowledge or experience (Parahoo 2014; Lopez, Willis 2004). Husserl rejects the division between matter and mind and supports the idea of phenomena existing in the consciousness of individuals (Parahoo 2014). This rejects Kantian duality. Husserl develops transcendental phenomenology, also known as descriptive phenomenological research, as an objective and generalisable method to explain the essence of a phenomena. His method aims to consciously remove the researcher by a process of epoché as a form of disciplined reduction to clearly see the phenomenon, without distortions from preconceptions (Pernecky, 2017; McWilliam, 2010; Lopez, Willis, 2004). This approach does not support the co-construction and emic position of the researcher advocated by this study. In addition, descriptive phenomenology aims to uncover the *essence* or structural characteristics of a phenomena (Lopez, Willis, 2004; Dahlberg 2006), whereas the focus of this study is to understand the nurses' *experience*.

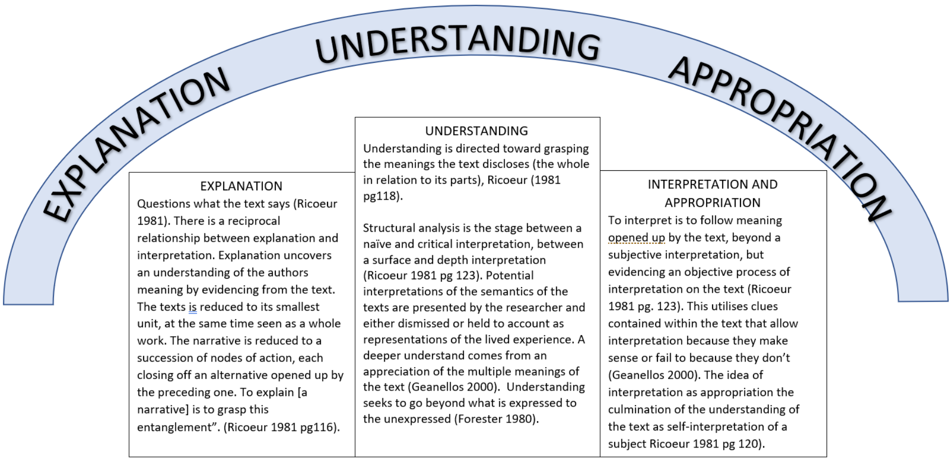
Heidegger offers a different approach to phenomenology by rejecting Husserl's idea of epoché and instead recognises that knowledge is co-created. How we experience something in the world is influenced by living and being in the world (Lopez, Willis 2004). Central to Heidegger's phenomenological approach is understanding the persons lifeworld; an individual's realities influenced by their experience of the world in which they inhabit (Lopez, Willis, 2004). Interpretative phenomenology does not explore the essence of the phenomena but seeks to expose the hidden experiences that may not have been uncovered by a descriptive approach (Lopes, Willis 2004). Heidegger also used hermeneutics to understand the lifeworld of individuals. For this reason, Heidegger's phenomenological approach is referred to a hermeneutic or interpretative Phenomenology (Parahoo 2014; Lopez).

Interpretative Phenomenological Analysis (IPA), has been developed within psychology to explore the personal lived experience, examining the lived experience without the prior psychological theorising or personal disposition of the researcher (Smith 2017). As a result, IPA is concerned with exploring, describing, interpreting how participants make sense of their experience (Smith et al 2009). An important concern for IPA is the psychological approach to the research process (Smith et al 2009). The approach utilises Heidegger's interpretative approach but unlike descriptive or interpretative phenomenology, IPA is less concerned about the phenomena and more interested in the experiences people describe (Parahoo 2014). IPA is an "idiopathic approach concerned with understanding particular phenomena in particular contexts" and for this reason focuses on detailed description from small fairly homogenous samples (Smith et al 2009 p. 49). The homogenous requirement of the sample limits its application to this study. Fundamental to IPA is a non-prescriptive approach to the method, allowing for flexibility and sensitivity for data collection and imagination and playfulness to facilitate successful analysis (Smith et.al. 2009). This flexibility causes Giorgi (2010) to be critical of IPA, questioning the absence of a clarity of method and Giorgi argues IPA lacks the rules and specific steps for philosophical analysis to make it fit within a phenomenological tradition. Van Manen (2017) is also critical of IPA claiming the original aim of the IPA approach was to make sense of people's life experiences and is framed from a psychological perspective, looking at problems and symptoms. This is not grounded in a phenomenological approach which should seek insights and understandings of human experiential lifeworld (Van Manen 2017). This study aims to 'understand', which is to become aware of the primal meanings of the experience or the heart of the experience (Van Manen 2017). Van Manen argues this is not possible with IPA because of the focus on the person, and personal, experiences and these are explored from a psychological concern. It is because IPA obtains psychological themes it does not achieve the primal meanings needed for understanding that it was not used for this study. Phenomenological understanding is gained by "exploring the edict or inceptual meaning structures" which can give original insights and understandings (Van Manen 2017).

The focus of interpretive phenomenology is on understanding the human experience of the life world rather than on the essence. Interpretive phenomenology is the method of bringing out and making visible human experiences that are normally hidden, using hermeneutics to look for meaning beyond essences (Van Manen 2017; Lopez, Willis, 2004; Van Manen 2017). With Interpretive Phenomenology the position of the researcher is to interpret, with caution, but is also dynamic and is recognised as having presuppositional knowledge, which is a valuable guide to the inquiry (Cresswell, Poth 2018; Van Manen, 2017; Lopez, Willis, 2004). In view of recognising this dynamic between the researcher and the subject of the investigation, and the focus on exploring hospital nurses' experiences of providing end-of-life care, an interpretive phenomenological approach was used.

METHOD OF ANALYSIS

The method of analysis used for this study was Ricoeur's hermeneutical analysis. Textural analysis is more than a literal understanding and supports the concept of hermeneutics which looks for the meaning behind the text (Gadamer 2004; Ricoeur, 1981, 1984, 2016). But Ricoeur is critical of Gadamer's theory of hermeneutic analysis, which results in a *speculative* structure of the individuals experience resulting is a fusion and universal understanding (Gadamer, 2004). Ricoeur's hermeneutic approach is a process of distanciation (putting something at a distance). The distance between the self and the other is reduced by a systematic process of analysis informed by the hermeneutic arc (*fig4*), moving between understanding and interpretation (Ricoeur 2016). This allows for the intentions of the participants meanings to be approached and understood, linking the knower with the known (Geanellous 2000). This objectification of the text and application of structural analysis is a more critical form of hermeneutics (Piercey, 2004) and more suited to clinical application.



EXPLANATION

Questions what the text says (Ricoeur 1981). There is a reciprocal relationship between explanation and interpretation. Explanation uncovers an understanding of the authors meaning by evidencing from the text. The texts is reduced to its smallest unit, at the same time seen as a whole work. The narrative is reduced to a succession of nodes of action, each closing off an alternative opened up by the preceding one. To explain [a narrative] is to grasp this entanglement". (Ricoeur 1981 pg116).

UNDERSTANDING

Understanding is directed toward grasping the meanings the text discloses (the whole in relation to its parts), Ricoeur (1981 pg118).

Structural analysis is the stage between a naïve and critical interpretation, between a surface and depth interpretation (Ricoeur 1981 pg 123). Potential interpretations of the semantics of the texts are presented by the researcher and either dismissed or held to account as representations of the lived experience. A deeper understand comes from an appreciation of the multiple meanings of the text (Geanellos 2000). Understanding seeks to go beyond what is expressed to the unexpressed (Forester 1980).

INTERPRETATION AND APPROPRIATION

To interpret is to follow meaning opened up by the text, beyond a subjective interpretation, but evidencing an objective process of interpretation on the text (Ricoeur 1981 pg. 123). This utilises clues contained within the text that allow interpretation because they make sense or fail to because they don't (Geanellos 2000). The idea of interpretation as appropriation the culmination of the understanding of the text as self-interpretation of a subject Ricoeur 1981 pg 120).

Figure 4 Hermeneutic Arc

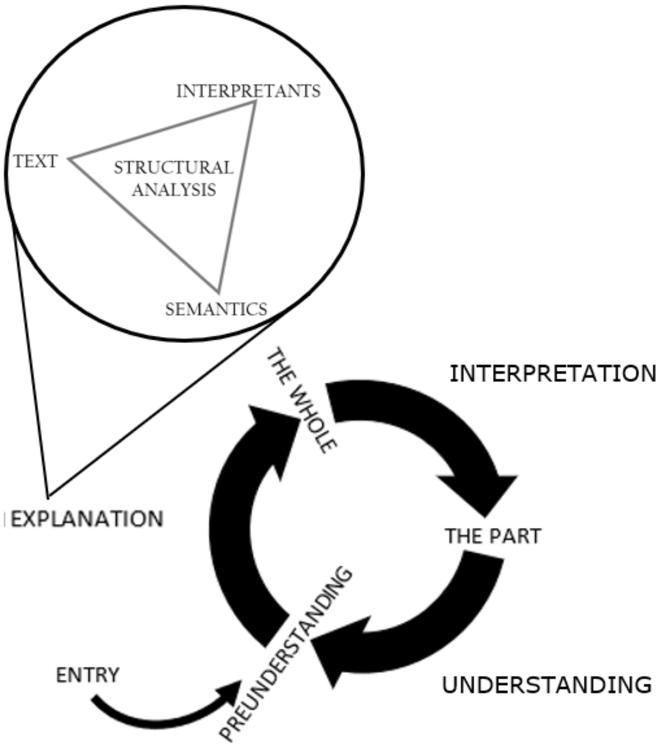


Figure 5 The Hermeneutic Circle (Stuart 2020)

Ricoeur's method of distanciation looks to discover the psychological intentions of another person which are concealed behind the text (Ricoeur 2016). Ricoeur applies the hermeneutic circle (*fig5*) as a representation of the interpreter's process of preunderstanding the text and the relationship between the interpreter developing an understanding of the text by interpreting the parts against the whole, and the whole against the parts (Geanellos 2000; Grbich 1999).

Ricoeur questions the logic of empiricism and maintains the hermeneutical circle should remain an "unavoidable structure of interpretation" and any form of interpretation is not authentic if it avoids some form of appropriation (Ricoeur, 2016 p. 140). Through the process of the hermeneutic arc, understanding meaning and self-understanding are negotiated as a continuum leading to appropriation which is therefore closer to an idea of 'self-presentation' of the truth (Ricoeur, 2016). What Ricoeur offers can be considered a form of critical hermeneutics such that to *appropriate* is to be critical (Piercey, 2004). The hermeneutic arc places the interpreter not by projecting themselves into the horizon, but by understanding themselves in front of the text (Ricoeur, 2016). Consequently, the researcher is continually interpreting the text through their own beliefs and prejudices and verifying against the truth of the text (Ricoeur, 2016).

This study used metaphor to uncover the nurses' experiences. Ricoeur explains the difficulty in understanding the intentionality of a metaphor can be when text is analysed according to syntax. This provides the reader with an understanding of what the author has said according to the rules of syntax, which gives a literal understanding (Ricoeur, 1981). Ricoeur uses the metaphor 'man is a wolf' and analysed literally as "man to be of lupine construction" no new meaning comes from this. Seeing the phrases as metaphor changes the meaning from one of none literal understanding, or 'metaphorical twist' (Ricoeur, 2003; Ricoeur, 1981).

To interpret the metaphor, text must be seen as more than a linear sequencing of the sentences, it is a cumulative holistic process that cannot be derived from just understanding the sentence (Ricoeur 1996). The text should be read in two ways with a reciprocal relation between the two, the first being explanation, the second interpretation. This process follows Ricoeur's hermeneutic arc (*fig4*) as a systematic process of analysis, moving from explanation of the text to appropriation. Structural analysis (*fig 5*) is applied to bring out interpretation from the explanation and is a stage "between naïve understanding and critical interpretation, between surface understanding and a depth interpretation" (Ricoeur, 2016). Structural analysis is achieved by moving between interpretation; the text itself, semantics and a series of interpretants which are tried against the explanation and either dismissed, or accepted (*inset fig 5*).

Knowledge generated from nursing orientated research should be applicable to clinical care (Thorne, Stephens & Truant, 2015). Ricoeur's critical approach to hermeneutic analysis focuses on authentic and justified outcomes offering more applicable meaning relevant to clinical care. In addition Ricoeur's systematic approach to understanding the intentions and meaning behinds the participants text is useful when considering metaphor is one of the main form the data took.

RESEARCH PROCEDURES

Interview Process

The focus of phenomenological interviews is to recall the lived experience, but the moment we reflect on a lived experience, the living moment is gone (Van Manen 2017). The challenge for phenomenology is to recover those lived meanings (Van Manen 2017). Coupled with a requirement of this study to uncover the emotional and hidden lived experience of providing end-of-life care, beyond the physical tasks, visual methods were employed to address both these problems. Visual approaches often encourage talk that is more emotional and can invoke different kind of memory and recall than talk only interviews (Rose 2016; Guillemin, Drew 2010). Discussing death and end-of-life can be an emotive, difficult topic, and could result in participants true emotions remaining buried. Visual methods can offer a way of exploring emotions and the persons relationship with the phenomena that language-based methods do not achieve (Gauntlett, 2015). It can allow interviewees to reflect on things they do not usually think about (Rose 2016). It can also give participants a degree of control over the disclosure as well as making is easier to discuss uncomfortable subjects, difficult with talk-based methods (Allen 2011). As a result, it offers the possibility for participants to locate end-of-life and death experiences that may not be easily accessible through traditional approaches. Language based interview methods are relatively time pressured and rely on participants being able to articulate their feelings in response to trigger questions (Gauntlett 2015). Visual methods provide opportunities to express the unsayable and record meaning, are reflective and are successful in gathering data where verbally articulating a response is difficult (Manny, 2016; Kara, 2015; Gauntlett, 2015; Guillemin, 2004). Consequently, visual methods helped the participating nurses to express their true emotional, existential and authentic experience of end-of-life care, that may not have been easily expressed in a language only interview.

Visual methods, combined with an elicitation interview were used to uncover the nurses' existential feelings and authentic-self. The difficulty with using such arts-based data collection methods with adults, is their reluctance to engage with such techniques (Guillemin, Drew, 2010; Mair, Kierans, 2007). For this reason, participants were given a range of magazines, paper, and scissors and asked to select images from the magazines that represented their experiences to creating a montage of images as visual metaphors of their experiences (example *fig6*). The discussion of their image was then explored in an elicitation interview to investigate the experience and the meaning attributed to the images. This study utilised participants constructing visual representations as metaphor for their experiences of providing end-of-life care.

Figure 6 Autumn;" a bit of mournfulness about it saying good bye to the year and another summer" (Participant)

Elicitation Interview

The interviews were conducted to obtain details to arrive at common concepts integral to the experience. To use a preconceived set of questions may direct the conversation (Lopez and Webb 2014). Participants should be able to express their sense of self as well as how their individual encounters are socially negotiated (Elliot, 2005; Andrews et al., 2004). Consequently, the interviews were structured to be free flowing, with participants answering questions, but simultaneously engaging in conversational forms (Holstein, Gubrium, 2011). Wengraf's (2001) model of lightly structured interview preparation, as a set of trigger questions, an interview schedule was used (Fig 7).

INTERVIEW SCHEDULE
Interview Question 1: Could you start by telling me, when you are caring for someone who is in their last hours of life, how does that make you feel?
Interview Question 2: How do you deal with your personal feelings?
Interview Question 3: Can you tell me more about when you make the decision to provide care for someone who is dying, what influences you in making that decision?
Interview Question 4: When you make decisions about the care of the person who is dying, what influences those decisions and how do you feel about the decision?

7

Figure 7 Interview Schedule

Recruitment

Participants were recruited using purposive sampling using a recruitment poster in targeted hospital clinical settings across three hospital trusts and post registration University courses (appendix 2). Inclusion and exclusion criteria (*fig.8*) was applied to respondents. Consequently, all the participants were registered general adult nurses with clinical experiences of providing end-of-life care in the acute hospital setting.

INCLUSION CRITERIA	EXCLUSION CRITERIA
1 Registered Adult Nurses who provide end-of-life care in the secondary care setting. 2 Registered Adult Nurses who are exposed to end-of-life care as part of their care requirement. 3 Registered Adult Nurses who are not specialised in providing end-of-life care	1 Registered Adult Nurses working in the Primary care and Third sector 2 Registered Adult Nurses working in specialist end-of-life care setting such as hospice and oncology. 3 Registered Adult Nurses who have no end -of-life experience. 4 Registered Nurses who are not adult focused in their care

Figure 8 Inclusion and Exclusion criteria

Interpretive phenomenology can generate a large amount of data from a relatively small number of participants (Morse, 2015). As a consequence, few interviews are needed to develop a collective story (Cresswell, 2007). A review of the evidence for the recommended number of participants for interpretive phenomenology research identified an average sample size of 6-10 (*fig.9*). Initially 6 participants were recruited for this study, followed by a further 4 to facilitate sample saturation (Parahoo 2014). A basic profile of the nurses is provided in *fig 10*.

INTERPRETATIVE PHENOMENOLOGY SAMPLE SIZE	
AUTHOR(S)	Number
Starks and Trinidad (2007)	1-10
Smith (2004)	5-10
Cresswell (2007)	6-10
Morse (2000)	6-10

Figure 9 Sample Size

Name	Age	Years in nursing	Clinical Experience
Virginia	59	39	Currently (14 years) I am Lead practice development nurse for the surgical division and I bank in surgery and trauma. Previously I worked for 20 years in acute surgery, covering urology, colorectal and vascular. I started my nursing career with 5 years in acute trauma
Jean	61	41	I worked in Coronary Care full and part time for 15 years as an enrolled nurse and as a registered nurse. Then cardiac rehab for 9 years. Currently I am a senior lecturer in adult nursing.
Edith	58	37	I have spent 7 years as a rapid response nurse looking after and supporting the clinically deteriorating patient in a ward environment. Prior to this I was a Practice Educator for a University supporting adult students in practice at a District General Hospital. I worked for 7 years in critical care involved in the care of both Intensive Care and High Dependency patients. Before this I work in a rural community support the District Nurse. I had previously worked in critical care in two different district general hospitals.
Nancy	52	32	Previously I spent 9 months on surgery nights, 1 year in A&E and 15 years in ITU where I started as a D grade progressing to senior sister. In ITU my final 3-4 years were as a practice development nurse senior sister grade. Currently a senior lecturer.
Hilde	34	13	Currently I am a Heart Failure Advance Nurse Practitioner and also Rapid Response Advance Nurse practitioner. My background in emergency medicine, cardiology research, cardiothoracic High Dependence Unit and cardiothoracic/cardiology wards. Through my heart failure role, I discuss advance care planning, and within my rapid response role I often review patients who are either acutely unwell, often being required to discuss DNACPR orders to ascertain appropriate ceilings of care.
Martha	31	6	Currently I have been working on a colorectal surgical ward for 5 years and 5 months. I previously I spent 1 month in a Hospice as part of my training.
Barbara	66	45	I have been Bereavement officer for last 11 years. Previously ward manager care of elderly and gastroenterology and senior Accident and Emergency Sister for many years with particular interest in witnessed resus and care of bereaved relatives after sudden death.
Louisa	41	23	My clinical career includes 8 years as a critical care outreach nurse, sister in general medicine, a D/E grade nurse working in acute and specialist medicine, ITU and urology.
Edna	34	15	I have worked in oncology, palliative care and in the community.
Mary	37	14	I have been an Advanced Clinical Practitioner within urgent care, in A&E, ambulatory care and emergency decisions unit for 6 years. Prior to this worked as a senior nurse in A&E, ITU/HDU and Emergency Assessment Unit. I also work as an ANP for GP Out of Hours

Figure 10 Participant Profile

Data Analysis

Ricoeur’s approach to hermeneutics was used to analyse the texts. Thematic analysis could have been applied, where the text is analysed thematically, assigning codes as names of meaning to passages of text, using the codes to identify a thematic idea (Creswell, Poth 2018; Gibbs, 2014; Grbich 1999,). Thematic analysis could have provided descriptive and literal interpretations of the text with a focus on both the latent and literal meanings of the text (Vaismoradi et.al. 2013). The declaration and removal of the researcher’s intentions and prejudice and preunderstanding by epoché are part of thematic analysis (Creswell, Poth 2018, Grbich 1999). This reduces the appropriateness for interpretive phenomenological study in which the researcher’s personal knowledge is recognised as both useful and necessary (Lopez, Willis, 2004; Geanellos, 2000).

The process of data analysis consisted of preparing and organising the data and finally representing the data as a discussion (Creswell, Poth 2018; Silverman, 2010). To prepare and organise the data the interviews were recorded, transcribed and uploaded to NVivo, a data analysis application. The visual images chosen by the participants from magazines were digitally recorded and made available for analysis alongside the participant’s transcript.

The method of collection resulted in data as visual images as metaphors of the nurses’ experiences and the elicitation interviews generated texts providing insight as to the nurses meaning of the metaphor. Exploring the intentionality of the metaphor utilised Ricoeurs’ hermeneutic arc (*fig 4*). Firstly, the text was read with an explanatory attitude and then with an interpretive approach (Ricoeur, 1981). Using the participant Mary’s Unicorn metaphor as an example the structural analysis was informed by a triangle of interpretations; the text itself, semantics and a series of interpretants (*fig 5*). The analysis followed a spiral, passing the same mediation points but at an increasing altitude (Ricoeur, 1984). Different judgements of Mary’s explanation and meaning of unicorn were explored (*fig 11*). NVivo nodes were used to organise the explanation of the text and the process of justification using NViVO by offering interpretations, and then either dismissing or supporting judgements. NViVO was useful for individual participants but became too cumbersome when combining participant's findings. Converting to word and more manual procedures was more successful. Explaining the text was a duel process being both deductive and inductive. The connection with the text and events Mary described about the Unicorn is a deductive process. Making judgements on the latent factors being inductive, giving weight to opposing arguments and defending, evidencing the reasons (Ricoeur, 1984). An example using this process is given in appendix 3. Notes were taken on possible meanings and links to similarities with others in the text to substantiate or dismiss the meaning, facilitating an objective understanding of the text. This led to a richer understanding of the meaning leading to interpretation, which continued with this process of mediation with the text as evidence, pulling together the different evidences and instances of meaning.

Following this process, interpretation was supported and mediated by the text, with ideas of interpretation being supported or dismissed (Ricoeur, 1981, Geanellos, 2000). Mary's idea of Unicorn and the meanings attributed were explored in the other 9 participants descriptions. The interpretation of what was meant by Unicorn; a reminder of the fulfilment of life, was informed by this process. The final stage was appropriation which Ricoeur describes as 'to make one's own' the final brace of the bridge, the actualisation of meaning, its base firmly set back in the ground of the lived experience (Ricoeur, 1981 p. 147).

Evidenced	Not evidenced
embracing life	Fantasy
colourful	Mythical
unique	Unreal
happiness	Magic
Family	

Figure 11Example of systematic analysis

Credibility

There has been much debate in qualitative literature regarding the application of terminology such as 'validity' and 'reliability', with such terms presumed to belong to scientific discovery (Grbich 1999). While some argue for open assessment of the effect the researcher has had on the setting, the interpretation and presentation of the findings, others argue credibility and trustworthiness are more appropriate terms (Grbich 1999). The credibility of the findings from a study can be made stronger by providing sufficient detail in the analysis for the reader to challenge or support the claims made (Parahoo 2014; Creswell, 2007, Grbich, 1999). Interpretive approaches involve the researcher in the analysis of the data, consequently are always open to re-interpretation (Creswell, 2007). The solution is to consider "judgement of the trustworthiness or goodness of the research": to make it worthy of trust (Creswell, 2007 p. 205). On the issue of interpretation, Ricoeur states there are no rules for making good guesses, but rules for validating our guesses (Ricoeur, 1981). Ricoeur argues for a process of verification akin to legal judicial procedures (Ricoeur, 1981). Ricoeur explains historians present their evidence for their accounts of the decisions they have made, as they would to a juror, reasoning why they believe events occurred for the juror to either refute or support those claims on the evidence presented (Ricoeur, 1984).

The result is several methods are available to support the trustworthiness of the research, which was achieved for this study by closely following Ricoeur's' hermeneutic arc; being reflexive and making evident to the reader the process of the logic of interpretation and having access to the relevant description of the texts. Reflexivity was used as a process of self-awareness to explain how personal prejudices could have impacted on the interviews and interpretation (Grbich, 1999). Also making the details of the relevant descriptions available to the reader so the rich text of the interpretations made can be clearly evidenced (Cresswell 2007).

Researcher Position

The focus of this study is on hospital nurses' experiences of providing end-of-life care. This is informed by my personal experience as a ward nurse then as specialist nurse in palliative and end-of-life care practicing in the hospital setting. My experiences led me to believe facing the death of another person can question one's own mortality leading to existential questioning. It can increase anxiety about death awareness issues and question personal beliefs and assumptions about one's mortality. When caring for dying patients and supporting them in their end-of-life care, the moment was never about me, the focus was about them. This necessitated me to be genuine and present and to be in control of my emotional self. Supporting people with the end-of-life decisions required me to have the knowledge, authority and power and sometimes courage to act on the decisions. This has informed some of the background to the study.

As a researcher and previously a nurse practitioner with experience in the field of study, this provided valuable insider knowledge as to the meanings and interpretations of participant's reality (Holloway, Biley, 2011). Consequently, the declaration and removal of the researcher's intentions, prejudices and preunderstanding by epoché was considered unsuitable for this interpretive phenomenological study in which the researcher's experience and knowledge was recognised as both useful and necessary (Creswell, Poth 2018; Lopez, Willis, 2004; Geanellos, 2000; Grbich 1999). The researcher maintaining an interpretive presence in the analysis was influential in choosing interpretive phenomenology but, despite epoché being inconsistent with this approach, making the researchers preconceptions explicit can be part of interpretive phenomenology by taking a reflexive stance (Holloway, Biley, 2011; Lopez, Willis, 2004). A reflexive approach to understanding the texts was used as it can be holistic, encompassing the researcher's experiences in the interpretation of the text by recognising pre-understanding (Gadamer, 2006).

ETHICS

Full ethical approval was granted prior to the study commencing (accepted 17th Sept 2016). Institutional research governance and ethical approval was gained before participants were recruited onto the study (appendix 2). The study did not involve patients or require entry onto NHS property, consequently, NHS ethics was not required. Recruitment posters advertising the study included a brief description of the study, methods and the email of the researcher for potential participants to contact for a participant information pack. The participant information pack contained detailed information about the project including background information on the project, the purpose of the interview and how confidentiality was to be maintained. Due to the potential sensitivity of the topic, support information was also made available in the packs. This was to ensure participants engaged willingly and to ensure consent was informed. A written consent form was included in the packs.

Confidentiality was maintained at all points of the study with no private information about individuals being disclosed. Participant identity after the analysis stage was changed to an alias to maintain confidentiality. At this stage transcriptions were retained but participant identification and personal information were destroyed. Work environments were kept generic e.g. ITU. Following transcription participant identity was coded and personal information kept secure following data protection. Following data protection and the study data management plan the study data was held securely in digital format for the duration of the study and only accessible by the principal researcher, archived with access only by the consent of the principal researcher.

Reflexive Thoughts

I anticipated in my research proposal the research method may require a reliving of experience and I had been prepared for this; in reality I was wrong. To prepare the environment, I put a box of tissues on the table but in the first interview the participant saw the box and before we began said "*I hope you are not going to upset me".* The tissue box became a challenging ethical issue for me. This was not a trivial matter, 7 of the 10 participants became emotional and tearful during the interview. I removed it for the second interview and had to break the interview to find the box. One participant was cross and felt I should have prepared better by having the tissues ready to be compassionate. The reality of the experience of the ethical issues will be explored in more detail.

My clinical background was not was disclosed to the participants through the participant information. They would be aware of my gender. As a heterosexual male interviewing 10 individual female nurses I was not aware of any gender issues or biases. This may be attributed to me being familiar with the situation from my practice experience, giving me an immersive perspective.

Disclosure

Visual methods allow expression of feeling that may otherwise be unsayable with word-based only methods (Guillemin, Gillam, 2004). The ethics application identified that should the participant share information that could be considered unsafe they would be encouraged to follow the correct procedure in disclosing this. One participant disclosed aspects about her practice that I found difficult to witness and could be described as incorrect practice, but this is uncertain. She disclosed focusing on the tasks of end-of-life care and avoiding emotional and existential engagement with the dying patient and their family. She was telling me something I was uncomfortable hearing, but this does not make it unsafe and I chose not to intervene.

Visual Images and Ethics

The visual images created by the participants are representations of their unique experiences and belong to the individual participant, consequently, copyright belongs to the person who created the image (Rose, 2016; Guillemin, Gillam, 2004). Permission to reproduce the image in publications, conferences, social media and other forms of knowledge exchange will need to be obtained from the individual (Rose, 2016; International Visual Sociology Association, 2009; Guillemin, Gillam, 2004). Participants were asked to give consent for the use of the image(s) for use in any knowledge exchange activity as part of the study consent form (appendix 2). The copyright for the images is more complex. UK copyright law allows for 'fair dealing' which allows for exceptions of copyright in circumstances such as non-commercial use in research (Owen 2015, IPO 2014). Post research 'fair dealing' allows for a *limited* (size) use of someone else's work for non-commercial gain and as a result is unlikely to impact on the commercial interests of the rightsholder (Owen 2015). The generalised statement "All images are copyright their respective owners" has been used to respect this position.

How to interrogate visual images has been cited as an ethical concern without having an understanding of the multiple codes the image might present (Bell

2013). An elicitation method allows the participant to clarify and reflects on what the images mean to them (Rose, 2016). Elicitation methods place emphasis on the participants interpretation of their own image as being the most significant (Guillemin, Gillam, 2004). In this way the researcher can analyse the interview and image concurrently with a reduced risk of misunderstanding.

Participant Well Being

Ethical consent was given for this study based on the agreement that participants taking part in this study would not be harmed. Undertaking qualitative research in sensitive subject areas risks causing emotional harm to participants, with emotional distress in the interview being possible signs of emotional harm (Cain, 2012; Dickenson-swift et al., 2007; Sullivan, 1998/99). The presence of the box of tissues in the first interview was an expression of a caring ethic by being aware of the sensitivity of the topic and being available to care during the research process (Noddings, 2012; Dickenson-swift et al., 2007). I did not see this as an indication that I would cause harm, as expressed by the first participant: *"I hope you are not going to upset me"*. The absence of the tissues in the later interview was seen as evidence of my lack of preparation and care and disrespect to wellbeing. Throughout the interviews my intention was not to cause distress, but I recognised that the nature of the subject may result in participants recalling events they found distressing, opening 'Pandora's box' (Manny, 2016; Dickenson-swift et al., 2007). As a nurse and a researcher my intention followed a care ethic approach by being present, empathic and responsive to the participants needs, regardless of the presence of tissues (Noddings 2012).

The strength of visual methods of data collection is their potential to overcome the limitations of language and open up the lived experience (Manny, 2016). This defamiliarization can lead participants to be confronted by elements of their experiences they had successfully kept hidden (Manny, 2016). Manny suggests this is an ethical balance between being open to the experience and keeping both researcher and participants safe from elements of their past. In this context I felt able to recognise the emotions being both suggested and expressed without losing the integrity of the interview. My post interview notes suggest the flow of the interview was difficult to maintain with some participants because of their emotions. Researchers interviewing care providers about end-of-life experiences should expect emotions, and integrating emotions into the interview, not ignoring them, is the recommended way to deal with such situations (Cain 2012). Holloway, Jefferson, (2017) suggests the research interview is helping the participant make sense and can be psychoanalytically informed and not a psychoanalytical event. The experience of my interviews suggests this is true where I used my skills from clinical practice to recognise, probe and uncover feelings and clarify experiences but I did not take on the role of psychoanalyst.

Researcher Well Being

Over the course of the interviews the participants disclosed information about their personal experiences. I was often surprised by the depth, detail, openness and willingness to disclose experiences to me, making me feel honoured that they had agreed to do this for me, guilty that they were doing this for me and not worthy of their time and effort of being there. This was amplified by their emotional distress. I did not account for this in the ethical submission, focusing more on the issues that would be uncovered. This follows through to the analysis where I felt the data had a value and had to be worthy of the participants contribution. Dickenson-swift et al. (2007) found similar feelings among researchers studying sensitive topics and feelings of gratitude leading to debt, and a sense of responsibility.

REFLEXIVITY

Authenticity and placing myself in front of the text during analysis required self-awareness in the form of reflexivity. To facilitate this, I used creative self-portraiture as a vehicle to respond to my position beyond the physical to explore my reflexive position that may not otherwise be visible (Rae, Green, 2016).

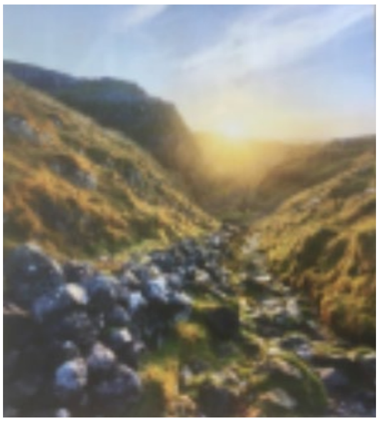


Figure 12 Self-portrait 1(Peter)

My initial notes and Reflexive self-portrait 1 (*Fig12*) present a craggy path beginning then disappearing, expectantly, into the sunset. I felt prepared, but unsure of the direction the interviews would follow. I understood the clinical environment, the nursing culture and the vocabulary. This positioned me as a practitioner-researcher having an insider (emic) view of what is being studied, rather than an outsider (etic) position (Holloway, Biley, 2011; Jooton, McGhee & Marland, 2008). The shared vocabulary and understanding I demonstrated from my emic position dispersed any power or authority I held and nurtured a relationship with the participants that contributed to an honest disclosure of experiences. I used my understanding to ask probing questions, ask for clarification without directing the participants responses. This came from my emic position, clinical experience and communication skills from practice.

My emically informed assumptions told me some nurses provided excellent end-of-life care, some try to avoid caring for dying patients. I expected to see evidence of this in the participants experiences, but the data did not support my assumptions. There became a point in the analysis where the explanation of the text and the ideas I held simply did not follow through. I found this surprisingly difficult to admit, I had to recognise aligning. I did not expect the outcome that fitted as result, and I found it difficult to embrace "the cosmic awesomeness of love". I disliked this vocabulary but had to accept love was what the participants experienced.

Figure 13 Self-portrait 2 (Peter)

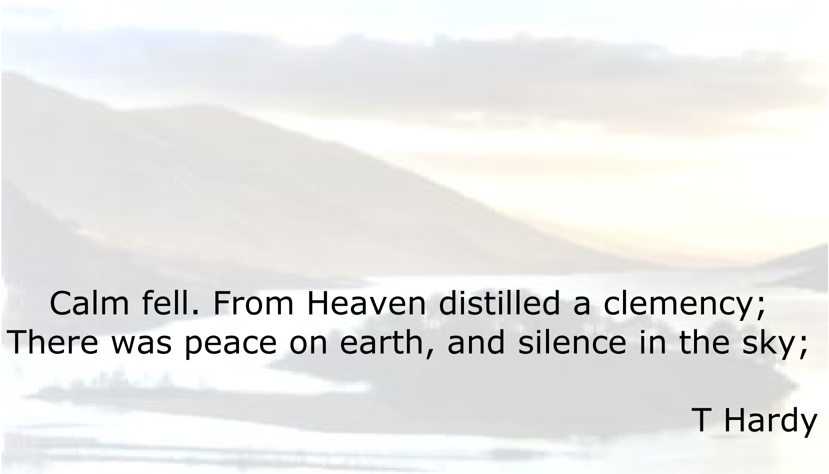
At this point, a change occurred within me in the research process. The reflexive self-portrait (*fig12*) was informed by my understanding of hermeneutic analysis at this stage, I had some awareness of the vague path I was following but Ricoeur does not provide a clear process to follow. I now felt I understood Ricoeur more and was more confident with the process of analysis, visually presented in self-portrait 2 (*fig13*), giving me a wiser, more authoritative position in explaining the data and more aware of my potential influence on the data analysis. I valued the emic context and meaning which enabled me to give deeper analysis and discussion, but at the same time I remain faithful to Ricoeur by not imposing my interpretation. In parts this became difficult, in the discussion on power and the dominance of the medical profession, I had to keep to the evidence provided by the participants.

Figure 14 self-portrait 3 (peter)

As I reached the stage of appropriation portrait 2 remained relevant but as I developed the recommendations, this emerged to portrait 3 (*fig14*). The deer with its head full of grass, weeds, moss, its vision obscured, the crow is not my supervisors. I found the authoritative position difficult, being filled with self-doubt, uncertainty- worrying I cannot see clearly. The crow is those that can see from a position of authority. I was surprised by the participants willingness to give of themselves to be part of the study and the emotions of the interview made me feel the study had to be worthy of their contribution, this added further pressure for authoritative and significant findings.

CHAPTER 4: FINDINGS AND DISCUSSION:

HOW HOSPITAL NURSES CONSTRUCT THEIR IDEA OF DEATH: The Calm After the Storm



Calm fell. From Heaven distilled a clemency;
There was peace on earth, and silence in the sky;

T Hardy

In this first findings chapter I explain how the nurses, working in the acute hospital setting, create their conception of how end-of-life care should be provided. To do so I explore the nurses' experiences of multiple exposure to death in a curative and treatment driven environment. Yalom (2008) describes the concept of staring at the sun as a metaphor of bringing into awareness the ever-present anxiety of death. I use this metaphor to explore how the nurses' exposure and experiences of death and dying influence their attitude to death, and how this shapes their construction of ideas of a good death. Ultimately, I explain how the nurses in this study see death not as something to avoid but create death as "calm after the storm".

In normal life, there are occasions where death is brought into awareness such as; news reports; television programmes; health campaigns, or more overtly, the death of a family member or friend (Yalom 2008). For nurses working in the hospital setting, those occasions can be multiple and above what could be considered 'normal'. The nurses in this study all practiced in the acute hospital setting, but in different clinical areas (*fig9*). Consequently, they experienced different types of death; some were expected following an illness; others were sudden and traumatic with aggressive "brutal" interventions (Louisa). Other types of death described were 'controlled' in ITU, with the patient sedated and the life managed by the clinicians, drugs and equipment.

Yalom (2008 p. 275) writes: “staring into either the sun or death is noxious”, we can only stand staring at the sun for so long. When staring at death, we face something too painful to bear; but the denial of death can render life meaningless. In being exposed to multiple deaths the nurses in this study are forced not to stare at the sun, but death. What follows is an explanation of the nurses’ experience of “staring at the sun”, and thereby death, the individual attitude to death, as a result of their experiences, and exposure to death and how this influences their perceptions and delivery of end-of-life care.

NURSES’ CONSTRUCTION OF DEATH AS CALM

Death is reported as traumatic and terrorizing with death anxiety among hospital nurses being shown to lead to some nurses spending less time with dying patients and discomfort when dealing with dying patients (Decker 2014; Peters, Cant et al 2013; Braun, Gordon et al 2010; Kastenbaum 2009; Yalom 2008). This was not the experience of the nurses in this study. The nurses participating in the study are representative of a diverse clinical environment and consequently their experiences of death are equally diverse. One common feature shared by most of the participating nurses in this study was the experience of dying as a calming event. Louisa provided the most explicit example of this. Louisa’s experience of critical care led to some patients arriving in the department needing lifesaving treatment. Despite the chaos of the clinical environment, Louisa describes her experiences of death as civilised and calm (*fig15*):

Figure 15 Calm (Louise)

> *The water is ever so calm, but also you can see that it is the end of the day, and I was thinking that quite often that when somebody is actually dying that is a very calming period. …so it's like knowing they are going to die, but knowing we want them to be calm, and the death itself, is not necessarily scary- it can be calm, and beautiful some times, and I think that is how we see a lot of death, rather than see the consequence of the death when people do die*. (Louisa)

Louisa's believes that with the calm:

> *We have moved passed the chaos of fighting the disease and the chemo and all of the horrendous things that go with treatment, that now we are recognising that it's not working so the calm [is] being; mental or physical*. (Louisa)

Having experienced death as calm, Louisa translates this to her provision of end-of-life care, explaining death as being "civilised" and calm, and for the family not to have insight of the reality of the trauma and chaos of the treatment. Louisa bases this on her belief that *she* would want to know that "Dad was well cared for but not to see the trauma". For Louisa, this means the family can see Dad has been cared for because "Dad's hair has been brushed; his teeth are in; he looks clean and presentable; he looks well looked after". Louisa describes "grotty situations", they are physical, "brutal", involve body fluids, "it can be a physical thing, so you are hiding the physical trauma". To present the patient as clean, comfortable and calm is Louisa's expression of kindness and love for another person, "making your patient comfortable, clean and hair brushed actually what you are saying is it's calm and look how well looked after dad has been and loved and here he is". Louisa exemplifies the nurses' attitude to death based on experiences, which are then conceptualised into practical ideas of a good death informed by those experiences and conceptions.

Figure 16 Tranquil (Hilde)

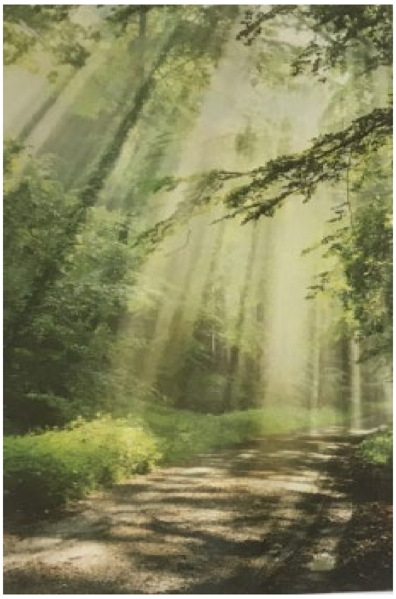


Figure 17 Green Path (Virginia)

This process is similarly experienced by Hilde who also transitions from chaos to calm, but her sense of chaos originates from her experience of death being messy "I have been involved where death has been physically messy and where death has been emotionally messy". Hilde's attitude to death as tranquil (*fig16*) involves controlling the emotional and physical mess for both for the patient and their loved ones, achieved by careful planning and understanding their wishes. As with Louisa, Hilde translates her concept of death to a practical provision of end-of-life care, believing planning and control can mitigate against the mess of death:

> *Just before they are not communicating very well, they like to escape, talking about lovely holidays or experiences. ... If there is family involved they start talking 'do you remember the time when …' they find that comforting. This is sort of about how to create the best comforting environment.* (Hilde)

Hilde discusses the importance of knowing the patients' needs and expectations for their death, as well as ensuring appropriate treatment and management is ready. Hilde needs this information, so she can control a comforting, calm and tranquil death for her patient.

Controlled calm is also evident in Virginia’s practical description of dying as a green path (*Fig17*):

> *The greenery the light is the peace I would like to provide for my end-of-life patients to shield them for the noise of the busy general war*d. (Virginia)

Virginia follows a similar process to Louisa and Hilde. Her experiences of death in surgery is also one of trauma and Virginia transitions from trauma to the green path with her metaphor of “removing the thorns from the rose”, which she describes as making the end for her patients, as peaceful as she can. Virginia’s construct of death as calm is informed by her wish to “shield” her patients, her protection of “providing peace”. Virginia discusses the practicalities of creating the green path and the “the everyday life of hospital” to “protect” and “shield” the person for the busy hospital ward so she can provide a “calm and peaceful environment” for her patients. Similarly, Ethel’s experience of death in critical care has led to a practical approach to end-of-life care. Ethel explains in critical care death is “often imminent” and “a common occurrence”, describing death as “bright, a little bit dark and also tranquil” (*fig18*) leading to a pragmatic understanding of death, “You cannot stop the reality of what has happened or is happening” with a focus on maintaining calm through practical care.

Figure 18 Tranquil (Ethel)

The nurses describe the process leading up to the final stages, in the hospital setting, as ‘stormy’. After the trauma of treatment, the final stages of life were seen as calm or tranquil. In the hospital setting, the transition from curative to end-of-life is problematic with hospitals being treatment orientated (Bergenholtz, Jarlbaek et al. 2016). The experiences of the nurses in this study suggests the provision of end-of-life care as calm after the storm transitions from curative to an end-of-life approach. The nurses attitude of providing calm and tranquillity is actioned by physical care. Virginia provides a calm setting for the dying patient, removing the thorns from the rose. Hilde aims to control the environment but also seeks to understand the patient's wishes for that environment: to make more personable the dying experience. Louisa presents the patient as calm, cared for and loved. These are constructs represented in other studies as nurses' ideas of a good death but not the central tenet evident in this study (Cotterell, Duggleby 2016; Becker, Wright et al. 2016; Hopkinson, Hallett 2002; Hart, Sainsbury et al. 1998;). A focus on being at peace, as well as free from pain and other distressing symptoms and fostering a peaceful environment is also described elsewhere (Cotterell, Duggleby 2016; Becker, Wright et al. 2016). A peaceful death is often seen by nurses as part of a 'good death' but not the overall aim of end-of-life care (Hart 1998). Defined as a 'revivalist death', this is characterised by an aware death, personal conflict and unfinished business are resolved, the death is according to personal preference, free of pain and other distressing symptoms and is a peaceful and dignified death (Cotterell, Duggleby 2016; Gott, Small et al. 2008). Being at peace for the patient *emotionally* was considered by hospital nurses in some studies to be part of a good death (Becker, Wright et al. 2016; Hopkinson, Hallett 2002). This differs from the nurses in this study whose personal construct of a good death is to provide their patients with physical calm and tranquillity.

NURSES' CONSTRUCTION OF DEATH AS A PROCESS

Some of the nurses experienced death as a process, accepting the inevitability of death. Barbara and Jean both worked in A&E, which may contribute to an attitude to death as inevitable, influenced by the sudden nature of death from their clinical areas. Barbara is explicit in this;

> *We are all going to die, death can be delayable but not avoidable. Why are people dying? Because they are ill, worn out, had an accident, because someone has caused them to die or caused themselves to die*. (Barbara)

Accepting the inevitability of death is evident in Jean's attitude to dying, originating from witnessing cardiac arrests recalling them as "violent team procedures", but accepted it was "what nurses did" and through her exposure, she saw death as a process and you need to be "hardy to the experience"; the patient either survived and went to another department or died.

Death as a controlled event was evident in Nancy's experience of care in ITU where patients were often sedated. Nancy talks about the peace patients had, "they would be given sedation and so from a patient point of view that was quite a nice way to go; to just slip off". Nancy's concept for the patient to be kept calm and comfortable, unaware of events:

> *My perception was [patients] had analgesia and sedation and we had made them comfortable and then they just slipped away. That may not have been the intention; we were sedating them to ventilate them but that was my perception. They are peaceful and comfortable, and it looked like a good death*. (Nancy)

Jean and Edith describe end-of-life care as a process partly due to not having the right skills to care for end-of-life patients. In an arrest situation, Jean was part of a team, and she describes the arrest situation as front-line care and needing to be "highly vigilant, highly concentrated with a good deal of technical skills" it was "resuscitate, die or go". This suggests a highly task orientated and mechanised approach to care. When it came to end-of-life care, Jean "could not breathe" which meant she felt "unprepared, unequipped and unskilled". Jean's construct of death as a process may not provide Jean with a transferable process of end-of-life care, leaving her "breathless" when faced with end-of-life care.

Figure 19 wind (Edith)

Edith depicting death as "wind" (*fig19*) and explains dying to be something serious, needing to be perfect, the best, and was worried about failing to achieve this. Consequently, Edith focused on the things she could control, resulting in being task focused, avoiding emotion and constructs *death as process*. Edith's practice required her to care for dying patients on a regular basis but reports finding the care easier when there is "something tangible to do with them". But when it came to talking about how they feel "I can't deal with this, it's bigger than me". Feeling too young Edith discusses not having enough life experience to be able to understand;

> *I still don't feel I I understand. I know what they must feel for me to actually give them anything that's… I sort of do the best job I can. But still feel I don't do the best job I can, I just think I'm not an adult enough to know what to do* (Edith)

This suggests, as with Jean, Edith is wanting knowledge of the right thing to do, but focuses on what she can do well, which is the tasks of end-of-life care. Jean cannot "breathe", whereas Edith's reaction is to become someone else,

> *My nursing technique changes a lot, my personality changes a lot. So for normal patients I would be buoyant and crack jokes and things like that. When [I] go to a patient who is palliative or dying, I feel like I swap hats…I've got to be an adult and that's what I've got to do.*

> *That's not necessarily what they need, but that's how I feel I want to be. I need to grow up be and be adult. Be serious and be perfect. I always use my quiet voice when I'm with people who are dying, so I use a different voice. So I change very much when I look after people who are dying.* (Edith)

Edith's construct of death is one of perfection and seriousness which she transfers to her provision of care by becoming the "serious nurse". To achieve this Edith focuses on achievable tasks, inhibiting emotional engagement and existential question's which she believes she is too young for, lacking the experience of life skills, to respond to. These place her approach to end-of-life as procedure and process.

Figure 20 Personable (Ethel)

Louisa and Hilde share what Ethel refers to as "personable things", these are the cleansing activities of nursing, making sure a person is kept presentable. Ethel uses the image of a woolly blanket (*fig20*) as a metaphor for these 'personable' actions of end-of-life care and recalls a positive caring event where one patient came in with her woolly blanket which Ethel kept with the patient, until she died. The family said the blanket made them feel good about the care. The blanket represents bringing home into the technical-medical environment and being able to manipulate the environment and adapt it for the patient-make it personable. Ethel's emphasis on the physical aspects of care, the practicalities of making the person and environment personable and peaceful, support her understanding of death as a process and her role as a nurse is to do exactly that.

Death anxiety is angst of the awareness of non-being (Yalom 1980; Tillich 1967). Nurses are human in their feelings of anxiety, but some nurses develop protective mechanisms of distancing from death by practicing death avoidance behaviours (Decker and Lee 2014; Peters, Cant et al. 2013; Dunn, Otten et al. 2005; Kondo, Nagata 2005). By providing death as a process, the nurses in this study may not be doing so as a distancing behaviour. Viewing death as a process such as Jean's "resuscitate, die or go" or Nancy's sedation at the point of death are indicative of their clinical cultures. Edith's focus on the physical tasks suggest not having the skills to know what to do other than the physical tasks of end-of-life care, placing their provision of end-of-life care as process. This suggests the focus is on physical tasks could also be a reflection on the clinical culture of what nurses do. Equally, Menzies-Lyth seminal work (1960) described nurses' emotional and professional detachment, as well as, an ability to refrain from excessive involvement can be part of the nursing systems of defence against anxiety.

NURSES' CONSTRUCTION OF DEATH AS HUMAN CONNECTION

Nurses exposure to death can be equated to grieving and associated with high death anxiety and a need to shield themselves from the emotional work and end-of-life care (Kondo, Nagata 2015; Peters, Cant et al. 2013a; Dunn, Otten et al. 2005). Jean believed she was not skilled or equipped for end-of-life and "could not breathe" when caring for dying patients. But for some of the nurses' human connection was part of their construct of death.

Figure 21 Getting-alongside (Barbara)

Barbara and Mary both practiced in A&E and emphasised the importance of family. Barbara's multiple exposure to death in A&E, lead her to construct an understanding of the importance of identity, and an attitude to death as "getting alongside the person" in the last few days to hours of their life by making the effort of getting to know something about them, giving the dying person an identity. Her image of a bird (*fig21*) represents a patient who she knew was a keen bird watcher, but the nurses caring for him, as he died, knew nothing about him:

> *What I've learnt over the years, to care for someone who is dying, is the only the time you get the opportunity to be alongside somebody at that sad time, and a hard time for some people.* (Barbara)

By being alongside somebody, you are not only physically present, but understanding more about them as a person, about the family dynamic, "to me it was so important to find out about the patient". Barbara links this to providing kindness and empathy," Just getting alongside somebody who is poorly coming to the last few days of their life".

Figure 22 family (Mary)

Figure 23 embrace (Mary)

Human connection and a personable approach with the patient and family is part of Mary's attitude to death. Mary associates the death of her brother, at a young age, and her bond with her own family, to a clear understanding of the "importance of family" and personalises the situation by thinking about how the death is going to impact on the family. This awareness influences Mary's attitude to death, thinking about how the death will impact on the family and how she can relate to them in a more personal way. Mary uses the image of a ring to represent this (*fig22*). Working in A&E Mary reflects,

> *I think if someone is dying I would [pauses] It makes you realise how clinical you are, so pushed for time, but … I would find the time. I insist that people would spend more time and sit and hold their hand ……. Because you know, touch and warmth, particularly in people who can't communicate, to know that somebody is there, [pauses] is [emotional] important.* (Mary)

Mary questions the clinical reality and being pushed for time with the realisation that her attitude to death, the importance of family, of being together (*Fig23*), warmth and empathy, may not be present in her clinical environment.

Figure 24 Loneliness (Martha)

The presence of another person is essential for Martha's construct of death. Martha recalls a situation that resonated with the death of her Dad seeing it as her mission to prevent the "loneliness", the "coldness" and the "isolation" of death, which is linked to her experience. This is represented in her depiction of death as a cold forest (*fig24*). Martha's understanding is the forest needs to be made warm by human presence.

This is similar to Virginia’s interpretation of death, coming from her training as a nurse and early experience of caring for dying people, that the dying patient should “never be left alone”. Virginia feels very strongly about this “It breaks my heart today that I do know some people do die alone in hospital”.

Some of the nurses construct of death as human connection emphasises physical presence as being a core part of the nurses’ construct of death. Loneliness, isolation and a lack of identity are difficult for Martha, Virginia and Barbara to witness. Saunders (2003) advocates in end-of-life ‘being with’, to be bare witness. Levinas also discusses facing the Other’s anguish and distress, and being present with the dying person is the highest form of selfhood by recognising one’s responsibility for the care of Other (Levinas 1966). The nurses in this study emphasise the importance of ensuring the dying patient is not alone.

Most of the nurses in the study created a provision of end-of-life care that involved human contact in some form. Human contact was identified as ‘getting alongside’ the person, which was making the effort to know them as an individual. Understanding the family and the importance of the family was also an important value of human contact. Not being alone as they are dying was a common theme. The construct of providing human contact is present in other hospital nurses ideas of a good death as ‘being fully present’, and ‘no one should be left to die alone’ (Becker, Wright et al. 2016; Beckstrand, Callister et al. 2006 ; Hopkinson, Hallett 2002). As Virginia reports: “it breaks my heart that I do know some people do die alone in hospital these days”. Equally, Hopkinson, Hallett (2002) report hospital nurses find the idea of a person being left to die alone as ‘abhorrent’.

THE NURSES CONSTRUCTION OF DEATH: A Good Death

The nurses in this study demonstrate that their individual attitude to death was a significant influence on how they provided end-of-life care. Overall, this was based on a belief that a good death should be calm and tranquil. For some of the nurses, the end-of-life care they provided was the care as they would want for themselves. By providing such end-of-life care they may be transferring their own beliefs of a good death onto the patient. This was typified by Hilde who recognised that “if I am going to die I would like to die the way I want to die”. Hilde needs a high level of control to achieve this:

> *I am someone who likes to have order and control and have a predictable [plan]. When caring for someone who is dying that is removed (laughs), so I can be very lost as to how best to really maximise how a positive death could be.* (Hilde)

As a result, Hilde transposes her idea of a good death, to be tranquil event, and exerts her control to produce the type of death she wants, where the patient, or the family, is able to plan the death. Louisa also describes the value she believes is important the;

> *Value of love, whether that is love for you or love for your family looking at you, and so how I display that sometimes is the hand holding and together and sometimes it is washing the blood away. It’s the same value*. (Louise)

Louisa describes the “brutal” “inhuman” clinical side of treatment and when that has failed; “What can we do to nurture you and physically love you” and it is this that informs Louisa’s belief of a good death which she transfers onto her patients care.

Mary, Barbara and Nancy cannot always provide care according to their idea of a good death. Mary’s provision of care as human contact, providing warmth and comfort for the family, can be lost in the reality of emergency care. Mary observes:

> *I find a lot of people don’t appreciate it in the unit, it becomes a very clinical death. They don’t relate to the family, or how they would feel themselves and put up a barrier as a reason for dealing with it*. (Mary)

There is conflict between Mary’s personal attitude to death and being unable to transfer this to her care for patients, which distresses Mary. Whereas Barbara feels frustration with nurses who do not comply with her attitude of getting alongside someone as they are dying, preventing her from transferring her provision of human connection.

Nancy believes the ITU method of sedation is a good way to go, peaceful and comfortable, for the patient and one she would like for herself:

> *"[I]think it's quite a good death and perhaps I would quite like it for myself actually. But it's not very nice for families [laughs] because it is very sudden. They would go off to sleep and they would never wake up; they would be given sedation and so from a patient point of view that was quite a nice way to go, to just slip off"*. (Nancy)

In transferring their personal attitude to death in the form of their provision of end-of-life care, the nurses are providing in some way their version of a good death and transferring it upon the patient. As the nurses in this study show, the dying process in hospitals is often controlled by health professionals (Cotterell, Duggleby 2016; Hart, Sainsbury et al. 1998). This can lead to a culture of death denial indicative of a wild death, which is a death to be feared and avoided (Zimmerman 2012; Aries 1974). To mitigate against this requires the health care worker to develop an attitude of death acceptance (Zimmerman 2012). The nurses' experiences in this study support such an attitude, with the exception of Edith who does not deny the reality of death but denies discussion of existential and emotional 'non-being'.

The nurses' attitudes to death are characterised as calm; death as a process and providing human contact. There are some similarities in Hopkinson, Hallett (2002) study which found hospital nurses' perception of a good death was 'maintaining presence' and 'keeping the patient calm'. Any perception of a good death is predicated on the need for an awareness of dying which is made uncertain with sudden death or acute illness that leads to death in hospital (Hopkinson, Hallett 2002). This uncertainty questions the value of the concept of good death in the hospital environment. Ideas of a good death, based on death awareness and peace are founded on revivalist ideas of good death, originate from hospice care (Gott et al 2008; Costello 2006; Walter 1994). As the nurses in this study show, the idea of what constitutes a good death among nurses in the hospital setting is transient and not fixed as well as bound by culture (Becker, Wright et al. 2016; Nyatanga 2016; Walter 2003; Hopkinson, Hallett 2002). Costello (2006) found hospital nurses idea of a good death focused on the death event rather than the dying process, the transitioning nature of the finds of this study does not support this. Costello also found hospital nurses idea of a good death was determined by a high degree of predictability, the death is desired by the nurse and takes place at an appropriate time. These findings are not consistent with the findings of this study. The nurses in this study had individually constructed ideas of death and end-of-life care and this supports the pluralistic view that there is no one concept of a 'good death'. Hopkinson, Hallett (2002) offer the approach of 'personally ideal death' which recognises the individual nurses understanding of an acceptable death. The evidence from the nurses in this study suggests, among hospital nurses, the ideas of good death are not exclusive and there may be an entwining between death as calm, death as process and death as human connection.

Transforming End of Life Care in Acute Hospitals (NHS England 2015) is positioned as a 'how to guide' for improving end-of-life care in hospitals and identifies principles such as death awareness; advance care planning; shared decision making; open honest communication; an emphasis on dignity and recognising the priorities of care for the dying person. These are values indicative of revivalist good death; an aware death, death according to personal preference, peaceful, symptom free and with dignity. The hospital nurses' in this study suggests some of these values of care are intrinsic in the values of nurses' individual idea of a 'good death'. There are some differences with the hospital nurses providing human presence, working to transition from the trauma of treatment to calm, with a focus on practical care.

STARING AT THE SUN: Hospital Nurses' Existential experiences

Yalom refers to staring at death as an awakening experience (Yalom 2008). Being forced, by the nature of nursing in the acute hospital, to stare at the death, the nurses constructed an understanding of death. The predominant construct was one of death being calm, this was inter-linked with death as human connection and death as process. Yalom emphasises that awakening experiences are an enrichment to life, more than a change in appearance, style, status or prestige, but ontologically focused, linking to Heidegger's concept of being by making life more authentic (Yalom 2008). There is some evidence of this with the nurses trying to make sense of their experiences of death by giving meaning to the experience of death.

All of us have cause to be mindful of 'being' (to be authentic) which is to be aware of the ability to make decisions about one's life (Blattner 2012; Reynolds 2014; Yalom 1981). The freedom to make choices and from these choices give our life meaning is existentialism. Evidence suggests nurses practising in palliative care environments are more likely to re-evaluate life and live a more meaningful life (Chan et al. 2016; Karlsson et al. 2016; Strang et al 2014; Vachon et al 2012). Although some nurses felt the experiences forced them to re-evaluate their lives some found the experience validated their existential meaning (Chan et al. 2016; Strang et al 2014). Death confrontation can challenge the beliefs of some nurses particularly those with no beliefs or meaning they could utilise at difficult times (Vachon et al 2012).

Not all the nurses in this study evidenced if exposure to death had caused them to re-evaluate life or outlook. Hilde, Nancy and Ethel explicitly describe how their exposure to end-of-life care has changed their outlook on life. Hilde and Nancy share similar outlooks on life because of their multiple exposure to death. Hilde explains;

> *You can't control or plan these things…life is incredibly precious … things can completely come out the blue and knock you and your family sideways. There is more to life than XYZ. I have seen the other side where it can literally be ripped away from someone. It just makes me appreciate my own life having my children, having a relatively healthy life. I think a frustration grows in that you see things and you think why are you doing that? You see people becoming so self-absorbed and you think why are you doing that you know that is quite minor?* (Hilde)

Nancy has a similar outlook that life can change at any moment:

> *Life is very fragile and literally your world can change in an instant… I don't live my life fearful of death, definitely NOT. Probably have been times where I have been more acutely aware of it than others, but live life for today not tomorrow. I have a philosophy towards money for example you can't take it with you so enjoy it while you have got it (laughs)*. (Nancy)

Ethel also takes this outlook on life and was affected by her exposure to end-of-life care;

> *If you get the chance to do something you say yes rather than no, planning for today rather than the future and if you get an opportunity take it rather than regret it.* (Ethel)

The reminder of 'being' and mortality and giving life meaning as a result of the exposure to end-of-life was less explicit with Mary's experience. Mary describes instances of end-of-life care as reminders of her own family. Having lost her brother at a young age, it makes her appreciate the life she has with her family "it makes me grateful for the life I have with them; makes me sad for the people who are losing their family".

Edith and Martha discuss how they try to alleviate the emotional consequences of being exposed to death. Martha talks directly about the passing of the person she is caring for, reminding her of her own mortality and that one day it could be her that is being cared for; "this is something natural, that we are a rational person that something we are born and natural has come to an end and is just part of the life". Edith has been exposed to multiple death of patients, but believes she is too young and inexperienced in life to know what it feels like to be wise enough to do the right thing.

Those nurses that expressed an existential change because of their end-of-life care, all lived in the moment, planning for today not tomorrow. They also described being more aware of the importance of family. As nurses working in the hospital, these existential experiences are not dissimilar to palliative care nurses' experiences in describing the death encounter as an awakening experience to lead a more authentic life (Chan et al. 2016; Karlsson et al. 2016; Strang et al 2014; Vachon et al 2012). In the palliative setting, death confrontation allowed some nurses to live a more meaningful life and to "be with" patients, which is to listen and be present as opposed to 'doing', as well as preparing for ones' own death which is not evident from this study (Chan et al. 2016; Strang et al 2014; Vachon et al 2012;). Consequently, nurses working within palliative care are known to be more comfortable working with the dying than hospital nurses (Carr and Merriman 1995). This difference could be accounted for by the conflicting and competing demands between 'rescuable' and dying patients presents a contradiction for hospital nurses that is not present in palliative setting (Peters et al 2013). This contradiction is not evident in the existential experiences of the hospital nurses in this study. Although Edith actively avoided existential concerns, her anxiety was around failure to adequately respond and not attributed to death anxiety.

As a result of "staring at the sun" and thereby death not all the nurses in the study describe being changed by the experience, those that did all lived for the moment, were more appreciative of life and family. Hilde's suggestion of prioritising life and not being self-absorbed in seemingly unimportant activities is not evident in other studies.

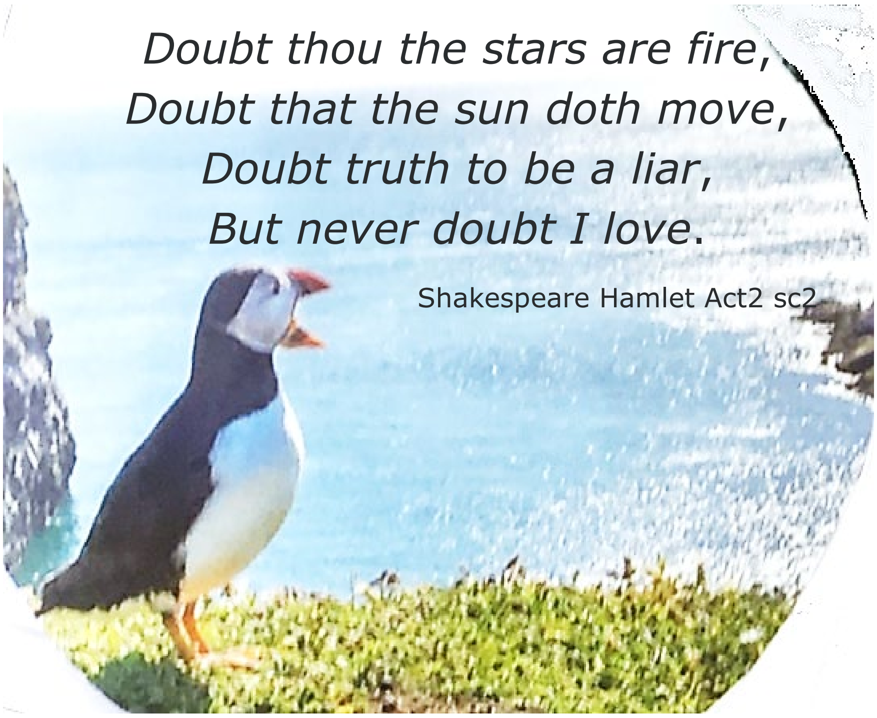
SUMMARY

By working in hospital and being exposed to death nurses are being forced to 'stare at death' as an awakening experience. This experience has been explored in the context of the relationship with the dying person and has not been described as a fearful, anxious or a grieving experience. Some of the values and behaviours evidenced by the participating nurses are congruent with current policy expectations, but the nurses personal construct of a good death differs to those based on revivalist ideals and therefore, current policy practice principles that provide end-of-life advice, such as patients preferred priorities of care and the importance of good communication, differ to some of the outcomes of this study. In the hospital setting the nurses have described attitudes to *death as* *calming*, represented by their experience that eventually, after the trauma, there will be calm. *Death as a process* is an attitude to death that focuses on the tasks and activities of death and dying. *Human connection* as an attitude to death where the focal point of the nurses' descriptions of their experiences of death was 'getting-along-side' the person. The dominant attitude to death was calm, but this was not exclusive, with the other attitudes being interwoven to influence the nurses' idea of what end-of-life care should be, leading to their individual ideas of a good death and end-of-life care. The nurses' attitude to death informed their idea of a good death, with a suggestion that hospital nurses construct of a good death differs to revivalist ideas and therefore may not align to some principles of palliative and end-of-life care.

Yalom's concept of being "forced to look at the sun" and thereby stare at death has, for some of the nurses, been an existential experience. This had led them to appreciate the life they have more, to live in the moment, be more appreciative of family and a suggestion of not being self-absorbed with unimportant activities or worries. The overall outcome is a more detailed appreciation of how hospital nurses assimilate their exposure to death experience.

CHAPTER 5: FINDINGS AND DISCUSSION

HOW HOSPITAL NURSES PROTECT THEMSELVES AND THEIR PATIENTS: Baked Alaska, Unicorns and Love



Doubt thou the stars are fire,
Doubt that the sun doth move,
Doubt truth to be a liar,
But never doubt I love.

Shakespeare Hamlet Act2 sc2

In this second findings chapter, I explore the nurses emotional experience of caring for dying patients. Having been forced to face death, the nurses in this study have responded to their unique experiences and construct individual attitudes to death, developing a provision of end-of-life care that supports their attitudes to death. The nurses in this study provide evidence that they protect themselves emotionally to be able to provide this care. To do this, they supress their authentic-self. Linked to existential philosophy, Heidegger explains to be authentic is to be conscious of one’s ability to be free to make life choices; to be inauthentic is to move through the day to day existence of life unaware of the freedom of one’s decisions (Reynolds 2014). Sartre identifies self is something that is made through individual choices and commitments that gives meaning and value to their world (Crowell 2012, Reynolds 2014). Authentic-self requires the person to exist in a way that discloses their Being, whereas inauthentic-self conceals itself (Zimmerman 1976). From this understanding, authentic-self is to recognise our freedom of being, to be inauthentic is to conceal or be denied life’s possibilities. Emotional authenticity is experienced when individuals are uninhibited in their emotional feelings and displays in ways that are congruent with their self-concept (Sloan 2007). Authentic-self is the uninhibited freedom to be genuine.

Theories of emotional labour partially help to understand the nurses' emotional protection of themselves, but the nurses in this study, by creating calm and tranquillity, extend their protection of themselves to include their patients. I focus on how the nurses manage the emotional impact of caring for dying people by exploring their protection of authentic-self, and how this protection is a form of suffering and sacrifice. The word 'sacrifice' becomes essential in the analysis. Unlike other studies that have focused on emotional distancing and emotional labour, when linked to other activities in protecting the patient and their family, the preservation of the nurses' attitudes to death by creating calm the nurses in this study, using Tillich's ontology of love as a foundation for the analysis, demonstrate evidence of their fulfilment of love.

NURSE PROTECTION OF SELF: Baked Alaska

There are conflicting accounts of how nurses in the hospital setting cope with caring for dying patients. Some nurses report caring for dying patients as worthwhile and important (Dunn et al 2005; Gama, Barbosa et al. 2012). Others report avoiding time with dying patients; higher levels of anxiety; less positive attitudes towards caring for dying patients and feeling less comfortable dealing with death and dying (Peters, Cant et al. 2013; Decker et al 2014; Braun, Gordon et al. 2010; Carr, Merriman 1995). These negative behaviours are indicative of distancing and avoidance behaviour to protect against the impending threat of death (Yalom 1980; Kastenbaum 2009). The nurses in this study protect themselves from the emotions of the situation but do so to continue providing end-of-life care .

Before continuing it should be noted Barbara did not describe any strategies for protecting authentic-self, having an open approach to death;

> *All my previous experiences looking after families had not made me hardened but gave me a stronger-strength to be able to do what I was doing*. (Barbara)

Because of Barbara's faith and experience, death was "an OK thing", not frightening. Congruence between personal and professional identity can result in authenticity (Obrien 2018) which is what Barbara describes and this may account for the absence of protecting authentic-self in her experience.

PROTECTION SELF: Professional Identity

Figure 25Professional hat (Mary)

Presenting a professional image to the patient and the family was one form of protection some of the nurses revealed. This was portrayed as a balance between being approachable and friendly, but also being removed or emotionally distant. 'Being distant' is being professionally present but emotionally removed. Mary describes wearing a professional hat (*fig25*) as a metaphor for this emotional protection: "[it] helps me to protect myself from getting too personally involved and that helps me protect myself". Mary disagrees that this is distancing:

> *When dealing with patients and families, they don't want to see me falling apart, crying and being upset. I'm not the person going through it, nor are they my family member. I'm there in my role; supporting them through their grief; supporting them through the process of end-of-life care… For me too emotionally breaking down would be inappropriate and unhelpful for them.* (Mary)

Mary is describing maintaining a professional position to allow her to support the patient and the family. Hilde and Louisa hold similar views and describe compartmentalising 'it' so they can remain professional, focusing on the patient:

> *If the [family] are present I can immediately be in nurse mode, so I can be in complete control and give [them] the best care I can. I allow myself a few moments to just to think 'come on, catch your breath', park any emotion in that corner, and do your stuff and be clinical in how I am making sure I do everything I can for the patient* (Hilde)

Ethel shares this view of holding it together for the patient, it's not her family member, she is there to do a job. Unlike Mary and Hilde, Ethel describes the tasks of nursing as a form of protection, giving her a function of care;

> *Being able to do something is easier than just going in and speaking to family; it makes it easier when you have got something to do. Thinking about the role of the nurse, that makes it easier to me about being an adult nurse and physical care.* (Ethel)

Sudden deaths for Ethel are more difficult than expected deaths; "it's the shock, it makes it more difficult" whereas, expected death, allow for some preparations and are easier to deal with. Ethel is less clear about keeping her emotions hidden and sometimes would be in tears with the family, other times "it can be quite cut off and you can park it, walk away … I would be calm and very much compartmentalise it".

Being the professional for Jean was also containing the emotion. Despite "some very difficult circumstances" which included 3-4 death a day, someone had to keep the unit going, answer the nurse-call-bells, and the phone "so whether I was on the verge of a cry or not I just had to get on". For Jean it was inappropriate to be emotional:

> *I think [death] becomes a process to an extent and rightly so because if you start to have an emotional wobbly in a massive cardiac arrest,*

> *it’s not a good situation, this patient is not in a good situation, we can’t have a team member having a wobbly, or this becomes an unsafe process, someone who panics in those high stakes situations* (Jean)

Mary’s metaphor of wearing a professional hat to protect herself is an example of using professional identity as emotional protection. Such professional values presenting the idea that emotion should be ‘contained’ to provide the care is what Menzies-Lyth refers to as the nurses uniform being used as a symbol of an expected inner and behavioural uniformity (1960). This is a different attitude to emotional distancing to protect authentic ‘self’. Emotional distancing implies a form of self-protection or avoidance with the emotional encounter. Emotional distancing is described by some of the literature as methods of emotional containment where the nurses mentally distance themselves from the threats engendered by their work (Decker, Lee et al 2015; Peters, Cant et al. 2013; Hayward, Tuckey 2011; Froggatt 1998). In this study, nurses engaged with the patients and their families but contained their emotions to remain professional to enable them to continue to provide end-of-life care. Hayward, Tuckey (2011) describe this as cognitive engagement with emotional distancing.

Nurses consider emotional engagement as an important part of excellent nursing care (Davenport and Hall 2011), but nurses need to regulate an emotional boundary between them and the interaction to maintain professionalism in their work (Hayward and Tuckey 2011). Theodosius (2008) advocates for the nurse to acknowledge rather than deny real emotions and argues nurses have a responsibility to recognise their own emotions, as that is important in helping other to identify theirs. As with Jeans’ example, expressing such emotions in end-of-life care may not be possible, the result is a boundary that can be manipulated to be emotionally distant or connected. As with this nurses in this study Haywood and Tuckey report nurses use their ‘professional face’ to prevent true emotion from being elicited.

PROTECTING SELF: DEFENCE OF SELF (Baked Alaska)

Figure 26 Defence (Nancy)

Being a professional nurse was a form of protection demonstrated by the nurses while providing end-of-life care. This form of protection ensures the job is done but does not allow the nurses to mitigate against the emotional effects of the end-of-life care situations. Baked Alaska was used by Nancy to describe the emotional work of a nurse:

> *We might have 4 patients in a shift die and you would have to get through that shift caring for all those patients regardless of how you might be feeling. So the Baked Alaska ice cream would melt if it came into contact with the heat so the ice cream is shielded by this soft outside* (Nancy)

'Defence of self', as Baked Alaska with the soft meringue shell protecting the ice cream centre representing the nurses' authentic- self . Presenting yourself as approachable, understanding and compassionate, but "frozen on the inside" was Nancy's description for Baked Alaska (*fig26*). Nancy was proud of her tough interior of being able to take charge of a shift or situation;

> *I couldn't afford to be crying all the time…I need to put those emotions into a box because I need to A-B-C for this family. There is a bit about protecting yourself, walling it off, I had to protect myself. I would like to think I was soft and approachable and could talk to the family and talk to the patient in a very compassionate way. But on the inside, I rarely got upset* (Nancy)

Using a shield to defend yourself emotionally was something Martha was told to do as a student nurse that she has maintained in her practice;

> *I went to a palliative unit and there was a nurse who told us that she tried to protect her part of emotions, sometimes it is difficult to think you have done enough, … when they passed away you are prepared, then makes you think about your own life really, you realise that can happen to you.* (Martha)

Both Martha and Nancy are protecting themselves from the emotional impact of the demanding situation they are in. They discuss self-protection as a defence, but do not avoid the end-of-life activity. The protection allows them to continue with their end-of-life care; maintaining engagement with their patients, but the baked Alaska outside shields their authentic-self, allowing them to remain approachable. This presents the nurses emotions in end-of-life situation as boundaried rather than Theodosius (2008) idea of empathic and reciprocal, and is congruent with Hayward, Tuckey's (2011) idea of nurses manipulating an emotional forcefield, choosing to engage or distance one's self. With this study the shield may be a way for the nurses to regulate anticipated or felt emotions. The manipulation of the boundary can be strategically engaged by the nurses, dependant on their drive to protect emotional resources, or invest in the relationship and, similarly to Hayward, Tuckey (2011) by shielding their emotional selves-they are being emotionally distant but engaging cognitively. The nurses in this study utilised the shield to defend their authentic-self and continue caring. This differs to Blomberg, Sahlberg-Blom's (2005) finding of palliative care nurses who also displayed *evasive* behaviour if situations became too painful and difficult.

PROTECTION OF SELF: Being Someone Else

Figure 27 Being someone else (Edith)

Emotional boundaries develop to become part of the nurses' professional identity, part of their uniform (Hayward, Tuckey 2011). Mary identifies:

> *When I am at work and in uniform I have a different personal identity…that helps protect me, just my uniform. When I go home to my family, I take my uniform off.* (Mary)

The uniform helps Mary to deal with the situation of the dying patient and their family face to face, "in the best way I can". Edith becomes someone else. When Edith usually cares for patients she is a "bubbly nurse", "less professional, but professional in a way but more jokey sort of carry-on nurse", with patients who are dying Edith leaves that nurse behind and becomes an 'adult' nurse:

> *I feel like, when I go into care for somebody, you physically and mentally brace yourself, to care for somebody.., that[s] when I get my professional hat on. Get "nursey-nursey"... I've got to be an adult. I need to grow up, be serious and be perfect sort of thing, and want the best for those people. Being a proper nurse is being all knowing all knowledgeable.* (Edith).

Mary and Edith are both using the nursing uniform as protection. Mary uses the uniform as identity to mask her emotions. Edith believes she is too young to know how to care for dying patients effectively, by becoming the 'professional' she can focus on the tasks of care and not the emotions of the situation. Both Mary and Edith give different examples of using the uniform as becoming someone else as protection. Mary uses her uniform to give her an identity different to who she really is, to keep her authentic-self safe. Whereas, Edith uses different types of identity when engaging with end-of-life patients, different to her authentic-self (*fig27*).

Froggatt (1998) describes nurses switching on part of themselves as they arrive at work and switching it off as they leave for home. This provides nurses with a choice of control over their decision to respond or not to their feelings at a particular time, containing emotions as the nurse choses. The nurses in Froggatt's study do not enter into the emotions of those they are caring for but keep a distance. In this study, the nurses' own emotions were suppressed with the intent of focusing on the needs of the patient and the family. Hilde talks about removing herself from the situation "I will allow myself to go to the toilet and release it all and I know I need to go to the next patient and I can't be carrying all that emotion". In Hilde's example she understands that she must provide the best nursing care she can for the patient and their family, but to do this she denies her own emotions, resulting in dissonance between her emotional needs and behaviour as a nurse. Without resolution emotional dissonance can lead to stress and emotional burnout (Zapf 2001,2002, Andela, Truchot, et al, 2016). For Hilde being the professional requires a suppression of the genuine Hilde's authentic emotions, necessitating her to present to patients and families inauthentic emotions, providing an example of emotional dissonance (Zapf 2001,2002, Andela, Truchot, et al, 2016). Nurses' emotional vulnerability, such as crying in the toilets, at moments of critical emotion laden situations where clinical decisions are needed can lead to exhaustion, stress, anxiety and frustration (Davenport, Hall 2011).

Being someone else requires the nurse to be available for patients and their families at a distressing time but presenting to the patient an alternative self to protect their authentic-self. This is being emotionally distant but cognitively present and is a form of emotional distancing mechanism which allows the nurse to continually engage with patients, make clinical decision, but be emotionally distant (Hayward and Tuckey (2011). Empathy can involve cognitive engagement, in the form of recognising, communicating and understanding another's feelings, as well as the affective which requires engaging with the feelings of the other person. The nurses in this study suggest a focus on the physical aspects of care, providing calm and tranquillity and it could be argued that their protection of authentic-self by suppression of emotional engagement denies empathic engagement with the dying patient (Haywood and Tuckey 2011). There is limited description of any empathic engagement by the nurses in this study supporting being emotionally distant but cognitively present and is further evidence of the effectiveness of the protection measures.

PERSONAL PROTECTION: Baked Alaska and vulnerability

The nurses in this study suggest effectiveness in protecting their authentic-self by remaining emotionally distant but engaging cognitively with caring activities (Hayward, Tuckey 2011). This does not mean they are not affected emotionally by the effects of end-of-life care. The nurses describe the need to talk about their end-of-life care experiences, supporting the need to recognise nurses' vulnerability when providing end-of-life care. Hilde describes allowing herself to go into the toilet, covertly, to release her feelings suggesting hiding feelings. Mary is also denied expression of her feelings in work:

> *Nobody has ever asked me if I'm all right after a death. I'm sure they have but … the more senior you get I think you become the person that makes sure that everyone else is OK and there is no one really to help you above (laughs) and I think your skin gets thicker and you learn that its part of your job to deal with death.* (Mary)

Mary describes putting on her uniform then taking it off, and the journey home gives her the opportunity to clear her head and by the time she gets home the shift is forgotten about. Mary also has other adaptive behaviours she uses that serve to 'clear her head' indicating the opportunity to 'debrief' is denied at work

> *My husband is also a qualified nurse so I can go home and tell him what has happened. So I almost debrief to him… he's my go to person to off load and process the information* (Mary)

Figure 28 Protection (Edith)

Martha and Edith also utilise their partners in their coping strategy. Despite Edith’s need to change who she is when caring for dying patients she reports “I’ve seen a lot of people die but it doesn’t affect my day to day life”. Her protection is symbolised by puffins (*fig28*) “A hug from my husband does help and I hope he understands”.

Virginia talks about the pressure of maintaining her composure and sense of calm and peace but needing to escape to somewhere. She describes “sometimes you get to the point where you think that I can’t do this anymore”. Virginia overcomes this by taking 5 minutes in the staff room, “having a little rant”, then carrying on “But really it is my frustration that somewhere along the line I am having to compromise the care I am giving to somebody”. As with the other nurses, Virginia is expressing her need for someone to hear her frustration, a need to be heard and to be given the opportunity to express those vulnerabilities and emotions. This is congruent with Andrews et al (2019) finding that little emphasis has been placed on the care of staff and calls for formal acknowledgment of nurses need for self-care.

Nancy felt “proud of myself in a way for being quite tough on the inside” but admits that this probably should be dealt with beyond “a drink with my mates”. Nancy was the only nurse in this study who identified the availability of formal debriefing or supervision following particularly difficult events in ITU.

To engage emotionally, nurses should identify their own emotional vulnerabilities (Davenport and Hall 2011). By forming an emotional defence, the nurses are denying those vulnerabilities. Henderson (2001) found nurses working in highly emotionally charged environments did not feel their nursing education had prepared them for the personal emotional cost of nursing. Consequently, the nurses did not have the necessary educational background to enable them to integrate their emotional resources into highly charged emotional work. Emotional preparation and knowledge of emotional cost was not a feature of the nurses in this study experiences. This could be a result of effective repression or shielding of emotions.

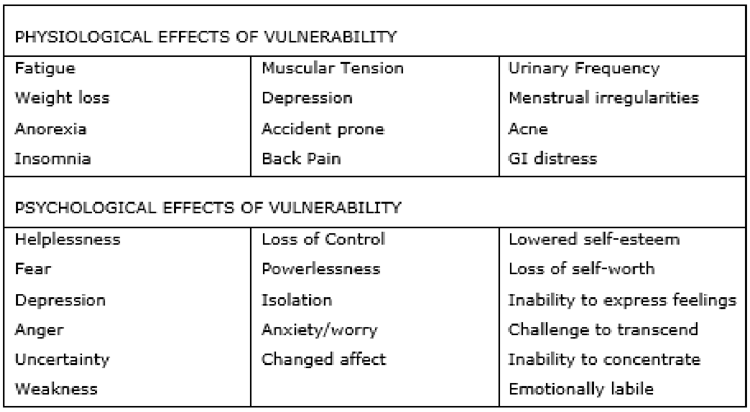
The experiences of the nurses in this study indicate hospital nurses providing end-of-life care were successful in protecting their own emotions in order to deliver end-of-life care. Emotional dissonance can occur as a consequence, with most of the nurses seeking informal forms of support. This implies that despite the success of the nurses' ability to protect authentic-self, they are emotionally vulnerable. Nurses witness others suffering and by doing so can share some of that experience as well as, become aware of their own fragility (Liu, Chiang 2017; Heaslip, Board 2012; Davenport, Hall 2011). Nurses vulnerability is socially constructed within the individual caring context (Davenport, Hall 2011). Hilde crying in the toilet is an example of socially constructed vulnerability. Nurses are expected to 'stop crying and get on with it' (Davenport, Hall 2011). To be vulnerable has negative connotations and is associated with fragility, weakness, being wounded and defenceless (Davenport, Hall, 2011).

Nancy's Baked Alaska represents the nurses' suppression of their emotions, in order to present an outward appearance of a professional nurse. The result is emotional dissonance which is the suppression of undesired emotions to present expected emotions by the role (Zapf 2001, 2002). The dissonance is due to a disconnection between the nurses' emotions and professional feeling rules. Feeling rules are what guide the emotional work by establishing the employees sense of entitlement or obligation governing the emotional exchanges (Hochschild 1983). Often organisations set the feeling rules, overtly or implied, but in nursing, emotional rules of behaviour are governed by social norms, expectations as well as implied behaviour rules (Zapf 2002, Henderson 2001, Froggatt 1998).

The notion of emotional dissonance is evident in Hilde's example secretly crying in the toilet. The suppression of her own emotions, necessitating her to present to other patients and families emotions she does not feel, is an example of emotional dissonance. Jean also describes the rule that it is not acceptable to "have an emotional wobbly in a massive cardiac arrest"; it's not safe in those high stakes situations. The nurses are providing examples of emotional suppression. This partly supports Smith (2012) finding that nurses are expected to cope with upsetting situations. The nurses in this study deny emotional expression partly due to ideas of nursing professional values. What differs is the nurses use those values to protect their authentic-self, rather than as Smith identifies, those values being an imposed expectation.

Menzies Lyth (1960) seminal work on social systems as a defence against anxiety found one of the ways the nursing service protected against such situations was by emotional detachment and a denial of feelings. This was structured into the social identity of nurses so that a nurse developed adequate professional detachment; an ability refrain from excessive involvement, and to be able to maintain professional independence. This helps to understand nurses' construction of feeling rules. Menzies Lyth recognised the uniform acted as a way of being indistinctive by being less individual-which aided repressing personality and keeping situations detached. Menzies Lyth's work helps to understand the social structure of nursing and, despite its age, still has relevance (Tutton, Langstaff 2015). The nurses in this study socially constructed idea of feeling rules and maintaining professional independence, adequate professional detachment and the depersonalization of the uniform do fit with some of Menzies Lyth's analysis.

Where there is a discrepancy between what an individual feels and what they display there is dissonance between the 'authentic-self' and the 'in-authentic self' (Obrien, Linehan 2018). The inauthenticity of faking expressions can threaten individuals' authentic-self by undermining their self-concept and self-worth (Obrien, Linehan 2018; Grandle et al., 2012). Frequent inauthentic behaviour can threaten a person's self-worth and self-efficacy (Grandle et al., 2012; Zapf, 2002). The nurses in this study protect their authentic-self to enable them to continue to provide end-of-life care is evidence of such expectations. Inauthentic behaviour is associated with psychological problems and is particularly associated with depression (Erickson, Grove, 2007, Zapf 2002). In this study, the nurses protect their authentic-self but with potentially hidden consequences. The health effect of vulnerability (*fig29*) and inauthenticity are similar and can result in physiological effect such as high blood pressure, as well as psychological effect, such as stress, emotional exhaustion; depersonalisation; reduced personal accomplishment as well as psychosomatic problems; depression; anxiety and burnout if left unmanaged (Zapf 2001 2002, Davenport, Hall 2011, Liu, Chiang 2017, Sloan 2007).



PHYSIOLOGICAL EFFECTS OF VULNERABILITY		
Fatigue	Muscular Tension	Urinary Frequency
Weight loss	Depression	Menstrual irregularities
Anorexia	Accident prone	Acne
Insomnia	Back Pain	GI distress
PSYCHOLOGICAL EFFECTS OF VULNERABILITY		
Helplessness	Loss of Control	Lowered self-esteem
Fear	Powerlessness	Loss of self-worth
Depression	Isolation	Inability to express feelings
Anger	Anxiety/worry	Challenge to transcend
Uncertainty	Changed affect	Inability to concentrate
Weakness		Emotionally labile

Figure 29 Rogers (1997)

SUMMARY: Hospital Nurses Protection of Authentic-Self

Figure 30 Baked-Alaska (Nancy)

The Baked Alaska ice cream centre represents the nurses' authentic-self (*fig30*). This is protected by the soft meringue shell which represents *professional self*; *defence of self*;; *being someone else*.

The nurses in this study use three categories of protection of authentic-self. *Professional identity* uses the professional image of nursing to distance their authentic-self from the nurse presented to the patient and family. *Defence-of-*

self uses an emotional shield to defend against the potential emotional trauma of the situation by cognitively engaging and presenting themselves as approachable and understanding while being emotionally distant. *Being-someone-else* is to take on an identity different in practice to one's authentic-self. In all these forms of protection, the nurses are successfully managing their emotions to continue to provide end-of-life care effectively. This meets Hochschild's definition of emotional labour as "the suppression of feelings in order to sustain an outward appearance that produces in others a sense of being cared for in a convivial, safe place" (Hochschild 1983 p.7). The difference is in regard to what Hochschild calls surface and deep acting. These are tactics employed as ways of deceiving others, or ourselves, about our true emotions in order to create the required feeling expression. Although there may remain some deception, the motivation is to protect authentic-self and continue with caring, rather than exhorting emotions not felt but are expected to.

NURSES PROTECTION OF OTHERS

Nurses providing end-of-life care work in highly emotionally charged situations, as Nancy describes "I would defy you not to cry where it is an 8 year old [who has died] and mum has dressed him in his football kit". By creating calm after the storm of the treatment or illness, the nurses were providing physical acts of end-of-life nursing care that facilitated a sense of peace for the patient and their family. These acts required the nurses to develop protective strategies that enabled them to function as nurses but keep themselves safe from the distressing situations they encounter. The motivation to regulate emotions and protect authentic-self may not be to avoid emotionally charged caring encounters, as suggested by some studies (Carr, Merriman 1995; Kondo, Nagata 2015; Pavish 2015; Decker 2015; Blomberg et al 2007) but to continue in the caring role as an enabling strategy. The nurses' acts of creating calm are done willingly, without desire, but with emotional sacrifice. As will be explored these are descriptors of love (Beals 2007; Selcomb 2007; Hand 1989). By protecting the patient, and their family, the nurses are demonstrating love for the dying patients and their families. Love in this form is indicative of neighbour-love (Fitzgerald, van Hooft 2000). These qualities of love in nursing are suggested to be ‘willingness’, ‘commitment’ and intention to place the good of the other before the self without reciprocity. (Fitzgerald, van Hooft 2000). What follows is an exploration of the nurses’ expression of their love through their protection of others.

Figure 31 Removing thorns (Virginia)

Protecting the patient, and their family was a core component of Virginia’s end-of-life care. Virginia used a metaphor of a rose without thorns (*fig31*) to describe this important part of her experience:

> *A rose without the thorns at the bottom is how I would like to make my patient’s journey. Usually when they die on the general surgery ward, as end-of-life, it perhaps means they have had cancer or whatever, so that I like to think we at least tried to make it into at least a peaceful end*. (Virginia)

Removing the thorns is making the process calm and peaceful, a desire to do *good*, without *reciprocity* or *gratuity*. But this is not always easy: “dare I say it, if you are under the surgeons, still surgeons will fight to the bitter end and sometimes you have to fight for your patient”.

Virginia recalls some of the fights she has had and describes the process as "a horrendous burden". This burden identifies *suffering* on Virginia's behalf, coupled with her need for protection forms a *sacrifice*. She finds it sad when she cannot make it all peaceful and roses for her patients:

> *I felt disappointed in myself that my patient got [resuscitated] when they probably should not have done, therefore didn't die with dignity which upsets me…I am sad we can't make it all peaceful and roses for whatever reason.* (Virginia)

Figure 32 Unicorn (Mary)

The environment of A&E often worked against Mary's idea of protecting the uniqueness of the individual in end-of-life care:

> *The nature of the area I work in, its all time targets so you feel you are constantly against [others] who have their own agenda and targets and pushing people through, to remind people that patents are human beings*. (Mary)

Mary uses the image of the Unicorn (*fig32*) to symbolise the ideal she has for her patients in this environment: "not everybody wants to be sad, upset and mourning end-of-life … they make the most of the time that have got together, it doesn't have to be a sad devastating thing". For Mary the unicorn symbolises embracing life, acknowledging the uniqueness of the individual, "recognise that they had a life and dreams and hope like all of us like when they got to the hospital bed about to die". The unicorn is a reminder that death does not need to be a process "it [unicorn] made me smile and its colourful, what comes to mind, death is sadness and darkness and black ". This is in contrast to the process approach outlined by the Royal College of Emergency Medicine *Best Practice Guideline for End-of-Life care in the Emergency Department* (2015). The Unicorn reminds Mary to *protect* her patient's identity and vulnerability, to make dying more personal, focusing on the person and the life they have had, protecting their identity, and values. Mary is working with *authority* and taking *responsibility* to do what she believes is right for the person. Mary also describes protecting patients by facilitating an environment of calmness:

> *The equipment, the stillness, a nice environment, because I know that particularly family will remember… you need to be part of that calmness when you walk into that room. That you have created. So that might be different to what is going on out in the main area.*(Mary)

To be part of that calmness, Mary may *suppress*, or deny her authentic-self, suggesting *sacrifice* to achieve this. Virginia and Mary's descriptions of their experiences of end-of-life care feature actions that include *suffering*, *sacrifice*, *protection* as well as taking *authority* and *responsibility* for end-of-life care. Levinas uses a variety of terms to describe love including authority, responsibility, conscience, call, suffering, sacrifice, here I am, genuine freedom, goodness and grace (Beals 2007 p. 32). In the use of the terms Levinas distinguishes between desire that is with concupiscence, a-satiable desire (*eros*) and metaphysical desire, which is an ethical desire of goodness (Beals 2007). By this Levinas means metaphysical desire can be a love without *eros*, a "love of one's neighbour" or *agape* (Beals 2007 p. 33). By protecting others, Virginia and Mary are describing the actions of neighbour love or love as agape.

Figure 33 Safe (Martha)

Martha also protects patients who are at the end-of-life and uses the metaphor of a bear to explain this, heading the bear image as "keep safe from hurt" (*fig33*). Martha recalls a situation where she works to understand what is happening asking "why?": why are things happening to her patients?; why plans are, or are not, being made. Martha, as the bear works to *protect* and *support* patients, answering their questions, making sure she has done all that she can. How we care for the dying can be indicative of how we care for the most vulnerable (DoH 2008). Martha's actions recognise the vulnerability of dying patients and works to protect them by advocating.

Martha refers to the doctors as the big bear and on occasions by advocating has to challenge or question some of the decisions:

> *I think about when I was at work and I try to contact everyone who can help me to do the proper thing… I fight for her [a patient]. I try to ask the doctors to think about the treatment, review the communication, if there wasn't another way to keep her more comfortable*. (Martha)

Martha is being *responsible* but *authoritative* in questioning that others have done all they should, as well as, *protecting* her patients and is also providing neighbour love for others. This suggests an ethical love or love as agape (Beals 2007).

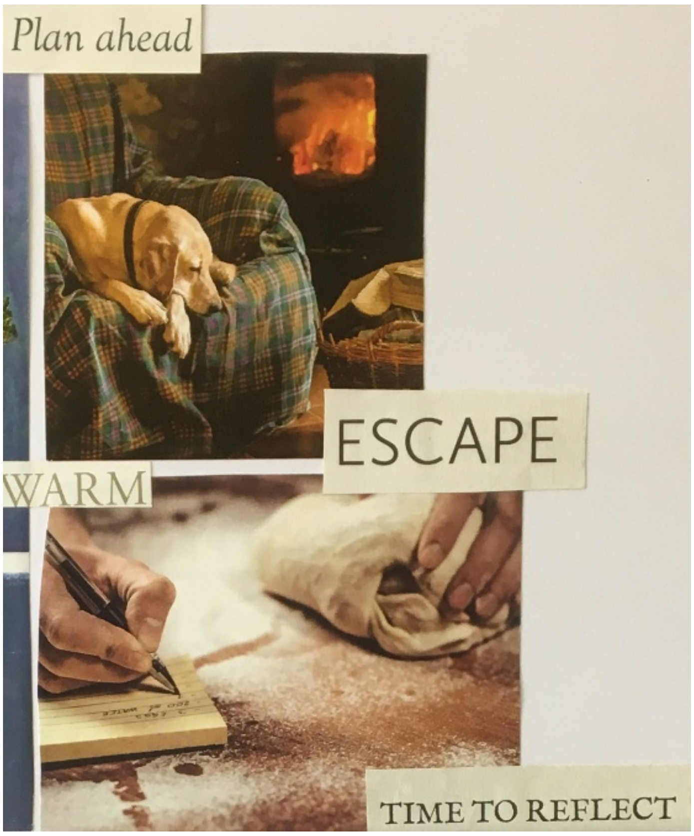


Figure 34 control (Hilde)

For Hilde, death is messy and she protects her patients by controlling the mess (*fig34*):

> *The nature of death, it is a finite thing you can't change that, so if when all these messy emotions are involved, it is a lot easier for the person who dies, you know there is completeness for them because they died. It stops there. Whereas, for their loved ones still have to carry on living with that* (Hilde)

Hilde hopes to protect the patient and family by allowing them to control the situation. This protection is achieved through careful preparation: giving them some input into the planning of the death, providing them control, protecting them from the impending mess of death: "My theory is by resolving all of the physical bits, then it may be contributing to all of the emotional bits". Similarly, advance care planning and advance directives also serve to protect a person's wishes at the end-of-life. Both these documents allow individuals to set out their preferences in advance for their end-of-life care with 12% of people age 75+ in the UK reporting having such plans in place (Davidson, Gentry 2013).

Hilde does everything she can to prepare for the death, "I will always make sure they have the medication and anticipatory prescribing is done well in advance*".* She puts plans discussed into action and communicates with her team the requests and plans to ensure the patient and families aims are met, continuing to question if everything has been done. Hilde is taking *responsibility* and having *authority* for the care and is motivated to do *good*, to give the dying person *freedom*. Hilde also suffers because of her actions, needing to protect herself from the effects of the care encounter, but this is done *willingly*. This meets Levinas' descriptors of love as agape (Beals 2007).

Figure 35 Goodbye (Louisa)

Louisa chose a puffin (*fig35*) to represent her experience;

> *I think he is saying goodbye, so I think there is that sense of whether you know the person well or not, you are saying good bye to them whether for yourself, or professionally, it is part of humanness.*
> (Louisa)

Louisa talks about protecting the family from the reality of what has happened:

> *As a relative how do you, in a cardiac arrest for example, understand all of the bits and pieces of the process? It's not your job to, but what they do understand is, I can see that dad has been looked after because his hair is brushed, and he has got his teeth in, because they are the bit about care that they know about. Whereby helping them by making your patient comfortable clean and hair brushed actually what you are saying is, its calm and look how well looked after dad has been and loved and here he is.*
> (Louisa)

Louisa's description suggests protecting the family from the reality of what happened, from the grotty situations, the "physical trauma" and not being traumatised by seeing it, they might want to know what happened "but they don't need to see it". The importance is for the family to know the person was cared for well and loved. Louisa reports:

> *For me it's the value, I want to make you loved, whether that is loved for you, or loved for your family. Looking at you, and how I display that, sometimes that is the hand holding, and sometimes it is washing the blood away. It's the same value. (Louisa)*

By doing this Louisa is protecting the family from the trauma of the event:

> *You don't want to see your family member suffer when they are dying and in trying to create that sense of [calm], in what drugs you might give, will be one thing but also physical, in what makes you look loved and cared for, peaceful as you approach death is peaceful, but not being traumatised by it, by the good bye. (Louisa)*

Louisa's value of "I want to make you loved" is expressing her desire to provide love for the person. In her description she identifies this as "I've loved you as much as I can as a nurse", not as Louisa. She recognises she has done all she can "not in an incompetent way I have tried but genuinely feel that I have done all that could have been done". The physical care may not resolve all the problems "you might still be in pain you still have secretions bubbling around but have I acted and have I made sure the right drugs are prescribed the medical therapy perhaps now can that happen does the dovetailing with my need to [create calm]". Louisa is motivated to *do good*, provide *selfless love* of for a person as they are dying, indicative of love as agape (Beals 2007, Selcomb 2007).

The nurses describe end-of-life care actions that are done willingly with goodness, selflessly, with authority and responsibility. These are terms that equate to Levinas's descriptions of love for one's neighbour or agape, suggesting that by protecting authentic-self and others, the nurses are demonstrating love for others. Love in nursing is explained as unselfishness that involves the responsibility for another's wellbeing, a selfless commitment to the needs of others (Watson 2003, Thorkildsen, Eriksson et al. 2015, Fitzgerald, vanHooft 2000). The nurses' in this study desire to create calm after the trauma, follows the idea of a commitment to the needs of others. This was also a constituent of Fitzgerald and VanHooft (2000) study of love in nursing which also found the protection of self provides evidence of the emotional protection the nurses employed to reduce the effect of any emotional sacrifice that providing their love required. Fitzgerald and VanHooft (2000) conclude that love in nursing requires "a willingness, commitment and intention to place the good of the other before the self without reciprocity". They argue this is different to care, taking nurses to a higher dimension of commitment and dedication. Love in nursing is not a contemporary subject and as a consequence the following explores the experiences of the nurses from this study in more depth in relation to this finding.

NURSES FULFILMENT OF LOVE

Defined from a theological perspective, neighbour-love is presented as *agape*, taken from the Greek word meaning to consider the interest of others, not simply one's own (Outka 1972). Levinas uses the term *agape* to mean metaphysical desire, neighbour love or ethical love which are interchangeable terms meaning a chaste love, a love without reciprocity, a responsibility for the Other (Beals 2007; Selcomb 2007). *Agape* is 'selfless love of humanity' and differs from *Eros* which is an erotic love, a love of life; *agape* is an ethical relation, not one born from sexual desire and carnal enjoyment (Selcomb 2007). The actions of the nurses in this study are indicative of neighbour love. This is a complex act encompassing regard for the Other which should not bring in ideas of the person being worthy of love, approving of the love, nor is it based on favouritism, it is universal and given unconditionally (Tillich 1967).

The nurses in this study describe a desire to do good for another and they do so *willingly*, being *responsible* for another, and being *selfless* in their care. Protecting others while requiring protection themselves from the emotional harm that act may cause, suggests *sacrifice*. These acts are congruent with Levinas's descriptions of neighbour-love and are also congruent with historical acts and attitudes of nursing, with the nurse "who has embraced agape—so devoted herself to loving and competent service that herself has been subsumed into care for others: achieving for herself and bringing to others radiant love and serenity" (Valatine -Mahler 2008). Mary's description of the Unicorn as embracing life, recognising the uniqueness of the individual, their hopes and dreams, and "the life they have had when they are get to the hospital bed about to die" represents Mary's understanding of her role in of end-of life care to be about helping family to maximise the valuable time they have left together.

Louisa is providing calm so loved ones can say good bye. These examples do not neatly fit into descriptions of love as agape. They indicate a vitality and passion for people which is present in *eros* but uniting *eros* with *agape* is rejected by many theorists as mixing "fire with water" (Pembroke 2006). Both Mary and Louisa present different examples suggesting contradictory evidence of a love that is not only *agape*, but is indicating a passion and love for humanity, a deeper commitment and selfless love of *eros*, that is given without reciprocity.

Tillich (1954) does mix fire with water and unites *eros* with *agape.* Tillich defines love ontologically as "life is being in actuality, and love is the moving power of life" (Tillich 1954 p. 25). To live life is not a reality without love:" love drives everything that is towards everything else that's is" (Tillich 1954 p. 25). By this Tillich means love is the drive towards the unity of the separated and presupposes an original unity, but love is not the reunification of those things that do not belong, it is the reunification of mainly the individual person as self-centred and complete being. The triumph of love is the ability to reunite the

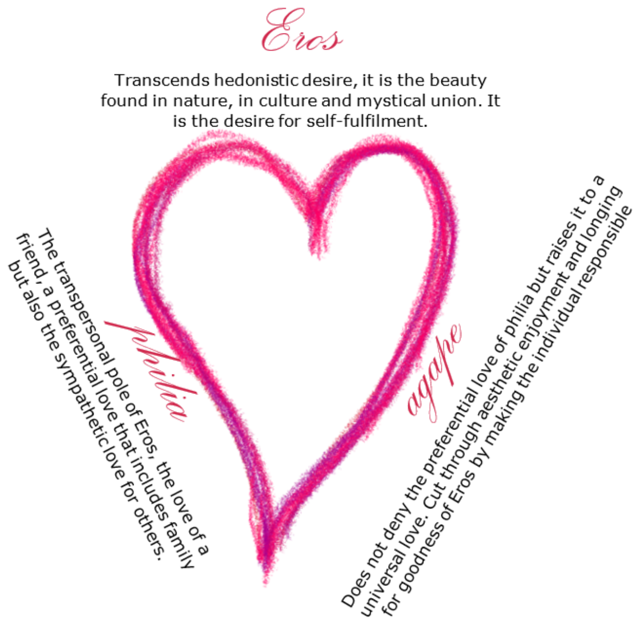


Figure 36 Love (Stuart 2020)

most radically separated beings. Unlike Levinas who separates neighbour love from *eros*, Tillich unites *eros* and *agape* adding *philia* as brotherly love. This triptych of love (*fig36*) combines differing aspects of love and Tillich emphasises he who cannot love the friend (Philia) cannot love culture (Eros) and agape cuts through friendship and indifference, desire and disgust, and it does not need sympathy to love, agape "loves in everybody and through everybody love itself "(Tillich 1954 p.119). Tillich describes *eros* as *libido* but not hedonistically as the desire for pleasure but the desire for self-fulfilment, a love of aesthetics, creation and natural goodness. In this sense, there is evidence of love as *eros* in the nurses' action to present and create calm as act of goodness. This is evident in Mary's image of a unicorn, symbolizing making the most of the time that is left and humanising the remaining time. Nancy discusses enabling a mother to put her dying 8 year old son in his football shirt. Louisa facilitates the calming of the storm, so the puffins can say good bye. Virginia removes the thorns from the rose, Hilde talks about enabling the family and the patient to reminisce about holidays or other comforting experiences, to unite the family one last time, as life for that person comes to an end. By doing so they are putting aside their emotions to unite love in the last stages of the person's life. The nurses in the study, by protecting themselves to continue caring, removing the evidence of the brutality of the storm, the thorns from the rose, to create calm and tranquillity for their patients and protecting their patients are presenting evidence of love as *agape, eros* and *philia*.

Tillich describes *eros* as *libido* but not hedonistically as the desire for pleasure but the desire for self-fulfilment, a love of aesthetics, creation and natural goodness. In this sense, there is evidence of love as *eros* in the nurses' action to present and create calm as act of goodness. This is evident in Louisa's actions to facilitate the calming of the storm, so the puffins can say good bye. It is also Nancy enabling a mother to put her dying 8 year old son in his football shirt, Virginia removing the thorns from the rose, Hilde talks about enabling the family and the patient to reminisce about holidays or other comforting experiences, to unite the family one last time, as life for that person comes to an end. By doing so they are putting aside their emotions to unite love in the last stages of the person's life.

The nurses have described love as the washing away of blood, the combing of hair as symbolic of 'you are loved'. This is also evident in actions that help control the mess of death and acts that aim to remove the thorns from the rose, all of which facilitate stillness, calm and tranquillity. Love is a genuineness of feeling that all has been done that can be done. An importance is given to the value of the humanness of the situation, as well as helping to value and make the most of the time left. Centring on the importance of family and for them death is unique and not a process.

As a result, love is; *Eros* as a desire for creativity and aesthetics by providing stillness, calmness and tranquillity, a value and virtue of natural goodness by wanting to show the person is and has been loved (*fig 37*). Love is also *agape* as a willingness to see the individual and not the process and to enable all that can be done for a family (philia) to make the most of whatever time they have together, however short that may be

Figure 37 Love in hospital End Of Life Nursing Care (Stuart 2020)

Love in hospital end-of-life nursing is:

> A desire to create calm, grounded by the virtue of natural goodness and a willingness to focus on the individual and their family, to make the most of whatever time they have left.

There is little contemporary nursing literature exploring love in end-of-life care. Bergenholtz, et al (2015) mention the term 'loving care' as used by the hospital nurses in their study to describe the care provided when patients entered the terminal phase. Although the term appeared in the nursing documentation, conversations and the interviews, it was not clearly explored, other than to describe a change in care by recognising the terminal phase. Watson (2008) conceptual model of love and nursing care incorporates the universal healing power of nursing love into nurse care. Watson's nurse uses the unity of their body and mind to release their infinite field of energy of cosmic love and connect with the body's "divine power system of the universe and mobilises this energetic life force of self to help co-create healing in others" (Watson 2008 p. 211,229). In caring for the dying, the most vulnerable and in despair, Watson's approach offers a space between breaths, a quiet pace to bow down and take new energy to love. The nurses in this study did not evidence utilising their divine power system to embrace the cosmic awesomeness of love (Watson 2003).

There are similarities in the nurses' experiences between love and compassion. Compassion can be defined as witnessing someone's suffering with a willingness to take action (Perez-Bret, Altisent & Rocafort 2016; Strauss et al., 2016; Kanov et al., 2004; von Dietze, Orb, 2000). To witness the suffering requires seeing the suffering through empathic understanding (Perez-Bret, Altisent & Rocafort, 2016; Strauss et al., 2016; von Dietze, Orb, 2000). It is a willingness to witness the suffering and to empathically engage that initiates the compassionate response (von Dietze, Orb, 2000). Through empathic connection with the person a compassionate response is formed (Strauss et al., 2016). Common to ideas about compassion are firstly it involves noticing the suffering, then feeling of concern, followed by being motivated to act (Kanov et al., 2004). In this study, the descriptions of the nurses' experiences do not always identify a recognition of the suffering of the person they are caring for.

The similarities between compassion and love are evident in the nurses' act of creating calm which could be both compassionate and loving. To be compassionate can be selfless (Strauss et al., 2016) and selflessness is indicative of agape (Fitzgerald, vanHooft, 2000). The nurses' motivation to create calm came from a sense of altruism, to do the right thing for the person as agape. A wiliness to recognise suffering is also a motivation for compassion (Strauss et al., 2016, Perez-Bret, Altisent & Rocafort, 2016, von Dietze, Orb, 2000).

In protecting their authentic-self, by being emotionally distant but cognitively present, the nurses may also be denying empathic engagement. Unlike love, compassion requires a sharing of the experience which this protective mechanism may inhibit (Kanov et al., 2004; von Dietze, Orb, 2000). The final stage of compassion is in an empathic response (Strauss et al., 2016; Perez-Bret, Altisent & Rocafort, 2016; Kanov et al., 2004). The nurses' descriptions of creating calm are not all inclusive of the patients' perspective, or clear indicators of empathic responses to the needs of the individual, this might be difficult in ITU or post arrest, but are created from the nurses' ideas of a good death, motivated by love. This is evidenced by their individual constructs of end-of-life care and their protection of authentic-self and their patients.

SUMMARY

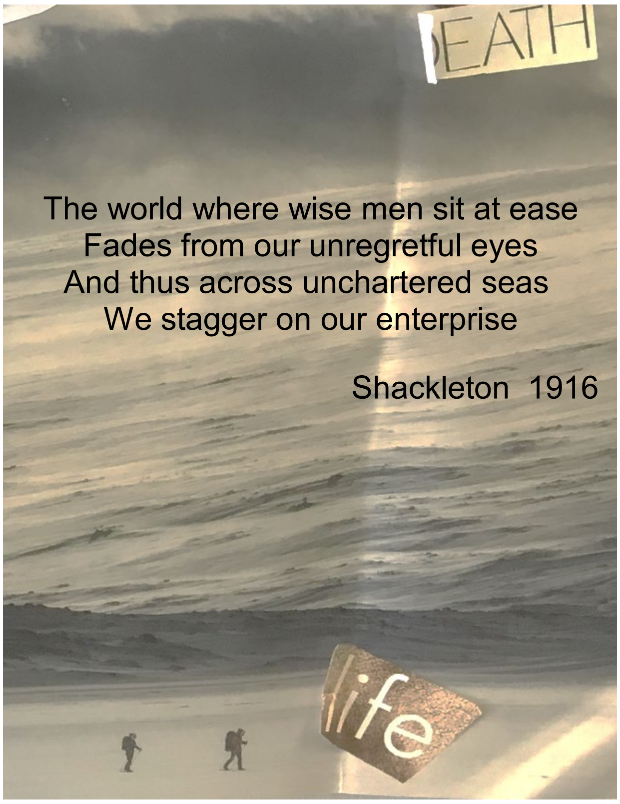
The nurses in this study remain human in their response to death anxiety, the angst of the awareness of non-being, but they continued providing end-of-life care. Indications of death avoidance behaviour were not present in this study. The experiences of the hospital nurses in this study indicate they were successful in utilising different forms of protecting their authentic-self from the emotions encountered to allow them to continue providing end-of-life care in the hospital setting. These forms of protection were; *professional identity*- using the professional image of nursing to distance authentic-self from the self presented to the patient and family, being professionally removed but appearing approachable; *defence of self*- uses an emotional shield to defend against the potential trauma of the situation by cognitively engaging, presenting oneself as approachable but emotionally distant; *Being someone else*- is to take on an identity different in practice to one’s authentic-self and present the inauthentic self. In all these forms of protection the nurses indicate they were successful with supressing their own emotions to continue to provide end-of-life care, and in doing so preserved their authentic-self.

This does not mean emotions were not present. The nurses describe the informal processes of support they access in response to being denied the expression of feelings at work. The consequence of concealing their authentic-self is to make an inauthentic-self visible, this has can have both physical and mental health repercussions, but this was not investigated by this study. The vulnerability of the nurses has been highlighted as a potential issue with a need for nurses to be better prepared and supported for the emotional demands of end-of-life care.

The nurses’ actions that facilitate the calming of the storm, so the puffins can say goodbye, removing the thorns from the roses’ stem, creating calm at the end-of-life, are all actions that indicate their love for Others. This was done through a desire to do good, without reciprocity and with these acts the nurses are fulfilling their love for Others by uniting *agape*, *eros* and *philia*. The overall outcome is love in hospital end-of-life nursing care is presented as; A desire to create calm, grounded by the virtue of natural goodness and a willingness to focus on the individual and their family, to make the most of whatever time they have left.

CHAPTER 6 FINDINGS AND DISCUSSION:

HOSPITAL NURSES EXPERIENCES OF CONTROL IN END OF LIFE CARE SITUATIONS: Crossing Antarctica



The world where wise men sit at ease
Fades from our unregretful eyes
And thus across unchartered seas
We stagger on our enterprise

Shackleton 1916

In this third findings chapter I look at how the hospital nurses experience control in end-of-life situations. The nurses' attitudes to death led to an understanding that after the trauma there will be calm. To enable this the nurses evidenced some degree of power to control such situations. The explanations of their experience identify their control is problematic due to the unpredictable nature of end-of-life. The unpredictability is attributed to changing clinical situations; difficulty with planning, resourcing, and unpredictable life courses. They also attribute professional knowledge as problematic, linking this to their feeling of control and unpredictability. There was inconsistency with the nurses' experience of providing the end-of-life care due to differences in degrees of empowerment, resulting in outcomes that are not always authoritative power-based decisions, but negotiated power, based on love. To gain a richer appreciation I explore this from the perspective of Foucault's concept of disciplinary power and contrast with Tillich's *power-of-being*. Foucault presents disciplinary power as a conditioning power that is asserted by detailed control of the body through hierarchical observation, normalising judgement and examination (Foucault, 1975). In contrast Tillich's concept of power as the power-of-being where everybody has a possibility for power, 'to be', through self-affirmation, of universal participation. From this comes the power-of-being; the power within of selfhood, becoming, dynamisms and freedom (Tillich, 1954).

HOSPITAL NURSES EXPERIENCE OF CONTROL IN IN END-OF-LIFE CARE SITUATIONS: Crossing Antarctica

Nurses aim to represent themselves as caring, knowledgeable and autonomous (Du Platt-Jones 1999). Fulfilment of this caring aim is essential in the clinical decision making and power relationships if nurses are to maintain their role of knowing the patient and speaking up for them (Fackler, Chambers et al. 2015). As an example of Foucault's normalising judgement, failure to uphold this expected standard and behaviour is to fail as a nurse. The nurses in this study describe end-of-life care situations as unpredictable, due the changing clinical situation, difficulty with planning, resourcing, and unpredictable life course. The nurses also explain their lack of end-of-life knowledge causes them to feel uncertainty. This influences their clinical decision making and power relationships, questioning their fulfilment of nursing's caring aim according to normalising judgement.

Figure 38 Unpredictable (Mary)

Being in control of end-of-life care situations was described as problematic by Nancy, Mary and Hilde. They identified unpredictability presented by end-of-life situations compromised shared decision making. Mary describes there always being an element of the unknown with end-of life patients in A&E, using an image of the people walking across the Antarctic to illustrate this unpredictability (*fig38*); "the challenge, the unknown with the weather changing at any moment of the journey, the path might change, they might need to adapt to what gets thrown at them" (Mary). Similarly, Nancy describes death in ITU as unpredictable due to events not going as planned, governed by "a bigger force beyond science" (*fig39*). Some patients survive that:

> *Quite frankly shouldn't when the odds are well and truly stacked against them yet, somehow, they pull through, and there are other patient who have every chance of getting out but, somehow for no apparent reason, don't*. (Nancy)

Figure 39 life-force (Nancy)

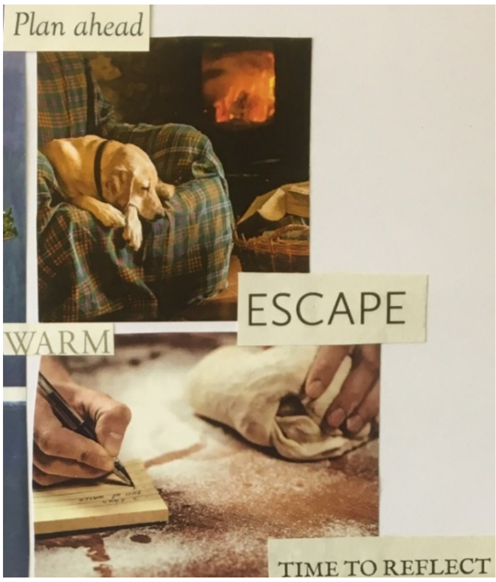


Figure 40 planning (Hilde)

Hilde aims to tame the unpredictability of death which she sees as 'messy', and needs control to reduce the mess:

> *In my experience some people feel very out of control in those final days and I think if they feel they have had some input into the planning of how their loved one is going to die, it helps them* (Hilde)

Hilde and Mary feel discomfort from not being in control, but Mary attributes this to knowledge:

> *I don't feel confident ... I like to know what I am doing, and portray that to my patients, and their families, so they feel confident knowing that I'm looking after them, and it becomes uncomfortable when you know you haven't got the correct resources, the correct knowledge and training to deal with making someone's journey better*. (Mary)

Mary is describing not being able to control the resources she needs for her patients, as well as not feeling in control of her knowledge and ability to manage the events. Nurses correlate knowledge with experience and confidence which contributes to their sense of power (Fackler, Chambers et al. 2015). Foucault entwines knowledge with power; "power produces knowledge and power and knowledge directly imply one another" (Foucault 1975 p. 27). This suggests Mary's unease and control is due to not having "the correct knowledge". Disciplinary power reinforces this by placing a professional expectation on Mary to possess the required knowledge to provide end-of-life care through normalising judgement, these are the rules which Mary should follow, specifying her actions and conformity. Her uncertainty as to what to do may add to her sense of unpredictability and powerlessness.

Nancy's also describes unpredictability that makes end-of-life decision difficult and situations where she feels lacking in knowledge but differs to Mary in how she represents this. Nancy describes how ITU experiences in certain end-of-life situations left her feeling helpless. Nancy means not knowing how to make the situation better for the family, or patient;

> *I would be left with the family and they would ask how long do you think nurse and if you could put a percentage on it, and all that kind of thing. Sometimes you would have to be brave, and operate out of our comfort zone, resist the temptation to run away (laughs). Without any training on it, watching what the doctors did, what other nurses did, I think I read around that and I know I wanted to*

> *get it right, so I knew how important it was. It never became easier, I never became comfortable doing it because it is still somebody's loved one whether they were 95 or 5 it was still devastating for them to hear.* (Nancy)

Nancy describes not having the knowledge to make the situation better for the family, she feels unable to achieve this. Disciplinary power is a surveillance power that aims to control individuals by standardising behaviour, so the individual operates in a desired efficient manner (Bradbury-Jones, Sambrook et al. 2007). This is similar to 'technical knowledge' (Eraut 2003; Fish, Coles 1998; Shöne 1983) which is the systematic discipline based knowledge derived from coherent and systematic evidence. As nurses, Mary and Nancy are expected to know what to do (Bradbury-Jones, Sambrook et al. 2007; Gilbert 1995; Henderson 1994). Nancy reports not having training, but has read and observed others, but feels this was not enough, and is aware of the devastating effect the situation will have. Nancy's situation is different to Mary, it is an awareness of the devastating effect of end-of-life situations and the professional expectation that she should know what to do that influences Nancy's sense of unpredictability and belief in a lack of knowledge. Nancy's actions are indicative of a technical rational (TR) approach, seeking a defined set of behaviours that she can deliver to help the family (Fish and Coles 1998). In this situation the standardising behaviour born from the objectifying gaze of disciplinary power and authoritative knowledge is not helpful for Nancy's end-of-life situation. A professional artistry (PA) approach which is more intuitive than rules-based TR may be more applicable. PA recognises the complexity and uncertainty of the 'real world' relying on a mix of professional judgement, intuition and common-sense in contrast to the prescribed and measured TR approach (Fish and Coles 1998 p. 32).

Figure 39 Battling (Nancy)

Nancy experiences other end-of-life situations where to provide what she believes is the right care for the patient, requires her to 'battle against the wind' (*Fig41*):

> *[it's like] battling against the wind, and you felt you know what was is the right thing to do and you were battling against the decisions. That could be quite a lonely place to be and to trying to get that message across, particularly if the hierarchy didn't want to listen.* (Nancy)

Nancy does not have the power to be heard. In this example Nancy's description of 'the hierarchy not wanting to listen' is disempowering and her contribution to end-of-life care was not validated. Nancy describes feeling she knew the right thing to do, and was speaking up on behalf of the patient, but she was not heard. Nurses need their voice to be validated by clinicians, as well as others, to feel powerful (Fackler, Chambers et al. 2015).

Nancy's experience of believing she knew the right thing to do in end-of-life care for her patient, but batting to be heard against the medical dominance, may also be an example the hospital institutional structure and the power of the social community of doctors over the social community of nursing. Tillich (1954) suggests in such situations authorities exercise power by the place they hold in the institution, Tillich refers to this as '*authority-in-principal*' an unjust repressive authority. Nancy's description of "battling against the decisions" and a "hierarchy that didn't want to listen" is indicative of the effect of an '*authority-in-principal'*. Foucault determines power is not held within a position, but with the knowledge the person holds. In the hospital environment the authoritative knowledge of the Doctor can pervade and dominate decision making, paying less respect to low ranking knowledge of nurses (Sambrook et al. 2007; Gilbert 1995, Bradbury-Jones). Foucault refers to such lower ranking knowledge as subjugated knowledge (Foucault 1980). Nancy's experience would suggest her subjugated knowledge may be given less value in the decision-making process than the authoritative knowledge of ITU Doctors in regarding end-of-life decisions, indicative of an *authority-in-principle*.

Hilde's experiences of end-of-life decision making in rapid response is different. Hilde stresses the importance of overcoming the unpredictability by careful planning, with the family, to facilitate the death the patient wants. Hilde recognises you cannot control exactly when patients will die, but you can try to plan as much as possible:

> *Making sure as much as I can that the patient is as comfortable as possible, or the relatives will think 'oh mum she was really in so much pain when she died' …. I would like to try to contain and resolve as many things as I can. My theory is by resolving all of the physical bit I then it may be contributing to all of the emotional bits*. (Hilde)

In contrast to Mary and Nancy, Hilde is describing her ability to centralise her *power-of-being*; to take control of what is happening, plan and organise events for the patients in her care. Significantly her degree of autonomy, and the social community hierarchies of power presented in Nancy's description are not evident. Hilde also involves the family in the planning of the care. In contrast to Tillich's *authority-in-principle*, an unjust authority, Hilde is describing an '*authority-in-fact*' a just authority which is the mutual dependence of all of us on each other of our power to stand by ourselves. Hilde is trying to share control with the family and the patient, and her colleagues. She is recognising the mutual dependence of each other, by involving the patient and the family in the care planning and is describing attributes of an '*authority-in-fact*'.

Foucault's disciplinary power describes hierarchical observation, normalising judgement and examination as forms of surveillance, which can lead to meticulous control of nursing practice (Bradbury-Jones, Sambrook et al. 2007). Mary, Nancy and Hilde have explained that despite this expectation, their control over end-of-life situations is not always possible due to the unpredictable nature of end-of-life care. The unpredictability has been attributed to the changing clinical situation, difficulty with planning, resourcing, and unpredictable life course. Bergenholtz et al (2015) also found the unpredictability of the patient trajectory problematic due to the hospital nurses needing specific instruction from doctors to proceed with 'loving care' as permission to initiate palliation. The nurses in this study differed, describing not having sufficient knowledge, or the right knowledge and authority in the decisions making process were identified as factors that contributed to the nurses control in end-of-life situations.

Uncertainty in end-of-life was contributory in nurses' sense of a lack of end-of-life knowledge. This may be indicative of the environments where the nurses work. The critical care, A&E, ITU and trauma/surgery areas of care represented by the nurses in the study are areas where patients were admitted for curative treatment but became terminal. The experiences of the nurses describe this as transferring from the storm to the calm and it is this transitioning that contributes to the nurses' sense of uncertainty and need for end-of-life care knowledge. This differs to Bergenholtz et al (2015) study in which the unpredictability of end-of-life was attributed to differences in clinicians understanding as to what palliative care was, if and when, to apply the care.

Managing uncertainty in end-of-life is part of the aim of the Amber care bundle, an effective systematic communication and care planning tool used in clinical practice when a patients' recovery is uncertain (Carey et al., 2015). Its approach of being systematic fits within a TR model. To help nurses in practice, such as Nancy and Mary, different education formats exist on end-of-life care provided by multiple organisations and settings. A scoping exercises and national consultation by The Democratic Society (2015) commissioned by Health Education England (HEE) produced a framework for such core skills in end-of-life care and a significant investment and partnership working with specialist bodies created extensive learning resources relevant to end-of-life care (HEE, Skills for Health & Skills for Care, 2017). Such resources are valuable in supporting the generalist in end-of-life care and is important content, but mostly indicative of a TR approach to education. The evidence from this study suggest the uncertainty around end-of-life care in hospitals may benefit from additional education following a professional artistry approach. Such a strategy could help Nancy to know what to say when the family's question in ITU about how long their son has left, knowing the devastation hearing the news will cause.

Foucault's concept of normalising judgement seeks for authority and control of the nurses' decisions and actions, which is evident in their need for control and certainty but negated by the uncertainty of end-of-life situations. Mary, Nancy and Hilde present evidence that suggests actions of an *authority-in-fact*, a just authority. These actions also imply an awareness of the effect of end-of-life events on the patients and families and are examples of Tillich's *power-of-being* which gives everybody the opportunity to actualise their power. Mary, Nancy and Hilde are acting as part of the social community of nurses and actualise their *power-of-being* by decision making with or for the patient and their family.

Standardising behaviour through disciplinary 'gaze' may not be helpful in hospital end-of-life care due to the unpredictable and often 'devastating' situations which require adaptability. This study suggests a TR approach does not fully equip the nurses with the knowledge they need. Mary and Nancy suggest they need to operate outside the objective knowledge base they hold when practising end-of-life care. Objective, technical knowledge alone may not be satisfactory for the development of a 'meaningful' nurse-patient relationship, the surveillance and control of disciplinary power has implications for subjective and unpredictable understanding of the patient which professional artistry may provide (Eraut 2003; Fish, Coles 1998; Shone 1983; Henderson 1994).

HOSPITAL NURSES EXPERIENCES OF DISEMPOWERMENT IN END OF LIFE CARE: Forcing Rhubarb.

Not all the nurses in this study were empowered in their provision of end-of-life care. Powerless nurses can be ineffective, and nurses need power to empower others with power in nursing includes practices which are used to empower patients (Sepasi, Abbaszadeh et al. 2016; Bradbury-Jones, Sambrook et al. 2007). The nurses in this study described different experiences in relation to disempowerment but linked to knowledge. The nurses' experiences suggest their lack of knowledge and their subjugated knowledge to be disempowering. Conversely, nurses objectified disciplinary knowledge can also disempower in end-of-life care.

Martha, Edith and Jean provide different accounts of disempowerment in end-of-life care. Advocating on behalf of her patients and fighting for her patients was part of Martha's experience of being 'the bear'. In this role she challenged and questioned decisions to make sure make her patient's symptoms were under control, asking herself why things were happening, but not knowing the answers:

> *I fight for [her] … I tried to ask the doctors to think about the treatment, review the communication, if there wasn't another way to keep her more comfortable, her condition and illness was so advanced, what would we achieve? What quality of life is she going to have if we bring her back [resuscitate]? It is sad (laughs, then cries) I went to the doctor and tried to clarify with him the plan, it is important.. to do the 'proper thing'.* (Martha)

Martha recalls the distressing situation where a patient was for active management (for resuscitation) but, from Martha's understanding, also with advanced cancer. Martha reports feeling frustration with others, the decisions they made, which she questions, and herself for not being able to do the "proper thing". Foucault discusses the primacy of the knowledge from disciplinary power, such as medicine, and describes other forms of knowledge as 'subjugated knowledge'. This is low ranking, naïve, non-scientific and disqualified knowledge (Foucault 1980). Martha questions her knowledge, but by asking the doctors if there is another way to keep her more comfortable, may also be suggesting her knowledge is subjugated, further reducing her power by acknowledging her understanding is insufficient. Martha asking the Doctor for clarity regarding the plan is indicative of authority-in-principal, rather than a joint decision based on authority-in-fact.

Edith's actions are both controlling and disempowering. Edith avoids emotional and existential issues with her patients which deprives them the opportunity to express these topics with her, thus disempowering her patients. In doing so Edith has control over the situation, blocking what she perceives as difficult discussion with her patients. Edith denies having the experience or skills to be able to fully engage with end-of-life patients, believing she is not wise enough with life experience to respond to patients' emotional and existential concerns. Her response is to focus on tangible, TR, aspects of care, the management of their symptoms and the equipment. By becoming the serious professional nurse Edith is controlling the care situation to reduce emotional and existential engagement with the patient and their family:

> *I still get very, sort of, I can't deal with this, and this is bigger than me. I still feel that now and I've been a nurse for 15 years so…I just think I'm not an adult enough to know what to do*. (Edith)

Edith describes the task of end-of-life care, the tangible aspects of her role that requires her to become the professional adult nurse to be able to function and action those tasks. Edith holds the position of dominance, or *power-over* in the decision making (Florckak 2012, Hawks 1991), utilising disciplinary power by adhering to her professional technical knowledge to objectively carry out her duties and tasks. Edith believes she does not have the life experience, knowledge and skills to be able to provide end-of-life care at a deeper level. Understanding social practices, family, and the meaningful relationship with the nurse and the patient are not objective forms of knowledge derived from disciplinary power (Gilbert 1995, Henderson 1994). Edith, as with all individuals, does have a *power-of-being* and by focusing on the task, not the existential and emotional needs of the patient, Edith, as the health professions, is providing decisions with an '*authority in principal*' which is unjust- she places herself beyond criticism by her position of power in their relationship because "it disregards the intrinsic claim of human beings to become responsible for ultimate decisions" (Tillich 1954 p.89).

Edith believes she lacks the knowledge, experience and skills to engage with end-of-life patients. Jean shares this view and uses the idea of forced rhubarb to explain her experience of providing end-of-life care. Jean, practicing in cardiac care, reports:

> *There is nothing better than seeing that poor person walk back onto the CCU 6 weeks later with a box of chocolates and say 'do you remember me?', and you say how 'the hell could I forget you, I would never forget you ever' and there is the reward. Absolutely, that's the bit… CCU was resuscitate, die or go out into the ward you didn't have a death, you had a cardiac arrest death, not a palliative death- an* end-of-life *death that was on the ward.* (Jean)

Figure 40 forced rhubarb (Jean)

Jean's view is shared by other nurses working in similar environments that despite the frequency of exposure to death, the nurses desired to avoid death by moving dying patient as quickly as possible to other departments (Decker, Lee et al. 2015). For Jean end-of-life care is 'forced rhubarb' (*fig42*) it is a completely different set of skills that are needed:

> *You had a cardiac arrest death, not a palliative death that was on the ward and this is forced rhubarb (fig42) forcing us as a group to do stuff we were not prepared for… Sudden cardiac arrests are totally different to the set of skills that you use to help and support someone at the end-of-their-life* (Jean).

Jean differs from Edith in describing "having the kit but not being equipped", not knowing how to use it, being unprepared. As with others in this study Jean believes she does not have the knowledge to undertake end-of-life care, but unlike the other nurses, believes nurses should not be "forced as a group to do stuff we were not prepared for". In this respect, Jean's terminology of "skill set" and “kit” indicates a TR view of practice and it may be this approach to knowledge and practice that creates Jeans feeling of being unequipped. Jean recalls two events where she did provide end-of-life care and describes a feeling of “it was a nasty death, I could not breathe, I felt unprepared, I did not know how to manage. I did not have the education”. Jean’s feeling of not being prepared, and not being able to breathe and this being a symptom of the dying patients she encountered “these cases were breathless, bless their hearts, and perhaps I could not breath something we had in common”. Jean is perhaps recognising her professional limitations from relying on TR practice and the authority of the disciplinary gaze and is disempowered by not having the perceived required knowledge for end-of-life care:

> *I brought up with every patient their sex life and I was used to sensitive intimate conversations, but the death one…This is rehab, rehab is life. I was not frightened to discuss certain subjects I just did not have the toolkit… when it came to the death stuff I had no prep, none at all… explicitly I had no education on palliation* (Jean)

Knowledge and power are intertwined (Bradbury-Jones, Sambrook et al. 2007). Martha, Jean and Edith’s end-of-life care actions were disempowered due to their knowledge, but in different ways. Jean has been practicing for many years and reports not receiving education in end-of-life clinical practice. Without understanding Jean felt ‘breathless’ and unprepared to manage the needs of end-of-life patients. Knowledge that is focused on observational knowledge or technical knowledge, as experienced by Edith, focuses on the tasks and clinical processes of end-of-life care and by doing so can disempower patients by allowing nurses to act with an ‘authority-in-principal’. This can disregard the patient in the caring interaction.

Nurses are often the ones in the closest proximity to the patient, who appreciate the subtle cues and trends as they arise, but they are powerless over others in acting on the content of nursing practice (Manojlovich 2007). This study supports this view to some degree. Martha was powerless with the Doctor acting with authority-in-principal. Similar to Nancy, Martha’s subjugated knowledge had less authority in the decision-making process to that of the Doctor.

Consequently, their lower ranking subjugated, or disqualified knowledge may be disempowering in clinical decision making, suggesting in end-of-life situations where the nurses belong to a subordinate social community, deferral of power to the dominant and more objectified knowledge-based group may occur.

HOSPITAL NURSES EXPERIENCES OF EMPOWERMENT IN END OF LIFE CARE: The Removal of the Thorns from the Rose.

Power and empowerment are interwoven and there can be no empowerment without there being power first (Bradbury-Jones, Sambrook et al. 2007; Aditi 2012). Empowerment in nursing can be seen a state in which the individual nurse has assumed control over their practice enabling them to fulfil their professional nursing responsibilities within an organisation (Aditi 2012). To empower others, such as patients, nurses themselves need to be empowered (Bradbury-Jones, Sambrook et al. 2007). Empowerment in nursing comes from a power derived from the workplace, that enables nurses to be personally capable of following their work goals (Laschinger, Gilbert et al. et al. 2010). But nurses may not operate from a position of empowerment, as they are often subordinate and unequal to others which gives the impression of being powerless (Christensen, Hewitt-Taylor 2006). The nurses in this study support this view to some degree. They may be subordinate but are also empowered at some level with their provision of end-of-life care by utilising an *authority-in-fact* enabled by their individual *power-of-being*.

The nurses in this study had varying degrees of empowerment. For Mary, Virginia, Louisa and Ethel the aspect they were most empowered to control was the patient’s environment:

> *The path with the greenery the light is the peace I would like to provide for my end-of-life patients, to shield them for the noise of the busy general ward.* (Virginia)

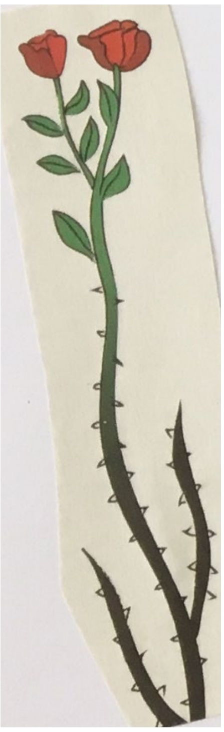


Figure 41 empowerment (Virginia)

To achieve this, they talk about withdrawal of items associated with clinical care. Virginia states the sideroom in hospital is not ideal but gives some privacy. Virginia uses the image of a rose to describe her care for end-of-life patients and her role is to remove the thorns (*fig43*), which goes beyond the environment and is about how she would like to make her patients journey:

> *Because usually when they die on the general surgery ward, well, at end-of-life it means they have had cancer or whatever, so I like to think we at least transition it into at least a peaceful end* (Virginia)

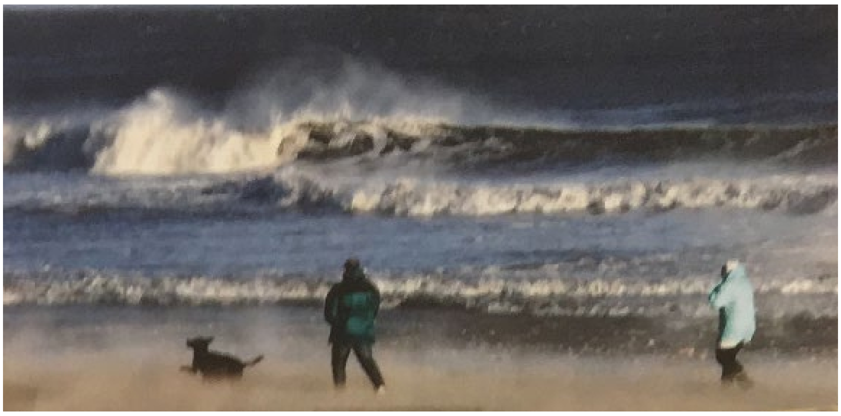


Figure 42 Transitioning (Louisa)

Louisa and Ethel control the environment by removing evidence of the storm, the trauma that has just occurred, to present the patient, as part of that environment, as calm. Louise and Ethel have similar descriptions. Louisa describes the process of controlling the storm in her picture of the people on the beach (*Fig44*). Her aim is to make them comfortable:

> *A windy day and a stormy sea, it's not a threatening one… We have moved away from the storm we're not calm, but it's not uncomfortable, it's not horrendous, there is a bit going on and things to tackle but there is a bit of a team there working together to get to calmer waters but it is still quite a beautiful setting, these are quite pretty picture, more emotional*. (Louisa)

Figure 43 Preparation (Ethel)

Ethel describes preparing the environment, but focuses on more personable things, using a 'shawley blanket' (*Fig45*) to symbolise the change in environment when someone is dying, to be homelier. Her encounter with a dying patient who brought her shawley blanket from home, reminded her of this. When she died, the patient's family commented that the shawley blanket made a difference for them:

> *Bringing home into the place…a really good death where there has been more preparation of the environment and changing it that way for the patient…There is comfort and care, I think those good old things, either approaching death or after death, just being able to do those personable things, making sure the person is clean and comfortable.* (Ethel)

The result is the storm has passed and now is the time to say good bye, to be calm. Louisa states:

> *Not everyone gets there at the same time…but when you are getting towards that period when they are actively dying, the relatives have move past the stormy period, and you quite often see relatives round the bed they are talking about pastimes, laughing and remembering, having a good reminisce of the times they had with their loved one.* (Louisa)

Louisa explains there are still things going on that need to be 'tackled' before reaching calmer waters, but the situation is less dramatic now, but emotional, with family around the bed, reminiscing. Both Ethel and Louisa feel empowered to remove the storm and create the calm for their patient. In both of their accounts there are no suggestions they interfere in creating the calm. Ethel and Louisa's descriptions do not suggest a disciplinary power of surveillance and an adherence to controlling processes. Louisa states:

> *For me it's the value, I want to make you loved whether that is loved for you or loved for your family looking at you, and how I display that sometimes that is the hand holding and sometimes it is washing the blood away- it's the same value.*

Louisa is describing actions of love. Tillich believes love is foundation of power, which presupposes a unity of love and power (Tillich 1954). The result is a dynamic process where power actualises itself through force and compulsion, and love is the criterion for the compulsion of power. This creates a *power-to*, which differs to a motivation for power-by desire or personal gain (Hawks 1991). *Power-to* involves cooperation, trust and shared leadership, whereas *power-over* involves dominance and force (Hawks 1991). A *power-to* approach is also evident in Hilde's acts of *authority-in-fact* where she tries to share control with the patient, family and colleagues.

Virginia has less autonomy in trying to control the environment and describes a negotiated empowerment where she recognises boundaries, limitations and works around them to achieve what she needs in end-of-life care. Virginia works to remove the roses' thorns for her end-of-life patients. In doing so, Virginia is controlling the situation by making their journey how she would like it to be for them, to make it peaceful as possible. Virginia describes some difficult situations where she has had to 'battle' for what she believes is the right thing to do for her patient and remove the thorns:

> *Dare I say it if you are under the surgeons, still surgeons will fight to the bitter end and sometimes you have to fight for your patient.*

Virginia describes the tensions that can occur with near death situations in the acute setting, and her role in trying to navigate around the different views of 'active management', her understanding and the families understanding:

> *I have to appease everybody because I know the doctor is right, all I really want to do is help my patient let them finish their lives really well. But I am agreeing with the doctor because that is right. That is the legal position, but I am also trying to juggle what the family feel*.

Virginia discusses an example of patients being resuscitated who she believes should not have been:

> *I felt disappointed in myself that my patient got resuscitated when they probably should not have done, therefore didn't die with dignity which upsets me.*

There are similarities with Mary, Nancy and Hilde's need for control, in that, Virginia is trying to be empowered to control the end-of-life situation and remove the thorns. Virginia discusses 'juggling' and 'appeasing' but also having to 'battle' for what she believes is the right action for her patients. This is a conflicting vocabulary that implies a negotiating process and is indicative of an *authority-in-fact*, and a *power-to* approach, with a mutual understanding between the clinician and Virginia motivated by love, which is not suggestive of disempowering actions Nancy and Martha experienced but a negotiated empowerment.

Mary also has less autonomy with end-of-life care and, similar to Virginia, develops a form of negotiated empowerment. Mary describes situations where her idea of the Unicorn; family, the humanness of the end-of-life situation, is conflicted with reality in A&E and her control to provide the care she would want risks being compromised:

> *Trying to create a tranquil environment and keep it calm, and thinking about it made me think that this is important, the equipment, the stillness a nice environment, because I know that particular family will remember, that.. I think you have a responsibility, a duty almost, not to add any further stress or anxiety to a stressful situation,* (Mary)

Mary recalls instances where she has been asked "*How long did I think somebody was going to take to pass away because they want the bed?"*. This creates a conflict for Mary as to controlling events for the patient and the focus of what is important:

> *It's all time targets, so you feel you are constantly against [those] who have their own agenda and targets and pushing people through. Reminding people that patients are human beings and people and it means caring treatment and it's about the care they need, not about how long they have been somewhere and where they need to be next. (Mary)*

Mary is describing the power of surveillance through disciplinary power which compromises her empowered decision making to provide what she sees as appropriate end-of-life care. Foucault's hierarchical observation describes the power of supervisors who are individuals tasked with discreet power of observing, monitoring, assessing other individuals (Foucault 1975). In Mary's example, she is subjected to the 'surveillance' of supervisors. There is evidence of increasing institutional control of professional activities by efficiency targets, audits, quality initiatives which reflect an increasing surveillance mechanism of control on nursing and is indicated in Mary's experience (Tutton, Langstaff 2015). Mary's response is to remind people that patients are human beings and need caring treatment, and in doing so she is displaying characteristics of *authority-in-fact*, a mutual understanding and awareness of the dependence of all of us on each other (Tillich 1954). By making others aware of the humanness and their needs, Mary is responding to this mutual understanding making others aware of the dependence the dying patients have on others, and their responsibility. This suggests Mary is empowered using a *power-to* approach by working cooperatively, collegially motivated by concern and love for the humanness of the end-of-life situation (Hawks 1991).

Virginia's act of 'battling' and negotiation in the decision making are not in keeping with the surveillance and control process of disciplinary power. Virginia's actions follow her individual *power-of-being* and are exercised as and negotiated in decision making as an 'authority in fact'. By doing so Virginia aims to empower and inform her patients and their families:

> *I can remember laughing and joking with a man and him saying to me I don't want them to resuscitate me if it happens again. But I can't tell them that because my wife will go mad. You tell them. We discussed it and he said 'would I tell his wife?' and I said I can't tell your wife, and he said 'what I want you do to it.. perhaps be here when I tell her, because she will go mad, and you need to say that I've had enough'. I found that really hard, but I did do it and she did, and she was so upset, and so wanted to change his mind, but again we had a cup of tea, and she didn't come to terms with it because, I don't know that I could. At least she knew that that was what he wanted more than anything, and she was prepared to go along with his wishes.* (Virginia)

Not all the nurses in this study were empowered to provide end-of-life care supporting the view it is the *individual* nurse that is empowerment to assume control over their practice (Aditi 2012). The variation in degrees of empowerment may be attributed to the different clinical environment, supporting Laschinger, Gilbert et al. (2010) concept of empowerment which focuses on working conditions, including adequate resources such as related nursing knowledge and skills.

To some degree, this study also supports the view that nurses may be powerless due to being subordinate and unequal to others (Christensen, Hewitt-Taylor 2006). However, some of the nurses in this study described a negotiated empowerment to overcome their subordinated position in end-of-life situations. The nurses that described empowering actions represented their power through a *power-of-being* by making decisions that were based on an *authority-in-fac*t. The nurses did not assume a position of authority as 'nurse knows best'; a *power-over* using and *authority-in-principal*. The nurses tried to work collaboratively, juggling, and appeasing where necessary, suggesting a *power-to* and an *authority-in-fact* approach that recognises the mutual dependence of those involved in end-of-life care. In doing so the nurses were not utilising their power out of an authority to control as a desire for themselves, or for 'truth' through adherence to disciplinary power (Florckak 2012; Hawks 1991). The nurses in this study actions suggest a motivation of power to driven by love.

SUMMARY

The experiences of the nurses suggest end-of-life care in the hospital can be unpredictable leading to problems of control. Crossing Antarctica represents this unpredictability as changing clinical situations; difficulty with planning; resourcing; unpredictable life courses; knowing what to do and being sure the right decisions were being made. The unpredictable nature of end-of-life care required the nurses to operate outside the objective knowledge base they held and utilise a more subjugated knowledge, which may be less powerful. This suggests objective technical knowledge alone is insufficient in end-of-life nursing care and the addition of professional artistry in the equipment toolbox may help compensate for this unpredictability. Nurses without sufficient end-of-life care knowledge may focus on the technical rational knowledge skills and clinical processes of end-of-life care and by doing so disempower patients by acting with an *authority-in-principle,* an unjust authority. This can disregard and disempower patients in the caring interaction. Consequently not having the knowledge to can both disempower others as well as disempower the nurse in of end-of-life care.

The nurses described different experiences in relation to disempowerment. Forcing rhubarb describes one nurses' expression of having insufficient knowledge in end-of-life care skills and being 'forced' to do things they are not equipped for. This study suggests nurses who hold lower ranking 'subjugated knowledge' may be disempowered by that lower ranking knowledge. Disempowerment can also occur in situations where the nurses may also belong to a subordinate social community and defer power to the dominant and more authoritative, objectified, knowledge-based group.

“Removing the thorns from the rose” describes situations where nurses can demonstrate empowering actions in end-of-life care through their *power-of-being.* The nurses in this study had varying degrees of power and therefore empowerment, depending on the clinical environment. The nurses described empowering actions represented through their *power-of-being* by making decisions that were based on an *authority-in-fact,* a just authority. The nurses did not assume the position of authority as ‘nurse knows best’, a *power-to* approach using an *authority-in-principal*. The nurses tried crossing Antarctica by working collaboratively, juggling, and appeasing where necessary indicating a *power-to* approach using an *authority-in-fact* by recognising the mutual dependence of those involved in end-of-life care. This suggests a negotiated control, using *authority-in-fact* with an overall provision of end-of-life care aimed at creating calm and tranquillity, motivated by a love.

CHAPTER 7: CONCLUSIONS

UNCOVERING HOSPITAL NURSES EXPERIENCES OF END-OF-LIFE CARE: The Harbour

The aim of this research study was to understand hospital nurses' experiences of end-of-life care. The study also set out to explain hospital nurses' existential experience of providing end-of-life care as well as to understand hospital nurses' attitudes towards death. Other intentions of the study were to explain how hospital nurses' authentic-self is negotiated when providing end-of-life care and to identify how hospital nurses use power and knowledge in end-of-life care situations.

The findings of this study can be represented as "The Harbour". At times the sea can be unpredictable, a challenge and the weather might change at any time, those involved might need to adapt and learn with experience. The harbour is calm, there is warmth in the homes in the harbour, representing human contact and love. Those around the harbour work together using a negotiated empowerment that recognises the mutual dependence of each other, cooperation, trust and love, rather than a 'nurse knows best' approach. The harbour is calm, out of the storm and surrounded by love created by a collaborative and negotiated power. This is how the hospital nurses describe their experiences of providing end-of-life care.

I will now explore the strengths and limitations of the study then go on to explain the implications of the study for future education, policy, research and clinical practice. This will be done using appropriation (to make one's own) in the form of The Harbour Model (*fig46*), which is the conceptualisation and culmination of the interpretations of the nurses' descriptions of their experiences of providing end-of-life care.

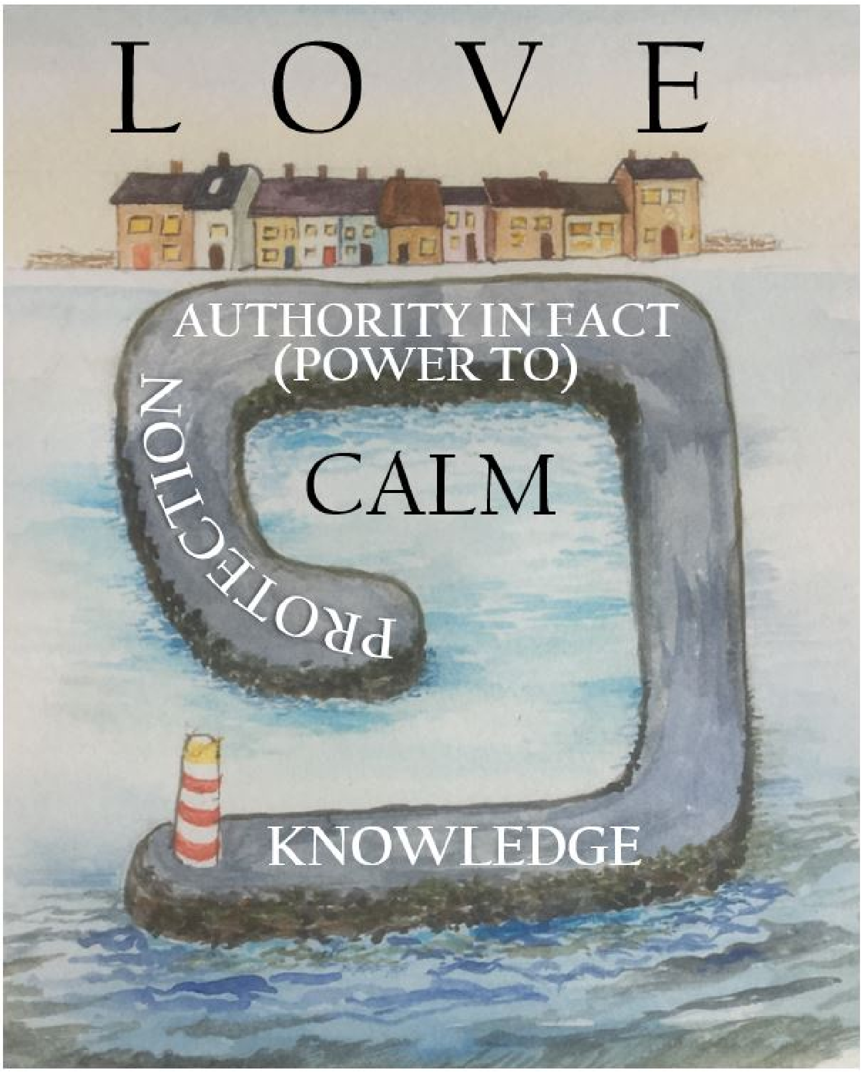


Figure 44 The Harbour Model of Hospital End-of-Life care (Stuart 2020)

CONCLUSION: Strengths and Limitations

Allowing nurses to "say the unsayable" by using visual methods was a strength of this study (Guillemin, Gillam, 2004). By using such an approach, authentic feeling of the nurses' experiences were uncovered which a language only approach may not have exposed. Using the visual images created as discussion points for the elicitation interview allowed the participant to have control over the direction and flow of the interview which was another strength of this study, giving further voice to the participant. One previous study of nurses caring for dying people in hospital (Hopkinson and Hallett 2005) recruited participants from similar clinical environment, whereas, this study recruited from a diverse range of clinical hospital environments, which is more representative of the disparate nature of hospital nursing.

Criticisms of the methodology used have focused on the objectivity of interpretive phenomenology and the findings due to the influence and bias of the researcher on the interpretation of the participants meanings (Creswell, 2007, van Manen, 2017, Grbich, 1999). The absence of epoché strengthens this argument with interpretive phenomenology. Combined with the interpretations of the researcher, there is a risk that the researchers concealed meanings, undisclosed power influence in the interviews and self-interest could produce superficial outcomes (Grbich, 1999). Structured processes for analysing the data are available to help researchers make sure the insights gained reflect that of the participants experience, and not the researchers subjective view and surface description of the experience (Creswell, 2007, van Manen, 2017, Grbich, 1999). Ricoeur's approach to hermeneutic analysis is structured, but not a clear method (Geanellos, 2000), and if it is not understood, it risks the outcomes being influenced by the prejudices of the researcher. To address this an open process of reflexivity was used and close adherence to Ricoeur's hermeneutic arc was maintained.

The outcome from interviewing 10 participants cannot be generalised to the population of all hospital nurses. Interpretive phenomenology is not a science and the experiences interpreted should not be generalised upon (Lopez, Willis 2004). Van Manen (1990 p. 118) states with regards to phenomenology "it is entirely fallacious to generalise from anecdotes … but empirical generalization is not the aim of phenomenological research". Van Manen makes the point that 'anecdotes' should be valued as a poetic narrative which describes a universal truth. What people say and do is accepted as a construction of reality and does not require cross checking to locate 'truth' (Grbich 2007). The strength of phenomenology is through investigation, interrogation, probing, reflection and analysis of individual experiences a depth of understanding which leads to new knowledge and primal insights (Van Manen 2017). The outcome is presented as 'meaningful insights'; inceptual meanings of the phenomenon which reveal the primal meaning and significance of a lived experience (Van Manen 2017). In doing so phenomenology singularises and provides a richness, depth and fullness of meaning that is missed out in a precise scientific generalised account (Van Manen 2017).

All the participants were female and therefore any gender variations of the experience of the phenomena cannot be accounted for. In particular emotions and protection of self among male nurses may be different with a suggestion that male nurses feel uncomfortable with emotional contact (Grey 2010). Male nurses experience of authority in end-of-life is also not addressed in this study. Although male nurses are perceived to hold more power to decision making, they can also be an oppressed group (Brown 2009).

- Further research exploring power and authority in hospital end-of-life care across both genders is needed. Targeted recruitment and purposive sampling would help with selecting participants with end of life experience from both genders and similar clinical settings. Using a phenomenological methodology would capture the experiences of individual nurses' power and authority in end-of-life care. This would also help to develop further the understanding suggested by this study.

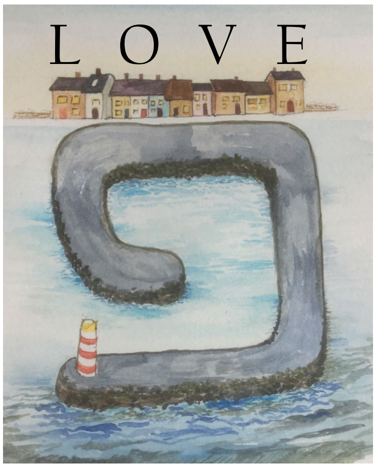
The participants were experienced nurses with between 6 and 45 years in practice. Current evidence suggests length of work experience is positively related to less anxiety about death (Peters et al 2013). As a result, recently qualified nurses may have different experiences, and this is not accounted for in this study.

- Further research exploring more recently qualified hospital nurses' experiences is needed. Targeted recruitment and purposive sampling would help with selecting participants who are more recently qualified. As with this study interpretive phenomenology would help elicit meaningful experiences to understand further those more recently qualified nurses, who's experiences are not accounted for in this study.

The nurses who took part were recruited through a poster campaign or by attending a University course. Consequently, participants self-selected to participate and had an interest in end-of-life care. Therefore, nurses who practice death avoidance behaviour may have been excluded from this study.

- Future research should be considered to include the experiences of nurses who are less comfortable, or even avoid providing end of life care. Observational methods, such as ethnography, may detect observed avoidance behaviours. Ethnography can utilise interviews, but it cannot be assumed the person observed practicing death avoidance would consent to interview. Institutional ethnography is concerned with the world of work and uses conversations as data as well as documentation and observation (Smith 2005). This methodology has the potential to explore praxis and feelings.

CONCLUSION: Implications



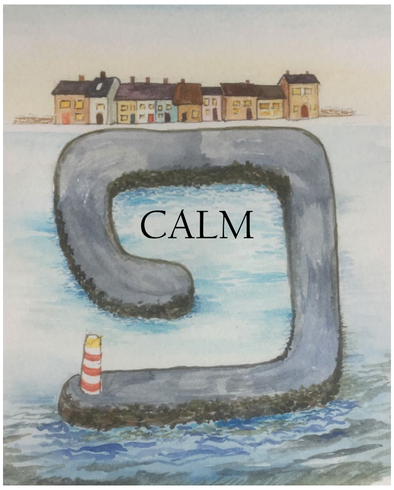
LOVE: Hospital Nurses' Fulfilment of Love in End-Of-Life Care

Love is the unifying element of the harbour. It unites the nurse's actions and provides motivation for their end-of life care. The nurses in this study, working in a hospital environment, describe a desire to create a sense of peace among the chaos of treatment, to do good for Others. They do so *willingly*, being *responsible* for another, being *selfless* in their end-of-life care. They are physically present in an act of 'getting-along-side' and indicate a vitality and passion for people, protecting themselves to continue providing care, transitioning from the storm to the calm of the Harbour they have helped create to protect their patients. By doing so the nurses present love in hospital end-of-life setting as:

> A desire to create calm, grounded by the virtue of natural goodness and a willingness to focus on the individual and their family, to make the most of whatever time they have left.

This study suggests it is love in the combined form of *eros*, *philia* and *agape* that drives hospital nurses' motivation to transition from the storm of treatment to calm and continue caring, despite the personal cost. Love is a not current topic in end-of-life care practice and research, especially hospital nurses' experiences. This study reveals hospital nursing end-of-life practice to be strongly principled by love and not compassion, which is the current emphasis of end-of-life practice. This differs to the current health policy context and nursing practice which concentrates on care being compassionate. Further evidence, debate and discourse between love and compassion would enhance this understanding to assist policy and practice development.

KEY POINTS
• Nurses' love in hospital end-of-life setting is: a desire to create calm, grounded by the virtue of natural goodness and a willingness to focus on the individual and their family, to make the most of whatever time they have left.
• The nurses in this study suggest their end-of-life practice is principled by love, not compassion, in the hospital setting.
• Further research is needed to explore further the understanding of love in end -of-life hospital nursing, identified by this study. Grounded theory explores complex social phenomena based on individual meaning connected to larger discourses and social structures (Bryant, Charmaz, 2011). This methodology would be useful to explore love in hospital end-of-life nursing care.



CALM: Hospital Nurses' Attitudes to Death

The dominant attitude to death among the hospital nurses was one of calm. This attitude to death formed the purpose of the harbour. This contrasts with existing knowledge which suggests a link between nurses' death anxiety and death avoidance and less positive attitudes towards death and caring for the dying among some hospital nurses (Peters et al 2013; Decker 2014; Carr, Merriman 1995; Braun, Gordon et al 2010). The Harbour is predominantly a place of calm, actioned by the nurses' desire to provide end-of-life care motivated by their fulfilment of love. Consequently, this study does not support the evidence that some hospital nurses try to avoid end-of-life care.

The findings indicate hospital nurses assimilate attitudes towards death to guide their end-of-life care. The nurses individual experience of death informed their attitudes to death and guided their end-of-life practice and ideas of a good death. This has differences to revivalist fundamentals of a good death that underpins current practice principles. These attitudes to practice and a good death were not mutually exclusive, but the dominant attitude was *death as calm* described as transitioning the patient from the storm of treatment to the calm of dying and is the purpose of the harbour. Other attitudes to a good death involved are *human connection,* emphasising not being alone, family and knowing the person as an individual, as well as *death as process* or 'doing' care, focusing on the tasks and activities of death and dying.

The Harbour brings together human connection and death as process to transition the patient from the storm to calm, motivated by love. Consequently, a different understanding of hospital nurses end-of-life care is presented. This is not a comparative study between nursing in the palliative care setting and hospital nursing. However, much of the current evidence and policy draws from the specialist palliative care setting making it important to delineate where any differences between the two areas of nursing practice occur. Nursing care in the specialist setting is predicated on revivalist ideas of a good death (Walters 1994). This study suggests Hospital nurses' practice and ideas of a good death are different and are informed by attitudes to death influenced by personal and clinical experience. The hospital focused policy and practice document "*Transforming end-of-life care in acute hospitals*" (NHS England 2015) provides informative but generalised end-of-life advice, such as an aware death and patients preferred priorities of care, indicative of revivalist attitude to a good death. The outcomes of this study suggest variations in attitude to a good death by hospital with nurses providing human presence, working to transition from the trauma of treatment to calm, and a focus on practical care and human presence. This knowledge is helpful by informing future practice priorities for hospital nurses and implies hospital nursing end-of-life is different to other areas of palliative and end-of-life care. This indicates hospital end-of-life nursing to be an emergent field of knowledge for development. Extending the evidence beyond the participants used in this study will contribute further to developing understanding of nurses' attitudes towards death and the development of ideas of a good death in the hospital setting.

KEY POINTS
• Hospital nurses' attitudes to death may be informed by personal and clinical experience and differ to ideas founded on an aware death. For this reason, hospital nurses end-of-life clinical practice may focus of transitioning from the storm of treatment to the calm of dying, as well as the practicalities of end-of-life care and human connection.
• The transitioning from the storm of treatment to the calm of end-of-life care present in hospital situation implies hospital nursing end-of-life to be different to other areas of palliative and end-of-life care.
• Further research to include less experienced nurses and nurses that may deliberately avoid end-of-life care would contribute further to the understanding presented by this study. Institutional ethnography is concerned with the world of work and uses conversations as data as well as documentation and observation (Smith 2005). This methodology has the potential to explore attitudes to dying and praxis of care.

CALM: Hospital Nurses' Existential Experience

There is a paucity of research exploring hospital nurses existential experience of end-of-life care and consequently this study makes an important contribution to that knowledge. Not all the nurses in the study, who were forced to stare at death, described being changed by the experience. Much of the current evidence regarding nurses' existential experiences of providing end-of-life care focuses on the palliative care setting. The findings from this study found hospital nurses live for the moment and were more appreciative of family and of life. A significant finding was the suggestion of not being self-absorbed with unimportant activities. These findings support the view that exposure to death can be life affirming rather than anxiety provoking.

KEY POINTS

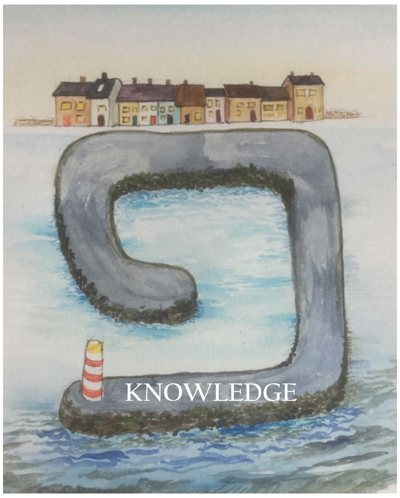
- As a consequence of their existential experience of end-of-life care hospital nurses live for the moment, were more appreciative of family and of life and may be less self-absorbed with unimportant activities.
- Further research explaining the praxis of the hospital nurses' experience would expand the knowledge this study presents. Methodologies such as Ethnography would achieve this although ethically challenging. Further research is also needed expanding the awareness of this study of how hospital nurses' existential self is influenced by change as a result of their existential experiences of end-of-life care.

PROTECTION: Hospital Nurses' Protection of Authentic Self in End-Of-Life Care

The Harbour requires protection to maintain calm. Previous studies have identified that nurses regulate their emotions to protect themselves, with the choice of emotional connection residing in the individual nurse (Roche-Fahy, Dowling 2009; Henderson 2001; Froggatt 1998; McMillen 2008; Hayward, Tuckey 2011). This study supports this concept but adds understanding by further explaining how hospital nurses regulate their emotions when providing end-of-life care. Three forms of protecting authentic-self from the emotions encountered while providing end-of-life care were described; professional identity; defence of self and being someone else. *Professional identity:* nurses used their professional image to distance their authentic-self and contain their emotions by being professionally removed but appearing approachable. *Defence of self:* a shield to defend against the potential emotional trauma of the situation for some nurses by cognitively engaging by presenting themselves as approachable, understanding and compassionate, but emotionally distant. *Being someone else:* taking on an identity in practice different to one's authentic-self. These containments of emotions enabled the nurses to continue with end-of-life care while protecting their authentic-self. The overall outcome suggests that the participating nurses were successful in utilising different forms of protecting authentic-self by being cognitively present but emotionally distant while providing end-of-life care.

This study furthers the understanding of how hospital nurses emotionally protect themselves to continue providing end-of-life care, rather than avoidance. The outcome for practice suggests hospital nurses may sacrifice their own needs and deny their vulnerability, with potential long-term physical and psychological consequences. The consequence of concealing authentic- self is to make inauthentic- self visible, which can lead to emotional dissonance. This has known consequences including risk of burnout, depression, anxiety, emotional exhaustion and depersonalisation. The nurses in this study also evidence unrecognised vulnerability and an absence of formal support in the hospital setting. As a consequence, practice areas need to recognise the emotional burden and vulnerability of their nurses providing end-of-life care and take appropriate measures to mitigate against the effects. Effective defence mechanisms should be integrated into education curriculum, and strategies to mitigate against the effect of end-of-life care should also be reflected in policy.

KEY POINTS
• Hospital nurses protect their authentic- self to be able to continue caring. Consequently, they are at risk of stress and emotional burnout. This needs recognising in the clinical setting.
• Hospital nurses are denied the opportunity to express their emotions in the clinical setting. The absence of formal support and unrecognised vulnerability risks stress and emotional burnout. This needs recognising in the clinical setting.
• Clinical areas need to take appropriate measures to help hospital nurses to mitigate against the effects of providing end-of-life care.
• Effective emotional defence mechanisms should be evaluated and integrated into education curriculum



KNOWLEDGE: Hospital Nurses Utilisation of Knowledge in End-Of-Life Care

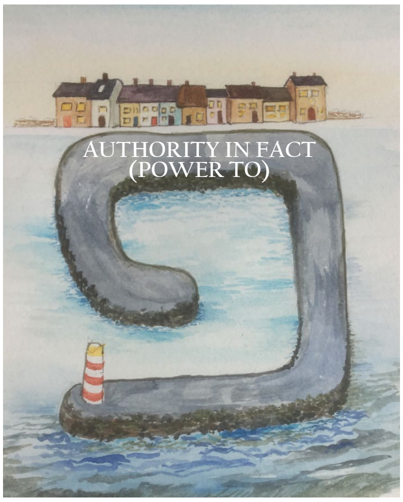
Knowledge is required to create calm in The Harbour and nurses are expected to know what to do (Gilbert 1995; Bradbury-Jones, Sambrook et al. 2007; Henderson 1994). The experiences of the hospital nurses in this study suggest this may not be reality. They explain end-of-life care to be like crossing Antarctica; unpredictable due to changing clinical situations and an unstable life course, leading to difficulty with planning and resourcing. The result for some of the nurses was not knowing what to do, being uncertain with their end-of-life skills and knowledge.

The nurses' attitude towards death as calm, led to consistency in expressing difficulty with end-of-life knowledge in achieving this approach to a good death. There is inconsistency in perception regarding the end-of-life education the nurses need. One nurse describes not being confident in their knowledge, others describe having sufficient knowledge in end-of-life care to be able to make a clinical decision, but not being heard, suggesting their knowledge has less value and subjugated.

Appropriate knowledge is needed to create and maintain calm in The Harbour. The Harbour Model values the objective technical and practice focused knowledge of end-of-life care such as managing equipment, monitoring symptoms, administering drugs, but recognises this may be insufficient when responding to unpredictable meaningful patient interactions. The hospital nurses in this study explain end-of-life care to be unpredictable due to changing clinical situations and an unstable life course leading to difficulty with planning and resourcing. The outcome for some of the nurses was not knowing what to do, being uncertain with their end-of-life skills and knowledge. The unpredictable nature of end-of-life care required the hospital nurses to operate outside their objective technical knowledge base and utilise a less authoritative subjugated knowledge. This may contribute to the uncertainty of end-of-life situations. The suggested outcome is for end-of-life education to be available as a combination of technical, objective based knowledge as well as knowledge based on principles, frameworks and reflection that helps nurses manage the messy nature of end-of-life care.

KEY POINTS
• Hospital end-of-life nursing care is unpredictable requiring a combination of objective, technical knowledge with knowledge based on principles, frameworks and reflection.

- End-of-life education needs developing for hospital practitioners. This should be based on objective, technical knowledge and knowledge based on principles, frameworks and reflection.



AUTHORITY: Hospital Nurses Utilisation of Control and Power in End-Of-Life Situations

To maintain calm and protection in the Harbour a collaborative power is required. Power and empowerment are interwoven with the individual nurse assuming control over their practice to fulfil their professional responsibilities, but not all nurses enjoy the same position of empowerment (Aditi 2012; Bradbury-Jones, Sambrook et al. 2007; Christensen, Hewitt-Taylor 2006). The findings of this study echo this to some degree and, with little other knowledge depicting hospital nurses' experiences of control and power in end-of-life care, this study expands upon current awareness.

'Removing the thorns from the rose' describes the nurses empowering actions in end-of-life care through their individual *power-of-being* (the recognition of the joint power an individual holds as self-affirmation) removing the thorns that are preventing the patient from transitioning to a peaceful end. This was achieved by being collaborative, 'juggling', 'appeasing' being motivated by a fulfilment of love. These are not indicators of the nurses using a power motivated by desire, self-gratification or personal gain but are altruistic, using cooperation, trust and shared leadership. This is an *authority-in-fact (or power-to)* use of authority recognising the mutual dependence of each other in end-of-life care and the nurse “does *not* know best”.

Using this collaborative authority, the nurses transition stormy seas to calm in The Harbour. In this study the nurses held varying degrees of control and power in end-of-life decision making. Most of the nurses used some form of authority-in-fact; a negotiated power with the level of collaboration depending on the clinical environment. Some form of negotiated empowerment to transition from the storm to the calm was needed in most situations. This study elaborates on the nurses’ activity in providing end-of-life care and suggests hospital nurses are involved in negotiating end-of-life patient care. This should be recognised so that the potential skills nurses need to lead and manage end-of-life care in hospitals can be realised and developed. Recognition of this form of power will also help with collaborative leadership of end-of-life care.

KEY POINTS
• Hospital nurses use a collaborative and negotiated form of authority in end-of-life care. They do not use an authoritative ‘nurse knows best’ approach.
• Further research developing the understanding of nurses use of negotiated power in end of life care found in this study is needed. Institutional ethnography is concerned with the world of work and uses conversations as data as well as documentation and observation (Smith 2005). This methodology has the potential to explore how nurses apply authority in their end-of-life care.

CONCLUSION: Summary

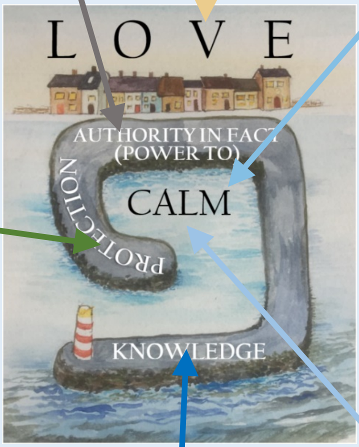
THE HARBOUR MODEL

LOVE in End-of-life Care. Love in hospital end-of-life nursing is a desire to create calm, grounded by the virtue of natural goodness and a willingness to focus on the individual and their family, to make the most of whatever time they have left.

AUTHORITY in End-Of-Life 'Removing the thorns from the rose' describes the nurses empowering actions in end-of-life care. Through these by the action the nurses the thorns that are preventing the patient from transitioning to a peaceful end are removed. This is achieved by being collaborative, 'juggling', 'appeasing'. This is not indicative of a power motivated by desire, self-gratification or personal gain but altruistic, indicative of *power-to* involving cooperation, trust and love.

Attitudes to Death
This study indicates hospital nurses assimilated attitudes towards death to guide their end-of-life care, based on experience and exposure to death. These attitudes to death are; *death as calm* which was the dominant attitude explained that eventually, after the trauma, there will be calm; *death as process* focusing on the tasks and activities of death and dying, with a provision of care that is physically focused; *death as human connection* emphasising not being alone, family and knowing the person as an individual.

PROTECTION: Management of Authentic Self
The nurses protected their authentic-self from emotions encountered while providing end-of-life care. Three forms of protecting authentic self were described; professional identify, defence of self and being someone else. The nurses were successful in suppressing their authentic-self, and in doing so, denied their vulnerability. The nurses also described being denied the expressions of feelings at work, implying unmet emotional needs and vulnerability when providing end-of-life care. The consequence of concealing authentic-self is to make an inauthentic-self visible, which can lead to emotional dissonance. This has known physical and psychological risks.



Hospital Nurses Existential Experience
Not all the nurses in the study described being changed by their experiences. Those that did explained, were more appreciative of family and of life. A significant finding was the suggestion of not being self-absorbed with unimportant activities.

KNOWLEDGE In End-Of-Life Care
The hospital nurses in this study suggest end-of-life care to be unpredictable. The result for some of the nurses was not knowing what to do, being uncertain with their end-of-life skills and knowledge. The messy nature of end-of-life situations required the nurses to operate outside their objective, technical knowledge base; managing equipment, monitoring symptoms, administering drugs. Supplementary education may be needed that recognises the uncertainty of end-of-life care and builds knowledge based on principals, frameworks and reflection, more suitable to messy end-of-life situations.

Figure 45 Summary (Stuart 2020)

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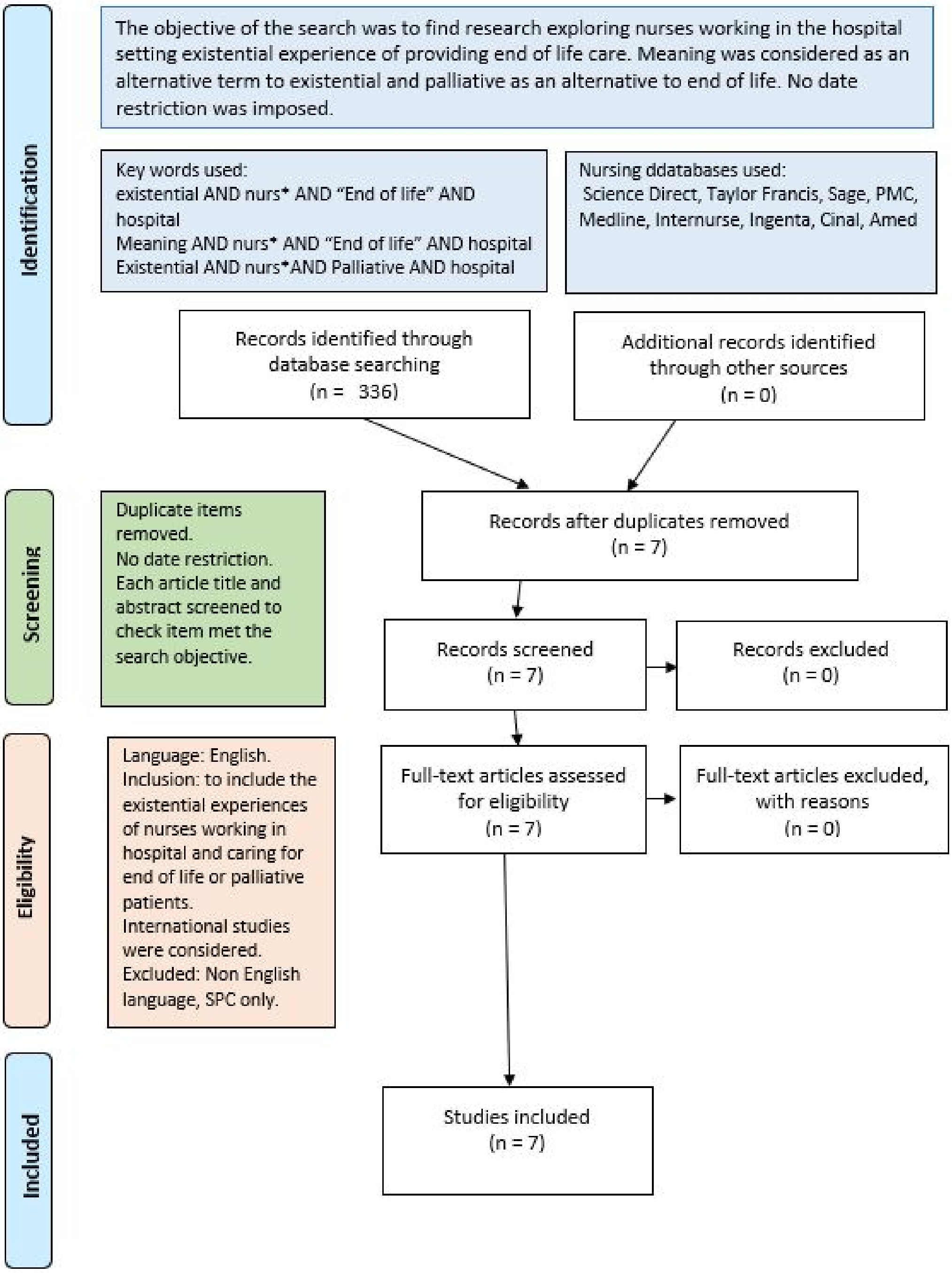
APPENDIX 1: Search Strategy

1 SEARCH STRATEGY: EXISTENTIAL EXPERIENCE



The objective of the search was to find research exploring nurses working in the hospital setting existential experience of providing end of life care. Meaning was considered as an alternative term to existential and palliative as an alternative to end of life. No date restriction was imposed.

Key words used:
existential AND nurs* AND "End of life" AND hospital
Meaning AND nurs* AND "End of life" AND hospital
Existential AND nurs*AND Palliative AND hospital

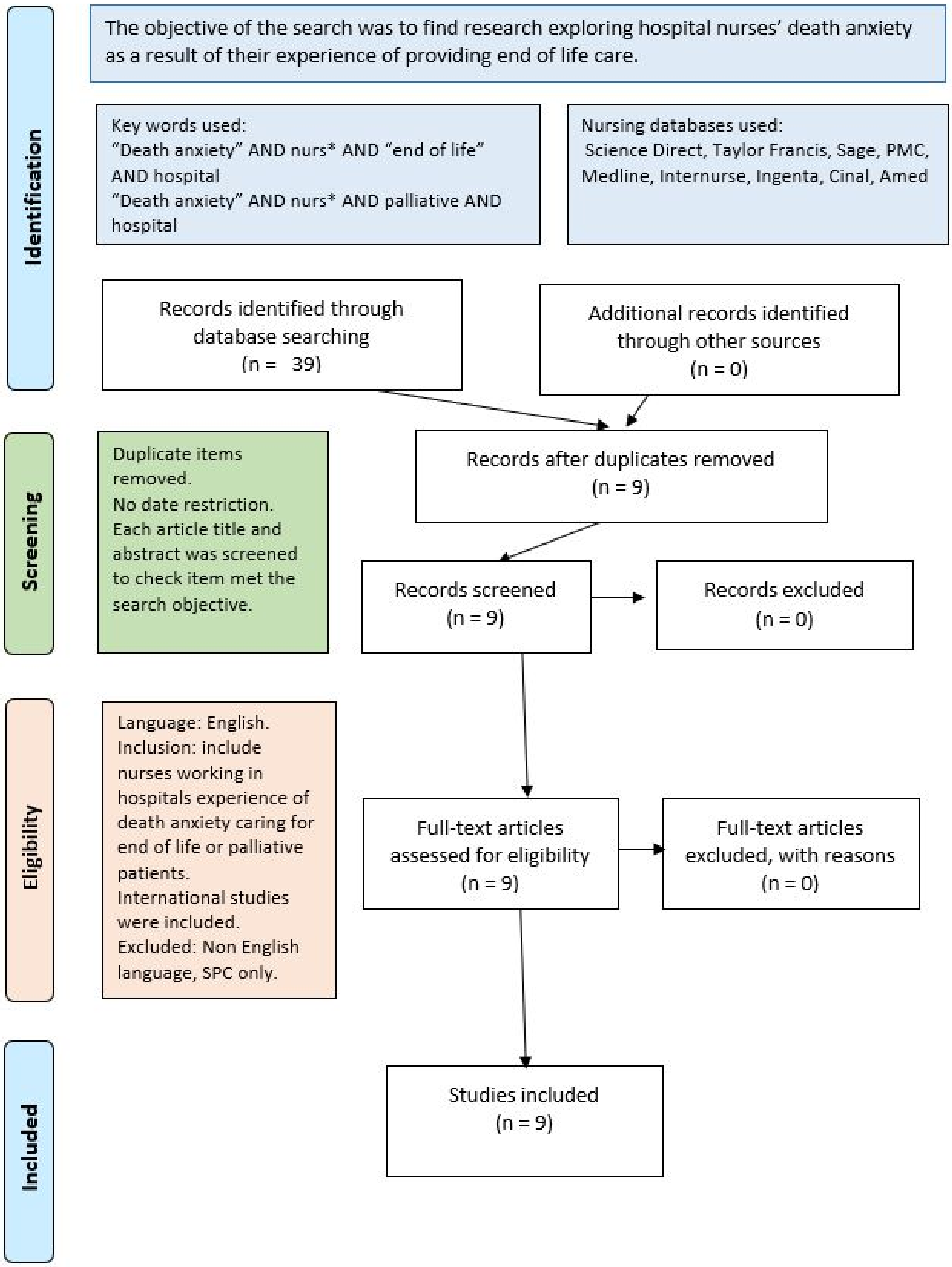
Nursing ddatabases used:
Science Direct, Taylor Francis, Sage, PMC, Medline, Internurse, Ingenta, Cinal, Amed

Duplicate items removed.
No date restriction.
Each article title and abstract screened to check item met the search objective.

Language: English.
Inclusion: to include the existential experiences of nurses working in hospital and caring for end of life or palliative patients.
International studies were considered.
Excluded: Non English language, SPC only.

Adapted From: Moher D, Liberati A, Tetzlaff J, Altman DG, (2009).

2 SEARCH STRATEGY: DEATH ANXIETY



The objective of the search was to find research exploring hospital nurses' death anxiety as a result of their experience of providing end of life care.

Key words used:
"Death anxiety" AND nurs* AND "end of life" AND hospital
"Death anxiety" AND nurs* AND palliative AND hospital

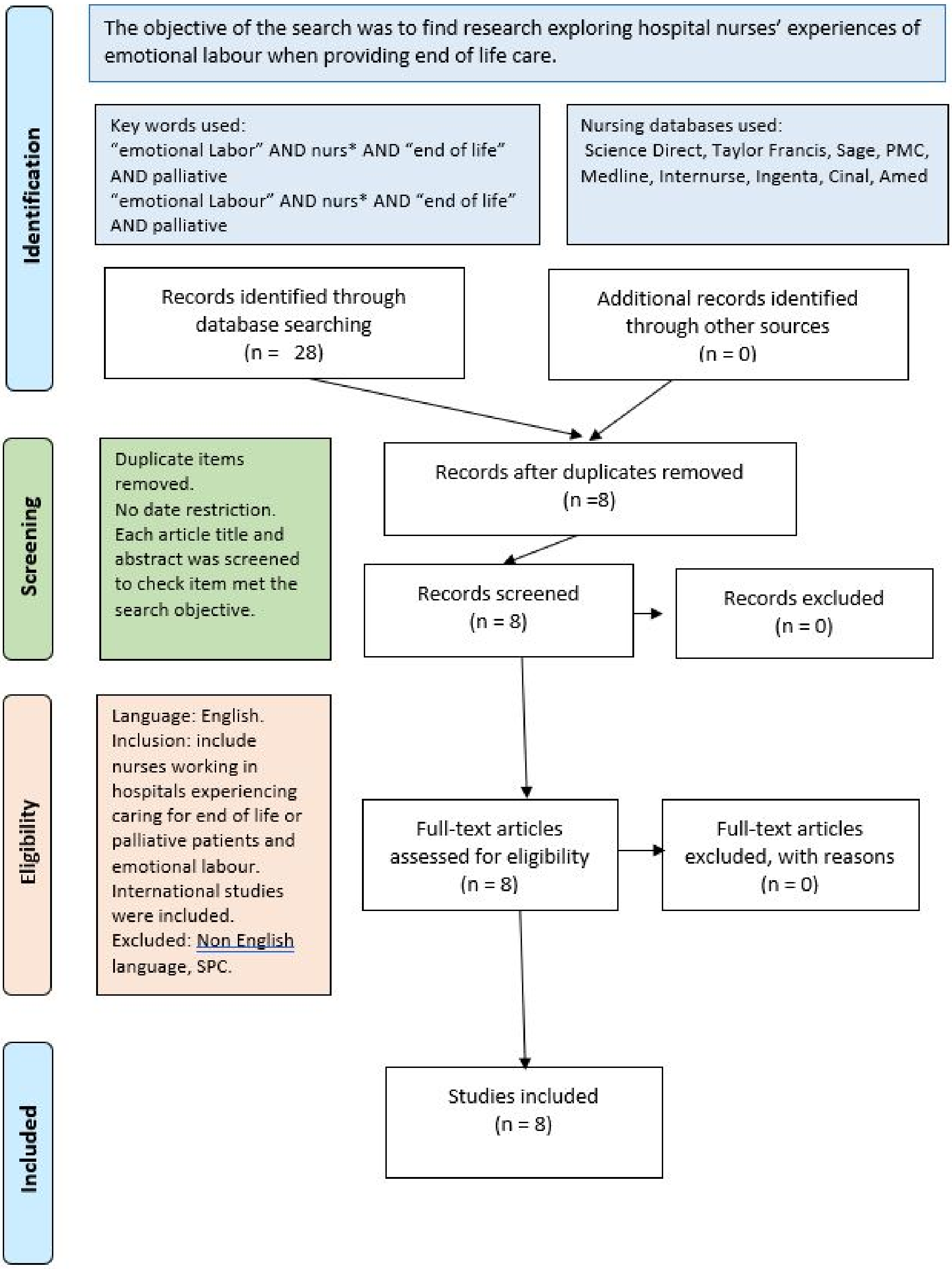
Nursing databases used:
Science Direct, Taylor Francis, Sage, PMC, Medline, Internurse, Ingenta, Cinal, Amed

Duplicate items removed.
No date restriction.
Each article title and abstract was screened to check item met the search objective.

Language: English.
Inclusion: include nurses working in hospitals experience of death anxiety caring for end of life or palliative patients.
International studies were included.
Excluded: Non English language, SPC only.

Adapted From: Moher D, Liberati A, Tetzlaff J, Altman DG, (2009).

3 SEARCH STRATEGY: EMOTIONAL LABOUR



The objective of the search was to find research exploring hospital nurses' experiences of emotional labour when providing end of life care.

Key words used:
"emotional Labor" AND nurs* AND "end of life" AND palliative
"emotional Labour" AND nurs* AND "end of life" AND palliative

Nursing databases used:
Science Direct, Taylor Francis, Sage, PMC, Medline, Internurse, Ingenta, Cinal, Amed

Records identified through database searching (n = 28)

Additional records identified through other sources (n = 0)

Duplicate items removed.
No date restriction.
Each article title and abstract was screened to check item met the search objective.

Records after duplicates removed (n =8)

Records screened (n = 8)

Records excluded (n = 0)

Language: English.
Inclusion: include nurses working in hospitals experiencing caring for end of life or palliative patients and emotional labour.
International studies were included.
Excluded: Non English language, SPC.

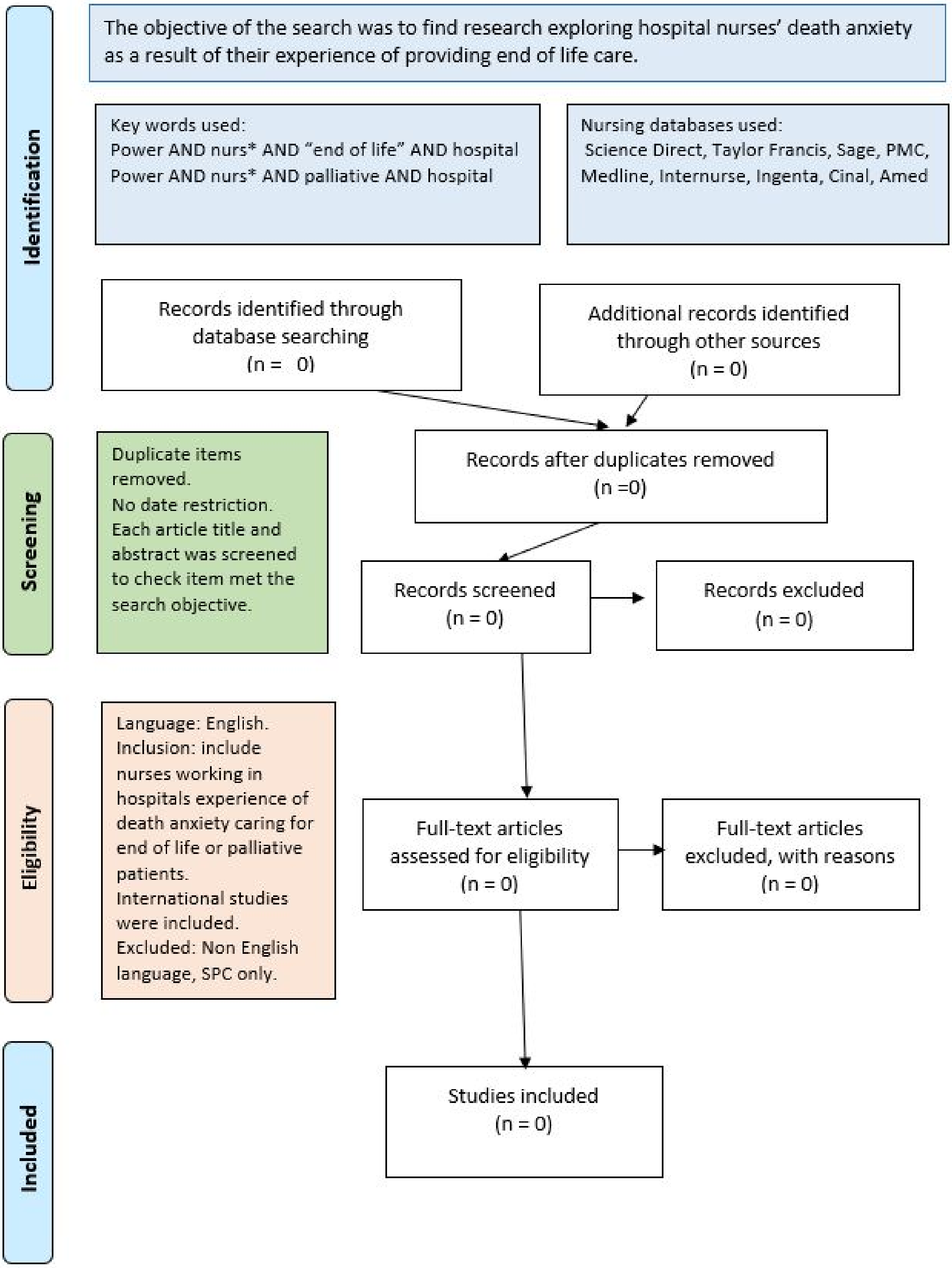
Full-text articles assessed for eligibility (n = 8)

Full-text articles excluded, with reasons (n = 0)

Studies included (n = 8)

Adapted From: Moher D, Liberati A, Tetzlaff J, Altman DG, (2009).

4 SEARCH STRATEGY: POWER



The objective of the search was to find research exploring hospital nurses' death anxiety as a result of their experience of providing end of life care.

Key words used:
Power AND nurs* AND "end of life" AND hospital
Power AND nurs* AND palliative AND hospital

Nursing databases used:
Science Direct, Taylor Francis, Sage, PMC, Medline, Internurse, Ingenta, Cinal, Amed

Records identified through database searching (n = 0)

Additional records identified through other sources (n = 0)

Duplicate items removed.
No date restriction.
Each article title and abstract was screened to check item met the search objective.

Records after duplicates removed (n =0)

Records screened (n = 0)

Records excluded (n = 0)

Language: English.
Inclusion: include nurses working in hospitals experience of death anxiety caring for end of life or palliative patients.
International studies were included.
Excluded: Non English language, SPC only.

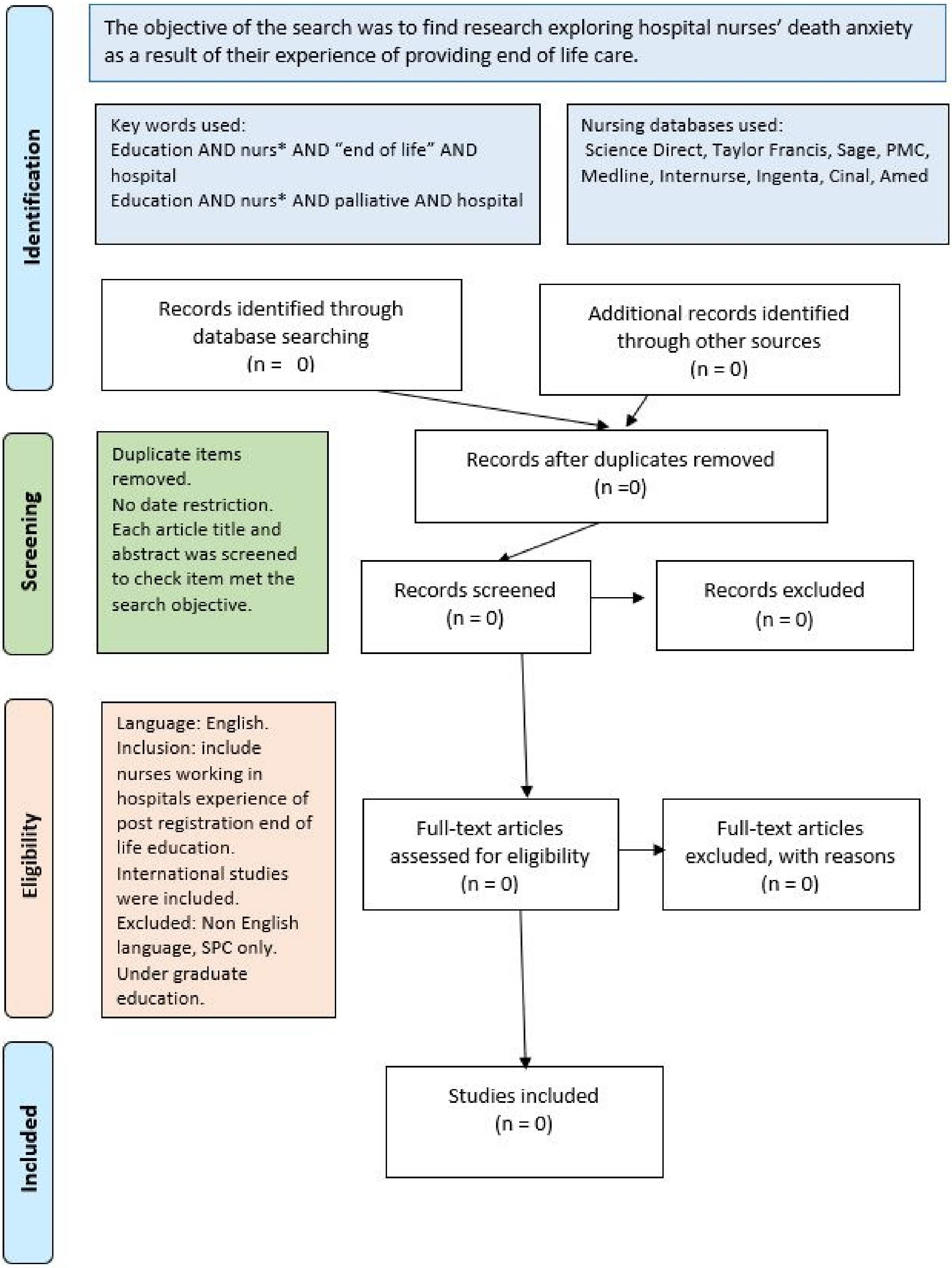
Full-text articles assessed for eligibility (n = 0)

Full-text articles excluded, with reasons (n = 0)

Studies included (n = 0)

Adapted From: Moher D, Liberati A, Tetzlaff J, Altman DG, (2009).

5 SEARCH STRATEGY: EDUCATION



The objective of the search was to find research exploring hospital nurses' death anxiety as a result of their experience of providing end of life care.

Key words used:
Education AND nurs* AND "end of life" AND hospital
Education AND nurs* AND palliative AND hospital

Nursing databases used:
Science Direct, Taylor Francis, Sage, PMC, Medline, Internurse, Ingenta, Cinal, Amed

Duplicate items removed.
No date restriction.
Each article title and abstract was screened to check item met the search objective.

Language: English.
Inclusion: include nurses working in hospitals experience of post registration end of life education.
International studies were included.
Excluded: Non English language, SPC only.
Under graduate education.

Adapted From: Moher D, Liberati A, Tetzlaff J, Altman DG, (2009).

APPENDIX 2: Ethics Submission.

CONTEXT: The study is a professional doctoral thesis.

Title: UNCOVERING THE ESSENCE OF END-OF-LIFE NURSING CARE

Research Question; What is it like for a nurse to experience end-of-life care in the general acute setting?
Objectives : To explore how the nurses 'self' is negotiated when providing end-of-life nursing care.
To explore the nursing culture relevant to end of life care
To explore nurses' motivation in relation to end of life care.

1 Does the research involve ethical issues?

In this study the combination of visual method and elicitation interview requires a reliving of experience. As identified this has the potential to cause participant to relive past experiences they have managed to avoid emotional engagement with, which may cause distress to the participant effecting their wellbeing and emotional safety. In addition, justifying the authenticity of the visual work and confirming the ownership needs to be clear.

Promoting Participant Safety and wellbeing. It is possible due to the nature of the subject being explored, and the elicitation focus of the interview, that participants may become distress during the interview. This will be managed at several points; the researcher is experienced in supporting distressed patients and has transferable skills in counselling; participants will be reminded of their right to decline to answer and to withdraw at any point without recrimination and reason; participant will be given the option to reschedule if they choose to; support services, employer assisted programs and professional supervisory support links will be made available in the interview if needed. Line managers and employers will not be notified without the consent of the participant, but participants will be encouraged to make use of the opportunities that are available to them.

Ownership. Creation of the visual image will be witnessed by the researcher which will confirm authenticity and photographed by the researcher. Participants will be asked to sign consent forms for reproduction of the images.

Researcher safety and wellbeing. The experience of the researcher identifies that although the researcher is comfortable with the subject matter, there can still be triggers that may cause the researcher to witness unexpected responses to situations. Having the opportunity during supervision to voice concerns and debrief would serve as an opportunity to reflect on the situation. If the effects of the interview are having a detrimental effect on the researcher's health and wellbeing formal external assistance may considered necessary through the employer assisted programme and occupational health.

As participants will be nursing staff not patients full NHS Research ethics approval is not required.

2. Who are the subjects or participants?

The participants for this study are registered nurses working in acute hospital clinical areas who are exposed to end of life care as part of their working life. Nurses that specialise in end of life care, such as hospice and oncology will be excluded from the study, as will nurses with no end of life care experience. A purposive sample will be recruited of 10 participants.

Participants will be recruited through advertising at education events, conferences, local and national nursing forums, mentor updates, and post graduate courses. The advertising will include basic information of the study and a web link and email address to express an interest for further information. Interested participants will receive more detailed information of further enquiry in the form of a participant information pack. The pack will include details of the study, what is involved, the length of time, there is no remuneration, the purpose of the study and the expected benefit to patient care, the option to withdraw, risk of harm, confidentiality, and viewing results. Also contact information for the researcher. Interested participants will be contacted by the researcher and, once the content form has been returned, an interview will be scheduled. Participant information (page 160) and advertising (page 167) is included in the application information.

3. Where is the research being carried out? What are the potential hazards?

Participants will be able to choose the location of the interview. This will be for ease of access, traveling, emotional safety, privacy, cost but also the ability to record and use the visual imagery needs to be considered. Confidentiality of the elicitation information will need to be considered alongside the choice of location.

4. What papers and permissions are required?

The researcher will have personal identification and clear DBS. The researcher will also have permission from relevant organisations to conduct the research.

5. What activity will the participants undertake?

Participants will be invited to attend a one and a half hour research event. Participants will be asked to recall and reflect on their feelings of caring for someone who is dying. They will then be asked to choose from a number of magazines to select images that represent their feelings and experiences. The emphasis will be on using the images as a metaphor for their feelings about end-of-life nursing. The discussion of their feelings will be explored in the subsequent elicitation interview. The elicitation interview will explore what participants experienced and what meaning they gave to their actions.

The format for the interview is an elicitation interview which will follow the format of provocative questions that allow participants to tell their story, with a light touch approach to the interview schedule, the questions aimed at providing minimum content and control. A broad set of interview questions as prompts can be found on page 164. To passively elicit information the researcher will use active listening skills to support and encourage the participant with their response with minimal active intervention from the researcher.

6. How will data be collected, recorded and stored?

The creation of the visual item will be photographed, and the elicitation interview will be audiotaped, with the consent of the participants. Consent to retain and reproduce the visual image will be obtained from the participant. The participant identity will be coded during the data analysis process to allow for identification, should it be necessary to return to the participant for clarification later in the analysis. Once the study has reached the publication stage identification of the participant will be destroyed.

The elicitation interview will explore what participants experienced and what meaning they gave to their actions. Interviews will be audio recorded and transcribed by the researcher. Additional transcription services may be used.

Consent will be gained from participants for the storage of transcriptions of the interviews. As with the photographs participant identity will be coded during the data analysis process to allow for identification, should it be necessary to return to the participant for clarification later in the analysis. Once the study has reached the publication stage identification of the participant will be destroyed. All data collected as part of the study will be stored in locked cabinets and transferred securely following the guidelines set by the Data Protection Act and Freedom of Information Act

-Where data is stored electronically, it will be placed on a secure server reserved specifically for the principle investigator and only accessible to them using a password.

A data management plan can be found on pg 165

A copy of the consent form can be found on page 168

7. What participants will be involved other than the researcher?

Participants will be informed prior to the interview that unless participants request to bring a chaperone or partner there will be no other attendees. The principal researcher will be conducting the interviews. No other researcher or administrator will be attending. The audio recording will be transcribed by the principal researcher. Private transcription services may also be used. No translation services will be needed.

8. What information will be provided to enable informed consent and the right to withdraw?

Informed consent will be obtained in writing- potential participants will be given a participant information pack which will contain detailed information about the project including background information on the project, the purpose of the interview, how confidentiality will be maintained, and how feedback will be given. In addition, due to the potential sensitivity of the topic, contact information for support organisations will be made available.

9. How will Confidentiality and if appropriate Anonymity be maintained?

Confidentiality will be maintained at all points of the study. No private information about individuals, or work organisations will be disclosed. After participation in the interviews, no information that can lead to the identification of individuals will be kept. Where names are needed, an alias will be used. Work environments will be kept generic e.g. primary care. Following transcription participant identity will be coded and personal information kept secure following data protection. Feedback to the participant may be needed requiring identification of the participants data during analysis. Once data analysis has been completed and the thesis is in the writing stage participant identity will be anonymised. At this stage transcriptions will be retained but participant identification and personal information will be destroyed.

Participant will be informed that they words may be used in the writing up of the study as direct quotes or extracts to illustrate points in the findings. Attention to this will be drawn to in the consent form.

It is possible that due to the nature of the discussion patient information, or identifiable information may be disclosed by the participant. This will remain bound by the confidentiality of the research and the names and other identifiable information will be removed at transcription stage. Participants will be reminded of confidentiality in the participant information, but not in the interview as this may alter the interview dynamics and disclosure.

10. What arrangements will be made for feedback and to respond to any concerns that the research activity may have raised for the participant?

Should participants become distress during the interview they will be asked if they wish to continue. They will be reminded that participation is voluntary, and they have the right to withdraw at any point, or they can return to take part at another time. Although there are no physical risks to the participants, the topic for discussion in the interviews may cause concern for some participants. Information for further support will be made available in the interview. The open nature of the interview process means the interviews will be unstructured and unpredictable and the topic of end of life care may open up issues previously hidden by the participant. While it is important to recognise the value of the participants contribution and being open to the experience, it is also important no harm should come to the participant. Should participants become distressed during the interview, the researcher will address the situation during the interview and make recommendations with the participant depending on the situation for further support. This will depend on the nature of the situation and the decision of the participant. The topic and the researcher's expertise are the same and the researcher will provide participants with further information, only if requested, should they wish to make use of it. The decision to access counselling services, or inform line managers, lies with the participant. Line managers and employers will not be notified without the consent of the participant, but participants will be encouraged to make use of the opportunities that are available to them.

11. Might the research uncover matters that are of wider concern?

Each participant will receive a summary of the research at data analysis stage together with contact details of the researcher. The open nature of the interview process means the interviews will be unstructured and unpredictable. Support for the participant has been discussed.

It is possible during the interview the participant may share information that could be considered unsafe. If the participant recognises this as unsafe post interview they will be encouraged to follow correct procedure in disclosing this. If the participant does not recognise this as unsafe practice post interview discussion may be needed to explore the situation in more depth. This may require line management involvement and notification by the researcher. Were the practice of others is raised as a concern the clinical area managers will be informed and the participant will be encouraged to raise an incident report, inline with the trust policy.

Depending on the nature of the practice and the participants actions it may be necessary for the researcher to take further action and inform the relevant practice areas for further investigation if patient safety or care is compromised. Participants will be informed of this.

The participant information will also inform participant of the researchers duty to report practice that is of concern.

12. Any other comments?

Giving participants a choice of interview location, including the participants own home, can put the researcher at risk. In the absence of a lone worker policy the Suzy Lamplugh Trust advice of Lone worker personal safety and keeping safe will be used. (Suzy Lamplugh Trust 2017). The following has been adapted from the resource.

1. The researcher will ensure they have easy communication with a designated other via mobile phone.
2. As part of the interview preparation, consideration will be given to possible exit strategies. Making note of how doors open, latches, and furniture arrangements so an easy exit can be given.
3. If the researcher is uncomfortable during the interview, stop the interview and leave.
4. The researcher is to inform a designated person of the date and time of the interview and, to protect confidentiality, provide them with a sealed envelope contacting the details of the personal details of the participant and location of the interview. The researcher is to inform them before entering the interview area and at what time they are likely to finish, giving a realistic time of completion, checking for phone signal. If no contact is made at the allocated time the designated person will assume the worst raise the alarm by contacting the police.

Participant Information

Study Title: UNCOVERING THE ESSENCE OF END-OF-LIFE NURSING CARE

Invitation

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important that you understand why this research is being undertaken and what it will involve. If, having read the following information, you are unclear about any aspect related to this study please contact me, Peter Stuart. My contact details are below.

Purpose of the research project

Very little is know about nurses experiences of end of life care and how they manage their personal feelings when caring for someone who is dying. Consequently this study aims to explain how nurse's personal feelings are managed. By doing so the study will provide practitioners with a better understanding of the skills nurses required to cope with end-of-life nursing care, and for nurse leaders to resource and support nursing staff.

Who the researchers are:

The researcher is myself, Peter Stuart, and I am a Professional Doctoral student undertaking a thesis module at the University of Northampton. I am also a registered nurse and a senior lecturer in the Pre-registration Nursing team. Previously I have worked in the hospice setting and several years as a CNS in Palliative care (Macmillan Nurse). As a professional doctoral student I am conducting original research that has a direct influence on nursing practice

What the study involves:

If you agree to take part in this study you will be invited to take part in a one-one interview with me.

The interview will last for approximately one and a half hours. I will bring lego, modelling clay, paper and pencil for you to use and ask you, during the interview, to use one of these materials to create a representation of what it is like to care for someone at the end of their life. No artistic ability is necessary, this is simply a way of uncovering thoughts and feelings about the experiences of end of life care. You don't have to do this, we can just talk. However, working creatively in this way can help people to express difficult experiences. Anything you create will be photographed with your consent and used as part of the research data.

What are the risks?

There are no physical risks to you as a person; you do not have to take part. The discussion in the interview is an open discussion but it is about end of life care and may trigger upsetting memories. The researcher is experienced in supporting people in such situations and will be sensitive to any problems that arise. You will be able to stop the interview at anytime, withdraw from the study at that point, or continue at another time.

What will happen to the information?

All information will be treated as confidential. Personal information will be stored according to the Data Protection Act (1998). This includes storing information about you where it can be only be accessed by me. Interview material will be anonymised and used by me for analysis. This includes removing any material which might identify you prior to its inclusion in research outputs (thesis and publications arising from the study). This anonymised material may also be shared with my supervisory team.

The information you give during the interview will be stored in a locked filing cabinet. The identity of each participant (you) will remain anonymous throughout the research process and in the report. I will do this by assigning a number for your views. From then on you will be known only by your number. Once the research is completed, any information identifying you will be destroyed. When I write any report of the study, it will not be possible to identify you or anyone else who participated in the study.

The information you give will be for research purposes, education, practice development and future research. It will not be given to any other party.

In the unlikely situation where practices that may be considered as harmful to patients, their families or other health care professionals are mentioned, I would be obliged to inform the appropriate agencies.

Do I have to take part?

No, you are *invited* to take part in the research. Only if you feel happy to proceed should you complete the consent form. If you do not want to participate, that is fine; you have the right not to participate and there will be no consequences for you should you choose not to take part. You can also stop at any time if you do not want to finish the study; just let me know when you are ready to stop.

What will happen with the findingsfindings?

A final report will be completed as part of the study and upon successful completion the findings (in the form of an executive summary) will be disseminated to colleagues in the University, the wider professional community through seminars, workshops and specialist conferences. Findings will also be published in nursing journals and practice journals, and used to inform education and future research. I will share a summary of the research with you.

Thank you for taking time to read this information.

Contact the Researcher:

For further information about the evaluation please contact:

Peter Stuart – (Professional Doctoral Student)

01604 893709 or peter.stuart@northampton.ac.uk (preferred method of contact)

If I am not there, please leave a message and I will call you back as soon as I can

Who has checked this research?

If you have any concerns about the study and your involvement,, please contact my Director of Studies and Research Supervisor**:**

Dr Sarah Neill

Associate Professor in Children's Nursing

Nene House

Institute of Health and Wellbeing

University of Northampton

sarah.neill@Northampton.ac.uk

Sources of support:

Information on appropriate support services will be discussed with you in the interview and made available to you.

RCN Peer support (if RCN Member) is a peer support programme for members with health issues related to their work https://www.rcn.org.uk/get-help/member-support-services/peer-support-services

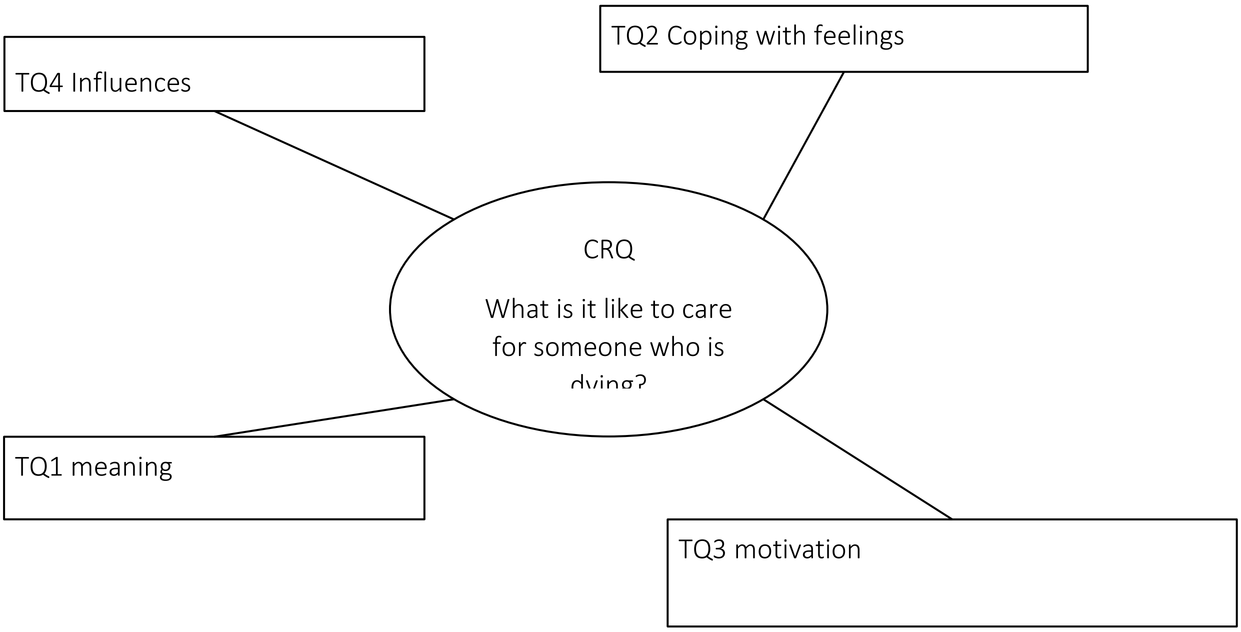
NHS employees health and wellbeing is a national strategy helping staff and trusts with health and well being issues at work.
http://www.nhsemployers.org/sitecore/service/nolayout.aspx?item=%2fhealthyworkplaces%2fway-health-wellbeing%2fpages%2fstrategiespoliciesguidance&layout=%7b00000000-0000-0000-0000-000000000000%7d&device=Default

Your trust Occupational health can also link to employer assisted consoling programmes if the issues at work are causing you distress and anxiety leading to stress and sickness.

Thank you for your interest and support. If you would like to participate in the research, please contact Peter Stuart via email peter.stuart@northampton.ac.uk **with your name, organisation and personal contact details and he will contact you to make further arrangements and discuss and questions.**

Interview Schedule

INTERVIEW GUIDE (based on Wengraf (2001) light touch approach).



Interview schedule (prompt questions). Opening Statement (suggested wording): “ You have created a visual representation in XXX (media used) of your experiences of caring for people who are dying. What I would like to do now is talk more about what you have created and what it means.”
Question 1. Would you like to start by telling me about what you have created and what it means to you.
Prompt Question 2. How do you deal with your personal feelings?
Prompt Question 3. Can you tell me more about the decisions you make when you to provide care for someone who is dying?
Prompt Question 4. When you make decisions about the care of the person who is dying, how do you feel about the decisions?

Wengraf, T. (2001) Qualitative Research Interviewing. Sage, London UK

Data Management Plan

Project Name My plan (DCC Template)
Grant Title Not applicable
Principal Investigator / Researcher Peter Stuart
Project Data Contact Peter Stuart, peter.stuart@northmapton.ac.uk
Description The research project is a phenomenological study exploring how nurses 'self' is negotiated, managed and experienced when providing end of life care in the general acute clinical setting. Participants will be asked to create a visual representation of their feelings, which will be photographed, followed by an elicitation interview which will be audio recorded and transcribed for analysis.
Institution University of Northampton

Data Collection

What data will you collect or create?

The types of data that will be created are:
Photographic data, which will be stored as jpeg images.
Audio data that will be encripted and then transcribed as digital data in micsoft word/mac pages format.
All data will be password protected and stored on the University's secure site. High volumes of data are not likley as the sample sixe is 10 participants.

How will the data be collected or created?

The methodology to be used is Hermeneutic phenomenology. The data will be collected as visual methods and elicitation interviews. Participant identification will be coded and the digital folders named according to the code

Documentation and Metadata

What documentation and metadata will accompany the data?

The methodology includes the researchers personal reflexive account and personal story as part of the data collection and analysis. The documentation will be included in the data files and be held within the data storage area for the study.

Ethics and Legal Compliance

How will you manage any ethical issues?

Ethical approval from University of Northampton sought.

How will you manage copyright and Intellectual Property Rights (IPR) issues?

IPA belongs to the University of Northampton

Storage and Backup

How will the data be stored and backed up during the research?

All data will be regularly backed up to the University's secure storage (R drive).

How will you manage access and security?

Data will be held on the University's secure site only.

Selection and Preservation

Which data are of long-term value and should be retained, shared, and/or preserved?

On completion of the study the data will have identified the essences of end of life nursing care and how nurses self is negotiated, managed and experienced.Participants will concent for the long term storaghe of thewir data for after to study has been completed. Data will be stored securly on the University secure drive.

What is the long-term preservation plan for the dataset?

The advice of the University records dept will be considered, however the assumption is the photographic images will become part of the University's repository.

Data Sharing

How will you share the data?

The data generated will not be openly shared. Findings will be published and disseminated though relevant channels.

Are any restrictions on data sharing required?

Participants will consent for data to be held after the study has been completed. Access to the data will be with the permission of the principal researcher.

Responsibilities and Resources

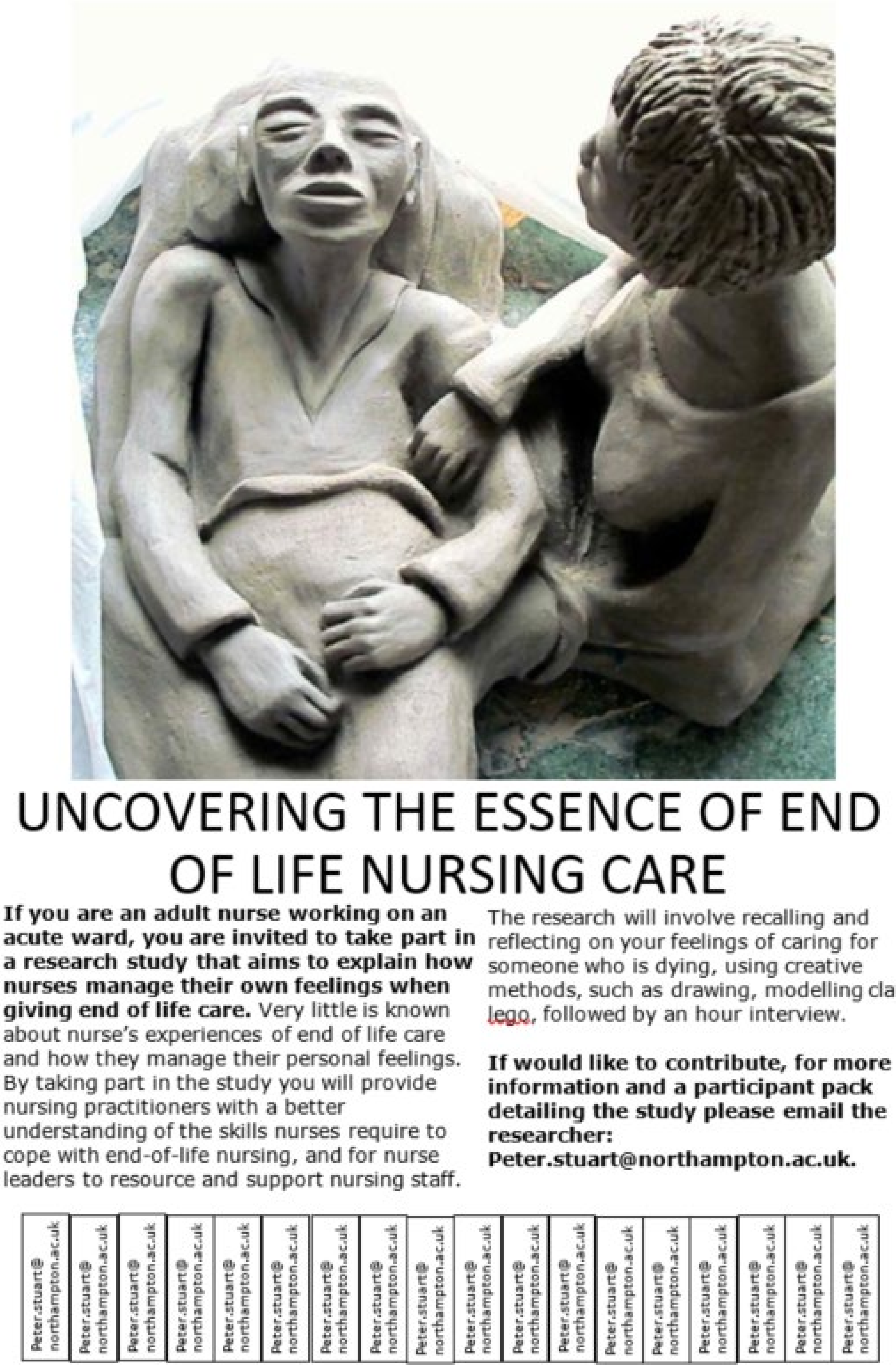
Who will be responsible for data management?

The principal researcher

What resources will you require to deliver your plan?

Support of University IT services

POSTER



UNCOVERING THE ESSENCE OF END OF LIFE NURSING CARE

If you are an adult nurse working on an acute ward, you are invited to take part in a research study that aims to explain how nurses manage their own feelings when giving end of life care. Very little is known about nurse's experiences of end of life care and how they manage their personal feelings. By taking part in the study you will provide nursing practitioners with a better understanding of the skills nurses require to cope with end-of-life nursing, and for nurse leaders to resource and support nursing staff.

The research will involve recalling and reflecting on your feelings of caring for someone who is dying, using creative methods, such as drawing, modelling clay, lego, followed by an hour interview.

If would like to contribute, for more information and a participant pack detailing the study please email the researcher: Peter.stuart@northampton.ac.uk.

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CONSENT FORM: UNCOVERING THE ESSENCE OF END-OF-LIFE NURSING CARE

Further details of the project can be found in the participant information sheet

Please ***initial*** the box

	Yes	***No***
I have read the participant information sheet version ….. dated …..and understand what is involved.		
I have had the opportunity to ask questions, and have those question answered to my satisfaction.		
I understand that the information I disclose will be anonymised but my identity will be known only by the researcher during the process of the study should they need to contact me.		
When it is typed up and before it is used in any project reports and that any information which identifies me will be destroyed on completion of the study.		
I understand that I can withdraw from the project at any time without me having to explain why and without consequence. Any data I have provided up to the point of withdrawal will remain part of the study.		
I understand that I can bring someone with me to accompany me to the interview, who will remain in contact outside the interview room, but I need to inform the researcher in advance.		
I am willing to be audio recorded as part of the participation in the interview		
I give my consent for the photograph of the visual item I create to be reproduced anonymously.		
I give my consent for words and phrases from the interview to be directly quoted, anonymously, as part of the publication of the study results, to illustrate points in the findings. I am aware the results may be used for education and future research and that any data may be held anonymously by the University for future reference.		
I am willing to participate in the study.		

Printed name of the participant ____

Signature of the participant ____________________________ Date ___________

Name of the person taking consent ____

Signature of the person taking consent ___________________Date ______________

Contact Information:

APPENDIX 33 Interview Transcripts.

INTERVIEW 1 WITH MARY

0:00 PS: So what we have done is create a visual representation of what it is like in your experience to care for someone who is dying. What i would now like to do is use this as the vehicle, if you like, to explore what is has been like for you to explore your experiences. So if you would like to start by telling me why you have chosen some of the images .
0:22 MARY So, shall I start..
0:32 PS Start wherever you like
0:32 MARY So I picked out the ring
0:32 PS OK
0:32 MARY So erm so whenever I care for someone who erm is dying it makes me think about my family erm and my own life at home so that is sort of representing my home life and my family and representing my marriage, how I think about looking after the person who is dying and how its going to impact their family and how I should approach that and how i relate to that in a personal way rather than just a professional way.. if ..that makes sense (1:47).
1:47 PS so what you are saying is the symbolism that you are using for the ring when you are caring form someone nearing the end of their life is having a personal resonance
2:02 MARY yeah
2:02 PS with your own family
2:01 MARY so what happened so I lost my brother at a young age so it resonates with that but also it think it makes it appreciate the life i have with my family so it makes me grateful for the life I have with them makes me sad for the people who are loosing their family.
2:24 PS So what happens to you in that caring relationship
2:24 MARY I think just from just being thankful that I'm not the person dying in the bed I think. feeling privileged that I can help them erm feel comfortable and that I can support through their final days hours and make a difference to them make me process it and feel more comfort with and helps me to process itit . (3:25).
3:25 PS The Key word you used was privileged
3:30 MARY Yea

3:30 PS Can you tell me more.
3:30 MARY So I. This is really hard for me. Obviously being a nurse a long time we deal with sudden death and palliative death that we know is going to happen we know you can prepare for things in different way if you know somebody is going to die … if there is nothing more certain in life than death so we are all going to die sometime we all going to no two death are the same as nurses you want to make sure that person has the most dignified death possible but also support the family of the dying patient so they can cope with it and deal with it in the most appropriate way possible as well for me myself it has come with experience so i think initially it think I first qualified I deal with lost of lots of different death I think the one that resonated most with me were the one that whose lives I could relate to and I could compare my life to I will always remember the death of a girl of a similar age to me but predominantly the people you are caring for are the people at the end of their life so erm erm older elderly so they have lived their lives so its the end of their life.. it sounds to it happens to all of us so to be part of that to make that the best experience possible for them is a good thing, is that making sense. You know when you are talking you don't know if you are making sense
5:44 PS So
5:44 MARY Laughs
5:44 PS you talked about it being a privilege, you talked about returning to the symbol you used of the ring the importance of the family, the experience of loosing your brother at an early age,
6:01 MARY mm
6:01 PS the resonance of family, when caring for someone who is dying,
6:13 MARY Yep
6:16 PS You talked about how you found it difficult is my word, caring for people of a similar age,
6:25 MARY mm
6:25 PS because of resonance
6:30 MARY yeah its more relatable I think
6:30 PS for you it is relatively easier when somebody is towards the end of their life
6:36 MARY mm
6:36 PS What I am interested in is you said it was difficult and how you manage that difficulty and how you protect your self
6:55 MARY So
6:58 PS The images help us to explore this if there is anything there that can help us to explore this.
7:04 MARY this image i saw first in the magazine. and this made me think about erm so I thought it sounds silly, so I thought of like a sheriff, that has got his hat on to do a job and I thought that she is ready to do a job, and that made me think about when I am at work and in a uniform I have a different persona an erm obviously you have your professional hat on and that almost and I think that helps me protect myself from erm getting to personally involved with a patient who is dying erm and that helps me protect myself just my uniform
8:09 PS ok so that is quite interesting so you are telling me that this this ring is about your personal experience of family but you are saying you are protecting yourself with your uniform by distancing.
8:26 MARY i don't know about don't know that it is distancing because
8:30 PS what word would you use
8:30 MARY Because I am don't to me I feel that particularly when you dealing with patients and families they dont want to see me falling apart crying and being upset with them because Im not the person going thorough it nor are they my family member I'm their in my role is supporting them through their grief supporting them through the process of end of life care so for me to erm emotionally break down would be inappropriate and unhelpful for them so I think what we should do as nurses i think with our uniforms and our professionalism i think is to deal with it face to face. in the best way that we can in to make it better for the patient and their family and probably drive home later and have a cry if its been an emotionally distressing and its touched a nerve
9:28 PS So what you are saying is it does effect you…
9:28 MARY Different not every death they'll be they'll be
9:28 PS some resonance for you
9:28 MARY Yeah
9:28 PS So some patients have some resonance with you but you have a professional value erm professional identity, professional unit, professionalism that I would like to unpick
9:28 MARY YEAH
9:28 PS A bit more with you in a moment but there is also a bit of you that is somewhere else.
9:28 MARY yeah I think erm yeah erm my so erm well we are human as well arn't we there are going to be things that effect us at that time but I'm always going to remain professional erm……there will be things that are going to effects us without realizing perhaps my judgement, when I leave a shift, erm I think oh I don't know…
10:54 PS OK lets explore some of the images
10:54 MARY I think is it it is expected of you isn't it that's and that the more you deal with it the more I don't think you necessary put up a barrier that would make me sound cold but as particularly with a sudden death in the emergency dept you have to have an element of erm dealing with the situation at the time can you change that outcome is there any chance of resuscitating that person or not erm so it becomes very cold and clinical ….but then you almost have to switch yourself to deal with the aftermath and then it becomes very family focused erm the approach is very different to an end of life patient because you can actually speak to them an individual and knowing so then you have got the information to share with them and you know their going to die that's quite uncomfortable, can be quite uncomfortable to deal with
12:21 PS what makes it uncomfortable to deal with

12:24 MARY because nobody wants to die do they do they? I don't think they do erm i think people accept with illnesses they can manage it cant they go though the process and when they can deal with it inevitably when it happens it is rarely an easy conversation to have with somebody talking about death and dying so its about that's what I was thinking about this picture about
13:07 PS the picture with the bracelets and bangles
13:07 MARY yes the picture of someone embracing somebody else so you are then the way you nurse and the way you deal with people is different you need to be personable and empathetic warm with somebody I don't know so does the do you change the way you are with somebody erm I don't know how to explain it on a day to day basis i would sit with my patients and hug them or …..
14:03 PS Would you want to?
14:03 MARY …… I don't know. I don't know i think that is where it changes I think if someone is dying I would . i….. it makes you realise how clinical you are so pushed for time but I would make I would find the time and I insist that people would spend more time and sit and hold their hand ……. embrace is embrace the right word? Because you know or touch and warmth erm particularly in people who cant communicate to know that somebody is there … i feel a bit emotional. It er,m important….sorry. its wired isn't it.
15:10 PS what we were talking about was the importance of touch and touching people and having the time to touch people and what is now becoming quite a complex set of motions staring with the ring and the importance of family and the resonance with you and your brother and then this image of the woman in the hat and the professional values that nurses hold and now we have this idea of being with someone who is dying and being able to touch them and hold them give them a hug and that's the bit now where we are stuck.
16:06 MARY yeah
16:09 PS there seams to be almost a triangle of feelings where does the nurse go? what you have told me is the nurse side
16:26 MARY Yeah I don't think we are very good as a profession at sort of de briefing erm protecting ourselves of having our own outlet as a profession i think like ive never nobody has ever asked me if im alight after a death im sure they have but ive never the more senior you get i think you then become the person that makes sure that everyone else is OK and there is no one really to help you above (laughs) and i think erm your skin get thicker and you learn that its part of your job to deal with death and it looking after end of life patient
17:37 PS listening to you and what i'm hearing are two separate things and what I am hearing is I have a professional duty and therefore I want to be able to hug and hold them and be with them but I cant do that event though.
18:19 MARY that's never the shift that you are on or the hours that You work that is not your sole responsibility no that you have however many other responsibilities that you also have things that you have to do for them and I can count on one hand that there has ever been a member of staff that has been available to sit with someone .
19:00 PS,
19:00 MARY and that's the frustrating bit
19:05 PS so palliative care is not the priority
19:05 MARY yeah the care is not what you would like it to be because of resources and staffing constraints time constraints event to the erm the hospital that I work in now the facilities are diabolical so you wouldn't want I feel embraced for the patient and the family for the environment they are in it becomes uncomfortable so you almost… you want to avoid it dont you.I dont know it s hard .
20:01 PS you want to avoid?
20:01 MARY well i so in my job roe now I would be responsible now for prescribing end of life medication which we don't do very often erm its a new thing they have started moving end of life patient into an emergency decisions unit erm nobody has been trained properly to deal with end of life patient properly, so ive had get involved get in contact with the end of life nurses in the trust for support and guidance so there is always an element of the unknown …and i I don't like it when I don't feel confident and competent in what I feel, yeah, I like to know what I am doing, and portray that to my patients , and their families so they feel confident knowing that i'm looking after them and it becomes uncomfortable when you know you haven't got the correct resources the correct knowledge and training to deal with making someone's journey better …so that becomes a frustration so I would unfortunately in my role now happily avoid and let my colleagues or let one of the drs deal with it that put myself in that situation were as when I have been less senior I have been looking after my own patients I would embrace that situation I think is to do with confidence, does that make sense
22:11 PS Yes I think so
22:11 MARY laughs
22:11 PS So within the your emit now when you have patient coming through your unit and needing that, I'm going to come back to this picture here, that embrace, that care that hug, what you are saying is the environment does not allow that.
22:38 MARY no it does not
22:38 PS So those patients are sitting there saying hug me please,
22:43 MARY So you have to deal with obviously what is there at the time and then with addressed it with out senior clinical manager, and said we don't think it is an appropriate environment for these patients,
23:02 PS But you have also said within that bit that no one has said to you are you OK.
23:11 MARY mmm
23:15 PS Again this return to my question as to where to you go in this caring relationship if no one is actually looking after you.
23:20 MARY I think I'm lucky than some because my husband is also a qualified nurse so I can go home and tell him what has happened so almost debrief to him he can relate to the situations that I have been in and the profession, so he knows which helps erm I can say he's my go to person to off load and process the

information soon after it, you don't get the time at work, to process what has happened to process what has happening on the shift
23:53 PS you mentioned time
24:22 MARY Unfortunately i would its, the the nature of the area I work in its all time time targets so you feel yoy are constantly erm against a management who have their own agenda and targets and pushing people though, to reminding people that patents are human beings and people and it means caring treatment and its about the care they need not about how long they have been somewhere and where they ned to be next so time is a massive
25:03 PS so this is represents
25:03 MARY by my BIG CLOCK
25:03 PS The very big clock sitting in the pictures
25:09 MARY but is also thought about that quite often you don't know with end of life people how long that its going to be before someone passes away and that is a big area of stress and concern particularly for relatives and its an issue you get drawn into quite a lot I think that you feel erm i always feel sad that I cant answer that question but nobody can answer the question
25:43 PS how doe that make you feel personally
25:43 MARY cause it would help the relatives deal with things . I think because I'm very im very ….. not a controlling person but I like thinks done in a timely manner and know a plan in my diary evey minute in my day is planned because of being busy and family life with children and constantly be busy as a result I am very much about time so I think I can relate to the family and patients when they want to know how much time is left or what is going to happen. because it is the uncertainty the unknown is uncomfortable for some people (laughs) eyah that's me,
26:45 PS That comes back to a point you raised about you said a patients asking about when you dont know how to respond and questions about time, which comes back to my original questions about your feelings and your rejection of your feelings
27:21 MARY maybe both ….. because….. you i think you always feel uncomfortable if i cant answer a question.
27:42 PE id the patient looking fo an answer
27:49 M I think with experience you learn it ok to say i dont know, but I can find someone who can fond out for you. So I think know I am OK saying I dont know. but I think …… i think if I was in their shoes I would find that quite a frustrating place to be because you want answers dont you so ….. erm…
28:36 PS is that tied into come back to the hat picture with the professional identity. and being the personal who has to provide answers and be not controlling, you deliberately didn't want to use that work, but you want to be that person, the nurse who has the answers, But also I am a human
28:51 MARY Erm i dont think people see nurses as human being though….. people need to be reminded . You are almost not allowed to be a human being you are a super robot.
29:40 PS that is quite an interesting point because I want to return again to the triangle that we have got of thr rings the person in the hat and the two people who are embracing which is where we had the difficulty but now we are brining in the clock which represents quite a lot of things for you including this idea of management pushing and bed management and questions and now you are saying this idea of we can't be human beings because management are.
30:17 MARY well no, yes, its just reminded me i even been asked for how long did I think somebody was going to to take to pass away because the want the bed
30:33 PS (groan) which goes against the warmth of caring you are trying to achieve.
30:33 MARY yeah which is why I went into nursing. erm…
30:51 PS hard to make those caring connections
30:55 MARY yea, its want makes it difficult for people to stay in the profession. you had so many ideas as to why you wanted do in the profession. but people put barriers up to stop you.
31:16 PS so you have got that, people not asking how are you, do you want 5 minutes, do you want a cup of tea,
31:25 MARY yeah, it depends on the team you are working with how well your colleagues know you. The colleagues you are on with, at the time do they know you, are they personable, have they been though it themselves so they can support other staff. I find a lot of people don't appreciate in the unity it becomes a very conical death they dont relate to the family or how they would feel themselves and put up a barrier as a reason for dealing with it but people who are younger perhaps[s and haven't got the life experience and had a close family member haven't got the same outlook and presume everybody deals with things the same and I think certainly once I've been a patient myself Ive related how staff act how it feels feels as a patient but also since having children it makes you more emotional to death because loss becomes more bigger. i think when you have got a child.
33:15 PS ok so if we use that as to where do you go in this caring relationship. what happens to you.
33:23 MARY I go home and have a large glass of wine
33:25 PS ok so again its going home
33:24 MARY is all yeah
33:31 PS So again we come back to this picture of the hat at work I control it at home
33:34 MARY Yeah or even the drive home so i used to find erm when i lived and work at Northampton i was only five minutes form the hospital I hadn't processed them and I things could bother me for days for weeks even because you haven't been able o process or deal with them at wok but since I work at Kettering now the drive home the drive clears my head so typically by the time I get home the shift is forgotten about so hat given me the time to process thing I'm in the car its peaceful there is nobody waning me for something I can focus on it process it deal with it and that helps and exercise I run a lot to clear my head. but I think tat is is the stresses of work…. that is jus life…..

35:08 PS management saying , patient saying, Im really interesting with the pictures that we have got the clock and the ring right in the middle is a a really bright unicorn
35:29 MARY yeah it made me smile about so… particularly in younger age groups death you cant think of not everybody wants to be sad upset and mourning end of life so particularly so if everyone knows they are dying they want to experience the work don't they and they make the most of the time that have got together and I just thought about making people smile and to make it a better experience for them . yeah. it doesn't need to be a if its an inevitable event is doesn't have to be a sad devastating thing
36:39 PS OK so does that bring thigs back on track for you a little bit
36:42 MARY yeah
36:46 PS at the moment on your picture, if its intentional or, not is the unicorn vomiting rainbows onto the hat
36:59 MARY no I hadn't seen that no that was just where I had stuck it,
37:15 PS so the profession representation and the unicorn is
37:26 MARY slap bang in the middle
37:26 PS symbolic of lets be free let be calm what gives this person identity if you like, and meaning, as they are dying, and identity, and I am struck by the fact the two..
37:45 MARY conflict each other
37:45 PS not conflict necessarily but you telling me these values are important so on your unit the manage say how long has the patient got and you
38:04 MARY yeah and you try to separate the two you end up yeak splitting yourself in half
38:16 PS and I return to my question I think where are you what happens to you
38:22 MARY I dont necessarily think you have got room for yourself.
38:25 PS you are saying family is really important from your past experience is central to your core identify where I go when O go home to them and I take my uniform off
38:39 PS so that keeps you safe
38:40 MARY yeah.
38:42 PS but at work i'm this person in this hat i value this person who embraces this and then there is this clock. directing what I do
38:58 MARY so this causes stress.
39:03 PS so the we haven't got an elephant we have a unicorn in the room and the patient is saying look at me
39:05 MARY yeah, mmmm,………
39:29 PS what I'm sensing is you are struggling with that.
39:31 MARY mmm I guess. I , haven't really though about, not every day. I don't. I think if you had come to work in a work environment and Id been in uniform you would have a different discussion.
40:08 PS So what you are telling me is your values are placed in the Unicorn are important
40:10 MARY yeah and that its about embracing life and that everyone's life is different and that we should treat everyone as individuals and recognise that they had a life and dreams and hope like all of us like when they got to the hospital bed about to die
40:29 PS Do you d that
40:43 MARY I like to think I would. if I was back in the scenario were I worked in a ward, er, and Id hope that when Im seeing these patient id make sure that the nursing staff are doing what Id like to be doing that I support them and guide them and ….
41:26 PS OK
41:29 MARY I didnt know, because it made me smile and its colourful what comes to mind death is sadness and darkness and black and a unicorn and coffins what yeah, I didn't notice the vomit though,…………..
42:11 PS is there another picture you want to explore.
42:22 MARY these just made me think that nothing is the same and no two people are the same……. everybody has got their lives and memories…….. so I think sometimes I find it difficult when everybody evidence shows there are pathways of care for conditions but sometimes we forget that that person is an individual and that sometimes people look at the pathway not the individual borrowing the same structure for end of life and I don't know and it just thought of reminded me to make it more patient focused and the make it more focused on the person and the life that they have had…..
43:37 PS so what is important for yu is remembering the life that they have had and supposed the unicorn and remembering that their life has had meaning and perhaps because remembering celebrating,
44:09 MARY I think so and them these are (landscapes) thinking about making ……. like trying to create a tranquil environment and keep it calm, and thinking about it made me think that this is important the equipment, the stillness a nice environment, now because I know that particular family will remember, the surroundings and what has happened.
45:10 PS so that environment calms is that because where the new unit comes in
45:15 MARY definitely
45:17 PS running around looking after other patients
45:28 MARY yeah but that's when having side rooms a quiet environment I think you all almost change when you walk into that room you need to be part of that calmness when you walk into that room. that you have created so that might be different to what is going on out in the main area
45:49 PS so what happens to you with whatever happens with the shift and the chaos is important to you is creating this calm.
46:13 MARY yeah i think you add another layer of anxiety or stress with other people and relatives and i think you have a responsibility to have make that the niceness calmness and care for them the basics you can, you have a responsibly a duty almost not to add any further stress or anxiety to a stressful situation, …..
46:57 PS so part of your hat and values form you is to bring that sense of calmness
47:05 MARY and to reassure and instil confidence that

47:10 PS so that hat is everything that is happening in your life anything that is happening in your life for you
47:20 MARY that gets that is a different yeah it gets pushed aside ina different box ………….
47:28 PS OK
47:31 MARY Mmmm I think this will always be you for me will always if I was the nursing looking after that patient that would be my first responsibility I would need to do that properly more than the best of my ability more than anything else when everything come in when other factors, when you are on shift, when get going your way, keep you focused keep you separated from everything else, …. but you cant always do it.
48:09 PS No….. the clock.
48:31 MARY it think that's why I say these little men struggling (artic picture) when not necessarily struggling but yeah, i just though sometimes its a struggle but you know what you have got to do to reach the end point that you want for your patient and your relatives I don't think you really think about yourself at the time.
49:10 PS In a selfless way? Your needs are not important.
49:19 MARY I think,
49:26 PS you look puzzled
49:26 MARY no im thinking, …. i dont know think you are expected to be selfless as a nurse, sometimes ……. mmmmm ……… I guess its having some self awareness I know I have had that if I paediatric comes in I am not the best person comes in I am not the best person to deal with that as Ive talked before I am not the best person to deal with that as its too close to my life ….. so I think when you have good team that has self awareness you can find the right person to deal with the situation at that time so that i Think if that for any reason I didn't feel able to care for any patient ay then end of their life I have the self awareness to say I don't have the ability to care for them and can find a colleague who could how would support me and I think I have a enough awareness to recognise if my colleagues were struggling with a situation and to try and help that support other people and to also let other people step in if needed.
51:16 PS So team working is important
51:23 MARY yeah particularly if anything surrounding to do with death and end of life
51:39 PS what is interesting i the picture that you have chosen of people there I suppose they are not completely alone
51:47 MARY they are more not is more about the unknown they are taking on a challenge and the weather it might change at any given moment of the journey and the path might change and they might need to adapt to what gets thrown at them, and you just learn with experience to adapt to situations
52:23 PS Ok
52:25 MARY mmm…… This just made me think about how different it is about caring from someone who is dying who is not conscious and someone who is awake and can communicate with you ……..
52:56 PS so they can express their needs and wishes,
53:05 MARY I think when they are awake and they are able to talk there are a different set of emotions obviously the conversation is there erm you can relate to that person you know them as a person awake you can talk to them alive as a person, whereas if you meet somebody not conscious you don't know them you don't necessarily get to know them personality or how they are its almost east to deal with them you have not met them awake before ………………
53:56 PS so with your unicorn and someone who is awake you
54:06 MARY yeah
54:08 PS are able to give life meaning, If they are not awake..
54:14 MARY you don't know them about them necessary relatives might be there to talk to them but they are its not that they are not a person………….. it think because to you have not built a rapport an emotional connection with somebody .. you've not talked to you don't know anything about them the eye contact the communication is not there ………. u=its then not as i don't find it a s distressing and I think that wen in A&E it hard to deal with someone who comes in who you know and you have had a conversation with how then deteriorate and dies in comparison with h=who comes win cardiac arrest and then die as you haven't had a relationship with them.
55:33 PS so there is more of a detachment
55:34 MARY yeah as clinical as it sounds. That sounds awful when you say it. ………………
55:56 PS but to be the professional person you need the detachment
56:05 Yeah…………. I think that all,

APPENDIX 3: Analysis of Unicorn

Reference 1 - 0.33% Coverage

correct resources the correct knowledge and training to deal ~~with~~ making some ones journey better ?

Reference 2 - 1.47% Coverage

Unfortunately I would its, the the nature of the area I work in its all-time time targets so you feel you are constantly erm against management who have their own agenda and targets and pushing people through, to reminding people that patents are human beings and people and it means caring treatment and it's about the care they need not about how long they have been somewhere and where they need to be next so time is a massive

→ Humanity

Reference 3 - 0.50% Coverage

well no, yes, it's just reminded me I even been asked for how long did I think somebody was going to take to pass away because the want the bed

→ Humanity

Reference 4 - 1.58% Coverage

Unicorn

in younger age groups death, you can't think of not everybody wants to be sad upset and mourning end of life so particularly so if everyone knows they are dying they want to experience the world don't they and they make the most of the time that have got together, and I just thought about making people smile and to make it a better experience for them. yeah. it doesn't need to be an inevitable event is doesn't have to be a sad devastating thing

→ Happiness

Reference 5 - 2.02% Coverage

PS symbolic of let's be free let be calm what gives this person identify if you like, and meaning, as they are dying, and identity, and I am struck by the fact the two.
37:45 LE conflict each other
37:45 PS not conflict necessarily but you are telling me these values are important so on your unit the manage say how long has the patient got and you
38:04 LE yeah and you try to separate the two you end up splitting yourself in half

? identity
not pontificate

Reference 6 - 1.16% Coverage

So, what you are telling me is your values are placed in the Unicorn are important
40:10 LE yeah and that it's about embracing life and that everyone's life is different and that we should treat everyone as individuals and recognise that they had a life and dreams and hope like all of us like when they got to the hospital bed about to die

Reference 7 - 0.85% Coverage

I like to think I would. if I was back in the scenario where I worked in a ward, err, and I'd hope that when I'm seeing these patient on respond id make sure that the nursing staff are doing what I'd like to be doing that I support them and guide them

Reference 8 - 0.34% Coverage

its colourful what comes to mind death is sadness and darkness and black and unicorns and coffins

Reference 9 - 1.95% Coverage

these just made me think that nothing is the same and no two people are the same……. everybody has got their lives and memories…….. so I think sometimes I find it difficult when everybody evidence shows there are pathways of care for conditions but sometimes we forget that that person is an individual and that sometimes oplet look at the pathway not the individual borrowing the same structure for end of life and I don't know and it just thfotht of reminded me to make it more patient focused and the make it more focused on the person and the life that they have had…

humanity

53:56 PS so with your unicorn and someone who is awake you
54:06 LE yeah
54:08 PS are able to give life meaning, If they are not awake..
54:14 LE you don't know them about them necessary relatives might be there to talk to them but they are it's not that they are not a person…

unicorn

ANALYSIS:
~~mythical~~, ~~fantasy~~, to protect, ~~magic~~, ~~unreal~~, its colourful, to help, challenge, fight, the system, provide dignity, make the most of what time is left together. Family, Memories, reminding people that patents are human beings, everyone is different, value identity,
Embracing life
Unique
Colourful
Happiness
Family
Challenging

values

protect

responcibility

humanity

NANCY

Family, dignity, challenging decisions ;the family know she is not going to work is it and the nurse is saying well we are doing what we can while we are thinking this is not working and all we are doing is prolonging the agony the consultant comes in let's do this lets do that and I had said I will talk to

question system & decisions

challenging ! unicorn

him on their behalf and I said what are we trying to do here and he said I'm trying to save a life what do you think in kind of a how dare you question me and he was really cross with me and off he stomped and is said I'm not really trying to question you but the nurse in there is crying and trying to do her best etc and to his credit he did bring in another consultant for a second opinion and they did withdraw treatment but that was quite a lonely place to be"

dignity

in ITU we ventilated and paralysed and sedated everybody regardless of whether or not they were dying it was considered best treatment then and unable to say what they wanted because they were sedated so it was very much the family so it was very much being there and some families did not very much from you some would go home and say give us all call when its happened because that it the way they coped other families wanted to be there washing the patient and that was fine you just had to be there and try and adapt to whatever the families wanted sometimes

? unicorn

Louisa

i think he is saying goodbye so i think there is that sense of you know whether you know the person well or not you are saying good bye to them whether for your self or for clinically professionally it is part of humanness

unicorn?

you don't want to see your family member suffer when they are dying

talk and reminisce and its not always doom and gloom and I think sometimes a bit like at funerals perhaps around the bed you are talking to family members you are not really you have not met up with for ages and there is that sense of you know it's quite nice to catch up and see you and I suppose that is what these bits of life are in that picture

happiness

makes most of time that is left

Hilde

this letter writing is to do with planning sort of writing lists writing letters to loved ones and that and I think you know lost so peoples start to reflect not necessary the patient but mostly the family when someone close to them is dying they escapism again I've had patient who like if they are not feeling great and just before they are not communicating very well they like to escape taking about lovely holidays or experiences they find that comforting in a way again sort of if there is family involved they start talk do you remember the time when blah bal ba they find that comforting

unicorn

Virginia

we nurse the family as well nut nurse but we care for the family as well it isn't just a the patient sort of and I think that is different to when nurses care for most patients on a general ward because although they care about what the family thinks they use the family's thoughts and feelings they are not used to having the family here continuously or almost and heaven forbid when the patient dies you then care for the family because that is when they really need you

I felt disappointed in myself that my patient got resused when they probably should not have done therefore didn't die with dignity which upsets me…

challenge

family

unicorn