Death and dying in the emergency department: a phenomenological study of the experiences of family members and nursing staff

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DEDICATION

This thesis is dedicated to the many end-of-life patients whom I have had the privilege of looking after during my nursing career. Thank you for allowing me to become the nurse researcher I am today. This nurse has not forgotten you.

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ABSTRACT

Background: The purpose of this qualitative nursing study has been to understand the experience of death and dying in the emergency department of a hospital, through listening to the experiences of bereaved family members and nursing staff. Death and dying remain taboo subjects in society today and therefore people may come to the end of their life without having thought about what death and dying might be like and what it is to have a good death. Culturally, individuals are unprepared for death, and when death occurs in an emergency setting it is particularly shocking. **Methods**: A phenomenological study was planned, based on the existential phenomenology of Merleau-Ponty; and framed by the nurse theorist Hildegard Peplau. Eleven bereaved family members and eight registered nurses gave in-depth interviews describing their experiences and the interviews were analysed using an adaptation of the work of Thomas and Pollio (2002) and Hycner (1985), consistent with Merleau-Ponty's theories. **Results**: The study brings new understanding of what it is like to die in an emergency setting through new understanding of what the family members of the deceased person experience, aided by new understanding of the experiences of emergency nurses. Uniquely, the voice of the bereaved family member is heard. **Conclusions**: Recommendations for improvements in education, clinical practice, research practice and policy are made along with suggestions for further research to be carried out on this topic. A nursing model for end-of-life care, based both on the work of Peplau(Peplau, 1991) and on the work of the nurse theorists Ruland and Moore (Ruland and Moore, 1998; Zaccara *et al.*, 2017) was devised for use in the Emergency Department.

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LIST OF ABBREVIATIONS / GLOSSARY

Emergency care	Care given in the Emergency Department of a hospital.
Family	People who are important to the dying individual. This may or may not include relatives either by blood or marriage.
End of life care	Medical and nursing care given to an individual at the end of their life.
Palliative care	Medical and nursing care aiming to improve quality of life in a situation where the patient is not expected to make a complete recovery.
ED	Emergency Department
LCP	Liverpool Care Pathway
PhD	Doctor of Philosophy
UK	United Kingdom
US	United States
NHS	National Health Services
NICE	National Institute for Health and Care Excellence
WHO	World Health Organisation
OSCE	Objective Structured Clinical Examination
IPA	Interpretive Phenomenological Analysis
ITU	Intensive Therapy Units

LIST OF DISSEMINATION OUTCOMES

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CHAPTER 1: INTRODUCTION

1.0 Chapter abstract

The first chapter describes the background to the research, introduces the reader to the concept of a good death and how this may be achieved and also introduces the concept of embodiment and the importance of this to nursing. The PhD study is described and the aims and objectives explained.

1.1 Background to the research

Death is certain and will happen to us all. We are organic creatures and thus we live and through living, we die. This is an undisputable fact. What is it like to die? We cannot know, but each of us would probably want to have a good death. The job of a nurse, notoriously difficult to describe, involves caring for people throughout their lives, to death and beyond. We need to ensure that the individuals under our care have as good a death as possible. This thesis is concerned with death and dying and aims to describe the experience of relatives and nurses being with a dying person and experiencing death in the emergency department (ED). Understanding the experience of those close to the dying person is arguably the closest we can get to understanding the experience of the patient themselves and will therefore, ultimately, enable us to offer the most appropriate support to patients and family within the ED.

At this moment in time, in the first world, we are under-prepared for death in general, and when it comes with great rapidity, we are particularly unprepared and this inevitably can lead to enormous shock (Reed and Greenwald, 1991; Kent and McDowell, 2004; Kõlves *et al.*, 2019). Furthermore, one of the characteristics of death in an emergency setting, in a hospital emergency department, is that it is sudden and in general not expected – people do not plan to die in an emergency department. Hence it cannot be assumed that we manage death well in this context. In order to find out, this thesis looks at what it is like to experience death and dying in a hospital emergency department from the perspective of those who accompany their loved ones, and the nursing staff who take care of them.

A novel approach to the research would have been to find out what it is actually like to die in an emergency setting. It would be so helpful to find out what answers could be gained from asking people about their personal experiences of end-of-life care. But of course, we cannot ask people what it is like to die. Instead, this thesis is based on a study designed to examine the experiences of the people who are closest to the dying or deceased person – the bereaved family members who have been at their side and the nurses who have looked after them to the point of death and beyond.

There are many reasons for looking at death and dying in the emergency department. There has, worldwide, for a long time been a drive to improve the care of the dying person, both in hospital and in the community. In general care settings (not emergency care units), certainly in the Western World, the principles of hospice care began to be applied from the 1950s and ‘60s (Quest, Marco and Derse, 2009). There is evidence that this has transformed end of life care in general wards (Quest *et al.*, 2012). However, the improvement in care in the acute setting led to a number of scholars, from both nursing and medicine, criticising the current situation regarding the care of dying persons in the emergency department setting (Cauthorne, 1975; Jones, 1978; Soreff, 1979; Ordog, 1986; Adamowski *et al.*, 1993). To try to improve this, in the United Kingdom, by the mid to late 90s, a framework designed to improve end of life care in acute settings - the Liverpool Care Pathway (LCP) - was established (Ellershaw and Murphy, 2005); this at first was felt to be a useful tool (Ellershaw and Murphy, 2005; Shreves and Marcolini, 2014). The LCP was a pathway designed to improve the care for all people at the end of their lives, whether on a ward or in the emergency department, but ultimately it fell out of favour in 2012 - 2014, possibly due to several too-rigid interpretations (Neuberger, 2016b). While it lasted, however there were many proponents of the Pathway, alongside evidence that it contributed to improved care (Jack *et al.*, 2003; Gambles *et al.*, 2006; Veerbeek *et al.*, 2008). Building on this, in 2013, a UK –wide body was set up, known as the Leadership Alliance for the care of the dying. This body published two documents suggesting that the care of dying patients should be based on five principles (England, 2014; Harrison,

2014) :recognising that someone is dying, ensuring sensitive communication takes place, involving the dying person and their loved ones in any decisions made, respecting and caring for the friends and family of the dying person and ensuring individualised care planning (Wise, 2014). This puts a great emphasis on enabling the patient to have a good death. The much-publicised demise of the LCP - and the publications of the Leadership Alliance, led to increased awareness of the need for good end of life care in all clinical areas and greater investment in hospices and palliative care services (Amador *et al.*, 2016; Bone *et al.*, 2016; Chan, Webster and Bowers, 2016; Boulanger *et al.*, 2017; Mah *et al.*, 2019). Despite this, it continues to be recognised that there is much room for improvement when it comes to end of life care in the in the emergency department (Dawood, 2019), not just in the UK but worldwide (LeBrocq *et al.*, 2003). This will be covered in more depth in chapter two of this thesis, which explores the literature around this subject. All initiatives to improve end of life care in any setting have one thing in common, which is to provide care which leads to a good death for the patient (Borgsteede *et al.*, 2006; Izumi *et al.*, 2012).

1.2 What is a good death?

Currently there are a number of recent books about death and how to die well available to the general public (Bastian and Staley, 2009; Swerissen, Duckett and Farmer, 2014; Atul, 2015; Clarke, 2017; Mannix, 2018; Butler, 2019). At the time of writing, Kathryn Mannix's book: 'With the End in Mind: How to Live and Die Well' (2018) has been an international bestseller for several months (Saad, 2018). This is not a piece of research, rather an opinion piece based on many years' experience as a palliative care physician. Mannix, in the introduction to her book discusses how she has found that in her experience, it is preferable to die in a familiar room with family close by, and at a time when the person is as physically and mentally / spiritually comfortable as possible. Her book is a series of stories about her experiences of caring for the dying; ultimately each individual in her book wants to – whether or not it actually happens- die in this way – comfortably, peacefully.

The idea of a good death has been around for as long as humans have had writing and thinking abilities. As a concept it may mean subtly different things to different people (Geijteman, 2018). In order to discuss the concept of a good death in greater depth, the work of the Reverend Geoff Walters, academic and head of spiritual services at a UK hospice group, has been used. His work is based on the premise that the historical conceptual development of a good death occurred in three major stages – the pre-modern good death, the modern good death and the postmodern good death (Walters, 2004). These stages, which are not distinct and often have very blurred boundaries, will briefly be explored.

1.2.1 The pre-modern good death

The development of the pre-modern concept of a good death, beginning in pre-mediaeval times, was based on religious beliefs. These were predominantly Christian in the UK, but it is important to note that a 'good death' is a real concept in every religion (Aries, 1981) . Some traditions even have as their holy book a guide to a good death (Lopez, 2011), which is to be read out aloud to the dying to facilitate a good death and the attainment of enlightenment. Within the Christian tradition a good death involved reconcilement with God; in the Catholic Church through confession of sins and reception of the sacraments (McCabe, 2000) and other denominations through prayer and acts of faith (Harrison, 2000). Historically according to the major religions, there is also here a fairly deep- rooted idea that a good death is not necessarily a comfortable one, so that a painful and distressing death, like that of St Therese of Lisieux (Russell and Th, 2000) was to be welcomed : suffering equals sanctity which was to be desired, so that even here the concept of a good death is not straight forward (Chidester, 1990; Puchalski and O'Donnell, 2005; Lakhan, 2008; Ayoub, 2011).

Ideas such as these do not stick to rigid timescales but are fluid. The concept of a good death in a premodern sense is still valid today among people who profess a religious faith (Puchalski and O'Donnell, 2005). In the premodern world and purely in religious terms, death is / could be also seen as terrible because it detaches us from earthly things, possessions as well as family and friends; a good death to very religious people is (still seen as) one in which the dying person can easily detach from these things (McCabe, 2000; Puchalski and O'Donnell, 2005; Ayoub, 2011; Lopez, 2011). This is really such a different idea to the comforting notion of a good death being about lots of care, lots of pain relief, many generations around the bed reminiscing (Gould, 2012)) and quite a difficult one for modern or postmodern minds: many people today might argue that the job of a Chaplain is primarily to comfort the dying and support the relatives and friends (Braun and Zir, 2001; LeBaron *et al.*, 2015), rather than help the dying detach themselves from earthly pleasures and prepare for the afterlife through the confession of sins (Aries, 1981). Walters (2004) does mention that in this situation, fierce value is placed on the individual's body and soul: they are not just another dying person, but an important soul to be helped to eternity. And of course a person would be judged on how they have helped others so this would impact on the care given, in fact Aries (1981) speculates that care of the dying would, in the pre-modern times, have been unrecognizably good, compared to today (Aries, 1981).

Religion remains central to many peoples' lives even today (Elliott and Hayward, 2009; Norris and Inglehart, 2011) hence it's involvement in what the concept of a good death entails, and its reflection in the concept of a premodern good death. A focus on spiritual care is an important part of the modern hospice movement, each palliative care team will have access to a Chaplain and Chaplaincy services are still very much a part of allied services throughout the NHS (Ross, 2006; Cook *et al.*, 2012) . A study by Braun and Zir (2001) who carried out focus groups with church members about the role of the church in end- of- life care, found that 'providing spiritual care' came up a lot but that this varied so much between individuals that it was a fairly meaningless phrase. Another contemporary doctoral study of end of life practices in Monasteries found that a good death was thought to be not simply one in which the Monk died reconciled to God through the sacraments but also one in which suffering was minimised if possible, and if not, bravely borne with the support of the community (Diat, 2019), a very recognisable idea of a (pre-modern) good death. From a non-Christian point of view, other faiths have similar beliefs about what a good death is and is not, connected to their particular religious faith and thus fulfilling the notion of a pre-modern good death (Tayeb *et al.*, 2010; Masel, Schur and Watzke, 2012; Chapple, 2014; Golbert, 2014).

In discussing the concept of a premodern good death, it is essential to emphasise that although much has been said about religious ideas that have lasted for centuries, to many people living in today's world, these are not meaningful and may even be offensive (Swift, 2016). The intention was not to assume that these ideas are relevant to all, but to demonstrate that the ideas were developed in premodern times and have lasted in some forms, having relevance to the idea of a good death.

1.2.2 The modern good death

Moving onto what Walters (2004) calls the 'modern' idea of a good death, the concept remains hard to pin down. Walters (2004) felt that the concept of a modern good death began in the mid eighteenth century at the beginning of the age of reason (Walter, Walter and Walter, 1994) when advances in medical science began to mean that many things that had originally caused death could be treated, cured or avoided (Walters, 2004). Ultimately this was the beginning of the separation of death from everyday life and perhaps also the beginning of death itself being seen as a failure: this stage lasted for a long time and is ongoing (Smith, 2000; Walter, 2003; Green, 2012). It is characterised by a feeling that death is either a long way off and needn't be considered at all or that it does happen but should happen out of sight, leading to a Western, or first world situation where people in their 70s and 80s have never seen a dead body (McNamara, 2001). A modern good death is one which happens peacefully, in which the dying person is pain free and suffering of any kind is minimised not only for the dying person, but crucially also their families, so that the messy and potentially distressing parts of the human death take place in hospital or a hospice, rather than at home(Seale, 1998; Steinhauser *et al.*, 2000; Walters, 2004; Scarre, 2012).

It could be argued that a good death is indeed like this, particularly the pain-free and comfortable element, as previously mentioned (Mannix, 2018). A pain free death is surely desired by all. During the recent and current pandemic, nurses have had many experiences of looking after patients with Covid-19 who have died alone, alone because it has been difficult to accurately predict the time of death in Covid patients (Wynants *et al.*, 2020) and also because it is hard for loved ones caring for others at home to come in to the hospital and then have to self-isolate. From personal experience, when the families have been spoken to after the death, the first thing they have tended to ask is: did he / she suffer? Was he/ she in pain? Similarly, families of killed soldiers in various conflicts are often told – it was quick, he didn't feel a thing, he would not have felt pain (Benson *et al.*, 1974).

Not dying alone is another facet of the modern good death. The relatives will also ask – was the person alone at the time of death? This is almost accepted in the literature ('no-one should die alone') so that it is taken for granted: it is a given. Meier et al carried out a literature review attempting to define a good death (Meier *et al.*, 2016) and identified eleven themes of a good death (pain free, peaceful, dignity attended to, wishes of the deceased attended to, spiritual needs attended to, good support from health care professionals) but none of these specifically mentioned not dying alone, although it was it was implied in the theme 'family' – their findings simply assumed that that nobody would ever die alone. Similarly Steinhauser et al (2000) carried out focus groups and in-depth interviews with different groups of people attempting to find out what they felt was a good death (the themes are repeated, namely lack of physical and mental suffering, clear decision making on the part of those caring for them, ensuring the dying persons wishes are met) and the idea of not dying alone was not specifically identified (Steinhauser *et al.*, 2000). Equally it was not specifically mentioned in Hales' et al (2010) work which is a systematic review of how to measure the quality of dying and death(Hales, Zimmermann and Rodin, 2010). However when Ko et al (2014) surveyed a group of homeless people over the age of 60, not dying alone was one of the most important themes, with the participants seeing a bad death as 'lonely' (Ko, Kwak and Nelson-Becker, 2015). It is possible that not dying alone is such an ingrained thing, at least in Western society that it is almost a given for a (modern) good death (Krishnan, 2017), whereas to the dying in the homeless community in Ko et al's (2014) study, it was centrally important.

Today's hospice movement was founded to relieve suffering at the end of life (Miličević, 2002) and thus promote the elements of a (modern) good death. Walters (2004) talks about how we might find it comforting that such places exists, as modern mind-sets tend to think about death in one of three categories: 'the death that does not happen yet' – in other words, let's not be morbid, who knows what will happen, 'the death that is not seen to happen' – death removed from daily life and hidden away in side rooms and behind curtains, and 'the death that happens without my noticing ' – for example, dying in one's sleep, or dying on the golf course doing something one enjoys. This also implies that ideally death will be pain free and sudden (Walters, 2004). The modern good death, then, is a death which is above all pain free, suffering is relived and it is not a drawn out process, a death which takes place in the presence of loved ones and at a time when the person is able to feel that they have reached a place of completion of their life (Steinhauser *et al.*, 2000; T, 2009). This is a recognisable modern idea; the focus will now move to the last of the three aforementioned stages, the post-modern good death.

1.2.3 The post-modern good death

The post- modern good death is very much a 21st century idea (Walter, 2003). It is characterised by the incorporation of the ideas of the modern good death but with development of these ideas (Walters, 2004). One of the most frequently cited descriptors of a good death in the contemporary literature is the idea of control at the end of life, that is to say, control over the way death happens, the timing and place of death and the idea of a dignified death (Cottrell and Duggleby, 2016). The hospice / palliative care movement set great store by this – setting the individuals and their wants at the centre of everything that happens, asking about preferred place of death and suggesting that death is planned, including funeral details (Field and Cassel, 1997; Gagnon and Duggleby, 2014b; Giddings *et al.*, 2017). Perhaps surprisingly, the other movement heavily invested in control at the end of life, is the right to die movement (Fontana, 2002; Rose, 2007), normally seen as diametrically opposed to the palliative care movement. The motto of the Hemlock society, a US-based group set up to provide assistance and knowledge to those who wish to take their own lives is in fact 'Good life, good death' (Doerflinger, 1995; Humphry, 2002) and proponents of the right to die movement feel strongly that a good death is a death that occurs under the individuals control (Fontana, 2002). Several countries around the world, famously the Netherlands, have voluntary euthanasia (Catling, 1996). It is not, at the time of writing legal in the UK, although the issue continues to be hotly debated (McCormack, Clifford and Conroy, 2012; Richards, 2017). Dignity appears almost the most important thing for people who advocate euthanasia (Raisio, Vartiainen and Jekunen, 2015), and this appears very much to be linked to the strong (phenomenological) feeling that people view their identity as inextricably linked to their embodied self (Haddow, 2005), imagining that losing control of ones bodily functions inevitably leads to a total loss of human dignity.

As human thinking has developed, it can be seen that there has been a shift in focus from dependence on the idea of religion controlling life and death to individuals themselves controlling these things and therefore a shift from a dependence upon ideas (religious ideas), in the premodern period, to dependence upon facts (the fact that we are embodied beings) in the postmodern period. So the post- modern concept of a good death, which exists alongside the modern idea of a good death, is characterised by a great emphasis on dignity of the body and control over the body at the end of life, exemplified by the ideas of individual choice and strong identification as a person with a body which is at the centre of the dying process (McNamara, 2004; Lawler, 2006; Bagheri, 2007).

The idea of a 'good death' is an idea which has been central to the palliative care movement but is equally important to every aspect of healthcare. The three categories of 'good death' have been discussed in depth to ensure immersion of the reader in the concept of what a good death is and how this may be understood by different people, how it has changed over time and how it is difficult, if not impossible, to pin down. However, in this thesis it is argued that the idea of a good death is extrinsically bound up with the concept of ourselves as embodied human beings – death causes our bodies to stop living, hence the importance of comfort for our bodies and control over our bodies in the idea of a good death. As the death of a person arguably (Sorabji, 2006) includes both the loss of the person as an embodied being, and also everything that makes them a person in their own right, it may be useful to discuss dying and the body, and the concept of embodiment further.

1.3 Introduction to the concepts of embodiment and relationality

Embodiment as a concept is central to the question: are we' just' bodies? Do we have a body or are we in fact our bodies? Embodiment is an important concept when considering what is a good death (Haddow, 2005) and relationality, the closeness between embodied beings, is linked to this. Having (rather than being) a body implies the body is owned by us, therefore our 'self' is somehow separate to the body (Sorabji, 2006). This is classic Cartesian duality (Felder and Robbins, 2011); Descartes' contemplations about whether he was or had a body have led to centuries of medical and societal division between the body and the mind (Haddow, 2005). The idea that bodies and minds are separate still very much exists in medicine today (McNaughton, 2013). Haddow (2005) speculates that this thinking has led to the idea of clinical detachment; for example the protagonist (a medical consultant) in Monica Dickens wartime novel, Thursday Afternoons is surprised, when delivering his own baby, that his wife meant no more to him than any other gravid body (Dickens, 1949). It can be seen that this idea of viewing a body as a problem to be solved, essentially being very detached, can be a helpful idea – it is probably fundamental to the development of learning through anatomical dissection, for example (Richardson, 1987), but particularly from a nursing point of view, it is problematic.

The concept of embodiment was valued by Florence Nightingale, who in 1859 published the first nursing 'textbook', and is credited as the founder of modern nursing practice (Nightingale, 1992). In her ‘Notes on Nursing’ she discusses her theory of disease as a state of disequilibrium of the human body (Boschma, 1994). She mentions that managing the disease or illness requires attention to many facets of the patient’s life including physical, environmental, and moral issues. It is one of the earliest examples in the nursing literature of attending to the whole care of the patient – or holistic care (Boschma, 1994; Benner, 2000). The idea of holistic care has grown and developed over the past century and can now be said to be central to modern nursing practice (McCormack, Dewing and Mccance, 2011; McCormack and McCance, 2011; Papathanasiou, Sklavou and Kourkouta, 2013). Holistic care, depending as it does on looking at the whole person, is a refutation of the Cartesian duality mentioned above – we do not merely have our bodies, we are our bodies. Our bodies are central to our being, our life, and our death. Yes, we are or may be more than our bodies, but we have to start with the body, we are embodied beings, and we cannot separate out the mind and the body. Nurses, whose job it is to deal with the whole of the patient by providing hands on care of the body are aware that nursing practice is fundamentally about peoples experience of embodied existence, perhaps particularly at those times when the body fails to function in a normal fashion and ultimately dies (Gadow, 1980; Wilde, 1999). At these times nurses look after, or care for, their embodied patients before, during and including after death, using all their skills derived from both their own experience of embodied existence and the development of relationality between themselves and the patient. So, for nurses there is no distinction between mind and body.

Relationality is a term derived from psychology describing connections between individuals (Tucker, 2011; McCarthy and Prokhovnik, 2014; Kontos, Miller and Kontos, 2017), particularly close connections. Embodiment is very important to this concept: relationality is an holistic, close, enfleshed relationship with another, where the separate states of ‘you’ and ‘I’ become ‘we’ and ‘us’ (McCarthy and Prokhovnik, 2014). Maclaren (2014) describes relationality as the development of close connections with another, as a kind of spatiality of intertwining of self and other, for which she coins the term ontological intimacy (Maclaren, 2014). Nurses, during the act of caring experience ontological intimacy and relationality with their patients, using their bodies to provide care for the patient as an entire embodied being for the duration of their existence and also after death. This concept of ontological intimacy is therefore related to the nursing-centred idea of a therapeutic relationship, one which develops between the nurse and patient and is used to aid the patient in whilst caring for them (Peplau, 1988). Relationality by definition also exists between people who love one another in any way - Kendrick and Robinson discuss the concept as part of the idea of 'tender loving care' or TLC, familiar to many nurses (Kendrick and Robinson, 2002) – and with a long connection such as a spousal or parental relationship, there is evidence that embodied relationality can continue after death (McCarthy and Prokhovnik, 2014). Some relatives, whilst absolutely understanding that the person has died, may experience ongoing physical signs of their dead loved one which may be unsettling or comforting, often dependent on the perception of whether the loved one experienced a 'good death' or not (Probyn, 1991; Hall, 2014; McCarthy and Prokhovnik, 2014; Maddrell, 2016; Carroll, 2020).

So, a good death from a nursing point of view would be the good death of an embodied being (the patient), who has been cared for with relationality by their nurse or loved one. This is fundamental to good nursing care implying the development of an empathetic rapport with the patient (Kunyk and Olson, 2001). The patient is an embodied being and therefore the comfort of the body, that it is clean, pain free, that the whole person is in fact cared for, is paramount (Wilde, 1999).

1.4 Death in the emergency department.

The above discussions have focused on an ideal good death for an embodied being and what the concept of a good death has meant to individuals over the past centuries. Unfortunately, death in the emergency department is different to death in other care settings. The ED is the gateway to hospital care. Despite what we may wish for in terms of a good death, (to die at home surrounded by loved ones etc) at least 60 % of deaths actually occur in the hospital settings (Costello, 2006; Broad *et al.*, 2013). Death in the ED is rarely, if ever, planned, it is often sudden and may be extremely traumatic (Edlich and Kübler-Ross, 1992). It may involve the patient going through a resuscitation process which can be distressing in itself for both the patient and family (Waldrop *et al.*, 2014), even if successful (Balian *et al.*, 2019). It is not an environment in which people would choose to die. Yet death in this setting is not infrequent. In the hospital in which the author works, there are an average of twelve deaths per month in the emergency department. Emergency departments are needed and their raison d'etre is to save lives (Bailey, Murphy and Porock, 2011d). Sometimes, however, patients cannot be saved. End of life care in the ED is an under-researched and under- funded area (Hogan *et al.*, 2016; Gloss, 2017; Carlin, Dubash and Kozlovski, 2020). This PhD study aims to add to this small body of literature and to build on the work of those who have gone before, on order to improve care for those who lose their lives in the ED.

1.5 How to measure a good death?

As discussed above, there does appear to be a general agreement in the literature that a good death is one in which the dying person is comfortable and pain free, receives appropriate spiritual care, is not alone and retains his / her dignity as an embodied being (Emanuel and Emanuel, 1998; Sandman, 2005; Borgsteede *et al.*, 2006; Hicks and Rees, 2008; Castledine, 2010; Gould, 2012; Kelly, 2014; Cottrell and Duggleby, 2016; Nyatanga, 2016; Krishnan, 2017). However although measures exist to examine the quality of death and dying (Hales, Zimmermann and Rodin, 2010), specifically the quality of death and dying questionnaire (Meier *et al.*, 2016), there is actually a lack of outcome measures specifically for good death (Krishnan, 2017). These are not necessarily two separate things although the concept of quality of life at the end of life may be differentiated from those of quality of dying and death and a good death, because quality of life at the end of life focuses on the person as a living being whereas looking at the quality of dying and death / good death, acknowledges that death happens and is inevitable (Curtis *et al.*, 2002).

As mentioned above, it is impossible to check whether someone has had a good death and ask them for ways it could have been improved. Therefore, any outcome measures for a good death rely on the accounts and experiences of those who have witnessed the death, and what they are looking at is the perceived quality of death / dying. While there are studies based on patients' accounts of their experiences prior to death (Borgsteede *et al.*, 2006; Ko, Kwak and Nelson-Becker, 2015) these are going to be potentially biased: any patient who is able to write or describe their experiences are going to have to be well enough to do so and willing to take part. Information therefore has to come from the personal experience of the patients closest relatives or friends who are with them at the time (Addington-Hall and McPherson, 2001; McPherson and Addington-Hall, 2003).

There is a difference, possibly a very great difference, between what we might theoretically consider a good death to be (and according to whom), and actual, witnessed, assessments of the quality of death and dying, assessments as to whether or not the individual had a good death. Hales et al, in 2012, interviewed twenty -two bereaved caregivers of patients who had died of metastatic cancer. Incidentally, all interviews were carried out between eight and ten months after the patient's' deaths, but the authors report that no participant had any problems with recall, suggesting that events at the end of life are highly memorable (Hales *et al.*, 2012). Their findings suggest that the quality of dying and death is an extremely complex and individual construct, and they recommend that clinical attention be paid to the family as the unit of care, and to the values, past experiences and expectations of this unit. Similarly, Curtis et al (2002) found that family members interviewed after death gave the next best possible information about the quality of dying and death (acknowledging the impossibility of asking the patient) and again suggested that the quality of dying and death is a complex and very difficult-to-measure concept.

Ultimately, attempting to find out (in a clinical setting) if the patients' family felt that the patient had a good death is more than merely assessing the perceived quality of the death and dying experience. It brings in the holistic idea of the family as a unit of care and all that this entails. Similarly, the feelings and experiences of the closest caregivers, the nursing staff, can be considered to be part of this unit of care, albeit on the periphery, but importantly as the facilitators of the death and dying experience (Wood, 2014). In the study on which this thesis is based, the family members are the proxies for the deceased persons, but the focus is on their views and experiences and equally the views and experiences of nurses.

1.6 This PhD research

The research undertaken for this thesis was designed to address the issues identified above (sections 1.2 - 1.4). Specifically, this research aimed to create new knowledge by describing the priorities and needs of dying patients who end their lives in the emergency department. Further, the research sought to generate new knowledge regarding the nature of the experience of family members of dying patients and the nurses who care for them by describing their priorities and needs. Finally, the study was designed to contribute new knowledge regarding the potential for improvement in the care for the dying in the ED which might be used in future research.

To meet these aims three research objectives were set:

1. To review and examine the literature surrounding the experience of death in the emergency department (chapter 2) from the perspective of bereaved family members and nursing staff.
2. To describe the experience of death in the emergency department from the perspective of bereaved family members and nursing staff (chapters 5 and 6).
3. To discuss the experience of death in the emergency department from the perspective of bereaved family members and nursing staff in such a way as to provide material for education, future research and clinical practice (chapters 7 and 8).

The three research objectives were met by means of a variety of research methods, which are introduced below and described in greater detail in the relevant chapters.

1.7 The planned study

The research was undertaken by means of a scholarship awarded by Oxford Brookes University in conjunction with Oxford University Hospitals NHS Foundation Trust, to facilitate further study into the care of dying adult patients in the emergency department and ultimately thereby to improve care.

1.8 The qualitative research

Objective 1 was addressed by an immersion into the literature around the subject including published material and grey literature. Following this, a systematic review of the literature was undertaken, the results of which can be seen in chapter 2 of this thesis. Objectives 2 – 4 were addressed by means of a qualitative research study, underpinned by the precepts of existential phenomenology. Phenomenology was chosen as the ideal qualitative research methodology when investigating individuals' experience of a phenomenon. Phenomenology has many variants and for this study, the existential phenomenology of the French philosopher Maurice Merleau-Ponty was chosen as the most suitable for the research area. Nineteen in depth semi-structured qualitative interviews were carried out, comprising data set one: eleven interviews with bereaved family members, and data set two: eight interviews with nursing staff caring for dying patients in the ED.

1.9 The thesis

The thesis has eight chapters. The background and introduction to the project are described in chapter one. The review of the literature is presented in chapter two. Chapter three describes the methodology, presenting the philosophical underpinnings of the thesis and chapters four is devoted to the methods used. Chapters five and six present the findings from the research project. Chapter seven is the discussion chapter, and the thesis concludes with chapter eight including recommendations for further research.

1.10 Conclusion

This introductory chapter has described the background and foundations of the project, setting the scene of a research project carried out by a nurse looking at a topic very relevant to clinical nurses. The chapter introduces the concepts of a good death and what it means to individuals to die as embodied beings. It has been discussed that from the nursing point of view, the aim of providing good end of life care in any setting is to look after the patient holistically and ensure that he / she has as good a death as possible. The concept of the ED as an unusual and undesirable place to die has been introduced. The aims and objectives of the research are delineated, and the chapter clearly shows how the thesis will proceed and fulfil the aims and objectives. The structure of the thesis is described. The next chapter, chapter two looks at the research literature and clearly shows the gap in the literature and the need for the PhD study.

CHAPTER 2: THE LITERATURE – WHAT IS KNOWN ABOUT DEATH IN THE ED?

2.0 Chapter abstract

This chapter describes an in-depth study of the specialist literature pertaining to the subject of the thesis. The literature search, results, discussion, and conclusion are described. This literature review was accepted for publication in 2018 (see below) and is updated here:

McCallum, K.J., Jackson, D., Walthall, H. and Aveyard, H., (2018). Exploring the quality of the dying and death experience in the Emergency Department: An integrative literature review. *International Journal of Nursing Studies*, 85, pp.106-117.

2.1 Introduction

Individuals may present to the Emergency Department in the end stages of life, from acute injury or from more chronic underlying causes. Ensuring these people are placed on the most appropriate pathway is essential, as they may not be in the most suitable environment for their needs. Emergency medicine is about triaging, diagnosing and treating life-threatening trauma and diverse medical / surgical conditions and managing prehospital and in-hospital emergency care(http://www.rcem.ac.uk, 2015; Medicine, 2018). There is a societal expectation that the goal of emergency care is immediate resuscitative, life- preserving treatment (Chan, 2006b; Clarke, 2008), rather than holistic care of the dying person, focusing on comfort and the achievement of a good death (Clarke, 2008), which may not often be considered.

2.2 Background – dying in the emergency department.

In health care generally, there is a growing amount of discussion of death and what makes a good death. Pivotal work in the United States by Glaser and Strauss, published in the mid-1960s (Glaser and Strauss, 1965; Glaser and Strauss, 1968) brought the idea of improving the death and dying experience for hospital patients in both acute and non-acute areas into mainstream discussion (Clark, 2007). Glaser and Strauss, both sociologists working in the US healthcare system, were instrumental in promoting the concept of awareness of dying, where both the patient and family member are aware of the approach of death, as opposed to closed dying where the patient was not aware, which had previously been the norm (Seale, Addington-Hall and McCarthy, 1997). This patient- focused stance was revolutionary, allowing the needs of the dying person to be fully explored and his or her problems to be those defined by the patient rather than by medical / nursing staff or family members. There is evidence that as far back as 1975, clinicians in the Emergency Department were beginning to discuss the management of the dying; and that this discussion has continued (Cauthorne, 1975; Jones, 1978; Soreff, 1979; Ordog, 1986; Edlich and Kubler-Ross, 1992; Adamowski *et al.*, 1993; Tye, 1996; Cooper *et al.*, 2018; del Mar Díaz-Cortés *et al.*, 2018). Topics of discussion include Jones (1978) work on communication between family members and staff in the Emergency Department, including the need for a comprehensive and compassionate approach, which was echoed by Sorreff (1979) and Ordog (1986). Recommendations included clear instructions on breaking bad news, supporting the family through their initial reactions and looking after the multidisciplinary team(Parrish *et al.*, 1987) . There is evidence from the writing of Tricia Scott, that Emergency Department personnel attempt to find meaning in even very difficult situations following a death (Scott, 2013; Scott, 2020). The writer discusses the 'dualistic culture' (Scott, 2013) which exists in the Emergency Department from the perspective of staff in which speed, rigor and perhaps separation of feelings are side by side with the spiritual matters which often come to the forefront when dealing with sudden death.

This emphasis on a holistic approach mirrors the principles of the emerging speciality of palliative care, being developed in the UK by Cicely Saunders (Clark, 2007), who was instrumental in opening the worlds' first modern hospice in 1967 (Clark, 2007). The term 'palliative care' could be said to have originated in Canada from the work of Derek Doyle in the 1970s and '80s (Doyle, 2003; Fadul *et al.*, 2009). His work was hugely influential in deciding upon a definition of the concept, ultimately accepted by the World Health Organisation (WHO): Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification of symptoms, assessment of the entire patient and the holistic treatment of problems (Gomez-Batiste *et al.*, 2013). The ultimate aim of palliative care is the achievement of a good death (Emanuel and Emanuel, 1998; Stewart *et al.*, 1999).

Despite the importance of palliative care, concern has been expressed that the concept is not widely or extensively taught in medical education generally (Sullivan, Lakoma and Block, 2003; Meo, Hwang and Morrison, 2011; Cheng and Teh, 2014; Frey *et al.*, 2014; Horowitz, Gramling and Quill, 2014), although the Royal College of Emergency Medicine does have a guidance document about end of life care (http://www.rcem.ac.uk, 2015). Linked to this, there is relatively little mention of end-of-life care in Emergency Department textbooks, either for medical or nursing students (Rabow *et al.*, 2000; Markovchick, Pons and Bakes, 2011). This is despite the early work by pioneers in the 1970s as mentioned above, emphasising the need for staff education to enable better care experiences for dying patients and their carers. Interestingly, these papers (Cauthorne, 1975; Jones, 1978; Soreff, 1979; Ordog, 1986; Adamowski et al., 1993; Edlich and Kubler-Ross, 1992; Tye, 1996) advocated core palliative care principles (NICE, 2017), although the term ‘palliative care’ was not mentioned and there does not appear to have been any explicit attempt to link-up the two specialties of emergency medicine and palliative care.

Currently, the evidence shows that there is no one accepted model of palliative death and dying care integration within the Emergency Department in the United Kingdom or elsewhere in the world (Chan, 2004; Chan, 2006b; DeVader, Albrecht and Reiter, 2012; Weil *et al.*, 2015; Chan, Webster and Bowers, 2016; Koh *et al.*, 2019; Reuter *et al.*, 2019; George *et al.*, 2020). Internationally, there is increasing recognition that this is an area of concern. Initiatives such as encouraging closer multi-disciplinary team working, are taking place in order to close the gap between these two specialities; in the United States (Lamba and Quest, 2011; Quest *et al.*, 2012; Lamba *et al.*, 2014; Young *et al.*, 2016), Australia (LeBrocq *et al.*, 2003; Weil *et al.*, 2015), and the UK (Bailey, Murphy and Porock, 2011c; Bailey, Murphy and Porock, 2011a). There is a conscious drive to include formal palliative care education in the medical and nursing curricula in many areas (DeVader et al., 2012; Quest et al., 2012) and initiatives to improve research in this vital area are being developed (Chan, 2006; Lamba et al., 2014). Emphasis is beginning to be given to looking at patient care in a more holistic manner than perhaps has been done in the past with a focus on viewing individual patient conditions as fluid and constantly changing, and assisting staff to be prepared for these changes (Bailey, Murphy and Porock, 2011d).

This chapter will review what is currently known about the quality of the death and dying in the Emergency Department, and what the experience is like for the carers and the staff looking after these individuals. Allowing people who have been through the reality of watching a loved one die or caring for a patient who is dying, to tell their story through whatever medium, is a very powerful concept and a way to humanise clinical events (Greenhalgh, 2017).

A note on definitions: End of life care is a term that has been used interchangeably with palliative care, hospice, and terminal care. Various writers have debated this term and proposed new definitions (Izumi *et al.*, 2012; Greater Manchester and Networks., 2015; Neuberger, 2016a). For the purposes of this chapter, the definition proposed by NHS (National Health Service) England (NHS 2016) , where end of life care is defined as support for people who are in the last months or years of their lives, is the preferred definition. Dying and death is the culmination of end-of-life care.

The term ‘carer’ is used as a generic term for friends, families, loved ones (Fuller, 2012; Ewing and Grande, 2013; Dosser and Kennedy, 2014). Throughout this chapter, the term ‘carer’ is used to signify caregivers, relatives, family members, friends and loved ones.

2.3 The review

2.3.1 Aim

The aim of the review was to explore the quality of the death and dying experience in the Emergency Department from the perspective of staff and carers.

2.3.2 Design and methods.

A systematic integrative literature review was conducted (Whittemore and Knafl, 2005; Aveyard, Payne and Preston, 2016). The review was designed with the aim of discovering the quality of death and dying in the ED, from the perspective of staff and carers.

2.3.3 Search methods

Firstly, a systematic search of PubMed, the Cumulative Index to Nursing and Allied Health Literature, Magonline (internurse), and the Cochrane library was undertaken. The search was limited to research papers written in English and published within the period 1990 – 2020. The search started In 1990, as this was the date in which the World Health Organisation (WHO) set out the scope and definition of palliative care and began to suggest how this should be pursued as a public health issue (WHO, 1990) . This was a global landmark for palliative care. The WHO paper published recommendations for the implementation of palliative care at the national level and therefore it could be assumed that papers published after this point are influenced by the ideas contained in this paper. Secondly the ‘snowball method’ (Perez-Bret, Altisent and Rocafort, 2016) was used. This involves selecting studies cited by the articles found. It is recognised that electronic searching may not identify all published material and hand searching was also undertaken looking at (for example) journal contents pages and reference lists.

The decision was made to exclude studies which focussed on the concept of resuscitation, specifically family witnessed resuscitation. There is much written about family witnessed resuscitation (Walker, 2006; Breach, 2018; Erogul, 2020; Grimes, 2020); it is one of the main topics of research in the ED focussing on family members. It was felt that excluding these studies allowed a fresh look at end-of-life care in the ED and the experiences of family members.

Table 1: Inclusion and exclusion criteria

Inclusion and exclusion criteria for electronic database reviews
Inclusion criteria:
Target population (the dying person) over age 18
Care setting (Emergency Department)
Papers written in English
Papers published between 1990 – 2020.
Primary research
Research looking at the experiences of clinical staff and carers.
Exclusion criteria
Care setting both Emergency Department and another area for example death and dying in the ED and in acute general medical care.
Papers, which focus on the concept of resuscitation.
Inclusion and exclusion criteria for snowball method
Inclusion criteria
Target population (the dying person) over age 18
Care setting (Emergency Department) – adult patients over 18 only
Papers written in English
Papers published between 1990 – 2020.
Qualitative and quantitative studies looking at death and dying in the Emergency Department
Exclusion criteria
Care setting both Emergency Department and another area for example death and dying in the Emergency Department and in acute general medical care.
Papers, which focus on the concept of resuscitation

Screening

A search strategy was devised using a combination of Medical Search Headings (MeSH) terms and key words.

Table 2: Search terms MESH headings

Concept	Dying	Emergency Department	Caregivers	ED staff	End of life
MeSH	Death Death, Sudden	Emergency Service, Hospital	Caregivers, Family, Spouses, Friends.	Nurses, Medical Staff, Allied Health Personnel.	Terminal care', Palliative care, Death, Sudden
Keywords	Dying, Death	'Emergency Department', Accident and Emergency, Emergency Nursing	Carers, Spouse	Doctors, Chaplains, Nurses, Allied Health Professionals	'End of life care ', Palliative care OR sudden death

Thirty-two articles were then examined. Of these, three were literature reviews of published work (Olsen, Buenefe and Falco, 1998; Norton, Hobson and Kulm, 2011; Roe, 2012) and were therefore excluded, not describing original research. They were, however, extremely useful and helped to inform the literature search. Figure 1 presents a diagrammatic representation of the search strategy.

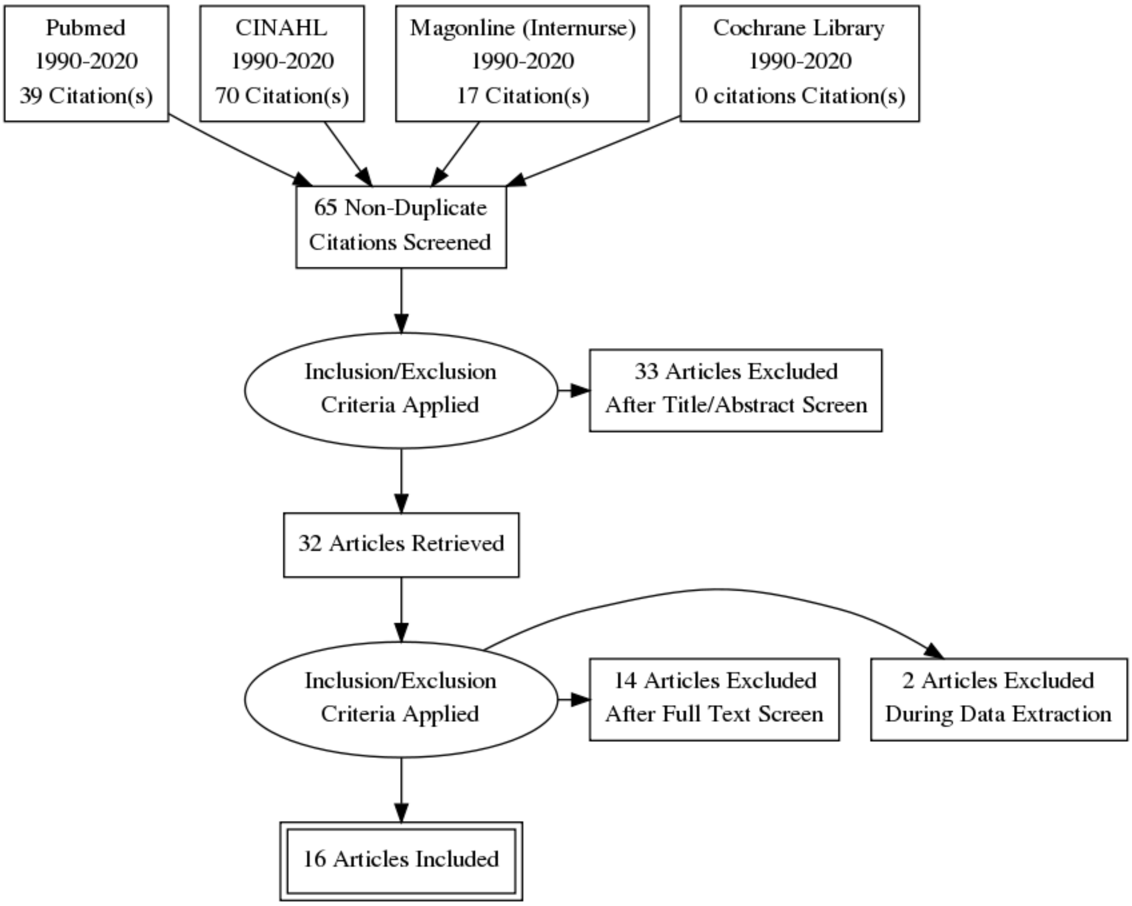

Figure 1: Prisma flow diagram to show search strategy (Moher et al., 2009)

2.3.4 Search outcome

Fourteen articles were excluded after full text screen and two during data extraction. Sixteen articles were included in the final analysis. Table 2 shows the characteristics of each paper. The papers were assessed for relevance and quality of research using the assessment tool available from NICE (National Institute of Clinical Excellence) (NICE, 2012; Zeng *et al.*, 2015), chosen because of the clarity of the material and the scoring system. Many assessment tools are available, and the NICE tool has much in common with other available tools (Flemming, 2007; Ryan, Coughlan and Cronin, 2007; Saini and Shlonsky, 2012; Greenhalgh, 2014). The tool consists of a clear checklist, comprising 7 sections, covering 15 questions: theoretical;

approach, study design, data collection, trustworthiness, analysis, ethics, and overall assessment. Each paper / study is given a final grading according to the following score:

++ All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are unlikely to alter.
+ Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.
– Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

The score for each paper reviewed for this literature review can be seen in Table 2. It is worth noting that whilst there are many studies looking at the experiences of nursing and medical staff, no study specifically asked carers for their point of view.

Table 3: Included articles

Article number	Author / Year / Country	Study Objectives	Setting / Sample Size	Methods	Results and main themes	Study Limitations	NICE score
1.	Bailey et al (2011). UK	To explore end of life care in the ED and to provide an understanding of how care is delivered to the dying, deceased, and bereaved in the emergency setting.	Large urban ED. Observations – n = 100 + Interview: Staff n= 15 Patients and relatives n=13.	Qualitative: Ethnographic approach using observation and interviews.	Patients who die in the ED are cared for in 2 ways – subtacular (worse experience) and spectacular (better experience).	Data collected from 1 ED only, not necessarily generalizable to other ED within and without the NHS. Majority of data collected from nurses, physician data limited and from SPRs only, may not be reflective of entire medical team.	++
2.	Bailey et al (2011). UK	To examine how space is used to 'care' for patients at the end of life and to explore further meaning behind attitudes to the dying in the emergency setting.	Large urban ED. Observations – n = 100 + Interview: Staff n= 15 Patients and relatives n=13.	Qualitative: Ethnographic approach using observation and interviews	Patients near the end of life who require palliation are often segregated in the ED and have little status. Some deaths are seen as 'out of place' and are concealed.	Data collected from 1 ED only, not necessarily generalizable to other ED within and without the NHS. Majority of data collected from nurses, physician data limited and from SPRs only, may not be reflective of entire medical team.	++
3.	Bailey et al (2011).	To explore how emergency nurses manage	Large urban ED.	Qualitative: Ethnographic approach using	ED nurses develop expertise in EoL care by progressing through 3	Data collected from 1 ED only, not necessarily	++

	UK	the emotional impact of death and dying in emergency work.	Observations – n = 100 + Interview: Staff n= 15 Patients and relatives n=13.	observation and interviews	stages of development: 1. Investment of the self. 2 Management of emotional labour 3. Development of emotional intelligence.	generalizable to other ED within and without the NHS. Majority of data collected from nurses, physician data limited and from SPRs only, may not be reflective of entire medical team.	
4.	Beckstrand et al (2012)b. USA	To determine what suggestions emergency nurses, have for improving EOL care.	Postal survey sent to national geographically dispersed random sample of 1000 emergency nurses.	Qualitative: Questionnaire survey using open-ended question: ‘What aspects of EoL care would emergency nurses change to improve how patients die in an ED?	5 major themes: increasing the amount of time ED nurses have to care for dying patients, allowing family presence during resuscitation, providing comfortable patient rooms, providing privacy, providing family grief rooms.	Responses were only obtained from nurses who were members of ENA and therefore can be generalised only to emergency nurses who ae members of ENA.	++
5.	Beckstrand et al (2012)a. USA	To determine how ED design affects EoL care nursing	Postal survey sent to 500 randomly selected members of the emergency nurses association (ENA).	Quantitative: 25 item questionnaire survey	2 main themes: lack of privacy for dying patients and their families, and general lack of space in the ED.	Nurses were not asked about the date of construction of their ED, not about how many shifts they worked per month.	++
6.	Beckstrand et al (2008).	To determine what obstacles, impede the	Postal survey sent to geographicall	Quantitative: 70 item	Response rate of 46.3%. Nurses reported that the greatest obstacles to	Small sample size, although randomly selected.	++

	USA	delivery of end-of-life care in emergency departments	y dispersed random sample of 700 ED nurses	questionnaire survey.	EoL care were lack of time, poor design of ED depts. and family members not understanding what ‘life-saving measures’ means.	Not generalizable to emergency nurses who are not members of ENA.	
7.	Grudzen et al (2011). USA	To understand perceptions regarding their illness of patients who present to the ED at the end of life	Urban Public Hospital. Convenience sample of 13 seriously ill ED patients with advanced illness.	Qualitative: Semi structured one on one interviews. Grounded theory used to analyse.	Patients with advanced illness present to ED when symptoms are out of control. They often have financial concerns, want to spend time with family and do not want to be a burden. Religious faith is important as is control over their own fate.	Small sample size. Generalizability to other EDs is limited. All subjects were seen by palliative care in the ED which may have influenced answers. Triangulation of findings through interviews with carers and staff may have provided richer data. Ethical approval for the study was not mentioned.	+
8.	Wolf et al (2015). USA.	To explore emergency nurses’ perceptions of challenges and facilitators in the care of patients at the EOL.	Questionnaire survey sent to 1,879 ED nurses geographically dispersed nationally. 2 Focus (n= 17 nurses) groups took place at an emergency nursing	Mixed Methods: quantitative questionnaire survey and focus groups.	Emergency nurses are comfortable providing EoL care in the ED. Challenges to providing good care include lack of space, time, and staff, also mismatch between the goals of emergency care and those of EoL care as well as the emotional burden of caring for the dying.	Limited generalizability of findings due to self-selecting samples both for the survey and the focus groups.	+

			annual conference.				
9.	Kongsuwan et al (2016). Thailand	To describe the meaning of nurses' lived experience of caring for critical and dying patients in the emergency rooms.	3 emergency rooms of tertiary hospitals in Southern Thailand.	Qualitative: in-depth individual interviews with 12 ED nurses. Data analysed using van Manen's hermeneutic phenomenological approach.	Experiences of caring for critical and dying patients revealed 4 thematic categories: defying death, no time for palliative care, lacking support for family and privacy for peaceful deaths.	As the study was conducted in Thailand, the possibility that Buddhist beliefs influenced the results (Buddhists require a calm and serene atmosphere before death in order to achieve enlightenment) may be considered to be a limitation and make the findings less generalizable. The authors do not recognise any limitations, which is in itself a limitation.	+
10.	Smith et al (2009). USA	To explore the attitudes, experiences, and beliefs of emergency providers (doctors, nurses, social workers, and technicians) about palliative care in the ED.	2 academic EDs in Boston, USA.	Qualitative: 3 focus groups with 26 providers. Data analysed using grounded theory approach,	Six themes: participants equated palliative care with EoL care, participants disagreed about the feasibility and desirability of providing palliative care in the ED, patients for who a palliative approach has been established often visit the ED because of symptoms, lack of communication between different departments	Limited generalisability to other settings. The extent to which participants interacted with the palliative care teams is unknown. Small sample size and risk of selection bias. Physicians were inexperienced and therefore again findings not generalizable to all physicians.	++

					leads to undesirable outcomes, conflict around withholding life-prolonging treatment is common, and training in pain management is inadequate.		
11.	Decker et al (2015). Australia	To describe the experiences of emergency nurses in providing end of life care in the emergency department.	3 EDs within an Australian tertiary hospital network.	Qualitative: 3 focus group interviews. Data analysed using grounded theory.	10 categories emerged from the data that described a social process for managing death in the ED, with the categories linked via the core category labelled 'dying in the ED is not ideal'.	Findings not generalizable to other settings in a different part of Australia, or other settings. Study very small.	++
12.	Weil et al (2015). Australia	To explore the understanding of palliative care by healthcare professionals caring for patients with advanced cancer attending emergency departments for EoL care.	2 Australian University Hospitals (first, focus group, stage), telephone interviews with purposive sample of staff across Australia.	Qualitative: 2 stage study, 8 focus groups followed by 11 semi structured phone interviews.	Main theme – health professionals held contradictory (and unhelpful) understandings of palliative care and its application in the ED. Palliative label may lead to unduly limited care in the ED.	Self-selected sample possibly representing people who were already interested in the topic, therefore may not be representative of other health care professionals. Focus groups can be influenced by particularly vocal participants.	++
13.	Chan (2011). USA	To identify different trajectories of approaching death in an effort	Level II trauma centre ED Northern California	Qualitative: ethnographic approach, interpretive phenomenologica	Data gave rise to 7 trajectories of approaching death in the ED. The author states that recognising and	Limited generalisability outside single community hospital in California. Small sample size and risk of	++

		to describe the EOL experience in the ED.		I study. Participant observation, brief interviews, and in-depth interviews.	using these trajectories will allow appropriate care, ease transition to EoL care and benefit patient, family, and clinician by allowing all possibilities to be explored including appropriate anticipatory planning.	selection bias. Only experienced individuals were included.	
14.	Hogan et al (2016). Canada	To explore the experiences of emergency nurses who care for patients who die in the emergency department in the Canadian context.	Large Canadian academic health sciences system. 11 ED nurses.	Qualitative design, interpretive descriptive approach.	Three major themes: ‘It’s not a nice place to die’ ‘I see the grief’ and ‘Needing to know you’ve done your best’. Environment of care was a big factor in complicating the care of dying patients and their families (unpredictability, busyness, noise, lack of privacy, need to manage several patients simultaneously).	Limited generalisability due to small sample size and self-selecting sample.	++
15.	Giles et al (2019). Australia	To explore nurses’ perceptions and experiences of caring for patients who die suddenly in the ED	Online survey sent to ED nurses throughout Australia. 211 responses	Mixed methods, some qualitative analysis on open ended survey questions. Grounded theory used to analyse.	Five themes: Key elements of EoL care, Systemic and environmental barriers, educational deficits, roles ambiguity and emotional impact.	Moderate sample size, survey tool was structured with pre-defined sections.	++

16.	Diaz-Cortes et al (2018). Spain	To explore and interpret physicians' and nurses' experiences regarding conservation of dignity in end-of-life care in dying patients in the ED	Two Spanish general hospitals. 16 nurses 10 physicians	Qualitative design using hermeneutic phenomenology	Two themes: dignified care in unfavourable (hostile) surroundings; The design of a system focused on the person' s dignity	Short period of time (8 months). No consideration was given to exploring differences in ideas / concepts depending on gender.	++

Keys:
EoL: End of Life
ED: Emergency department
ENA: Emergency Nurses Association (USA)
SPR: Specialist Registrar (UK).

2.3.5 Quality of the evidence.

The papers studied are mainly qualitative papers, with three quantitative and four mixed methods studies also included. In order to analyse papers written using different methods, it was appropriate to undertake a thematic analysis. This approach allows a qualitative synthesis of original qualitative, quantitative and / or mixed methods studies through the extraction of first data codes and then emerging themes (Thomas and Harden, 2008; Dahan-Oliel, Shikako-Thomas and Majnemer, 2012). Themes are built from the text of selected studies allowing full appreciation of the richness and depth of the data (Dahan-Oliel, Shikako-Thomas and Majnemer, 2012).

2.3.6 Data abstraction and synthesis

Text from the selected studies was coded by highlighting relevant parts of the text and assigning code words to these areas. Following this an iterative process was used to develop categories by combining codes. Descriptive themes were attached to each category and are discussed below.

2.3.7 Results

After analysis, eight themes emerged from the literature: care in the ED is about living not dying, staff perceive that death is a failure, staff feel underprepared to care for the dying patient and family in this environment, there is limited time for safe standards of care, staff stress and distress, staff use of distancing behaviours, the care of the dying role is devolved from medics to nurses at the end of life, and patients and staff perceive that ED is not the preferred place of death. Figure 2 is a graphical representation of the relationship between these themes. It is intended to show visually that the themes are all inter-related, and that each theme flows from the previous one and is indivisible from it.

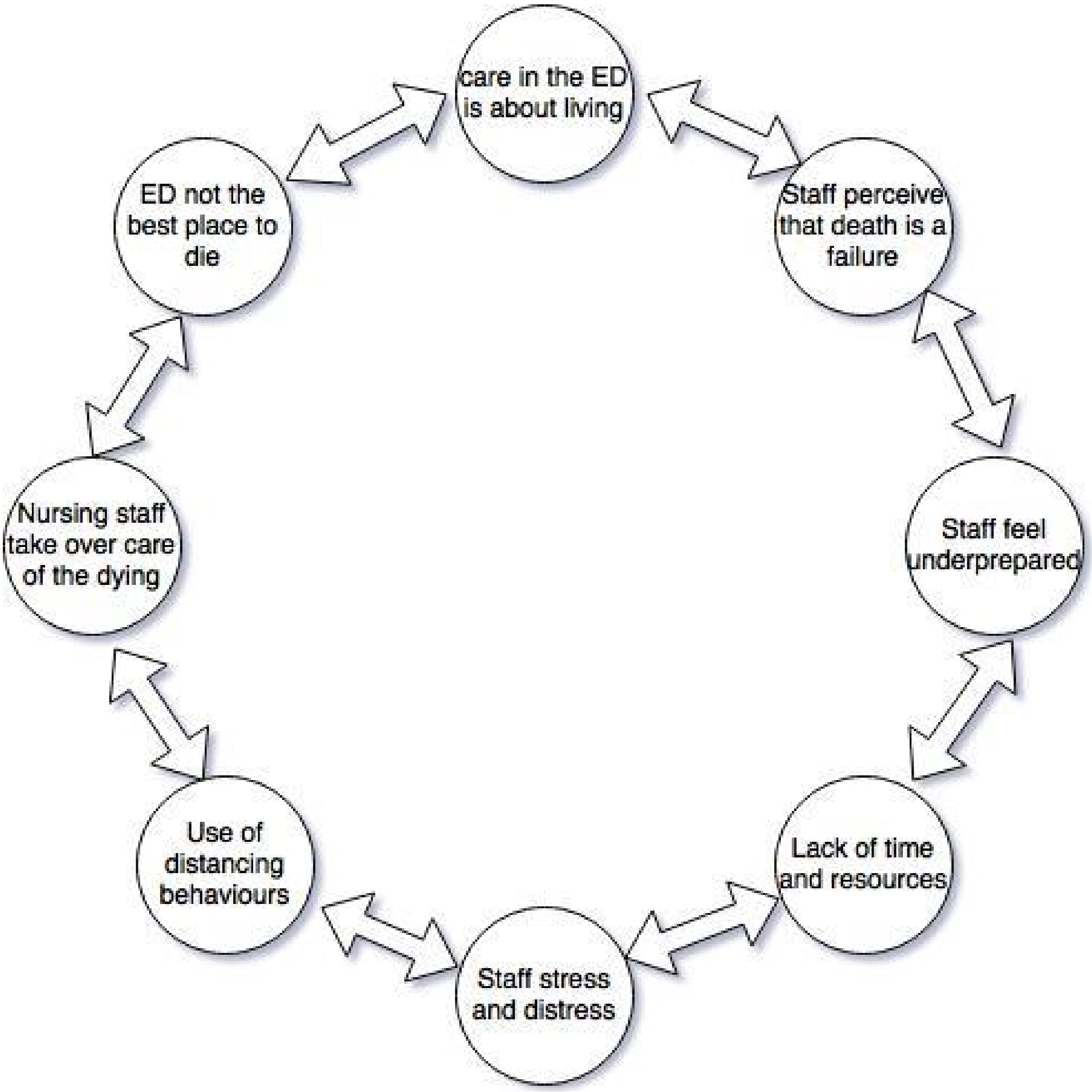

Figure 2: Issues, which may contribute to the quality of the death and dying experience in the Emergency Department from the perspective of staff and carers

2.3.8 The themes

Staff perceive that the focus of care in the Emergency Department is about living, not dying.

This was the most common theme to emerge (Smith *et al.*, 2009; Bailey, Murphy and Porock, 2011c; Bailey, Murphy and Porock, 2011d; Chan, 2011; Grudzen *et al.*, 2011; Marck *et al.*, 2014; Decker, Lee and Morphet, 2015; Weil *et al.*, 2015; Wolf *et al.*, 2015; Kongsuwan *et al.*, 2016; del Mar Díaz-Cortés *et al.*, 2018). Patients are seen as 'living' and the focus is on preserving life, until life ends, therefore there is no period of time where a patient is said to be 'dying'(Bailey, Murphy and Porock, 2011d) . Bailey et al also found an emphasis on 'spectacular life- saving'. One of the sub-themes of Diaz-Cortes'(2018) study was 'Reorienting the aim of healthcare provision' , noting that people who go to the ED to die require comfort instead of treatment and this is very hard for the staff to accept (del Mar Díaz-Cortés *et al.*, 2018). Bailey at al's' (2011b) ethnographic study explored patient pathways towards death in the Emergency Department (Bailey, Murphy and Porock, 2011c). This builds on work by Timmermans (2005) who explored the various pathways towards death and the cultural influences on these pathways. The authors found that there were two ways of dying (trajectories) which they define as spectacular (acute, sudden, resulting in traumatic loss of life, will always include a resuscitation event) and subtacular (quiet, expected deaths, often of those who have been ill for a long period of time, not a priority to staff). Patients who had 'spectacular' deaths were not considered to be 'dying', and there was much necessary action around these deaths.

Similarly, a Singaporean retrospective study (Yash Pal *et al.*, 2017) looking at deaths among people over 65 in the Emergency Department, found, that there were two main trajectories of dying: patients with a known chronic illness and those who experience sudden death. Of those who had a known illness, very few had had previous end of life care discussions which led to unnecessary and aggressive life preserving treatment being given (Yash Pal *et al.*, 2017).

Staff perceive that death is a failure.

In a further paper (Bailey, Murphy and Porock, 2011d) found that staff felt that the Emergency Department was not appropriate for end of life care and that death was seen as out of place, with the dead body almost seen as taboo, to be hidden away, staff perceiving the body itself to be a physical sign of failure. Failure in the context of Emergency Department death is mentioned by Marck et al (2014) and Kongsuwan et al (2016). One nurse participant is quoted as saying that ‘palliative care in the Emergency Department is focusing on saving life’ (Kongsuwan *et al.*, 2016), thus denying the possibility of death being seen as a natural part of life. One study of the views of clinical staff, found that stigma was associated with dying in the Emergency Department, especially if the dying patient was young – ‘it looks like [the Emergency Department] didn’t do their job’ (Wolf *et al.*, 2015).

Staff feel underprepared to care for dying patients and their carers in the Emergency Department.

Staff feeling unprepared to care for dying patients was a common theme. Nursing staff felt particularly underprepared, (Bailey, Murphy and Porock, 2011c; Beckstrand *et al.*, 2012b; Decker, Lee and Morphet, 2015; Hogan *et al.*, 2016; Giles *et al.*, 2019) although both Weil et al (2015) and Smith et al (2009) show that this is a concern for the whole multidisciplinary team. Feeling underprepared took the form of a desire or recommendation for formal education (Bailey et al 2011; (Giles *et al.*, 2019) in order to replace /enhance relying on learning from others, and their own experience (Bailey, Murphy and Porock, 2011c).

Physicians not feeling prepared to assist patients who are dying in the Emergency Department was identified by Smith et al (2009) in a focus group study. Smith et al (2009) concluded that palliative care is neither a goal of emergency medicine trainees nor a focus of their training, and this was mentioned as a statement of fact rather than a desire to change things (Smith *et* *al.*, 2009). Further education in pain and symptom management was however a goal for all staff groups in the same study, and emergency medicine residents in particular were troubled by the lack of this (Smith *et al.*, 2009). In addition, diversity education was identified as needed as there was a perception that ethnic minority patients have a worse outcome as regards pain and symptom management; a perception borne out by the literature (Pletcher *et al.*, 2008; Mills *et al.*, 2011; Dickason *et al.*, 2015).

Inconsistency in the use of the term palliative was an education-focused problem found in the work of Weil et al (2015), who discovered that participants in general thought palliative care was synonymous with terminal care (Weil *et al.*, 2015). This is an unhelpful confusion, which is common throughout the literature (Smith, 2011), and could be assuaged by further education (Head *et al.*, 2014; Kamel, Paniagua and Uppalapati, 2015).

There is limited time for safe standards of care.

Eight of the published articles mentioned the lack of time and / or resources to allow staff to properly care for the dying patient and their carers in the Emergency Department. Perhaps unsurprisingly, when Beckstrand et al (2012) asked emergency nurses what things they felt would improve end of life care in the Emergency Department, the first and most important finding was increased time (Beckstrand *et al.*, 2012a; Beckstrand *et al.*, 2012b). Interestingly this shows that the perception of the nurses was that dying patients require more time and consistent nurse presence, and that dying patients and families were currently not receiving optimal care because the time was not available. One nurse mentioned that she knew what to do (to care for dying patients) but unfortunately, she never had the time to carry out essential care of the dying (Beckstrand *et al.*, 2012b).

These researchers also mentioned the need for a better environment for the dying This would optimally include a comfortable room in which to nurse these patients and allow more privacy at the end of life. These findings echoed the earlier work of Beckstrand et al (2008), who found that emergency nurses' workload was too great to enable the time needed for good end of life care (Beckstrand *et al.*, 2008). This was perceived as an important obstacle in the practice of end-of-life care and one that caused distress to the nurses surveyed, also known as a constant issue and problem for the (USA) Emergency Nurses Association (Wolf *et al.*, 2017).

Lack of space, time and staff are again cited as the most important challenges for emergency nurses in attempting to care for end-of-life patients in the Emergency Department, in Wolf et al's 2015 study (Wolf *et al.*, 2015). Nurses were distressed by resource limitations, perceiving that patients may feel 'neglected' because 'we're always short staffed'. It is an issue perceived as something, which it may not be possible to 'fix' – one respondent stated that education is not the answer, 'it's not going to … bring those resources' (Wolf *et al.*, 2015). Nurses felt impoverished by this inability to give patients the time they need, and this had a real impact on practice (Ceci, 2006). Lack of resources impacts everything – nurses are traumatised because they have to prioritise some patients over others, and importantly make decisions, for example about moving a bereaved family out of an area so that another patient may move into it (Wolf *et al.*, 2015). This trauma has a huge effect on staff and is a large part of the general stressors affecting those who work in the Emergency Department (Johnston *et al.*, 2016).

A lack of time is echoed in the work of Kongsuwan et al (2016), Decker et al (2015), Marck et al (2014), Giles et al (2019) and Diaz-Cortes et al (2018). Findings indicated that the stress of being unable to provide what the participants describe as a 'peaceful' death (due to lack of time) was particularly great for the nurses in Kongsuwan et al's study, partly perhaps because, as the writers remark, the study took place in a prominently Buddhist country where the concept of a peaceful death is particularly important to practitioners of the Buddhist faith for spiritual reasons (Kongsuwan *et al.*, 2016). The participants in Deckers (2015) study describe a less than optimal death trajectory as one in which there is no time and no space to care for patients and relatives during and after death in the Emergency Department (Decker, Lee and Morphet, 2015). Marck et al (2014) found that the busy nature of the Emergency Department with its lack of time, privacy and senior staff led to poor communication between patients' carers and staff, potentially leading to a suboptimal care experience. Following on from this, Hogan et al (2016) emphasised the need for nurses to feel they have done their best for their patients, and this involved trying to manage the constraints of lack of time and space as well as possible (Hogan *et al.*, 2016).

The participants in Giles et al's (2019) study also mention time pressures, describing that critically ill patients are often prioritised over dying patients due to both staffing and times issues (Giles *et al.*, 2019), and they also discuss that dying as a process takes time, which they do not have. In Diaz-Cortes et al's (2018) study, when asked what measures the participants would recommend in order to improve care of the dying in the ED, participants overwhelmingly proposed dedicating more time to patients (del Mar Díaz-Cortés *et al.*, 2018).

Staff stress and distress.

Stress and distress from the viewpoint of the staff caring for these individuals was specifically mentioned in six of the papers. Staff in Bailey et al's 2011 study discussed feeling completely out of control when caring for a dying patient in the Emergency Department and because of this, feeling powerless. The stress felt can be overwhelming (Bailey, Murphy and Porock, 2011d). The writers focus on this further in a congruent paper (Bailey, Murphy and Porock, 2011a) discussing a devised model to explore the development of emotional intelligence in nursing staff around death and dying in emergency work. The aim of the model is to build awareness in managing the emotive aspects involved in care delivery and develop fundamental skills of nursing patients near the end of life. Other writers have commented on the particular need for Emergency Department nurses to maintain emotional intelligence (Codier, 2014; Codier and Codier, 2015; Powell, Mabry and Mixer, 2015), stating that development of emotional intelligence in the clinical setting holds the potential for both improved patient care and reduced burnout amongst nursing staff (Codier, 2014).

One group of authors, Hogan et al (2016), discuss the effect on nursing staff of witnessing the grief of others. The researchers found participants mentioning that they felt they were looking into peoples' lives in the most sad and tragic moments (Hogan *et al.*, 2016). Nurses discussed how they dealt with this kind of emotional stress and concluded that the need to feel they had done their best was extremely motivating in these circumstances (Hogan *et al.*, 2016).

Distress was also seen to be a problem, as shown in the work of Giles et al (2019), who found that their participants experienced high levels of emotional distress, mainly due to the problems in attempting to deliver good end of life care when constrained by time, and lack of resources (Giles *et al.*, 2019). Dealing with death and dying on a regular basis is acknowledged to be emotionally draining and the debriefs, when provided, were often described as completely inadequate and apt to cause more stress (Giles *et al.*, 2019).

Poor communication as a source of stress and distress is specifically mentioned only in the paper by Smith et al (2009) who wrote that poor communication between staff, families and between other departments in the hospital and community, leads to poorer outcomes (Smith *et al.*, 2009). An example mentioned in the text is problems occurring when the patient has a do not attempt resuscitation form in their community notes, but this is not known when the patient presents to the Emergency Department. This therefore may potentially lead to the need for further discussions about resuscitation, possibly causing distress to all parties.

Staff use of distancing behaviours.

The use of distancing behaviours was mentioned in seven of the studies. Caring for carers both during the dying process and following death was seen as particular challenging (Bailey, Murphy and Porock, 2011d; Decker, Lee and Morphet, 2015; Kongsuwan *et al.*, 2016). A lack of time, and perhaps emotional energy are cited as reasons for this with some staff reporting to use distancing behaviours towards carers because they do not have the time or ability to get more 'involved' (Bailey, Murphy and Porock, 2011c; Decker, Lee and Morphet, 2015), and some staff report a feeling of almost resentment towards the carers because of a perception that very sick patients at end of life present to the Emergency Department because carers cannot cope (Smith *et al.*, 2009).

From the carers point of view, distancing behaviours are recognised for what they are, and contribute to an overall negative experience (Bailey, Murphy and Porock, 2011c), with carers citing general lack of communication, and issues such as feeling in the way or being ignored (Decker, Lee and Morphet, 2015). It is important to note that these views are second order constructs, told informally (by carers) to nursing staff who have then repeated them to the researchers. No study specifically asked carers for their point of view, as previously stated.

The care of the dying role is devolved from medics to nurses at the end of life.

Despite the stress, and the feeling that dying patients do not belong in the Emergency Department, some nurses felt privileged when looking after dying patients (Hogan *et al.*, 2016; Giles *et al.*, 2019). Participants in Bailey et al's (2011) study felt that as soon as the patient was declared 'palliative' – i.e. no more active treatment, the care passed over to the nursing staff – the care was 'relinquished' to the nurses (Bailey, Murphy and Porock, 2011d). This is explored further in another paper by the same authors (Bailey, Murphy and Porock, 2011a) who describe how care of the dying is seen by nurses themselves as a predominantly nursing role, implying that nurses who are 'good' at their job, and manage to develop emotional intelligence as above, find reward in their practice, leading to a more positive experience for all concerned. The idea that care of the dying is the province of nurses predominantly is borne out by other literature and could be explored further (Smith, 2012; Browall *et al.*, 2014; Gagnon and Duggleby, 2014a; Lopera Betancur, 2015).

Patients and staff perceive that the Emergency Department is not the preferred place of death

Patients' views, studied in 2011 (Grudzen *et al.*, 2011) were that attending the Emergency Department would be just a 'safety net' if symptoms were out of control or they were concerned about being a burden to their families. It would be inappropriate to die in the Emergency Department (Grudzen *et al.*, 2011). As mentioned above, the idea that staff had failed in some way if a patient died was paramount.

The idea of palliative care having a negative connotation in the Emergency Department is explored further by Smith et al (2009); the authors quote an Emergency Department physician as saying that people who go into emergency medicine as a career want to ‘sort of act, and do, cure’ (Smith *et al.*, 2009). Without meaning to be uncaring, indeed this very idea – that care in the Emergency Department is about living not dying – is in itself a source of distress for staff (Decker, Lee and Morphet, 2015; Weil *et al.*, 2015); end of life patients who are requiring palliative care ‘get left’ and ‘come last’ in the list of priorities in the Emergency Department (Decker, Lee and Morphet, 2015). Another study found that patients presenting to the Emergency Department with a palliative ‘label’ or being referred to palliative care whilst in the Emergency Department (but perhaps not expected to die whilst in the department), were immediately linked to limited care in the Emergency Department and an assumption of a ‘terminal prognosis’(Weil *et al.*, 2015).

Alternatively, Marck et al (2014) found that there is a perception that patients presenting at the end of life may undergo futile and pointless treatment in the Emergency Department. 65 % of the respondents to their online survey felt that patients near the end of life are subjected to medical treatment, which is unlikely to benefit them (Marck *et al.*, 2014). The authors write that it is important to challenge constantly the need for investigations and treatment and instead question where the best place is for this patient to be (Marck *et al.*, 2014).

2.4 Discussion

Despite a comprehensive search, only sixteen articles met the inclusion criteria, and only one sought the views of patients, none of the articles sought the views of relatives. The review findings suggest that patients whose lives cannot be saved may have a relatively poor experience of care, along with their carers, when they die in the Emergency Department. The reasons for this are multifactorial and as has been shown, they include the very culture of the Emergency Department, lack of palliative care training for staff and lack of a suitable environment in which to care. Other findings from this review have explored staff stress and distress, the use of distancing behaviours as ways of coping and the eventual take -over of care by nursing staff when patients are considered beyond saving. Ultimately, both patients and staff perceive that Emergency Department is not the best place to die, for all these reasons. The themes are closely linked (see figure 2) and are not distinct, stand-alone themes. To address any of the issues means addressing all the issues.

The idea that the Emergency Department is a place where the focus is on living rather than dying is the main theme to emerge from the literature. The attitude is borne out by the 2015 Best Practice Statement from the (United Kingdom) Royal College of Emergency Medicine(http://www.rcem.ac.uk, 2018); the document begins by stating that members should 'start from a presumption of prolonging life and not hastening death' (http://www.rcem.ac.uk, 2015). As an illustration, Chan (2011) writing about deaths in the Emergency Department mentioned that a female patient attended the Emergency Department with a gunshot wound to her chest and in PEA (pulseless electrical activity, a cardiac condition with a generally grave prognosis (Littmann, Bustin and Haley, 2014)) – but was saved due to an unusual intervention. The staff member reported 'at least five nurses jumped to [this patient]' (Chan, 2011). The patient was very severely unwell, but there was a chance of saving her – this was the patient that the staff attempted to save.

It is important that the focus on saving life in ED does not overshadow the important work that needs to be done with those who are very clearly at the end of life. Similar issues were being raised in the Emergency Department literature in the mid-1970s (Cauthorne, 1975; Jones, 1978; Soreff, 1979), and the themes from these papers resonate with current findings. Several writers have mentioned the need for further research into ways of improving end of life care in the Emergency Department (Chan, 2006b; Quest *et al.*, 2011; Quest *et al.*, 2013); it seems clear that energy needs to be put into ensuring this research happens and that , as Beemath and Zalenski (2009) state, society recognises that birth as well as death are key milestones of life (rather than a 'failure' on the part of the staff attempting to save the patient) and that medical and nursing training needs to be focused on both of these milestones, allowing good deaths to take their rightful place alongside good resuscitations, where both are recognised as different kinds of excellent care (Beemath and Zalenski, 2009).

Having shown that professionals feel underprepared, currently, it appears that the culture of the Emergency Department therefore is not conducive to providing good, holistic palliative care to patients whose lives are drawing to an end. There are colliding ideologies when medical and nursing staff are expected to provide good palliative care in an environment which is not set up for this, either in terms of time for safe care or the physical environment. It is clear that this in itself is a source of stress.

Several studies reported the use of distancing behaviours from the professional staff, for a variety of reasons. However, consistent with previous literature, this review found that nurses have a pivotal role to play in the management of the death and dying experience once this has become inevitable (Olsen, Buenefe and Falco, 1998; Norton, Hobson and Kulm, 2011; Roe, 2012). Historically, as in many areas of professional nursing (Laurant *et al.*, 2005; Martinez-Gonzalez *et al.*, 2014), this has been led by medical staff (Cauthorne, 1975; Jones, 1978) but as noted above, when care is relinquished by physicians, nurses take over and manage the end of life phase (Bailey, Murphy and Porock, 2011a; Bailey, Murphy and Porock, 2011d).

The Emergency Department is not generally the preferred place for death, as the only study looking at patients' views showed. An individual facing a terminal illness is likely to worry about how the people close to them will cope. This was the most important concern mentioned in the paper by Grudzen et al (2011) which detailed reflections of patients at the end of life visiting the Emergency Department (Grudzen *et al.*, 2011). Family was seen as very important, and the participants mentioned a real need to maintain self-sufficiency for as long as possible for the sake of their carers. Not being a burden is seen as highly important. In the light of the discussion above regarding poor experiences of carers, it is clear that care for the patient cannot be separated from care for the carer, poor care towards one will impact on the other and on the staff caring for them. Carers are the lasting legatees of these experiences and their opinions matter. Rather like at a birth, people do not forget the experience of a loved one's death and how this happened (Fuller, 2012; Dosser and Kennedy, 2014; Cronin, Arnstein and Flanagan, 2015).

Despite this, none of the articles examined directly asked the carers about their experiences. When their views are mentioned, it is as a secondary source, voiced in the opinion of the nursing and medical staff. This is a major gap in the literature and one that needs to be filled. Voices of carers need to be heard; as Fraser (2012) states, involving carers makes a difference to outcomes for patients (Fraser, 2012). To improve the outcomes for patients of the future, carers views must be sought. The experiences of the carers themselves, who may be left experiencing complicated grief or other negative sequelae from poor or suboptimal end of life care are also extremely important.

2.5 Strengths and limitations

Strengths of this review have been noted including the original area of exploration and the exacting integrative review process undertaken. Limitations of the study relate to the search strategies undertaken, the heterogeneity of the studies identified (including several from the same data set) and limitations of the quality framework used. There is also the potential for language bias (all the studies were in English) and publishing bias (publications post 1990 only).

2.6 Implications for the study

This review has shown that while there is a body of evidence to suggest that care of the dying patient in the Emergency Department needs to be improved, there is a general lack of research evidence available regarding the experience of carers and nurses when a patient dies in the Emergency Department. There is therefore (since it is impossible to study the experience of patients who have died) little evidence to inform practice related to how best to care for dying patients and their loved ones in the Emergency Department. Findings from this review highlight the need for further study in this area, and in particular from the relatives, patients and nurses themselves.

2.7 Conclusion

There is ongoing multinational societal and healthcare debate on the need for high quality care at the end of life. This integrative review as part of a nursing PhD thesis has contributed to these discussions through bringing together literature about care of the dying individual in the Emergency Department, the experience of the nurses and the support needs of their families and friends (carers). This area has not been well explored to date and as highlighted, in particular, the views of the carers have not been researched. This review has therefore proved that there is a need for the PhD study on which this thesis is based by raising awareness about this important issue, articulating the need for further work to inform practice and contribute to the evidence base for end-of-life care.

CHAPTER 3: METHODOLOGY

3.0 Chapter abstract

This chapter discusses the methodology (Merleau-Ponty's interpretation of phenomenology) used in the thesis, expounding upon the reasons for using this approach, and what it brings to the study. The relevance to the discipline of nursing is explained.

3.1 Introduction: why choose phenomenology

This chapter is concerned with explaining the thinking behind the conception and working of this nursing research study. To begin, it is helpful to state the ontological viewpoint of the author, which is that there is no single reality or truth, and that reality is created in groups by individuals (Nicholls, 2009; Peck and Mummery, 2018). Developing from this is the idea that reality needs to be interpreted to discover the underlying meaning of situations or events (Risjord, 2010; Durepos *et al.*, 2018). This thesis is therefore situated within the interpretivist paradigm and adopts the philosophical position of social constructivism which synchs with the methodology (as in 'what method can I use to answer my question'), which is phenomenology.

The nurse phenomenologist and researcher, S. Kay Toombs (Toombs, 1987), describes her initial interest in phenomenology as stemming from her own experience as a patient: 'In discussing my illness with physicians, it has often seemed to me that we have been somehow talking at cross purposes, discussing different things, never quite reaching one another rather than representing a shared reality between us, illness represents two quite distinct realities the meaning of one being significantly and distinctively different from the meaning of the other. '(Toombs, 1993). She goes on to explain that her work is dedicated to examining the nature of this fundamental disagreement. In Toombs' mind, hearing the story of the patient, rather than reducing the patient to a body or a mind is of great importance as it is the closest clinicians can get to the patients' own experience. This is what this research study has attempted to do.

The chapter introduces the reader to the existential phenomenology of the French phenomenologist Maurice Merleau-Ponty. It opens with a section describing a personal reflection upon the choice of phenomenology as a research methodology and then goes on to discuss phenomenology in greater detail and the importance of phenomenology to nursing research, with a discussion critiquing phenomenology as a research method.

3.1.1 The value of stories in research

Research is about a drive for inquiry. This drive starts with stories. Stories have always been fundamental to how nurses understand their practice. (Parker, 1990; Heinrich, 1992; Allen, 2001; Hudacek, 2008). Get a group of nurses together, and they will tell stories about the things they have witnessed and taken part in during their clinical careers. Most of these stories will include something shocking because these are the things that get remembered. Why these things cause shock varies – they can be very tragic, very surprising, involve stories of immense human heroism and bravery. Benner, writing about the importance of stories to nursing research, observes anecdotally that a lot of these stories come from the early days of an individual's nursing practice when nurses are young and impressionable ,have excellent memories and importantly never forget these stories (Benner, 2000). Stories are interesting, not just because of their content, but also because of how they can make the reader feel. Good stories allow the reader to imagine what it was like to experience the events. Stories shed light on these events and help the listeners to understand them. One of the central premises for this thesis was that hearing the stories of those who had lost a loved one in the ED, and those who care for the dying in the ED, would help to make sense of what it is actually like to die in the ED and how things can be improved. Stories from those who were with the patient who died in the ED are at the heart of this thesis.

3.1.2 Narrative methodology and phenomenology

There are several qualitative methodologies that incorporate the stories of others as a central component. One of these, narrative methodology, is also concerned with making sense/ analysing stories (Frost and Cliff, 2004; Wang and Geale, 2015). Qualitative research has often very blurry boundaries, and at the beginning of a researchers journey, methodologies can seem very similar (Hennings, Froggatt and Payne, 2013; Leavy, 2014; Casey, Proudfoot and Corbally, 2016). Narrative methods have much in common with phenomenology, particularly when researching difficult or sensitive topics (Overcash, 2004; Holloway and Freshwater, 2009). However, narrative is concerned with the telling of the story, the events that happened to the participants and how this fits in with the world around them (Kelly and Howie, 2007). The story of the fairy tale 'Red Riding Hood' is about the (narrative) events that take place as the story unfolds; if the story was entirely concerned with how Red Riding Hood felt whilst the events were unfolding and what her perception was of the experience, then 'Red Riding Hood' could be a phenomenology (Maitland, 2012).

Phenomenology is about the investigation of a specific, named phenomenon (in this case, death in the ED) and involves understanding the essence of this lived phenomenon (Wertz, 2011). Phenomenology also draws heavily from philosophy and psychology, rather than the humanities; it is fundamentally a philosophical methodology rather than deriving from anthropology, history or educational science (Wertz, 2011). Phenomenology also relies on the stories told by the participants, but unlike Narrative, phenomenology focusses purely on the experience – the stories told by the participants describe what the experience was like for them and how it made them feel. Therefore, the methodology for this project is phenomenology. Stories are used to obtain this in-depth understanding of the phenomenon of experiencing death in the ED.

Phenomenology is concerned with understanding the experiences of those in a particular situation. These experiences are likely to be told to others as stories. Using a phenomenological approach can help to make sense of the stories told by those closest to the patient. The stories shed light on what something is like, and nurses can learn a lot from asking what something is like, as the question allows the nurse to vicariously experience the world of the patient. This is really important: without some understanding of this world, it is impossible to work authentically as a nurse or to enter into any sort of therapeutic relationship with the patient. Therefore, unless we understand what it is like to die in the ED, we cannot provide good nursing care for those who are in this situation.

3.2 The methodology used in this thesis

The philosophy of the French phenomenologist Maurice Merleau-Ponty forms the basis for the methodology used in this thesis. The choice of phenomenology as a methodology and the choice of the phenomenologist through which the work is to be focussed may be controversial. Criticism is sometimes levelled at nurse researchers who use phenomenology. Researchers have been criticised for ignoring the philosophical background of the discipline, and it is sometimes claimed that therefore their work is less rigorous (Paley, 1997; Paley, 2005; Petrovskaya, 2014; Paley, 2017; Zahavi and Martiny, 2019). This thesis aims to avoid this criticism: every effort has been made to go back to the primary sources and relate the work directly to the phenomenological lens through which it is desired to be viewed.

The rest of this chapter will focus on this phenomenological lens, culminating in a brief theoretical description of Merleau-Ponty's Phenomenology of Perception, included as a pre-summary to the preceding text.

3.2.1 The phenomenology of Merleau-Ponty

The philosophical underpinnings of the project originate from existential phenomenology, specifically the phenomenology of Maurice Merleau-Ponty. Merleau-Ponty was part of a group of French intellectuals who were active in the mid part of the 20th Century. He was contemporaneous with the writer-philosophers Sartre, de Beauvoir and Camus. To begin to understand his ideas, it is useful to describe his biography in brief. Merleau-Ponty was born in 1908 and had as he often acknowledged, a golden childhood (Bakewell, 2016). Intellectually brilliant, he received his DES degree (diplôme d'études supérieures, approximately equivalent to an MA thesis) in 1929, worked for the philosopher and father of phenomenology Husserl at

Leuven university and went on to receive his doctorate in 1945, by which time he had served in the French army in WWII, been invalided out after the Fall of France and returned to lecturing under the Nazi occupation of Paris. Living through this time appears to have honed Merleau-Ponty's unique blend of phenomenology and existentialism (an interest in the experiences of life whilst always being aware of the truth that one is going to die (Merleau-Ponty, 2012)) – it was a frightening time, in which nothingness – total annihilation - seemed imminent (Thomas, 2018a). Merleau-Ponty died early at the age of 53, leaving much work uncompleted (Merleau-Ponty, 2005). However the ideas he documented in this relatively short life have been very influential and remain so today, particularly adapted to use as a nursing research methodology (Thomas, 2018a).

Through his work in the Husserl archives in Leuven, in the early stages of his academic career, Merleau-Ponty developed many of Husserl's ideas and made them uniquely his own (Dahlberg and Dahlberg, 2004). Merleau-Ponty essentially rebelled against the idea of dualism in philosophy, the problems of the dualism between subject and object (Dahlberg and Dahlberg, 2004), mind and body, as discussed in chapter 1 of this thesis. In developing his ideas of the lifeworld, he was particularly influential (Connelly, 2015). Each person has a unique story resulting from their own unique place in the world, and this is their lifeworld, which is simply a term for the world in which we exist and experience as perceiving individuals (Errasti-Ibarrondo *et al.*, 2018). Merleau-Ponty was interested in trying to understand what it, the lifeworld, uniquely means for each individual (Connelly, 2015). Other phenomenologists such Husserl and Heidegger also used the concept of the lifeworld, but it was Merleau-Ponty who outlined the four fundamental life world perspectives: body, time, world and others (Connelly, 2015). It is this emphasis on the importance of lived, personal, experience that is of particular relevance to nursing and nursing research and can help shed light on the experiences of those who care for those who die in the ED.

Historically there have been described two major traditions of phenomenology. Descriptive phenomenology originated with Edmund Husserl, who believed firmly that describing a phenomenon was the key to understanding this phenomenon, getting down to the essence of the phenomenon (Elliott and Timulak, 2005; Reiners, 2012; Matua and Van Der Wal, 2015; Patton, 2020). However, Heidegger, who was also a former student of Husserl, developed a different approach which he labelled interpretive, or hermeneutic phenomenology, the aim of which was to move beyond describing the phenomenon to seeking the meaning of the phenomenon (Patton, 2020). Phenomenology from the point of view of Merleau-Ponty does not fit easily within either of these traditions, because to him, both description and interpretation were important (Thomas, 2010). Indeed, the philosophers Dahlberg and Dahlberg (2004) contend that trying to 'fit' Merleau-Ponty's phenomenology into one of these two 'boxes' is a left-over from positivism. Merleau-Ponty should perhaps be seen as a 'Lifeworld' phenomenologist (Dahlberg and Dahlberg, 2004; Tuffour, 2017), focussing as he does on the importance and uniqueness of each individual's lifeworld. This makes his ideas directly relevant to those methodologies of qualitative nursing research that use the patients' experience through stories situated in the lifeworld of the patient.

Merleau-Ponty believed that the key to understanding human life was to acknowledge the profound role that perception of an experience plays in daily life (Merleau-Ponty, 2012), writing that if we can show others how we perceive an experience , we can help others to understand our own life worlds (Merleau-Ponty, 2012), thus linking our own experience with that of others. This is what makes Merleau-Ponty's phenomenology unique, the emphasis that he places upon the perception (rather than description) of experience. His ideas developed from those of Husserl and perhaps could be said to have developed in parallel with Heidegger; neither of those philosophers were particularly concerned with perception (Baldwin, 2007; Seamon, 2014). Merleau-Ponty wrote arguably his most famous work on perception, which was hugely influential and will be discussed below. He argued that we learn through perception as young children – we learn that for example, an orange looks round and feels smooth and tastes sharp– we do not, after we have learnt this, mistake a round orange thing as a toy or a Christmas bauble. Perception is accompanied by proprioception, the sense that tells us where parts of our body are, in relation to other parts. It was clear to Merleau-Ponty that through perception, the way the body informs the mind, the body was not merely an object and the mind was not the essence of life. Rather, the body and the mind are inseparable, creating the unique person (Mehta, 2011) This realisation made Merleau-Ponty argue, as mentioned above, that Rene Descartes' extremely influential theorem of mind-body duality was incomplete (Matthews 2006) and allowed him to develop his ideas about embodiment, (of which more below) , the importance of which make his ideas uniquely valuable to nurses. If perception can be briefly described as 'how we feel' the value of these ideas in a health care, specifically nursing research context can be seen. Surely only by asking people how they feel, can any understanding be gained of their experiences and importantly how these experiences can be improved.

Merleau-Ponty argues that not only do our minds and bodies have an inseparable role to play in our everyday existence, but so do the minds and bodies of other people – we are social animals and grow up with people talking to and playing with us, showing us how to experience such things as oranges and how to read and understand the behaviour of others (Bakewell, 2016). This is, in essence, the human experience of the lifeworld. Despite this, more than sixty years after Merleau-Ponty's death, the mind-body theory can be seen to be strongly entrenched in daily life, perhaps particularly in medicine , and also nursing, despite a slightly different and possibly more holistic approach influenced by Nightingale's early emphasis on both the body and the mind (Nightingale, 1992). An example of the mind-body theory in action is the (medical) consultant giving the bad news about what is wrong with the body, perhaps an incurable cancer, and then , having done their bit, leaving the room to allow the nurse to do the 'soft and fluffy bit' and talk about the patient's feelings, a traditional model for cancer clinics which persists (Maguire and Faulkner, 1988; Hardie and Leary, 2010; Urquhart *et al.*, 2011) despite much work on the value of the nurse as an independent practitioner rather than just a dispenser of tea and sympathy (van der Linden, Reijnen and de Vos, 2010; Leary, White and Yarnell, 2014; Leary *et al.*, 2016). The doctor, in this example focusses on the body of the patient, the nurse on the mind. This can create its own problems: Toombs argues that the focus on the sick body rather than the whole person creates a barrier between the clinician and the patient (Toombs, 1987) and prevents the clinician entering into the life world of the patient, thereby impeding the development of a therapeutic relationship based on understanding of the patient experience (Peplau, 1997; Nyström, 2007).

The example of the rejection of Cartesian duality shows that Merleau-Ponty's ideas were therefore revolutionary, relevant to daily life particularly in a health care setting and remain so today. For many years, his writings were not translated into English so were not widely available for nurse scholars writing in the post war period (Thomas, 2018a); moreover phenomenology is not a widely taught subject in health care courses at any level (Halling, 2012; Silbersweig, 2015; Bosch and Casadevall, 2017; Ralph *et al.*, 2017). However, Merleau-Ponty's phenomenology deserves to be more widely known and implemented. (Thomas, 2018b).

3.2.2 Existential phenomenology and death

Merleau-Ponty's form of phenomenology was heavily influenced by existentialism, and he is synonymous with the term existential phenomenology (Thomas, 2010). Existential phenomenology describes subjective human lived experience, bounded by birth and death, focussing on values, purposes, ideals and emotions (Zahavi, 2018). To understand the background to the philosophical influences of this thesis, it is helpful to explore existentialism further.

Existentialism has been described as fundamental to nursing practice (Clemence, 1966), focusing as it does on the commitment to care for ones' own life and that of the patients under ones' care (Clemence, 1966; Doona, Haggerty and Chase, 1997) . Existentialism as a movement focusses on the freedom and authenticity of the human experience, putting this in a central place, whilst acknowledging that death is certain (Risjord, 2014). According to existentialist thought, individuals are responsible for freely managing their own lives through their choices and actions, and personal growth is achieved through experiencing life's problems and obstacles (Thomas, 2018a). Existentialism is relevant to the concept of a good death in that it is related to the idea of freedom and control over ones death, dying comfortably having adjusted one’s mind to the inevitability of death (Frankl, 1959). Therefore, the use of Merleau-Ponty’s existential phenomenology as the philosophical foundation of this thesis, allows in-depth exploration of the experiences of the research participants in the ED.

Phenomenological research is about description and meaning, specifically as related to human beings and their worlds (Giorgi, 2005). It was the theologian Kierkegaard, regarded as the first existential philosopher (Kierkegaard, 1998) writing in the mid nineteenth century, who stated that each individual alone was responsible for giving meaning to life and living it ‘authentically’ – with serious depth and awareness (Hannay and Marino, 1998). He thought it essential to be fully aware of our existence, and this included the fact that we will die, hence the term existential angst, or guilt (Breitbart, 2017). It can be seen from this that existential phenomenology, concerned as it is with the emphasis on the experience of being aware of our mortality and attempting to live life in the best way we can, may be a good fit for qualitative nursing research, particularly research concerned with death and dying.

3.2.3 Existential phenomenology in everyday life

Merleau-Ponty feels that we exist through compromise with the world (the lifeworld) and that this is positive (Thomas, 2018a). Through Merleau-Ponty’s eyes, what matters is that we observe and understand the nature of our existence, and through this the experience of others. This he described as ‘being-in-the-world’ (Yount, 1990; Thomas, 2018a).

The nurse phenomenologist Sandra Thomas (2005) writes that the report of an existential phenomenological study can take the reader into the lifeworld of the participants, often producing astonishment as well as empathy and compassion, essential attributes for nursing, hence helping the nurse understand the lifeworld of the patient (Thomas, 2005). It can be noted that these things are primarily emotions and indeed Thomas writes that, philosophically, only within existential phenomenology (as a philosophy) has emotion (as opposed to reason) been given a central place in human existence (Thomas, 2005). Emotion matters particularly to nursing; having an emotional sensitivity to other human beings – in the case of nursing to patients – allows the nurse, either in clinical practice or as a researcher, to perceive more accurately the context and perspective (lifeworld) of the patient and thus provide the sort of nursing care that the patient needs at that time (Scott, 2000). As Matthews (2006) writes, the various forms of being emotional are viewed as diverse ways of being-in-the-world, and of great interest to phenomenologists.

The study of human experience and feelings is of course not unique to phenomenology. What is unique is the specific philosophical lens through which such a study is viewed. Phenomenology, in the version of Merleau-Ponty, is concerned with exploring the science of human beings (Cohen, 1987). As Thomas (2005) remarks, Merleau-Ponty believed that practising true philosophy meant relearning to see the lifeworld (Thomas, 2005). It is about seeing the world exactly as we experience it without being influenced by science, history, or any other concept.

Merleau-Ponty's phenomenology, is essentially about holism – the influence of the mind on the body and the body on the mind including psychological, spiritual, and physical aspects of being. As existing beings, we learn through lived experience (Thomas, 2010). Do individuals remember/learn more from lived experience, than from second- hand experience such as reading / screen learning? It depends of course on what is being learnt, but evidence exists that in terms of understanding human emotion, learning from lived experience can be vital

(Gillespie *et al.*, 2018; Halton and Cartwright, 2018; Stacey and Pearson, 2018; Tamachi *et al.*, 2018). This learning is a part of being human, and learning happens as a nurse, as a researcher, as a patient and fundamentally as an individual. Importantly, in the context of nursing practice, it can also lead to improved empathy through an understanding of the person's experience(Suarez, 2003; Lorenz, 2011). A pupil of Husserl's, the phenomenologist Edith Stein, worked on the phenomenology of empathy and felt that empathy is about recognising a lived experience and standing alongside that person (Richardson, MacLeod and Kent, 2012). The emphasis on the importance of the lived experience in terms of learning about empathy is clear, and this quote is very relevant to the practice of nursing both as a clinical nurse and as a researcher.

Merleau-Ponty saw phenomenology as part of the 'general effort' of modern thought (Matthews, 2006), which can be taken to mean living as authentically and deeply as possible, noticing things as they occur and noticing our reactions to these which then become part of us – the modern trend of mindfulness has elements in common with phenomenology (Gustin, 2018). Phenomenology is a philosophy, a way of living and thus researching. The principles apply whether the individual is using these principles in their nursing practice, their teaching practice or as a nurse researcher. Thomas (2010) writes that through being aware of one's own being, though attempting to live as authentically as possible, one can be open to others experience of living: a crucial mindset for a nurse phenomenologist.

Phenomenology, in Merleau-Ponty's mind therefore combines a form of subjectivism with a form of objectivism. It is subjective in that it recognizes that all experience is someone's experience, that 'how things appear' means 'how they appear to a particular individual (Thomas, 2010). A description of a particular phenomenon must therefore necessarily be a description of subjective experience. The external world, Merleau-Ponty says, is not something we simply think about, but the place in which we live our lives, the world we carry out our daily tasks in in, have feelings, worries, and hopes about, as well as the world we aim to know about. The nurse researcher must be aware of this, and the context in which the participants have lived / are living their own lives. Phenomenology in this sense is therefore a kind of anti-philosophical philosophy. It doesn't seeks to rise above our practical and mindful (emotional) involvement with the world in order to offer an explanation or justification of why the world is the way it is, but to describe our existence in the world, our various methods of being-in-the-world, which comes before our conscious reflection and theorizing, by which is meant our individual way of making sense of our experiences (Matthews, 2006). Merleau-Ponty also developed rethinking as a method (Bakewell, 2016) and was not ashamed to change his academic and moral opinions as his thought developed – for example moving away from a communist ideology once the Stalinist atrocities became known to the West in the 1950s. This indicates humility and constant questing, in the true existentialist tradition.

Existentialist phenomenology, as defined by Merleau-Ponty, therefore is an appropriate methodology to use when researching death and dying within the nursing discipline. Some further thoughts on the use of phenomenology in nursing are explored in the next section.

3.2.4 The application of Merleau-Ponty's phenomenology to the study.

Nurse researchers have used phenomenology as a method for understanding the life world of the patient for several decades (Toombs, 1987; Van Manen, 1998; Thomas, 2018b). Without thinking about it, nurses use it in a practical form every day in their clinical practice– consider the question 'what is your pain like?' All nurses have heard the dictum ' pain is whatever the patient says it is, existing wherever he or she says it does' (Quinlan, Alam and Knox, 2017) – this is a phenomenological inquiry. It is about the patients unique experience of pain, and the nurse interprets the reply rather than inferring her or his own thoughts about the pain (Thomas and Pollio, 2002). Even the routine inquiry 'how are you feeling today' is a phenomenological one – the emphasis is on what the patient is feeling. Nurses don't (or shouldn't) impose their own thoughts, they don't say: 'it's a lovely sunny day, you should be feeling great in the sunshine', they ask how the other person is, and listen to the reply.

Even though phenomenology is an everyday concept for nurses in practice, as a research methodology, phenomenology is not without its critics, as touched on earlier (section 3.2). One of the most critical nurse academics of recent years is John Paley, who has written at length on the problems (he sees) with phenomenology (Paley, 1997; Paley, 2005; Paley, 2017; Paley, 2018a; Paley, 2018b). Paley writes that there are two ways of looking at phenomenology: phenomenology as philosophy and phenomenology as qualitative research (Paley, 2017). He is exceptionally critical of the latter approach in his 2017 book, stating that none of the qualitative researchers using phenomenology understand what it is or can explain what meaning is even in their own work (Paley, 2017); this is also the stance of the academic Michael Crotty (Barkway, 2001). Paley also writes that he is not concerned with the 'various philosophical heavyweights '[Husserl etc.] as from the point of view of his book, none of them matter, since nurses have not been using their work correctly (Paley, 2017). A convincing argument to this criticism is supplied by Dan Zahavi, (Zahavi and Martiny, 2019). Zahavi feels that, on the contrary, what nurse researchers wishing to use phenomenology ought to do is make use of the vast resources available around the field of phenomenology including returning to the classical sources rather than relying solely on the second hand and artificial methodology of [some, named] qualitative researchers.(Zahavi and Martiny, 2019).

Zahavi is also critical of Interpretive Phenomenological Analysis, an approach derived from classical phenomenology by Smith et al (2009). He feels that this approach, called commonly IPA (Smith, Flowers and Larkin, 2009) is too generic and is critical of Smith et al's (2009) claim to use the term phenomenology (Zahavi, 2019b). This thesis takes the viewpoint that if nurses are going to use the term phenomenology correctly it is essential to understand the sources as with any field of intellectual inquiry (Petrovskaya, 2014). Phenomenology is more than just description, and to conduct such research is not merely a question of being broad-minded and interested in first-person experience. As Zahavi (2019) says, it is also about finding out and then employing a comprehensive theoretical framework concerning the relation of the subject to herself or himself, to the world around them and to others in that world.

Rapport and Wainwright are qualitative researchers who also take issue with the nursing portrayal of phenomenology for not going deeply enough into the sources of the discipline, that is to say not paying enough attention to the philosophical roots beneath modern phenomenology. They suggest that nurses need to be aware of these sources and not worry too much about the minutiae of various contemporary writers (Rapport and Wainwright, 2006). They write that phenomenology is uniquely suited to nursing research because it – nursing - is both descriptive and interpretive – the nurse-patient/carer relationship is explicitly concerned with the subject experience of all the individuals concerned. The nurse brings his or her own subjectivity to any patient/carer encounter and is being-in-the-world with the patient/carer (Rapport and Wainwright, 2006) . All elements in a phenomenological study matter – the experience of the patient/ carer matters, and the experience of the nurse also matters (discussed further in chapter 4). Rapport and Wainwright (2006) discuss how the nurse-patient/ carer relationship is one of interdependence and constant movement, a connection between two individuals which bears some resemblance to Merleau-Ponty's ideas around the balance that exists between consciousness and the world, the interwoven chiasm of things that cannot exist without the other (Matthews, 2006).

3.2.5 Epoche, bracketing and phenomenological reduction

One step in any phenomenological study which has excited interest and criticism from both Paley (2017) and Zahavi and Martiny (2019) is the epoche and the bracketing step. This is, in theory, an important part of any phenomenological study and was first advocated by Husserl (Cohen, 1987) in the early years of the twentieth century. Husserl himself distinguished between the transcendental epoche and the technique of bracketing or reduction (Overgaard, 2002; Zahavi, 2019a). These ideas were further developed by Merleau-Ponty (Merleau-Ponty, 2005). The process starts with the epoche, an opening up of the mind, to bracket, or suspend belief in the absolute existence of the world (Zahavi, 2019a) and continues to the reduction, where the individual begins to understand that reality is always revealed and delineated by some perspective or other and it is realised that ones' unique way of looking at the lifeworld affects the perception of reality - it is a kind of systematic analysis of the link between the world and ones' subjective experience of it (Zahavi and Rochat, 2015; Zahavi, 2019a).

It has been noted that reduction in this sense does not mean to make something smaller, it is more like the biological meaning of the word - an attempt to purify something (Pollio, Henley and Thompso, 1997). This can be seen from the etymological meaning of the word (from the Latin) re and ductare - to lead back to some origin (Pollio, Henley and Thompso, 1997). Concretely, Husserl used reduction to mean the conscious removal of any suppositions brought from prior philosophies (Gallagher, 2012). As applied to nursing research, it is a step in which the researcher consciously steps back from him or herself (bracketing their own presuppositions and world view) (Harris, 2017) and thus is able to enter into the unique world of the research participant (Hycner, 1985). It is quite impossible, of course for this to be a complete bracketing so that there is absolute objectivity. Merleau-Ponty himself was aware of this and writes that the amateur philosopher must be aware that the very process of reduction teaches us that a complete reduction is impossible – the more one thinks about one's own preconceptions and attempts to move away from these, the more concentrated one becomes on them (Smith, 2005; Merleau-Ponty, 2012). The very value of trying to perform the reduction lies in the flawed act itself.

The philosopher Dan Zahavi (2019) writing for qualitative researchers and specifically nurses, argues persuasively that in the non-philosophical application of phenomenology, it is neither desirable nor actually completely possible to carry out the epoche and reduction (Zahavi, 2019a; Zahavi and Martiny, 2019). His premise appears to be that phenomenology is complex enough and has far more features relevant to the qualitative researcher than the epoche and reduction which he feels are more suited to the pure philosophical application of phenomenology. This is refuted by Morley (2019) who accuses Zahavi and Martiny (2019) of disciplinary hegemony over the claim that the epoche and reduction belong to philosophers only. Morley is a practising psychologist; it could be argued that any practising clinician would be aware that they have many years of ingrained clinical experiences around their subject (in the case of this thesis, bereavement, death and dying) and many suppositions and prejudices which may influence their ability to access the reality inherent in the participants' experiences. For the study on which this thesis is based, reflective journaling (Miller, 2017a) was used throughout and an attempt was made to attempt the epoche and reduction. This can be seen below:

3.2.6 Reflection on the attempt at epoche and reduction: Situating myself in relation to this research study

I am carrying out this study as a female nurse with over 20 years' experience of caring for the dying in a variety of roles across the United Kingdom (in Northern Ireland, Scotland, and England). Having had my own personal bereavements, I am aware of the gamut of emotions and feelings which can be experienced and how difficult it often is to put these into words. I am aware that sometimes one may want to talk about one's experience and sometimes one can't bear to do so. Truthfully, I have always found it incredibly difficult to talk about my own situation at all. As a nurse I also know that we, as health professionals, need to be aware of these things, and that people react differently. Sensitivity is so important here.

I am currently working as an advanced nurse practitioner in acute oncology which role requires me to meet and advise on the care of dying patients and their relatives across a variety of inpatient settings including the Emergency Department. I am also working as a listening volunteer for the Samaritans, a British charity which aims to help distressed people by providing a safe space where they can talk about their problems without fear of judgement (we will listen to absolutely anybody talking about absolutely anything). Many of the people who ring, or email are suicidal. We do not give advice, and respect self-determination. I am aware that years of nursing and my charity work (which I have been doing for over twelve *years) have given me various preconceptions about human life and emotion. I am very comfortable with talking about death in the abstract and perhaps do not realise that not everybody is so comfortable and there may also be an element of judgement for those who are less comfortable. Equally I have seen a lot of death and am always rather surprised when other people have not and may be afraid of it. This is not the same of course as being comfortable with talking about my own experiences as I mentioned earlier.*

I found that bracketing myself for the bereaved relative interviews, which were carried out first was much less difficult than for the nurse interviews. I believe this is due to my feelings of compassion for the bereaved relatives, all of whom became upset during the interviews and yet stated that they found talking to me therapeutic. When I was carrying out the nurse interviews, it was hard to put my own nursing experience aside and to refrain from internally judging some of the participants for what they were saying – that is to say some of them may have sounded like they were lacking in compassion or feeling. I carried out the reduction mentally before each interview and jotted down my own feelings in my reflective diary so as to start each interview with as clear a head as possible. I am still not sure why it was more particularly difficult with the nurse participants. I also discussed my reduction with a colleague and was challenged by her on a variety of points some of which I was not consciously aware of. An example of this is my feelings about perceived poor care. As a nurse I have always attempted to provide excellent care but as in any profession there are many barriers to this such as time and busy-ness. I therefore have a definite feeling of anxiety, which is similar to frustration, when patients or relatives complain about what I perceive to be slightly petty things (such as perhaps feeling neglected by the nursing staff even when the nurse has been in the room every 10 minutes or so). It was helpful to have this identified when I spoke with a bereaved relative who had many complaints about her father's care.

3.2.7 Lifeworlds

Existential phenomenology helps people to understand and acknowledge that everyone lives in a specific context (Connelly, 2015). To make sense of the meaning of an experience, it is necessary to understand this context. This can be done by looking at the lifeworld of the person to whom the experience belongs, and this is important because each person experiences a certain phenomenon in a unique way. As mentioned above, the term lifeworld is a phenomenological concept used to describe the subjective nature of human life. Merleau-Ponty felt there were four fundamental lifeworlds perspectives: body, time, world and others. This idea was further developed (and updated) by Van Manen (2003), who called the perspectives: lived body, lived time, lived space ('world') and lived human relationship ('others'). His feeling was that individuals as human beings experience phenomena in their bodies, in a specific space in the everyday world, at a particular time and in relation to other human people (Van Manen, 2003). For the purpose of this thesis, the Van Manen interpretation has been used alongside Merleau-Ponty's original work. This has been done to allow use of the more research- friendly terms that Van Manen utilises. For Merleau-Ponty and Van Manen, the lived experience could be divided into four specific areas, as above, each contributing to a full understanding of the lived experience. The following section explores these areas more fully.

Lived Body

Lived body –corporeality – refers to the fact of individuals living their lives through their embodied selves. It is an obvious fact that nothing can be experienced without the body and by extension the bodies of others. Van Manen (2003) talks about how the individuals' sense of their bodies changes under observation by others – critical observation, such as in an OSCE can make people clumsy, admiring observation can make people stand up straighter, smile more. Nursing a patient in pain can make the nurse feel vicarious pain, such as wincing when dressing a painful wound. Because humans are embodied creatures, they can relate to the sensations experienced in another's body and for the nurse, this ability has the potential to be used therapeutically.

Lived time

Lived time – temporality, is a subjective construct. This is time as it is experienced, rather than the hours and days marked out by the watch on an individual's wrist. The sensations of time speeding up – when one is enjoying oneself, or slowing down – awaiting a hospital appointment, are very familiar to all. The sickening feeling of waiting to be told bad news makes seconds feel like days. Van Manen also talks here about memories and what constitutes personal time in peoples own lives (Van Manen, 2003), and how this changes over time so that each person is made up of the past, present and future in his or her own bubble of time.

Lived space

Lived space – spatiality – is the felt, bodily, experience of space. 'Felt space', as Van Manen (2003) puts it. Humans tend to think of space, in relation to the body, in mathematical terms – height, depth, width, when discussing the dimensions of a room. Or in terms of distance – how far something is from something else, measured by miles or kilometres. How space is experienced is very personal and goes back to the idea of felt space, it is entirely related to the body (Merleau-Ponty, 2005). A cathedral feels different to a shopping mall, even if one is there at the very end of the day on a Sunday when it is nearly empty. A hospital feels different to a motorway service station or a school. Van Manen (2003) talks about the space of one's home as having an almost sacred feel to it – a place one can truly be oneself. He speculates that this is why people feel the horror of becoming homeless – the space of home is so much more than the roof over one's head. Perhaps this is also the root of the fascination with 'outer space' in a science fiction context – the fear and excitement of endless, unknown space. There is also the concept of personal space, which is interesting from a nursing point of view. To perform core nursing activities, nurses have to invade their patients' personal space and when comforting a patient or relative the nurse must decide how close to get to the other individual – it is worth noting that it is not simply the patient's personal space that is invaded but also that of the nurse.

Lived human relationship

Lived human relationship – 'other' – relationality – concerns the way humans experience others. As embodied people, others are experienced as corporeal individuals, and impressions of them are formed by the way they are experienced as embodied others. Even if people are only experienced virtually or on the telephone ideas are formed of what their embodied person would be like. Being aware of an individual's tendency to do this is helpful and may help, in a societal or educational sense to manage prejudice based on race or gender. Having a sense of others as embodied individuals also allows people to transcend the corporeality of themselves and others and achieve communication at the genuine level of the self (Wilde, 1999).

These four concepts can be differentiated but not separated and they each make up the 'whole' of the holistic lived experience. They will be used in the analysis of the data from this research study and as a lens though which to view the data. As an example, consider a nurse helping a dying bed bound patient to have a wash. The lived space has contracted for both the patient and the nurse to the bed area within a curtained place of privacy, For the period (lived time) of the bed bath this is the lived space for both individuals and they exist within it including perceiving all sights and smells that are in that space with them. From the point of view of the lived body, the nurse is using her body – her hands and her body-centric skills to gently turn the patient, to help them change their night clothes and put a clean sheet underneath them. The nurse may notice a problem with the patient's body – a new pressure area perhaps and manage that problem appropriately using her embodied nurse-skills. A sense of lived time is again experienced by both although this will be different for each and may include memories such as a time the patient was admitted when they were less ill, a time when they could wash themselves. There may be sadness at how quickly time is passing, and from the nurse's point of view, there may be memories of other patients and episodes in her personal life and how she was taught these skills and honed them. Finally, they are together as embodied individuals having this experience and having created this complex if temporary bond based on trust and mutual respect, in a situation of lived human relationship.

3.2.8 The methods used

For the purposes of this study the approach chosen was the framework devised by Sandra Thomas and Howard Pollio (2002), and by Hycner (1985) both of whose approaches was directly influenced by Merleau-Ponty (Hycner, 1985; Thomas and Pollio, 2002). Their methods are not entirely replicated in the study for a number of reasons. Thomas and Pollio place great importance on the idea of the bracketing interview which is called by other authors 'reduction' and bears some resemblance to the 'epoche' originally described by Husserl and discussed above (Cohen, 1987), although the epoche and reduction are not the same thing , being mainly a two-step process (Zahavi, 2019a) – the epoche is step one, the moment in which the researcher steps outside their own life and accepted world. The reduction is step two, using the insight gained from the epoche to allow themselves to be used as a tool to describe the phenomenological process (Zahavi, 2019a). As Thomas and Pollio (2002) describe it, the bracketing interview is undertaken prior to the commencement of the participant interviews, and involves the researcher being interviewed by a peer about the thoughts and feeling around the research topic with the intention that thus being made aware of his or her biases, the researcher can 'bracket' these and not allow them to influence the forthcoming interviews. This study has used the bracketing technique and a reflective diary was also kept which includes thoughts about the topic prior to the interviews and reflections following each interview. The reflective attempt at bracketing can be seen above (section 3.2.6).

Considering the practical elements of a study, Pollio et al (1997) discuss the ‘difference’ of the phenomenological interview (meaning different from other qualitative interviewing techniques) (Pollio, Henley and Thompso, 1997). This difference comes from the fact that the questions, statements, and summaries used by the interviewer are designed to evoke descriptions of an experience, not to confirm theoretical hypotheses. Description of the experience is key. All knowledge, including knowledge of the self, is constructed in social discourse (Merleau-Ponty, 2012), and therefore the description of the experience as it emerges in a particular context, becomes, or in fact is, the experience of that individual. That description of the experience is ultimately the truth of that experience as it affects the individual. The phenomenological real exists only in the ongoing fluid and ever-changing context of the social and natural lifeworld; the real is what we experience at any one time (Pollio, Henley and Thompso, 1997). Therefore, the research interview is entirely focused on the participant, and the job of the researcher is to facilitate a descriptively rich and mutually informative dialogue, specifically focussing on the experiences of the participant (Pollio, Henley and Thompso, 1997).

As a piece of nursing research, this thesis aims to show that phenomenology can be a very accessible and important methodology. The final section of this chapter, below, goes on to briefly give a theoretical summary of the central ideas behind Merleau-Ponty’s thinking to allow the reader to clearly see the relevance to the nursing discipline.

3.3 Phenomenology of perception: Key concepts

Phenomenology of perception, Merleau-Ponty’s magnum opus, first published in 1945 (Merleau-Ponty, 2012) allows the reader to understand the building blocks of Merleau-Ponty’s philosophy. In the preface to the work, Merleau-Ponty states that phenomenology has not at the time of his writing, been fully defined. However, he does not see that this makes any difference to the practice of phenomenology. His feeling is that the practice of a philosophy is the means by which it continues to evolve and develop. Its purpose is to question the very meaning of existence, and to present an account of the existential concepts of space, time, and the world as they are lived. The intention of phenomenology is to re-achieve a direct and primitive contact with the world. The process of phenomenological inquiry is based on the assumption of the taken-for-granted, the 'always 'already there'' nature of the world i.e. phenomenology takes as given the existence of a pre-reflexive world (Merleau-Ponty, 2012).

3.3.1 Perception

For Merleau-Ponty, perception is a means of describing the lived experience of human life. Phenomenological inquiry focuses on the everyday-ness, even mundanity, of human activity and the context of that activity. This is the essence of phenomenology. In order to carry out a phenomenological investigation the phenomenologist returns to the minutiae of the things themselves in order to explain the perceived experience of the world in which these things exist. It is perception that allows direct experience of human activity in relation to objects and other humans. Perception is direct, it requires no intermediary, and its concern is the continuous and reciprocal relationship between the individual and the world, whereas intellectual thought and the use of language present the world to us 'at a remove' (Sadala and Adorno Rde, 2002). The phenomenologist turns to the world, perceives the world and makes direct and primordial contact with the world, experiencing ‘wonder and astonishment’ (Merleau-Ponty, 2005). Phenomenology can be described as a method of investigation that enables its exponents to arrive at a 'direct description of our experience as it is, without taking account of its psychological origin and the casual explanations which the scientist, the historian, or the sociologist may be able to provide' (Merleau-Ponty, 2012). The participants in the study on which this thesis is based were asked about their perception of the quality of death and dying in the ED both as proxies for the patient and because as nurses they were close to the patient. The later chapters will demonstrate their perception of the events.

3.3.2 The World and Intentionality

Human individuals exist in the world and are bounded by its horizons. The individual person orients themselves according to this world horizon, so that what they perceive about the world is actually the world. The individual's understanding of being-in-the-world (that is to say, in a specific context) derives from their orientation to the world horizon. Intentionality describes this experience of continual orientation to the world. Human beings have a dialectical connection with the world; the individual and the world co-construct each another (Sadala and Adorno Rde, 2002). Humans exist, according to Merleau-Ponty as embodied creatures, indistinguishable from the real world (Merleau-Ponty, 2012). It could be argued that Merleau-Ponty's philosophy has only one question at its core: how can we, as human beings, make sense of the world in which we are present? (Seamon, 2014). Individuals are enmeshed in the world and the world is simultaneously enmeshed in them (Seamon, 2014). Humans communicate with the world through the perception of their embodied selves; the body is the channel, the opening through which all experience can take place (Kelly, 2005). Intentionality means being conscious of this perception, living life with awareness of the experience of perception (Seamon, 2000).

3.3.3 The Body

Merleau-Ponty built on Husserl's concept of the lived body to develop his ideas around the concept of embodiment (Wilde, 1999). It is important to Merleau-Ponty that the lived body is understood as an experiencing body, meaning that human consciousness is experienced, understood and expressed through the medium of the body, which is in a reciprocal relationship with the surrounding world and therefore the bodies of others (Wilde 1999). For Merleau-Ponty, the body is not to be understood as its constituent parts, it is to be understood as a congruent whole, as it is lived; in essence 'I do not have a body; / I am my body' (Sadala and Adorno, 2002). The body and the self are indistinguishable, and the perceptions of the body influence what is perceived and understood by the self (Wilde, 1999). Therefore, the body as it exists as an experiencing body through which the world is experienced, and which allows the world to exist for the owners of the bodies. Sartre also talked about this link between the body and the self – people cannot help existing as a body in a pre-given world but the world does not define the embodied person (the self) because the embodied person is an individual responsible for making his or her own choices within the context in which they exist (Sartre and Mairet, 1960). Merleau-Ponty wrote that ones' body is in chiasmic interaction with other bodies (Moran, 2013); therefore when another body is removed through death, one's lived body (for example the body of a son who all his life has had a mother and now no longer has her), is irretrievably altered (DuBose, 1997). One experiences this alteration as part of grieving (DuBose, 1997).

The body exists within the context of world, time, and others; and therefore, it exists in a dialectic relationship with these existential concepts. This is important as Merleau-Ponty believed that phenomenological activity focused on gaining an understanding of how individual people live their embodied lives within the world. A phenomenological study looking at the experience of death and dying in the ED can therefore help the nurse to truly understand and put him/herself in the place of the bereaved relative, the dying individual.

3.3.4 The perceiving body

As above, knowledge of others, the holistic world and time is rooted in the individual's perspective as an embodied being. Therefore, individuals perceive, know, and understand phenomena from an embodied perspective (Sadala and Adorno, 2002). Humans live through their bodies, and when they die, they do so as embodied individuals. The testimony of those who are been with a dying person is therefore crucial to understanding the experience. Objects (phenomena) are both transcendent (unknown and unknowable) and immanent (inherent in the universe). Phenomena are seen because they stand out in contrast to a background, or horizon that is determined by its context (Benner, 2000). Merleau-Ponty compared the body with a work of art such as a painting, an orchestral symphony, a novel, because the body incarnates ideas, thoughts and world (Benner, 2000). The body is therefore of immense importance; it is crucial that nurses understand this. It is easy to reduce the body to the medical model of the ‘object’ body (Draper, 2014); to provide true holistic care, nurses need to be aware of the immensity hidden within the body (Benner, 2000), not just of the patient, but of themselves.

3.3.5 Time

Merleau-Ponty understands time as a fluid continuum. He describes the history of humankind as a story that has no beginning and no end and individual lives are part of this story (Merleau-Ponty, 2005). Time to an individual is not linear as the present contains the future and the past. However one must understand the limitations the time sets upon us – individuals exist, are situated in the here and now at the time of their being- in- the world (Merleau-Ponty, 2012).

3.3.6 Others and empathy

Perception and embodiment depend on the fact that people are situated in a world comprised of themselves and others. People, in fact, live in a community. Merleau-Ponty conceptualised the embodied person existing in a knot of relationships that opens the person to the world (Benner, 2000). This is very much not a new idea; Donne was describing this in the seventeenth century (Donne and Fallon, 1988). A viable community relies on good empathic communication (Määttä, 2006; Ordille, 2016). Empathy itself is notoriously hard to define, but essentially it is about attempting to understand what the other person may be going through (Meneses and Larkin, 2012; Richardson, MacLeod and Kent, 2012), and is closely aligned with compassion, which allows action to be taken as the result of empathy (Richardson, MacLeod and Kent, 2012).

As humans all have to live in community with one another, attitudes towards each other are tremendously impactful. The attitudes of people who are complete strangers to one other are particularly important, in part because they cannot rely on previous knowledge of one another’s’ background, character or beliefs, or make allowances for sub-standard behaviour. The German phenomenologist, Edith Stein, who wrote her doctoral thesis on empathy under the supervision of Edmund Husserl, and was admired by Merleau-Ponty, described empathy to be an intuitive knowledge of another person’s present experience (Meneses and Larkin, 2012). She discusses empathy and its part in the caring role, stating that caring occurs through a mixture of the conscious and intuitive, blending practical tasks and intellectual attitudes (Meneses and Larkin, 2012; Ordille, 2016).

In nursing, empathy is essential to the development of a therapeutic relationship with the patient (McCamant, 2006; Williams and Stickley, 2010; Ward *et al.*, 2012). A study looking at the quality of death and dying in the ED must be aware and pay attention to the concept of empathy.

3.3.7 Truth and reality

Integral to Merleau-Ponty’s understanding of the nature of perception and its importance to the conduct of phenomenological enquiry, is acceptance of the facticity of man , the undeniable fact of existence ('I am the absolute source') and the World (Carel, 2016) . An individual's thought is understood to be factual truth and being-in-the-world to constitute reality. The world exists as what the individual perceives and therefore human perception of the world is reality.

However, Merleau-Ponty understood that to be human means growing and changing (Benner, 2000) and therefore truth itself is a fluid concept that changes with an individuals’ changing perception of the world. This is what makes us human and illustrates the ambiguity of lived experience. Merleau-Ponty’s view of the world accepts a truth which is mutable and relative. Lived experience changes so truth also changes, but it does also remain the truth (Sadala and Adorno, 2002).

When examining the lived experience of individuals through a phenomenological study it is crucial to be aware of the nature of truth and reality. The participants in the study on which this thesis is based told their stories as they recalled them. This was their truth.

3.4 Summary. Phenomenological method: A rigorous science

In the introduction to Phenomenology of perception, Merleau-Ponty described phenomenology as a 'rigorous science', existing to facilitate the search for the essence of everyday life (Merleau-Ponty, 2012). Individuals exist in the context of a world that pre-exists reflection: it is always already here. Phenomenology seeks to understand human beings within the context of this existing, pre-reflective world (Sadala and Adorno Rde, 2002). Phenomenology is both descriptive and interpretive, involving embodied individuals using self-reflection to arrive at understanding (Van Manen, 2003).

This thesis describes a study designed to draw out the quality of the experience of death and dying in the ED and describe the phenomenon in depth. The reason and means of doing so are described above. An attempt has been made to counter the classic criticism of nurse phenomenologists – that they don't spend enough time examining the original sources of the discipline.

Methods that were congruent with the underpinning methodology were chosen for use in this study. These methods and their application to research practice are discussed and critiqued in the following chapter.

CHAPTER 4: METHODS

4.0 Chapter abstract

This chapter focusses on the data collection. The planning of the phenomenological interviews is discussed, along with the recruitment methods. The chapter also covers the ethics of the study, rigour, the relationship of the methodology to the methods, the interviews, and the analysis of the data. Two papers from this section were accepted for publication in 2019 and 2021:

McCallum, K.J., Jackson, D., Walthall, H. and Aveyard, H., (2019). A focused mapping review and synthesis of current practice in qualitative end of life research with the bereaved. *Nurse Researcher*, 27(3).

McCallum, K.J., Jackson, D., Walthall, H. and Aveyard, H., (2021). Self-care while undertaking qualitative nursing research. *Nurse Researcher*, 29(2).

4.1 Introduction

The academic John Paley has written extensively (and critically) about phenomenology, as discussed above (Paley, 1997; Paley, 1998; Paley, 2005; Paley, 2017). In his latest book, he asserts that there are two ‘types of things’ that are called phenomenology (Paley, 2017). These are phenomenology as philosophy and phenomenology as qualitative research. He believes the two are quite distinct and phenomenology as qualitative research should not pay any attention to the ‘comings and goings’ of ‘classical’ phenomenologists. The previous chapter has shown that the study on which this thesis is based was not designed to ignore ‘classical ‘phenomenology. It has been shown that the philosophical background to this thesis is essential to the methodology and design, and that in this case, the phenomenology as qualitative research is heavily influenced by the concept of phenomenology as philosophy.

Moving on, this chapter describes what was done to answer the research questions. It opens with a discussion regarding qualitative interviewing and the reasons for choosing this data collection method, followed by a description of the processes undertaken to ensure ethical approval had been granted for all aspects of the study (sections 4.1 - 4.3). This includes a description of the ethical issues identified as being of relevance to the conduct of the study and a presentation of the criteria against which the rigour of the conduct and reporting of the research were measured (section 4.4). Recruitment, sampling, data collection, method of data analysis and preliminary findings are addressed in sections 4.5 - 4.8. Moving away from an emphasis on the research participants, chapter 4 closes with a discussion of issues pertaining to the role of the researcher, specifically when researching sensitive topics (4.9).

4.2 Planning the study

In deciding how data was going to be collected for the phenomenological study, several methods, including surveys, focus groups and observation were considered, but ultimately, to fit in with the phenomenological ethos of the study, the data had to be collected via interview. Qualitative research generally tends to be concerned about the experiences and stories of individuals (Lowes and Prowse, 2001; Thorne, Stephens and Truant, 2016), and the aim of qualitative interviewing is to facilitate the telling of these experiences (Dilley, 2004). Miller (2017) asserts that for the last century, the interview has been the basic information gathering tool of the social sciences (Miller, 2017b). It is a familiar and established method of capturing data, and Miller (2017) also claims that university ethics committees are so familiar with the method that they rarely have a problem with a study that proposes using interview. However, an interview based study should still be meticulously planned and attention paid to the fact that there are different kinds of qualitative interviewing (Sorrell and Redmond, 1995). Importantly for a Merleau-Pontian study (Thomas, 2010), but also in all kinds of qualitative interviewing, it should be remembered that the interviewer him / her self is the tool used to facilitate these (Sorrell and Redmond, 1995).

4.3 Phenomenological interviews

The purpose of the phenomenological interview is not to predict, decipher or generate theory; instead it is about exploring and understanding meaning by finding out from the participant exactly what it was like to live through the experience under consideration (Wimpenny and Gass, 2000). Phenomenological interviews are unstructured or semi-structured (Lowes and Prowse, 2001), but unstructured interviews in the Merleau-Pontian phenomenological technique are more common (Sorrell and Redmond, 1995). The interviewer should aim to establish a rapport before asking the participants to describe their unique perspective of an experience (Sorrell and Redmond, 1995). The emphasis is on description of the experience, rather than interpretation of the experience – questions such as what were you feeling at the time? Or what was it like when that happened? are useful (Clegg and Butryn, 2012).

In planning the interviews, some texts were particularly helpful. The work of Gorden (1975) was very useful when considering how to use phenomenological techniques to approach the interview. Gorden (1975) suggests that thoughtful probing by the interviewer can help elucidate meanings in the interviews; he suggests that two techniques may be particularly useful, both of which were used in this study: the recapitulation technique and the silent technique (Gorden, 1975). Recapitulation involves taking the participant back to the beginning of their narrative to see if there are further details they would like to add (Sorrell and Redmond, 1995). It is similar to the summarising technique (Britten, 2006; Mikėnė, Gaižauskaitė and Valavičienė, 2013), where the interviewer checks that they have the correct details by summarising what the participant has said.

The second technique mentioned by Gorden (1975) is the silent probe, which involves the researcher being comfortable with silence; allowing the participant to describe their experiences in their own way. This is particularly valuable in Merleau-Pontian phenomenological research which is especially concerned with the actual experience of the participant, what actually happened to them and how they felt about it (Wimpenny and Gass, 2000). This was particularly useful in the study under consideration, where the subject was potentially distressing. Participants may struggle to find words which are adequate to describe their experience - Van Manen (2003) describes this as an ‘ epistemological silence’, by which he means knowledge which is not immediately accessible to linguistic competence (Alerby and Westman, 2013) ; in other words, things that the individuals knows but cannot either describe or discuss for a potential multitude of reasons. Qualitative phenomenological interviewers need to be sensitive to this in order to get the most out of the interview : as Chamaz (2008) describes, qualitative phenomenological interviewing can bring very rich , previously hidden data to the surface particularly if the interviewer listens carefully to the stories and attends to silences and goes deep into the experience (Charmaz, 2008). It is a fairly recent idea, the thought that silences matter, and seems to be due to the growing importance of qualitative research (Mikėnė, Gaižauskaitė and Valavičienė, 2013). In the past, silence in interviewing has been thought to be problematic (Collins, 2014) and to be avoided (Bengtsson and Fynbo, 2019). In the study on which this thesis is based, silences were used in the interviews and it is felt that they allowed the participants to open up further about their experiences.

4.4 Ethical approval

Every hospital / clinical setting and every university will have their own ethics committee, working on the principles derived from the Nuremberg Code of 1945 and the International Helsinki Declaration of 1964 (Haahr, Norlyk and Hall, 2014). Beauchamp and Childress (2019) discuss how ethical practice can be assessed against four principles: beneficence (the principle of acting with the best interest of the other in mind), non-maleficence (the principle of doing no harm), autonomy (the right of an individual to their own choices) and justice (a principle advocating fairness and equality among individuals) (Beauchamp and Childress, 2019; Shea, 2020). The seminal text by Beauchamp and Childress : *Principles of Biomedical Ethics* is now on its 7th edition (Shea, 2020) and has for forty years been influential in healthcare ethics (Shea, 2020). The principles of beneficence and non-maleficence are reflected in many professional codes, for example in the UK, nurses working in any setting, including clinical research, must act within the limits set down by the Nursing and Midwifery Council Code (NMC 2015). This includes the instruction to '*Be aware of, and reduce as far as possible, any potential for harm associated with your practice* '(NMC 2015).

Following selection of the data collection technique, it was important to look at the requirements for ethical approval. Gaining ethical approval means making sure that the ethical needs of the participants are being considered. Johnson (2004) discusses various published clinical research papers whose authors obtained results by means which appear shocking to modern readers – starting with the seminal work by Glaser and Strauss in the 1960s (Glaser and Strauss, 1964; Glaser and Strauss, 1965; Glaser and Strauss, 1968) in which the researchers used covert observation, thus violating all four principles of biomedical ethics discussed above (Johnson, 1992), replicated in a similar study 20 years later (Knight and Field, 1981) in which the researcher worked as a nursing auxiliary on a ward and therefore 'did not have to' disclose that in fact she was a researcher studying the care of the dying (Knight and Field, 1981). Merleau-Ponty's phenomenology has an emphasis on authenticity (Thomas, 2005), therefore both from an ethical and a methodological point of view it was important that the participants in the study on which this thesis is based were aware that the researcher was both a nurse and a PhD student. Full disclosure in this kind of situation and thus the protection of the rights of the participants are rightly paramount currently (Colt and Mulnard, 2006).

4.4.1 Recruiting bereaved people into research studies

The question as to whether it is ethical to ask bereaved people to recall in an interview setting some of the most painful experiences of their lives, came up early in the research planning process. A phenomenological interview based on Merleau-Ponty's phenomenology has the potential to delve very deeply into these experiences (Thomas, 2010). As above, it is clearly essential that individuals' ethical rights are protected. In planning the submission to the University Ethics Committee, a useful guide was the Research Governance Framework (Health, 2005), along with the principles of biomedical ethics (Beauchamp and Childress, 2019). The following ethical issues were identified as of relevance to the conduct of the research and are discussed in more detail below:

- safeguarding participants
- informed consent
- confidentiality and anonymity
- the utility of the research (Flinders, 1997; Rubin and Rubin, 2011)

4.4.2 Safeguarding the participants.

This was an essential part of the planning stage. The study must act with the best interests of the participant in mind, do no harm to the participants, ensure that they are respected as individuals and treated with justice. In theory, taking part in a research interview has potential benefits and drawbacks for both the participant and the interviewer, all of which needed to be considered at this stage. For the interview participant, there is sometimes genuine altruistic pleasure to be derived from helping others, who may learn or benefit from their experiences (Peel *et al.*, 2006). There is also the natural human pleasure to be derived from talking to someone who is interested in the person as an individual and who wants to listen to them talk about their experiences (Monroe, 2003; McLoughlin, 2010). However there is always potential for emotional distress when discussing sensitive and emotional issues such as end of life care (Moore *et al.*, 2013), and it was important to bear in mind that support may need to be offered at the time of the interview, with the consideration also of ongoing support which the participant could source themselves from Cruse bereavement care or similar charities as appropriate. The question is, should these issues be avoided in that case, should the potential participants be denied the chance to take part in research? It remains a very controversial issue, but a recent review of the literature (influenced by the topic of this thesis), shows that there is no evidence that recruiting bereaved persons into research causes harm and that bereaved people were / are generally very willing to be involved in research (McCallum *et al.*, 2019). It is worth mentioning that one of the research participants in the study on which this thesis is based, said 'you are not going to make me upset. The loss of my husband made me upset. I am pleased to have the opportunity to talk about him'.

The participants in this study were not just bereaved family members, however, but also nursing staff. Whilst there is less written about the effects on nursing staff of taking part in qualitative research, and less controversy, safeguarding needs to be considered and should anyone have become upset they would have been offered support and if needed made aware of other organisations that could offered support such as the Samaritans (freephone 116123), RCN or Unison support as appropriate. Finally, safeguarding as applied to the researcher was also considered and such strategies as the use of a reflective diary, debriefing with the supervisory team and a mindful focus on self -care were adopted (McCallum *et al.*, 2020).

4.4.3 Informed consent

Participants have the right to be informed about the nature of the study and what participation would entail and the potential effects that involvement in the research may have upon them (Holloway and Wheeler, 1995). This is important in terms of treating individuals with respect and fairness and respecting their autonomy (Beauchamp and Childress, 2019). All participants in the study on which this thesis is based were provided with an information sheet and subsequently signed a consent form. These documents can be found in the appendices to the thesis.

4.4.4 Confidentiality and anonymity

Protecting the interests of the participants and preventing harm from coming to them involved being aware of confidentiality and anonymity. Confidentiality and anonymity are associated with privacy when disclosing sensitive or personal information (Novak, 2014) and the researcher has a legal duty to maintain confidentiality. and Aall the bereaved relative participants were assured that their participation in the research would be kept entirely confidential and that their anonymity would be fully protected (Giordano *et al.*, 2007). The nursing staff who participated were assured that within the limits set by the NMC code of conduct, their participation would remain confidential (Shaha, Wenzel and Hill, 2011).

4.4.5 The utility of the research

It was felt by the researcher to be important for this study to have direct clinical relevance.. In effect this meant that there were two ethical and moral obligations to be considered. One, to provide a phenomenological description of the findings that allows the reader to look at the phenomenon in a different way – Thomas (2005) states that (nursing) phenomenology should be 'transformational' to those who practice or read it. Secondly, the findings are relevant to clinical practitioners and therefore dissemination of the results needs to be considered carefully as the 'normal 'dissemination via academic journals and conferences may not reach the target population. Again, the four principles of biomedical ethics were considered. Justice was particularly important in this case. The participants had freely and generously given their time and shared their often difficult and very personal memories as part of this research. It was felt that use should be made of these stories, to help others. Participants were asked if they would like to receive a summary of the findings and throughout the project, much discussion occurred with clinical colleagues about the research, including updates at the Trust end of life care group meetings and informal discussion with peer colleagues.

4.5 Rigour

As the study on which this thesis is based is a qualitative phenomenological study, it was essential to consider rigour. Rigour is an important concept in qualitative research (Koch, 1994; Koch and Harrington, 1998; Long and Johnson, 2000; Cope, 2014; Johnston *et al.*, 2017), and in phenomenological research in particular (Thomas and Pollio, 2002; Zahavi and

Martiny, 2019). Basically the concept is a measure of the truthfulness and ‘trustability’ of a study (Reid *et al.*, 2018), and by definition a measure of the quality of the research (Ahmed, Burt and Roland, 2014). Rigour, as Koch and Harrington (1998) point out is an evaluation criteria which is ‘borrowed’ from quantitative research and does not necessarily ‘fit’ well with qualitative research (Koch and Harrington, 1998); in fact they suggest that the emphasis on rigour from within the qualitative researcher community is a hangover from the days when a positivist epistemology was felt to be gold standard for research. Particularly within the phenomenological tradition, the idea of rigour can be perplexing – one researcher describes a conflict between phenomenological researchers who apply a rigid methodological stance to their studies and those who approached their data in a more creative and flexible manner(Pereira, 2012). He does suggest that a single set of criteria may not be appropriate for all types of qualitative, even all types of phenomenological research (Pereira, 2012). Work by de Witt and Ploeg (2006) presents a new framework for measuring rigour, specific to phenomenological studies was found to be helpful when planning the study on which this thesis is based, as it is specifically tailored to phenomenological research (De Witt and Ploeg, 2006).

Their five criteria are: balanced integration; openness of the study to scrutiny; concreteness of issues related to context; resonance, or the effect on the reader; and actualisation – the future effects of the research findings. To expand further, balanced integration refers to the clear articulation of philosophical principles in the context of the topic, the method and the data (Pereira, 2012). This was considered carefully in the ethics application. Openness of the study emphasises the demand for transparency within the study, hence the need for openness about the aims and purpose of the study (section 4,3 and 4.3.3). Concreteness of issues related to context allows the reader to be situated with regard to the data and also their own lifeworld, and again openness and consent were carefully considered (section 4.3.3) (De Witt and Ploeg, 2006) and resonance refers to the experiential or felt effect upon the reader when reading about the study, considered during the planning of the phenomenological interviews

(Manen, 1997). Actualisation addresses the future realisation of the resonance from the research findings , and was considered when the utility of the research was planned (section 4.3.5) (De Witt and Ploeg, 2006).

These five criteria are all phenomenology – specific and involve the reader of the research being involved in the findings which should bring them into a sense of the meaning of the findings within their own lifeworld. Throughout the journey which this thesis describes, these criteria were used as a framework to prove rigour within the study.

4.5.1 Congruence of the research question, methodology and methods

A research study begins with a research idea that is condensed down to form the research question. In order to ensure that the research is rigorous and trustworthy from this point, it is essential that the research question and the methodology employed in a study are congruent. That is to say, the methodology should be one from which it is feasible to derive an answer to the research question (Thorne, Stephens and Truant, 2016; Twining *et al.*, 2017). The qualitative study on which this thesis is based was designed to describe the experience of death and dying in the emergency department from the perspective of bereaved relatives and the nursing staff whose job it was to care for them. Phenomenology is an appropriate investigative method with which to answer this research question as it enables the researcher to arrive at a description of a phenomenon from the perspective of individuals who have direct experience of that phenomenon.

Equally, the selection of a methodology to underpin a qualitative research study has implications for the methods employed in that study's research process. It is essential to the requirements of the rigorous conduct of qualitative research that the methods chosen are congruent with the underlying methodology (Wimpenny and Gass, 2000).

4.6 Recruitment

4.6.1 The recruitment of the bereaved participants

When considering how to recruit the participants, several recruitment methods were considered, once the design of the study had been finalised. Aside from the issue discussed above about whether it is desirable to use bereaved people in research studies, actually finding people who had been bereaved in the emergency department proved more difficult than had been expected. Initially the idea of recruiting for the study from a single NHS hospital base was considered but this was felt to be ethically unacceptable due to the researcher's role as a nurse employed by the Trust. For the study, the researcher also wanted to collect participant experiences from a variety of places rather than just one hospital ED. It was felt that any conclusions drawn from the research might be stronger if it could be shown that similar situations existed in different areas.

The research team then approached the charity Cruse bereavement UK. Cruse bereavement care is a charity founded in 1959, which exists to provide support to bereaved people and also works to enhance society's care of bereaved people (Parkes, 1987; Care, 2005; Jalland, 2013). They have branches throughout Great Britain and Northern Ireland. The researcher and one of the supervisory team met with the local branch who were very helpful and ethical approval was applied for from the Charity. This was granted after discussion at the Charity's ethics committee.

However, the method of recruitment still had to be decided. After much consideration and discussion with other researchers, the idea of recruiting via social media was trialled. This received approval from both the University and the Charity ethics committee. The idea of seeking out people who write illness blogs and contacting them was considered (Hansen, Sheehan and Stephenson, 2017) but ultimately felt to be an unrealistic method due to the fact that many deaths occurring in the ED are unexpected (Bailey, Murphy and Porock, 2011c), and only talking to people whose loved ones had died after long term illnesses would be a very unrepresentative sample. It was decided to trial the use of Twitter and Facebook to recruit, as these methods have been used with success by other researchers (O'Connor *et al.*, 2014; Guillory *et al.*, 2016; Wilson and Usher, 2017; Benedict *et al.*, 2019).

In conjunction with Cruse bereavement, an advertisement was designed which could also be printed off as a paper flyer. This advertisement can be seen attached to Appendix 2 of this thesis. This advertisement described the study and included a photograph of the researcher with a mobile number and email address attached. Over a period of twelve months, the advertisement was re-tweeted and re-linked every week. Contacts of the research team were asked to kindly forward the advert to their contacts which they did diligently. Several paper flyers were printed and given to the local Cruse office, and also distributed to local undertakers, and churches– sadly this did not prove fruitful and no participants were recruited via the flyers. The staff and student network at the University was also targeted via email using the electronic advertisement. The majority of the participants were recruited via the Twitter advertisement.

4.6.2 The recruitment of the nurse participants

Following the completion of the recruitment process for the bereaved participants, the focus turned to recruitment of the nurse participants. The same approach was taken – the original advertisement was adapted to describe who the researcher was looking for and then posted on Twitter and Facebook. All the nurse participants were eventually recruited via Twitter.

4.6.3 Sample size in phenomenological studies

Sample size can be a challenging issue in qualitative research (Leavy, 2014). Unlike in quantitative research, the participants are not chosen to ensure that the data gained from the study is generalisable to other populations; far more importance is placed upon the information the participants are likely to impart about a particular phenomenon than on the number of participants themselves (Sandelowski, 1995). Several key principles are said to apply when considering sample size : small numbers are chosen so that the issue can be studied intensively, purposeful sampling is used, selection is commonly sequential rather than pre-determined, and a rationale for selection is necessary (Cleary, Horsfall and Hayter, 2014).

Different sample sizes are needed for different forms of qualitative research (Nicholls, 2008). Sandelowski (1995) quotes Morse (1994) as suggesting that phenomenologies aiming to uncover the essence of an experience should include about six participants, with ethnographies and grounded theory studies requiring up to fifty participants (Morse, 1994) . De Chesney (2014) surveyed several nursing research studies over a period of time and found that phenomenological studies had between 5 and 20 participants (De Chesnay, 2014); this was also found by Thomas and Pollio (2002) who felt six may be the optimum number of participants.

Sandelowski (1995) concludes her seminal paper about sample size by arguing that an adequate sample size is one that permits deep analysis leading to rich data; naturally depth of analysis is not possible if the sample is large and unwieldy, and likewise, new, varied and rich understandings of experience are not possible if the sample is too small (Sandelowski, 1995).

To ensure the research study on which this thesis is based collected as much data as necessary, data collection stopped after eleven bereaved relative participant interviews and eight nurse interviews. Rich data was obtained. Saturation was clearer in the nursing sample; participants began to repeat similar stories and therefore the recruitment of the nurse participants concluded after 8 interviews. The family member participants all had (very different) compelling stories, and recruitment could potentially have carried on, however it was important to present honest accounts of their experiences and there was concern about individuals voices becoming ‘lost’ if more and more data was obtained. Hence recruitment concluded after 11 interviews. Heterogeneity was considered and the method of recruitment (social media) worked well here as the participants were from a variety of backgrounds including geographical and cultural, and ages ranged from 30s to 70s.

4.7 Data collection

4.7.1 Preparing for the interviews

Data collection, once the participants had been recruited and consented to take part, was via unstructured interview, informed by the Quality of Death and Dying questionnaire - QoDD (Heckel *et al.*, 2015; Mah *et al.*, 2019), a validated instrument used as a survey with bereaved family members. Many such tools exist ; a recent systematic review examined 33 studies using 67 tools designed to measure the quality of death, dying and care (Kupeli *et al.*, 2019) – the authors found that the QoDD performed well and is extensively used, being translated into German and Spanish and used by both relatives and health care professionals. The Questionnaire consists of six domains : symptoms and personal control, preparation for death, moment of death, family, treatment preferences and whole-person concerns (Downey *et al.*, 2010). The QoDD domains, related as they are to the experience of death and dying, were found to be useful for focus when preparing for the interviews. Before each interview, the domains were re-read and a list of topics to cover was jotted down.

Most of the interviews took place over the phone or via zoom; three of the family member participants and two of the nurse participants were interviewed in person. These interviews were conducted in rooms booked at Oxford Brookes University.

4.7.2 The phenomenological research interviews

Phenomenological research in the Merleau-Ponty tradition particularly, requires that the researcher adopt a phenomenological stance during the interviews (Sadala and Adorno, 2002; Thomas and Pollio, 2002). This means consciously making an attempt to enter the life-world of the participant, being open to their perception of their experience in a non-judgemental way, assuming nothing, advising nothing and being open to purely listening (Sadala and Adorno, 2002). Phenomenological listening involves listening without prejudice and with the researchers natural attitude being held in abeyance (Giorgi, 1997; Thomas and Pollio, 2002).

The participant should feel they are being listened to in a supportive way and allowed to reveal the descriptions gained from their experiences in their own time and without as far as possible, interruptions from the researcher (Pollio, Henley and Thompso, 1997). The interviewer must also be aware of the importance of non-verbal communication, and try to maintain a calm, encouraging and open physical stance during the interviews, making sure that the participant is comfortable before the interview starts and being completely aware of how the participant is coping with the interview (Pollio, Henley and Thompso, 1997); this advice was most helpful when collecting the data for the study on which this thesis is based – one of the bereaved participants did become quite upset and the recording of the interview was paused whilst she was given support and thus became able to collect herself . All of the bereaved participants and a number of the nurse participants displayed signs of distress during the interviews. Reassurance and support were given.

Merleau-Ponty was a philosopher rather than a clinical researcher and did not leave instructions for carrying out phenomenological interviews. He does, however have an opinion about the importance of communication, writing in the Phenomenology of Perception : ‘'the spoken word is significant not only though the medium of individual words, but also through that of accent, intonation, gesture and facial expression, and these additional meanings no longer reveal the speaker's thoughts but the source of his thoughts and his fundamental being' (Merleau-Ponty, 2012). As a phenomenological researcher, it is important to pay close attention to all forms of communication with the interviews to gather as much as possible about the experience being studied. For this reason, interviews were conducted either face to face or through zoom / skype as much as possible, and awareness was always given to all forms of communication – this was particularly important, as this study was researching sensitive and potentially distressing topics.

4.8 Method of data analysis

4.8.1 The 12-step process

To begin the analysis of the data, a process was designed, adapted from the work of Thomas and Pollio (2002) and Hycner (1985):

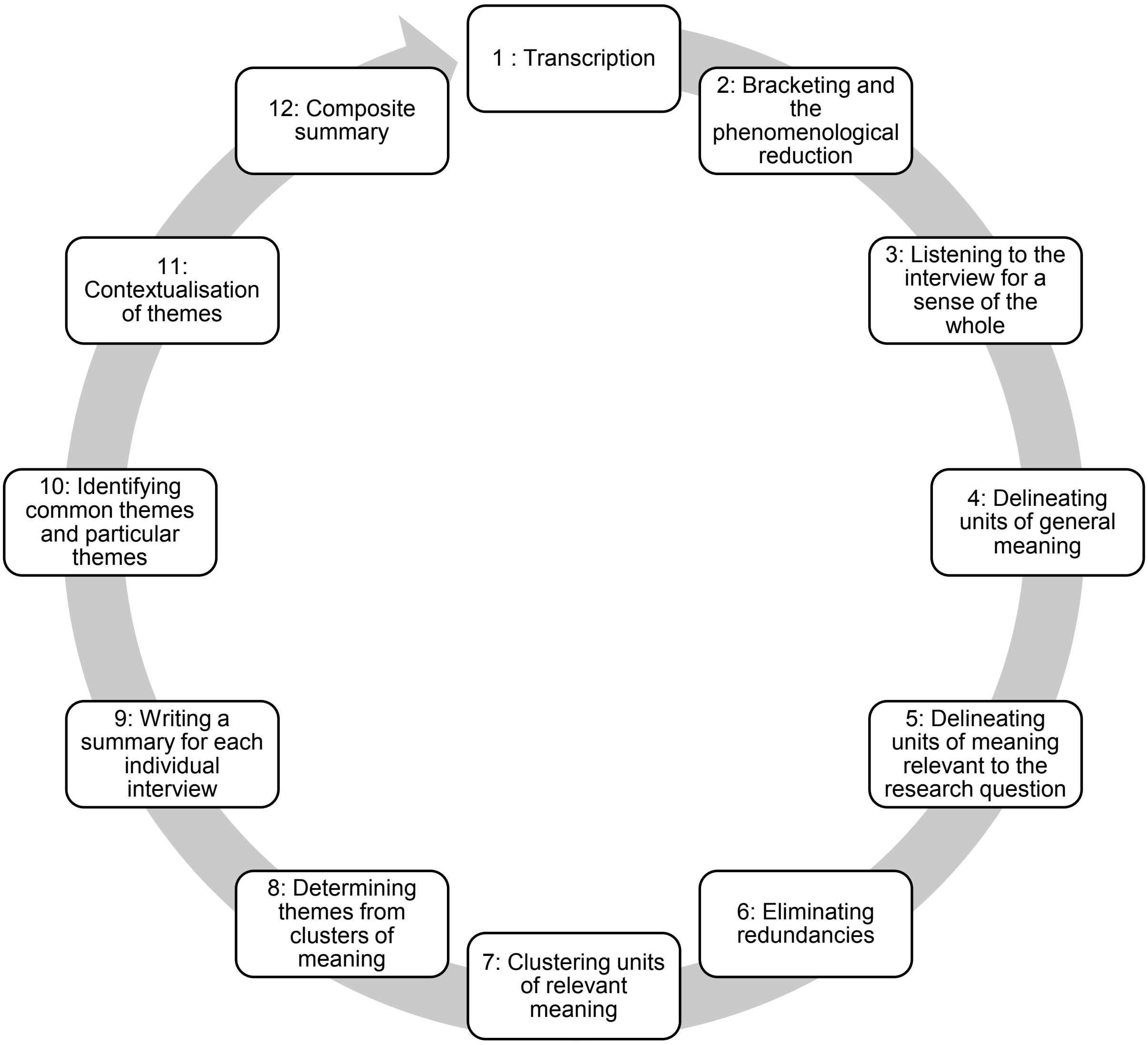

Figure 3: Process for analysis

This has been presented as a circular activity as the process of analysis was found to be a fluid and non-rigid technique (Hycner, 1985; Thomas and Pollio, 2002).

The steps are as follows:

- 1: Transcription – the first step in understanding what the participant was saying. The PhD candidate transcribed the interviews.
- 2: Bracketing and the phenomenological reduction – this was discussed in chapter three.
- 3: Listening to the interview for a sense of the whole – being very aware of what was said and what was not said.
- 4: Delineating units of general meaning – this step involved finding the 'stand-out' points from the interviews. The question was asked: what were the main points the participant was trying to get across?
- 5: Delineating units of meaning relevant to the research question – this step involved looking at the 'units of general meaning '(stage four) in the light of the research question.
- 6: Eliminating redundancies – anything which the participant discussed which was irrelevant to the research question. For example, one participant talked at length about her mother's care in her Nursing home prior to admission to the ED. This was very relevant to the participant but not to the research question.
- 7: Clustering units of relevant meaning – relevant units of meaning being those units of meaning that are deemed to be relevant to the research question. These were then examined carefully to see if any of them naturally clustered together. For example, Hycner (1985) gives the example of looking to see if there are any units of general meaning which could be clustered together under the heading of 'bodily reactions to the phenomenon'. These units would then be placed together.

- 8: Determining themes from clusters of meaning – the researcher then had to examine very carefully all the clusters of meaning to decide if there are specific themes which express their essence. The themes were then looked at individually to assess if they did describe the condensed essence of the clusters of meaning. This was a very long process.
- 9: Writing a summary for each individual interview – this was a very helpful step to again see if the themes made sense in the context of each interview.
- 10: Identifying common themes and particular themes – the first step was to notice if there were themes common to most, or all of the interviews. If so, these themes were clustered together, indicating a general theme. If themes were not common, but unique to different interviews, these were important counterpoints to the general themes and were classed as particular themes.
- 11: Contextualisation of themes – phenomenologically, this was a really important step, as context is one of the determiners of the phenomenon (Hycner, 1985). The themes were related to the context in which the experience occurred, and the meaning of each theme was therefore enhanced by its background.
- 12: Composite summary – this is the phenomenological summary of the collected data, describing what happened and what the experience of the happening was like at the time (Hycner, 1985).

Both the methods on which this framework is based – Thomas and Pollio (2002) and Hycner (1985) - are very similar and involve an iterative several step process, similar to that described above. The method was adapted, because the researcher was not working as part of a research group but as a single PhD candidate, and Thomas and Pollio (2002) and Hycner (1985) both include steps in their analysis which involve taking the initial findings back to a group of peers for discussion.

Another way in which the process differs is that both Thomas and Pollio (2002) and Hycner (1985) advocate returning to the participants for a second interview once the themes have begun to emerge. The decision was made for this study not to consider returning to the research participants to discuss the topic further. Some scholars do feel that returning does show respect to the participants (Hycner, 1985; Liamputtong Rice and Ezzy, 2007); however it was considered that there are limitations with this method, particularly with the demographics of the particular participant group under study. Member checking – asking the participants to revisit their research story - has many proponents (Creswell and Miller, 2000; Carlson, 2010; Harper and Cole, 2012), both for its perceived therapeutic value to the participant, and also for reasons of rigour and validity (Creswell and Miller, 2000). However, the participants in this study were considered to be a generally vulnerable group, (Briller *et al.*, 2008) and the possibility of causing further distress by revisiting the topic felt ethically wrong. There are many scholars who dispute the value of member checking as a test of rigour and reliability (McConnell-Henry, Chapman and Francis, 2011; Thomas, 2017). It can represent a real threat to the emotional safety of the participants. This step in the analysis of the data was therefore not included.

4.8.2 Analysis of the interviews – what was said and what was not said

One thing that was found when transcribing and analysing the qualitative interviews was that the silences showed up the things that were not said. According to Mazzei (2004) postmodern research provides great opportunities to challenge the researcher to engage and enliven his / her ways of doing research and one of the ways she chooses is to focus on deconstructive practice (loosely, the practice of examining what is not said or written (Rolfe, 2004)) in her (discourse-based) research (Mazzei, 2004). Her paper, describing a qualitative study exploring the experience of racial identity in white teachers, is interesting in that she explains how a focus on things that were not said increased her listening and allowed her (a previously experienced researcher) to fully live with the narrative in a richer and perhaps more authentic way (Mazzei, 2004).

The transcripts contained a great deal of data and significant silences were recorded. Bengtsson and Fynbo (2018) discuss how the use of silence on the part of both the interviewer and the interviewee can alter the power balance in the interview in a positive way, allowing both parties to feel in control during the process (Bengtsson and Fynbo, 2018). They also mention that the use of silence is a helpful method for managing emotion, a view which is echoed by other scholars (Denise and Makie, 2015; Kawabata and Gastaldo, 2015). Silences can also allow the participant time and space to order their thoughts (Kawabata and Gastaldo, 2015). It was initially hard during the interview process to allow silences but some of the most significant data came to light after a significant period of silence.

Listening was hugely important and if anything, the participants said was unclear they were gently asked to elucidate. The principles of active listening were adhered to : listening should be an active process, described as listening for a purpose (Louw, Todd and Jimarkon, 2011); and listening should include being aware of nonverbal and well as verbal cues (Talmage, 2012).

4.9 Preliminary findings

Using the four existentials of the lifeworld, (section 3.2.7) a framework was designed to aid in making sense of the experiences of the study participants, see figure 2 below. There were two data sets: data from bereaved relatives and data from nursing staff. Each data set was initially analysed separately. Analysis began by delineating 'units of general meaning' (Hycner, 1985; Thomas and Pollio, 2002) from the data. This is the beginning of revealing the participants meaning from his or her words. The aim is to be as broad as possible without at present addressing the research question to the data (Thomas and Pollio, 2002). Hycner (1985) describes units of general meaning as those words and phrases which express a clear and unique meaning (not at present related necessarily to the research question) and which can be differentiated from words and phrases preceding and succeeding it (Hycner, 1985).

The next stage involved identifying units of meaning relevant to the research question itself. To prepare for this, the research question was re-examined along with the aims and objectives of the study. The question – 'what was the experience of death in the ED? 'was written at the top of each transcript. The aim was to look at the previously delineated units of general meaning and decide if the participant had said anything, which may, however subtly, have answered and illuminated the research question. These units were isolated from the transcripts.

The next step was to examine the units of relevant meaning to identify if any units cluster naturally together. A separate 'clusters of relevant meaning' file was created for each transcript. In theory the preliminary themes should then emerge from the clusters of relevant meaning by a process of going backwards and forwards through the transcripts, determining if there are any central themes that express the core meaning of the clusters. This is a flowing and circular process (Thomas and Pollio, 2002). When the above stages were completed, it was recommended by both Hycner (1997) and Thomas and Pollio (2002) to go back to the individual transcripts and write up a summary of the interview incorporating the themes to give a sense of the whole and to contextualise the themes. Contextualisation is an essential step as what matters here is solely the participants' experience of the phenomena itself (Thomas, 2005; Thomas, 2018a). Having carried out these steps the emerging themes were then compared.

From the above processes and looking at the data sets both separately and together, it began to be clear that the emerging themes had many similarities. Although the themes are common to all participants, for clarity they will initially be discussed separately (see chapters 5 and 6). There are four common themes, with various sub themes. They were mapped onto Merleau-Ponty's four fundamental life-worlds perspectives as developed by Van Manen, and discussed above, in section 3.2.7 (Van Manen, 2003). The themes were identified inductively but were found to fit with the framework. These are described in figure 4:

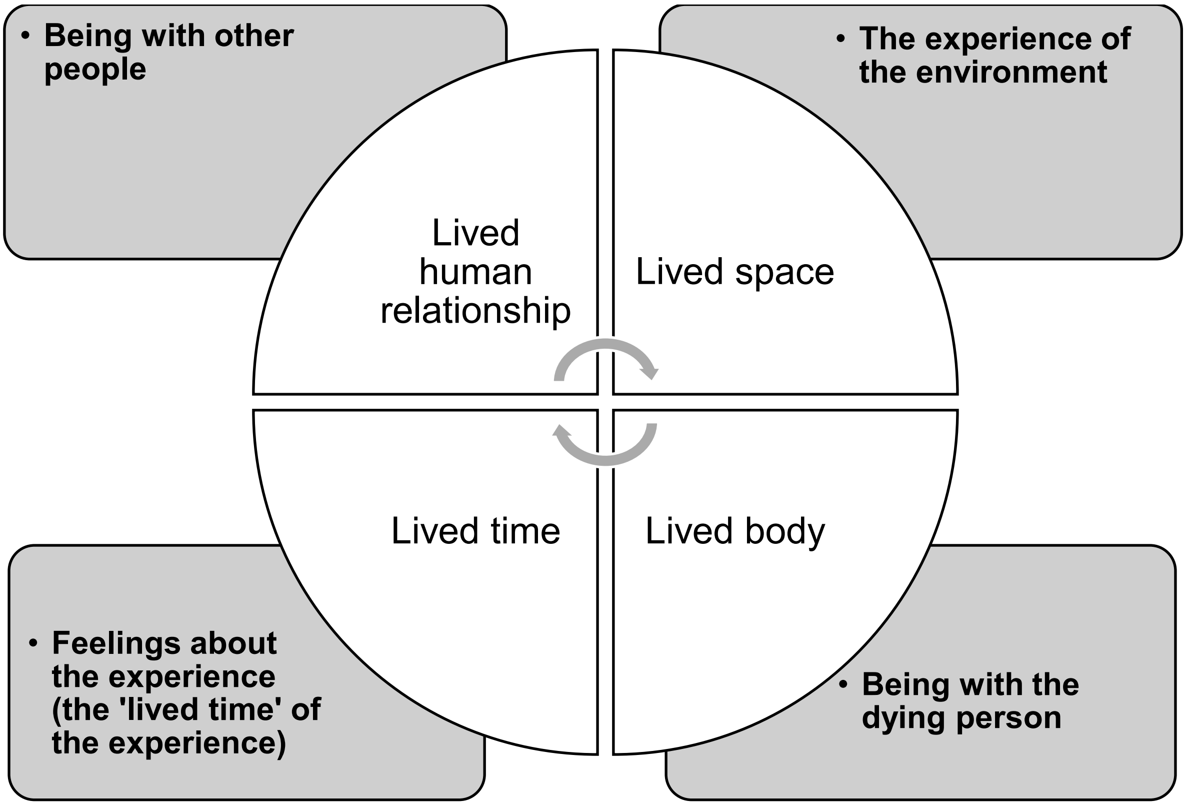

Figure 4: Four common themes to all participants

Themes:

- The experience of the environment of the ED
- Being with the dying person
- Being with other people
- Feelings about the experience
- These will be discussed in greater length in the following chapters.

4.10 Considerations for the researcher when researching sensitive issues for a phenomenological study.

4.10.1 Researching the experiences of bereaved individuals

It is important to take into consideration the cultural and professional background of the researcher (Visser, 2017), as it can lead to unconscious bias (Buetow, 2019) which must be noted . In the study described in this thesis, it was important to be aware that views from the researchers professional and personal life may be both a source of bias and also an added source of stress and distress. Death and bereavement are universal experiences; being exposed to the grief of others not only in the research study but also in clinical practice and to some degree in personal life may be challenging.

To manage stress and distress and minimise bias, self -awareness and self -care are very important (Beck, 2011; Ashton, 2014; Butler, Copnell and Hall, 2019). Whilst undertaking the study on which this thesis is based, self-care was managed by use of a reflective diary both pre- and post- interview, regular peer discussions and debriefs, and meetings with the supervisory team. The reflective diary was possibly the most helpful as it allowed thoughts and worries to be put down on paper before the interviews and thus created a personal space purely for the researcher (Zahavi and Rochat, 2015). Despite these it must be acknowledged that the topic being researched (death) was in every way a sensitive topic and therefore always potentially distressing to the investigator as well as the participant.

4.10.2 Researcher self-awareness: the reflective process

The reflective diary was also useful as a means to build resilience. Reflection and reflexivity are integral to the qualitative research process (Ortlipp, 2008). Reflexive practice is a method of thoughtful, conscious self-awareness (Colbourne and Sque, 2004), related to reflection , as Colborn and Sque, (2004) comment, in that the process is a continuum with reflection as a steady progress of thinking about an issue, moving on to the more dynamic and fluid ‘reflexivity’ (Colbourne and Sque, 2004). Reflexivity can be seen as a fluctuating multi-focal process (Buetow, 2019) which has many applications in the field of qualitative and phenomenological research (Day and Higgins, 2016; Miller, 2017b; Rettke *et al.*, 2018), all of which come back to the central point: reflexivity helps us to know ourselves (Dimaggio *et al.*, 2008). In terms of research into sensitive topics, this is profoundly important – to understand why one is being affected by a topic helps to rationalise the response and thereby potentially lessen the impact (Heron and Reason, 2006). By doing this, reflection can help also build resilience (Grant and Kinman, 2012).

4.10.3 Potential issues to be considered

Researchers are urged to consider any potential threats before commencing a research study (Barbara, David and Sally, 1999). If the physical risks are put to one side, it could be posited that there are five concerns to be taken into consideration when planning qualitative nursing research, all of which are linked: 1) the cultural and professional background of the researcher, 2) personal experiences which may impact upon the project, 3) The way research impacts the researcher. 4) self-care when carrying out research into sensitive topics 5) dealing with the unexpected (McCallum *et al.*, 2020).

The cultural and professional background of the researcher and personal experience are important, and it is clear that a researcher needs to be self -aware and honest both with him / herself and also with any colleagues. Self-awareness in nursing is known to reduce stress (Heffernan *et al.*, 2010; Por *et al.*, 2011).

Personal experiences, which may have impacted upon the project, also needed to be considered. Nurses are good at telling stories about their clinical experiences and nurse stories are often used as the basis for teaching and further research (Bond, Mandleco and Warnick, 2004; Milton, 2004; Orland-Barak and Wilhelem, 2005). There is very little literature about how nurses’ personal experience unexpectedly impacts upon either their clinical or research work. However, as private individuals it is clear that traumatic experiences in one’s personal life, particularly those that align with the subject under study, may affect the researcher - even if there are no or minimal personal experiences to consider, listening to participant accounts of their experiences may certainly trigger vicarious trauma and this may be entirely unexpected. Any strategies to reduce stress and increase resilience are therefore important.

4.10.4 Conclusion: Researcher self-care

In the planning stages, it was important to take these issues into account. The literature shows that nurse researchers must consider self-care when planning a project. All aspects of the researcher's role, including personality, background, personal experiences and stress triggers need to be considered. From the literature, strategies for self-care include ensuring peer and supervisory support, regular use of a reflective journal and maintaining a healthy lifestyle including breaks and time away from the project. Whilst it is impossible to eliminate the potential for stress and distress, it is clear that self-care using these tactics can lead both to stress reduction and also to increased self-awareness, ensuring greater compassion both for the researcher and for the research participant (McCallum *et al.*, 2020).

4.11 Conclusion

This chapter has described the methods used when preparing for, collecting, and analysing the data for the study on which this thesis is based. Explanation has been given as to how the themes began to emerge and how they are mapped onto the phenomenological concept of the 4 fundamental life-worlds perspectives to form a thematic framework for the analysis of the data. Chapters five and six will continue to discuss the emerged themes. Consideration of any potential risks to the researcher have also been demonstrated. An attempt has been made to show that the underpinning philosophy has been relevant to every step taken during the data collection and analysis journey. Further development of the data analysis and preliminary findings are discussed in Chapter 5.

CHAPTER 5: THE EXPERIENCE OF DEATH IN THE ED: THE PERSPECTIVE OF BEREAVED RELATIVES

5.0 Chapter abstract

This chapter describes the findings of the study relating to the first data set, the bereaved family members.

5.1 Introduction

As described earlier, the contextual grounds of the family members' experiences (lived human relationship, lived space, lived body, and lived time) will be elucidated before moving on to explanation of the figural themes. The themes should be understood against these grounds, in keeping with the tenets of phenomenology. The sample consisted of eleven participants who shared their experiences. Demographical details can be found in the following table 3. Information about cultural and ethnic identity was not specifically collected, however, the participants came from a range of backgrounds and were not culturally / ethnically homogenous; the pseudonyms chosen reflect this:

Table 4: Bereaved relatives participants

Name * Pseudonym	**Transcript number**	**Approximate age**	Length of time since bereavement	**Relationship to deceased person**
Nicole	1	40s	2 years	Daughter (of mother)
Max	2	40s	3 years	Son (of mother)
Jilly	3	60s	3 years	Daughter (of mother)
Danisha	4	30s	5 years	Wife (of husband)
Bella	5	60s	3 years	Daughter (of father)
Laura	6	60s	2 years	Daughter (of mother)

Pete	7	60s	4 years	Son in law (of mother-in-law)
Judy	8	60s	3 years	Daughter (of father)
Carmel	9	50s	15 years	Daughter (of father)
Patricia	10	50s	7 years	Daughter (of mother)
Elizabeth	11	60s	2 years	Wife (of husband)

The four themes that emerged from the data (as discussed in the previous chapter) are shown below:

The experience of the environment of the ED *– subthemes: The busyness of the ED / The openness of the ED*

Being with the dying person

Being with other people – subthemes: Being with family members / Being with hospital staff

Feelings about the experience

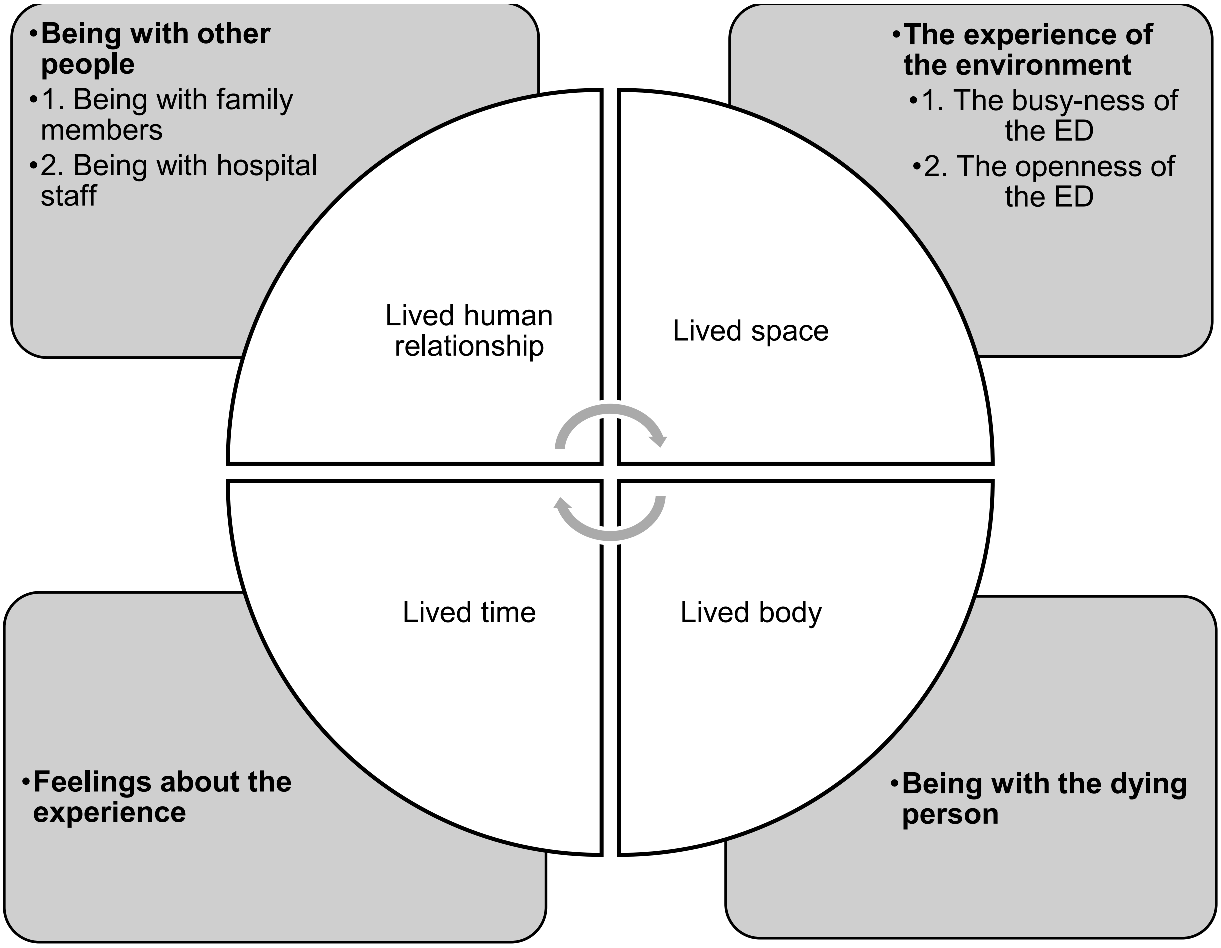

Figure 5: Themes

5.2 Lived space: The experience of the environment of the ED

The unique point of the study is not so much the experience of the death of a relative, but the experience of the death of a relative in the emergency department. The participants lived through the hours they describe, being in the World of the ED. Although some of the participants were either healthcare personnel themselves or had attended the ED previously in some other capacity, to all of them, the experience was new and fresh because of the circumstances of that experience. The bereaved family members described two main issues with the environment in which they found themselves, and therefore there are two sub themes: 1. The busyness of the ED, 2. The openness of the ED.

The busyness of the ED

Many participants negatively described the busyness and chaotic nature of the ED. Nicole's mother, who had advanced cancer, was taken into the ED overnight. She was crying in pain and:

> *'when we got there, it was a complete mess. No one knew what was going on … it was hard to find anyone they were so busy'.*

For **Nicole**, this was a real problem – she states:

> *'…they were so busy – I didn't feel anyone cared, really'.*

Danisha is a young woman whose husband had been chronically ill following a head injury sustained in a car accident some years earlier. Unfortunately, he became very unwell at home and was brought into the ED. When she tried to get help whilst in the department, she described:

> *'when I called for help, the response was a bit lax... They were so busy'.*

Bella attended the ED with her father, who had collapsed with a cerebral bleed at home. Whilst appreciating that her father had been put in a side room, she talked about how the main part of the ED was:

> *'the usual carnage, very busy'.*

Asked to expand on the word 'carnage', **Bella** explained she meant 'very chaotic, everyone rushing around'. **Bella** is a trained nurse herself and accustomed to the environment of other clinical areas. Her use of the word usual implies she expected the ED to be busy and indeed it was.

Pete was with his mother- in- law who had become unwell in a care home. He was in the ED as a proxy for his wife who was too disabled to attend. **Pete** felt slightly emotionally distanced from the whole situation, explaining that his real concern was his wife at home and that he had to keep ringing her with updates. He stated in the interview that he believed that this gave him a very good memory of the whole experience, one of the reasons he had volunteered for the study. He described vividly:

> *‘She [mother-in-law] was in a [separate] cubicle, but it was bright and very noisy. Lots of rushing around’.*

Later on, he recalled:

> *‘she stayed in that big noisy place until the end … the whole place was really busy. It seemed to be busy all night’.*

Asked to expand upon the busyness of the environment, he said it made him feel more alone. He was a solitary figure amongst a team of people who knew what was going on and he didn’t:

> *‘I was on my own and I didn’t really know what to do and the staff were busy busy. I don’t blame them at all, but it was a lonely few hours’.*

Judy’s experience was somewhat similar; she describes when she arrived at the ED in an ambulance with her father, who had had a stroke:

> *‘it was so busy. It was August bank holiday. I think loads of the staff were on holiday as well, they seemed really short staffed… they were run off their feet. I was always having to go and look for them, you know, if he needed anything’.*

For these individuals, the experience of the environment was a blur of people, all with a purpose and knowing their way around the department and fitting in, whereas the participants quoted above felt that they were in the way, causing bother to the busy staff and crucially that they / their relative was not uniquely important. This led almost to a feeling of disembodiment. As soon as the family members arrived at the hospital, they were removed from their previous selves as loved parents or spouse and were instead an object that was a bit of a nuisance to be cared for by the very busy staff. Unlike a ward or other clinical area, there was no time to get to know or build up a rapport with the staff: this may be a crucial difference when being looked after in an ED. Almost by definition, a patient and their relative is not in the department for a long time : in the UK there are usually time constraints (Excellence, 2018). In all the cases quoted, the patient was described as ‘unconscious’, ‘in a coma’, ‘out of it’ so would have been unaware of the situation, but the relatives described feeling alienated by the busy environment and vicariously disembodied by it – **Nicole** for example was distressed that the staff had not put her mother into the mother’s own nightdress, her feeling was that they were too busy to do so:

> *‘they were so busy … they had put her into a hospital nightie – that really irritated me, we had packed her own clothes, but there was so much rushing in the department’.*

All of the participants felt quoted that they had been removed from normality to an alien place where the staff were too busy to really pay them any attention, where there was much rushing around, and they felt that they, and their family member did not matter to the staff. The busy nature of the various emergency departments was seen as a very negative thing.

The openness of the ED

The participants experience of lived space during the time of their family member dying in the ED translated often into experiences of lack of privacy. When a private space was wanted, they found themselves in a (semi)-public space. Several of the bereaved participants in this study mentioned the openness and lack of privacy and linked it to lack of caring. For **Judy** it was one of the actual worst things about the whole situation:

> *‘he had a horrible death … there was no privacy and no caring’*

Her abiding memories are of her father being put in a:

> *‘sort of cubicle, not very big, but there was another gentleman in a bed at the end … it was horrendous. Awful. The worst thing was that he died, and my Dad had to witness everything [because he was in the same cubicle and there was no getting away from it] and then they put another chap in the bed after that’.*

She and her mother found this lack of privacy incredibly upsetting, and she goes back to it time and time again:

> *'It was horrible… we so needed privacy'.*

Judy's experience was for her, particularly unpleasant. And she found nothing positive about the situation. **Max**, too, remembered everything about the unusual open environment, the strangeness of being in the resus area where he could overhear everything about another patient's problems:

> *'I think he'd fallen off a trampoline so that was quite funny although not really'.*

Max talked about how he, as an individual unwittingly intruded into the lived space of others in this public area. He mentioned how he couldn't help seeing other people's bodies, catching glimpses of screens showing others 'x-rays – an intrusion into a very intimate situation - and also how he noticed things like some drops of blood on the floor:

> *'being there with someone else's broken body … you're trying to find something normal in a situation which is definitely not normal'.*

Again, **Max** remembered privacy and dignity in an open area being a real issue – his mother had to receive personal care in an open environment, it felt very public:

> *'she was being fed through a PEG, and the material, the feed, was going into her but was coming straight out. I mean, that's unpleasant, isn't it? My Dad was trying to explain this, and my dad dealt with a tremendous amount of indignity, having to explain this in public'.*

Jilly mentioned her mother dying in the Majors area of the ED (the place where the most dangerously ill patients are cared for) with just a curtain separating her from the rest of the (public) area, and drunk people wandering about outside:

> *'you step outside and you hear people laughing and talking and it's – odd. This momentous event happening behind the curtains and life going on outside'.*

Elizabeth also really struggled with the open area of the ED and the lack of privacy:

> *'It was all open, I could see people going about their lives and R* [her husband] *was dead'.*

Perhaps this was less physical privacy than mental privacy. She found some interactions with health professionals very intrusive:

> *'a nurse came in and she said is there a neighbour or a friend that could come with you? And you know there wasn't one and I didn't want to talk about it. And she asked me again'.*

Elizabeth explained that she felt judged by this nurse – she explained that they were a very close family and had very few friends – there really was nobody she could have called on in this situation, and she felt that because of this she was felt to be lacking in some way by this nurse. Later she had to ring her adult children and tell them their father had died and remembers:

> *'she* [a nursing assistant] *just pointed me to an office and there were two ladies in the office, and I rang my daughter and told her … and I said to the ladies did that sound OK? And you could see they must have been embarrassed but they didn't say anything, and I didn't know what to do'.*

There was a lack of support for her at this crucial time. When eventually she was taken to see her deceased husband in the viewing room:

> *'one of the clerical staff came and opened it up for us. But she sat in the corner and whilst I don't know why, it was a bit off putting. And there was a barrier between us and* [my husband] *and I stepped over the barrier and put my arm round his head so that we could reach him, and we could tell him we loved him and kiss him.'*

Elizabeth wasn't able to explain why a member of the clerical staff was with her at this point, but this is a very clear memory of an unnecessary intrusion into her privacy.

Bella's father did die in an open area, but although she mentions this, she found it a positive experience:

> *‘we said if it was possible, could he stay here* [in the ED] *and because it wasn’t madly busy* [it was early in the morning] *… they said that would be fine. He was in a big open space, but he didn’t get moved to a corner of another ward with all new staff and everything. And I think that to me … these things were quite significant’.*

The fact that she mentions it ‘wasn’t madly busy’ illustrates the point that a busy ED is no place to die. **Bella’s** father was moved to a special side room still part of the ED after his death, so the family had privacy:

> *‘then they put him in a really nice side room, and he was sort of laid out, not in a shroud or anything … he looked peaceful’.*

Her memory of that time is that the side room was a sanctuary, a place apart from the hustle and bustle of the outside world. Her perception of the lived space shifted from the busy-ness of the large ED to the smaller lived space of the side room.

> *‘for us there was a little bit of sanctuary, a little bit of solace in that cool, nice room when he was in there and there was no rush’.*

Pete also remembered that his mother-in-law had been in a cubicle ‘*with a curtain across the door’* so that they were alone in a place apart. His and the patient’s lived space during this period was denoted by this curtain, the barrier to the outside world, away from the openness of the ED.

Laura too remembered that her mum was moved, and this was a positive experience:

> *‘she was in resus and then they moved her to a quieter area, still within A and E, a single room…they [the staff] got a lovely mattress for us by the side of mums bed, they were so kind, and we could have a rest… mum was just completely comatose’.*

For the participants, the lived space, the openness of the ED was a genuine issue. Even those who experienced the environment positively, did so because they appreciated that they had some space and privacy to themselves, in contrast to the openness of the area.

5.3 Lived body: Being with the dying person

This section describes what it was like to physically be with the (embodied) family member as they were dying. **Nicole** had an overwhelming sense of it having been an awful experience, because of her mother's symptoms. Her mother was still on chemotherapy and got uncontrollable nausea and vomiting after her second or third treatment so was taken to the ED:

> *'she was in pain, crying with pain in her abdomen … I asked a nurse for some pain killers and it took an age to get anything … [the doctor said] he thought the situation was very serious, she was really sick, she was vomiting by that stage … I felt really desperate'.*

Nicole's world had shrunk to the sight of her mother's suffering body in front of her. Sadly, her mother developed laboured breathing, described by **Nicole**, a nurse herself as Cheyne-stokes breathing, and again it was hard to get any help:

> *'I ran to get someone, but it was hard to find someone, they were so busy'.*

Max's experience of being with his mother was similar in that he realised that she was dying, her body was shutting down:

> *'my mum was not really able to speak but her eyes were open as it were, but the light had gone from them. You see for all my mum's illness, she still had something about her eyes, they were still there, very expressive. My sense was this was it'.*

After she had died, **Max** unhappily felt:

> *'I had a very intense time with her in accident and emergency you know … the memories of my mum were all about when she was ill, and at the end, the smell of her hair, her unwashed head and all that … my visual memory has all been erased of my mum as a healthy person'.*

The fact that his memories of his mother are all about her time in the ED is important; the memories are so consuming that they have obliterated all other memories. It is vital for staff to be aware that these extremely vivid memories will stay with the bereaved person.

Jilly, who received a phone call at home and rushed through the night to be there when her mother died in the ED talked about the experience of being with her mother as she died:

> *'they took us in to have a moment, then we left the room, they took off the breathing apparatus and then we went back in and she sort of, it was sort of quite quickish at that point… it was hard. We weren't even quite sure when she'd gone'.*

When asked if she had had enough time with her mum, **Jilly** said:

> *'yeah, I mean in a way, once my sister and I had seen her, and seen how devastating the effect [of the stroke] was – patently she was pretty much gone… we felt like we got to say goodbye even though obviously – well who knows what people can hear, but patently her brain was gone'.*

For **Jilly**, this amount of being with was enough:

> *'they didn't make us feel rushed but on the other hand we didn't feel the need to sit there for a long time. Either. [The suddenness of it] for her it was brilliant, obviously. For us, though it was shocking actually you embrace it because it was good for her'.*

For **Bella**, the essence of the being with really happened after the death of her father, but she uses the phrase' being or be with' multiple times in her discussion of her experience:

> *'we were by his side, of course all this time he'd had no response, but we were able to be with him, say good- bye, be on our own with him'.*

This 'being with' forms an incredibly important part of **Bella's** memories of the passing of her father She says again:

> *[after the death] 'we had time, again there, to be with him before he went down to the morgue or whatever'.*

The fact that she was able to be with him in this way led her to say:

> *'I need to tell people that you can have a good experience even here at the end of life like this.'*

Laura, too, who spent many hours, at her mother's bed side found the 'being with' element the most profoundly important of the whole experience:

> *'just watching mums breathing really and remembering hymns and going through, you know, all her dogs and all her gardens and everything she had loved. She was completely, obviously out of it the whole time.'*

For **Laura**, being with her mother at this time was also remembering all the incarnations of her mother: she was seeing her mother as everything she had been, every aspect of the woman she was, rather than just the elderly lady, dying peacefully in a hospital bed.

Judy found that 'being with' her dying father was really a very bittersweet experience, perhaps because her knowledge of her father outweighed what she was told by nurses:

> *'Dad got weaker by the hour. And the nurses kept saying that he couldn't hear anything, but I knew that he could. I was leaning over him in the afternoon, wiping his mouth, and he grasped my wrist really firmly. I said I love you, Dad, and he smiled at me, it was so lovely'.*

For **Judy** it was significant that the nursing staff were seemingly unaware of the need to give holistic care, to see the patient as more than just a dying body. The memory is painful to her, that her father wasn't important to the staff:

> *'they clearly weren't going to remember him- he was just another body to be cleaned and dealt with'.*

Judy felt angry that her family was almost dismissed by the staff. She had expected more, particularly from the nurses:

> *'I did get the overwhelming sense that it was just a job for all of them. And I think nursing should be more than a job'.*

Unfortunately, she was unable to articulate what she meant about it being more than a job, just that the nurses should be more '*caring'*.

The participants found it difficult being with their dying family member but all quoted above acknowledged that they needed to be there, that it was important to them, even if it meant being, like **Nicole**, with someone in terrible pain and suffering. Their memories were very vivid.

5.4 Lived human relationship: Being with other people

Many other people were present in the participants narratives. Apart from the hospital staff, nearly all the participants had someone with them at the time, nearly always a family member.

This theme has two subthemes: *Being with family members* and *Being with the hospital staff*.

Being with family members

Sharing the experience with a family member was not always a positive thing - **Max** talked about how difficult it was coping with the fact that his brother was upset:

> *'My stress is about that he's getting edgy and being abrupt and rude with the nursing staff'.*

Later, **Max** analysed this himself and said:

> *'it's all about displacement, isn't it? Yeah – my mum is ill, she's dying – it's easy to be angry with my brother. Perhaps it [the anger] helped me deal with such a difficult situation'.*

The demands made upon **Max** by his brother were very real:

> *'[after the death] my brother asked, did I want to go and see Mum's body and I said no, I didn't want to go. If I went it would have been to support him'.*

A more common experience was that the participants found the family members supportive, even comforting, as **Laura** mentions:

> *'The consultant came and talked to us…we all decided, my partner and my sister and I to just go with what they said. To go with the medical opinion*

> *and not fight it … it was good, we knew precisely what was happening and what route we were going down'.*

Having her partner and sister there as well, making the decisions meant that she was less alone despite the awful situation. It also meant that Laura was less alone in her worries after the death.

Judy, who was with her mother the whole time that her dad was dying in the ED felt the same, she wasn't alone:

> *'we were OK together - we didn't really want to see anyone else'*

Being with others is not always straightforward. **Carmel** had a friend with her; but her mother (who had found her father having a heart attack and had called the ambulance) couldn't cope with the situation and had left the hospital. This was distressing for **Carmel** even though she did understand:

> *'I think ultimately the person who initially raised the alarm, they are so shocked themselves, they don't really have the capacity for others around them'.*

Carmel was grateful that her friend was there, but ultimately felt very disassociated and shocked which coloured her whole experience and memories of that experience:

> *'… you're in some sort of weird limbo'.*

Some of the participants didn't have anyone with them at all. **Elizabeth** had lost her husband and **Pete** was in the ED with his mother- in- law. For both **Elizabeth** and Pete, one of the defining things about the whole experience was that they were alone. **Pete** felt very isolated:

> *'the doctor came …he started asking me all these questions – like what was my relationship with my mother- in- law and what other family were there. I started to get a bit worried then because I thought he was building up to bad news. Of course, there is only [his disabled wife] and me which is a bit sad really'.*

Later he says:

> *'I think the biggest thing was that I was so alone'.*

Elizabeth, also was on her own and remained on her own after her husband died until her adult children arrived:

> *'I just walked up and down the corridor and I just waited. And I thought well, I must wait for [her son]. So, I stood outside the hospital just waiting for him to come along. He came. I took him to the room and talked to him, of course he was just desperate. Then [her daughter] must have gone to reception and they brought her to me, and she was in floods of tears'.*

It is a haunting memory for her, that time when she paced around the emergency department for several hours, knowing that her husband had died and waiting for her devastated children to arrive.

Being with family members or friends can bring its own problems, but both the participants who were alone through the dying process (**Pete** and **Elizabeth**) describe particularly negative experiences of being so alone.

Being with the hospital staff

The experience of communication ('Being with') with health care professionals was not always straightforward for the participants. Good empathic communication, the essence of 'being with' is hugely important when considering the experience of being with a dying loved one in the ED. Unfortunately, many of the bereaved participants had less than optimal experiences of being with the staff. **Nicole** vividly remembered an interaction.

> *'… the nurse came back with some tablets and mum was vomiting at that stage and I said, she can't take those, she needs an injection of morphine or something strong anyway. But the nurse just stood there, I'll never forget, it was, well, inhuman'.*

This interaction resulted in the behaviour of the nurse seeming to be off-hand and uncaring. It made **Nicole** feel more alone. She was not supported by the staff and had no connection with them. Recounting this episode upset **Nicole** more than recounting her mother's actual death, and she returned to it later:

> *'I didn't feel anyone cared, really … nobody introduced themselves, nobody showed that they understood. I never knew any of their names which I find quite horrifying … the inhumanness of it'.*

Already isolated from the everyday life going on in the Unit by the fact that her **Mother** was so sick, Nicole felt isolated by the interactions with the nurses. By poor communication, not introducing themselves, it seems as though the staff showed their lack of care for **Nicole** – it felt like she wasn't worth their time. Her memory of the nursing staff was that:

> *'They just rushed past, not saying anything. We didn't matter to them''*

Nicole was present but her experience was that she felt she was not important enough for the staff to pay any attention to her. She felt the attitudes were unkind and uncaring.

Max felt satisfied that his mother was very well looked after and the staff generally communicated with the family well, leading to a feeling from **Max's** side, that the family had a relationship of sorts with the staff. However, a slightly different feeling came up when he was being told by a doctor that his mother was dying:

> *'we had that moment with just the three of us [Max, his father and his brother] in a very serious situation with the doctor, and he said, he said – I'll see you later. But he went off shift… that's not a big thing, but it's still you know, the mundanity of it … it's just a figure of speech isn't it, but we took him at his word.'*

Again, the behaviour of the staff member was offhand. **Max** remembered this episode with a sort of wry humour:

> *'I didn't feel like we were abandoned or anything like that, but real life intrudes, doesn't it? He went home'.*

Max's strong memory of this incident is actually a memory of feeling a bit silly. He recalls:

> *'…there was a slightly awkward British thing, we were saying, he said he'd be back, should we wait? And when we found out that he wasn't coming back we felt slightly ridiculous for waiting around to see what will happen'.*

It has stayed with him and rankles:

> *'When a shift comes to an end, the shift comes to an end. But he could have explained that – my shift finishes in a couple of hours and it may be a colleague who sees you – we would have been fine with that. If I am irritated, it's because of feeling a bit of a shmuck, waiting around to see what will happen.'*

The doctor (again **Max** was not told his name), by not coming back, betrayed the fragile relationship that **Max** had begun to perceive with the ED staff. **Max** then felt distressed because he had apparently 'misjudged' the sense that there was a relationship of sorts. There was no 'being with' on the part of the doctor. The family were simply not important enough to him.

Laura talks about a similar 'being with' problem between her and the staff looking after her mother:

> *'this is all a bit odd, so obviously it's all person-centred care where they like to involve the family. But that's quite difficult when you've never been in that situation … the theory of it I think is fantastic, but it's really difficult because they expect you to monitor how mum's doing and let them know so they can get the drugs. Now I don't know the signs of patient discomfort, so I was googling away, and it was hard.'*

Laura was uncomfortable with the communication with the staff during this interaction and felt completely unprepared for the difficult task of monitoring her mother for discomfort and it created some friction between her and her sister:

> *'we were having these massive – not arguments- but massive discussions about – do you think we should get more morphine? We couldn't remember anything – when did she last have morphine, oh I think it was about 12?... or we thought we should ask for some sedation if she moved or something. So, it was really awkward and really stressful'.*

The family felt that the staff were really trying to do the right thing: as **Laura** says above, she understood that the idea of getting the family involved in care was a good one, but this again was **Laura's** abiding memory of this time:

> *'So, we said to the consultant, we're a bit uncomfortable about this integrating us into this care plan … we don't know what to ask for or when to ask for it etc… I think the problem is we didn't know where or what … so we asked for the staff to take more control and they did'.*

Laura gives the impression that she and her sister were made to feel inadequate by the staff, and this mirrors **Max's** experience of feeling slightly foolish as he waited for the doctor to come back, not knowing the doctor had gone home. This is the opposite of empathy. **Laura's** impression of the quality of the communication focussed a great deal on information: she felt that she didn't have enough knowledge, as above:

> *'medically we didn't know and the sister, she didn't understand the blood thing and I really wanted to know, because I wanted to know what we were dealing with. I'd looked it up, but I wanted to ask them if there was any hope of getting better.'*

Again, she says:

> *'we couldn't remember anything – when did she last have morphine, oh I think it was about 12? Now on reflection I'd keep records, write it all down. Or we thought we should ask for some sedation if she moved or something. It was really awkward. We didn't know what to do properly. And it was really stressful'.*

Ultimately, **Laura** did feel that the family had experienced good care but really what caused the distress was the lack of in-depth information, and that made her feel that she didn't know if she was doing the right thing for her mother. It created uncertainty for her and her partner and sister:

> *'… and uncertainty. The uncertainty about whether you're doing the right thing and all of that. Not just about the initial decision [to withhold treatment] but about the processes you go through after that.'*

Judy definitely felt that the quality of the communication in her father's case had been poor:

> *‘It was barbaric, that’s what it was. We were told he might take several days to die but they weren’t going to give him fluids. I remember they put a catheter in and at first lots of urine came out but then it all dried up. I felt like he was being dehydrated. Nobody could or did explain properly. In the end he died very quickly, we never left accident and emergency’*

She felt as though she and her mother were abandoned, and nobody told them anything:

> *‘We saw a doctor a couple of times. Probably. It’s hard to tell because they were all in the same sort of scrubs. No introductions. Anyway, they only seemed to come and say things were worse. So, we didn’t really want to see anybody, we knew it was the end.’*

In the context of human relationships, abandonment is very distressing. **Judy** and her Mother felt isolated and alone. There was no relationship with the staff and no attempt on the part of the staff to make one. There was no sense of ‘being with’ here, and sadly this again translated into not feeling cared for:

> *‘I think the staff were too busy and Dad was obviously not going to get better, so they didn’t want to waste too much time on him’.*

Judy felt that the staff saw her Dad as a potential waste of time. **Judy’s** experience of the nursing staff was sadly overwhelmingly non-empathetic and the communication was very poor:

> *‘I don’t remember them ever coming in unless I asked them … [a nurse] came in and said yes he is gone, it was like so every day and so matter of fact… it just didn’t feel at all caring… no-one sat with us and explained what was going on or talked to us about how we might be feeling’.*

Because of this perceived lack of caring, **Judy** has a very negative image of nurses, as discussed earlier. The ripple effect of these experiences cannot be over-rated.

The comments were not all negative. **Max** ultimately felt that he and his mother were well looked after by the staff, and felt safe with them:

> *‘They explained everything. I had a very intense time with her [his mother] and it was enough, really. I felt she was very well looked after’.*

He noticed that the staff were struggling because there was uncertainty about what was wrong with his mother. The uncertainty, as with **Laura** above, was memorable and distressing:

> *‘In terms of her treatment it felt to me as though people were doing what they could. They said that and it was obviously true. And I felt for them because it wasn’t clear what was wrong, what was going on … there was a collective sense of slight helplessness … there was no answer to it. It wasn’t as though she had come off a motorbike’.*

Jilly was full of admiration for the staff. She was very satisfied with the quality of the communication. She felt that it had been very clear and that they had prioritised her mothers’ care:

> *‘They … effectively kept her alive until we got there, but the doctor really made it clear that mother wasn’t going to get through this … the hospital was very good, they were very nice’.*

She was very taken with the fact that they had put her mother on some sort of supported breathing apparatus, **Jilly** called this a ventilator:

> *‘… and as I explained earlier, they put her on this ventilator so that we could see her before she died. They told us everything. They were kind enough to make that decision without consulting us so that we could get there, they could have just let her die, which presumably is what would have happened if they hadn’t ventilated her … I thought that was such a kind decision on their part, knowing we were on our way, to allow this to happen… we felt like we got to say goodbye.’*

Saying goodbye was very important for **Jilly**. Afterwards she recalls how the staff took her sister to see the mother’s body after her sister had returned from abroad:

> *‘my sister came back from France … they let her see – well the viewing as they call it, which was good … it was nicely done and I really can’t fault the hospital, they didn’t make you feel rushed or that you were a problem or that you were asking something that wasn’t reasonable’*

Patricia arrived at the ED to see her mother after admission. It was her sister who had been with the mother prior to admission and had accompanied the paramedics. **Patricia** talked a lot about the witnessed resuscitation attempt:

> *'I was happy with the care. And we were told everything every step of the way. It's just - I think for J [her sister] the thing she couldn't get over was when she saw the hospital staff doing resus. It shocked her. It was just the power that was used …that was the vision for her that stayed with her. I said did you hear any bones cracking, and she said she didn't, but she couldn't believe they didn't. And then she watched them shock her, the whole lot and just the power of it … it took her several months to get over watching them do it… but we were grateful, we had no regrets about the way she died at all, it was right to do this, and the staff were lovely to us'.*

There is something here about the appropriateness of the ED. **Patricia** says: *'It was right to do this'*. **Carmel** too felt happy that her father had had been taken into the ED:

> *'I think the fact that he had been taken into the hospital was very helpful, if I'm honest. It was really really helpful. They did everything they could … we saw that people did care enough to do everything. And the system worked for him even though it wasn't a good outcome'.*

Bella also found being with the staff very helpful and she feels they worked to ensure that her experience was as good as it could be. They communicated well. When she arrived at the emergency department, her father was unresponsive and needed personal care:

> *'…because he'd wet himself you know, and the nurses said we'll do it. I was wanting to wash him you know but they said we'll do it we'll make him comfortable and clean. And during that time, as a family, we discussed with the sister and the A and E consultant that his wishes had always been that he never wanted to be dependent, never wanted to be resuscitated or anything like that. So, it was good that the nurses were looking after him while we talked.'*

She was really impressed with the staff and this came over many times during the interview:

> *'they were very caring and careful, and they treated him with utmost respect …they washed him and talked to him and put him in a gown and made him comfortable'.*

This was so important for **Bella**; her last memories of her Dad were peaceful ones, even after death:

> *'they put him in a nice calm side room, and he was sort of laid out, not in a shroud or anything but his hair was brushed, not sure of they'd shaved him, but he looked peaceful'.*

Even looking back, having been asked if there was anything at all that she thought could be improved she didn't think so:

> *'I could see they were good in the A and E, their professionalism, they were good, very sensitive, they knew when we needed to cry, we weren't hassled at all about going out and going to a ward … in terms of nursing care they were sensitive … if someone comes in who can't be saved you would think there might be a lack of interest maybe. But there was nothing like that.'*

This is in direct contrast to the experience of **Max**, above, regarding the care that his mother received after attending ED with a non-traumatic illness and at the end of life. This is truly empathetic, good quality care – knowing when the relatives needed to cry.

Those participants who had a better experience of being with the hospital staff describe overall more positive experiences. It is really important that staff are aware of the impact and lasting effect of poor communication.

5.5 Lived time: Feelings about living through the experience

This was an in-depth part of each interview but a most important one. For some participants it was the first time they had been asked to think about their feelings beyond the shock of the grief and loss. In presenting this section, the transcripts were examined again as a whole rather than individually, and they were read through in one sitting in order. There is naturally distress and grief coming through the words of every participant. Every participant is accepting of the death, however, even **Danisha** whose husband was a young man in his early thirties. It is not so much the fact that the death happened, as the manner of it's happening. This section captures the effect on the relatives of the experience they had, and in some cases, it seems to be ongoing.

It is worth also noting that the feelings about the experience include the feelings about talking about the experience, including talking about the experience in the context of a research study. This is important because of the perceived notion that bereaved people will not want to take part in a study, that it is cruel and unfair to ask them and that their interests need to be safeguarded. The data from this study, backed up by the evidence from literature (McCallum *et al.*, 2019) shows that this does not seem to be the case, that bereaved people on the contrary are extremely keen to talk about their experiences, feeling in many cases that they have been unable to do so before.

Max for example was really happy to tell his story:

> *'She [his mother] had a very full life. And that's what I take from this: I have no regrets. There isn't anything bad. I saw your advert on twitter and I thought, I could do this. And I thought, hang on, surely this should elicit greater upset – and yet it doesn't, and that's because of all that went before it and that the system worked. And it's good to tell you that.'*

Jilly, perhaps uniquely had no complaints at all and felt the experience was the best it could have been:

> *'It's very vivid in my mind, it does stay with you… I've got no complaints. You're probably hearing some bad stories of other people but from our point of view it was good'.*

Like the others she said:

> *'I'm glad I've got a good story for you … I think it's a really great idea that you're doing this'.*

She was happy to talk to a researcher about the experience, as was **Danisha**. **Danisha** was a junior doctor at the time of her husband's death and felt this had coloured her remembrances of the experience:

> *'I was a junior doctor at the time, so in the case of knowing how this will pan out, you don't really see the full implications [of her husband being brought into the emergency department], but you do see that this is not something which is easy'.*

Danisha explained that for a long time she was unable to talk about her husband's death:

> *'I think with time you get to process some of the emotions around the death and actually at this point I find it much easier to talk about it and that's why I was comfortable talking to you about it. For a long time, I couldn't tell anybody what I felt about it'.*

She felt that everything that could have been done in hospital was done:

> *'For the setting that he was in, he had the best possible care.'*

Her feelings were (quite naturally) complicated though:

> *'I was angry. Because somehow you feel that you've failed. And I was disappointed … I think you're angry with the health system [before he was admitted to the ED] and you're angry with him, you know? ... and you're also angry with yourself … you're sad because there is going to be a lot of changes.'*

Danisha also said:

> *'I'm hoping all this information will help you make changes which will be better for all of us.'*

There is something shocking about the suddenness of death in the ED. Even if death is expected, it is not expected in the ED. Many of the participants described very unpleasant sensations and feelings when enduring the experience of being in the ED. **Carmel**, who lost her father as a young girl of 17 has retained vivid and distressing memories of the entire experience. She found actually the moment of entering the ED particularly terrible. Later in the interview, she talks about the fact that it felt like a movie with ominous music. The idea of the environment of the ED being almost uncanny, so alien and frightening was expressed very eloquently by **Carmel**, describing the death of her father:

> *'I think it was at that point, [entering the ED] everything just seemed really strange and everything started to move in slow motion, really'.*

This could also be the effect of shock, of course, and **Carmel** was aware of this. She goes on to say:

> *'I don't remember seeing anyone else, there were people all round, but I just didn't see them … it was like a very strange void … I remember the chairs, that awful funny plasticky smell… it just felt really strange as though there was nothing, just an awful emptiness'.*

She discussed that the ‘emptiness’ was her memory of the physical space and perhaps mixed up with the ‘emptiness ‘that she was feeling emotionally. She did wonder aloud whether she had been in a state of shock at the time:

> *‘I must have been in a state of shock, I think anyway that’s the nearest I’ve ever been. It was a very strange mind space because it was almost like a premonition…of course I thought something [bad] had happened but it’s almost as though you know but you can’t believe it. And the weirdness of the whole place didn’t help.’*

Elizabeth, whose husband died completely unexpectedly also talks about feeling in a void, a state of shock:

> *‘I walked [up and down the ED corridor], I didn’t know what to do so I more or less just walked … there were lights on, but it just felt dark, it felt strange to me … I just walked up and down the corridor and I just waited’.*

Shock at the death of a loved one is not of course unique to death in the ED. The strangeness and unfamiliarity of the way the death is managed in the ED is unusual, however. **Jilly** talks about the strangeness of being in the room after her mother died:

> *‘I don’t know if you have ever seen someone die, well die unexpectedly … it was weird, being in that room afterwards’.*

Max, going into the room where the doctor was to tell him that his mother was dying felt:

> *‘quite present… quite calm’.*

But he was aware that something was wrong because:

> *‘it was the family room … of course at that point you fear the worst … I was upset but calm, maybe that is shock, do you know what I mean?’*

Danisha felt time moving very slowly, and her sensation was that on arrival in the department she called for help and the nurses: ’took lots of time’. She acknowledged that this was her perception only. A clear example of the perception of lived time. Whilst not describing shock in a classic sense, **Nicole** also experienced overwhelmingly negative feelings about her mother's death in the ED. She could not recall any mitigating factors:

> *'No-one sat with us or offered a chaplain or anything. We're not that religious but I think it would have helped, just to feel someone cared … I didn't feel anyone cared, really … nobody showed they understood'.*

She did state:

> *'I don't mind talking about it. I like talking about Mum and I want to help in a small way to improve things for other people'.*

The comment about being alone and no one offering care or chaplaincy support highlights the nature of death in the ED rather than a ward or hospice. **Nicole** had a traumatic time in the ED with her mother, during and after her mother's death. The fact that she was happy to share her experiences, indeed was eager to do so illustrates the earlier point about allowing the voices of the bereaved to be heard. **Nicole** was not alone in this. **Max**, as has been mentioned elsewhere, described the sense of shock that he and his family felt in the ED, but did not remember it as a wholly negative experience. **Laura**, discussing her experiences, focuses on the lack of information given to her by the staff, her feelings seem to hang on this issue, as she said right at the beginning of the interview:

> *'I think there is a problem with information, you don't get enough information'.*

After her mother died, **Laura** explained:

> *'… even after that the nurses were lovely. Everyone was brilliant, brilliant. But as I said, you need more information. I think it should be an option. There should be leaflets [asked about this, she indicated she meant information leaflets about being with a dying person and what to expect].'*

This was discussed further as an attempt to find out what was at the bottom of her concern about information. It actually went very deep and it became obvious that she was talking about the dying process itself:

> *‘The consultant doesn’t have time to sit down and say look, this is what happens in Britain, we don’t have euthanasia but in fact we do, and this is our equivalent [the decision had been made to provide comfort care only]’.*

The perception of time is interesting here - different individuals in this situation had different ideas of time. **Laura** felt that because the decision had been made to not use antibiotics, the care given to her mother was a form of euthanasia (the participant’s words). This was completely on **Laura’s** mind and had been since the death three or so years before. At the time of interview, she was very distressed about it, illustrating how important care is for the relatives:

> *‘I mean they tell you what’s going to be happening and it will be short lived, but – they could get Mum back, they could have done. They said that but it’s very short lived and that’s what they should explain. You see, we still don’t know what she died of. They put breathing problems on the thing [the death certificate] but she didn’t die of that, she died of Alzheimer’s, because she couldn’t fight back because of the Alzheimer’s … they didn’t really explain that’.*

Laura was aware that this need to understand had complicated her grieving process:

> *‘I need to know about this. I’ve got so many questions. I am always waking up at 3 am and worrying and need to know stuff … so I definitely think information is the issue.’*

She did say she was given time to ask questions, but this doesn’t really correlate with her comment above about the doctor not having time to sit down and explain things properly, and also her comment quoted below. It does not seem that in practice, she was given time to ask questions:

> *‘But of course, you don’t ask any questions at the time because it all comes after… it’s horrible’.*

It seems that the problem is a lack of understanding on the part of the medical and nursing staff that lay people generally will not necessarily know how people die. **Laura** gives a very good example of the distress caused to her family by this not knowing how people die:

> *'… we were all confused because the palliative care nurse and the consultant were both saying if you give liquids it goes to places it shouldn't – and we were all really confused about that, asking each other: what does it mean? What does it mean?'*

Laura's distress was so intense, she had even been doing her own research:

> *'I've got a whole list about dying of pneumonia. I've got all this stuff about euthanasia in this country and in Holland, and papers on it … it's haunting me'.*

The idea that there may be no adequate explanation about death is difficult. **Laura's** mother spent the longest time in the ED of all the participants, over a whole day and night, presumably because of bed shortages and therefore took the longest time to die, hence this issue (lack of explanation about the drawn- out dying process) is unique to **Laura** in the participant group; however, with the exception of **Danisha** who herself was a doctor, the other participants were equally not familiar with death and dying and this is a very real issue to be considered.

One thing that many participants mention is how the lack of aftercare, of bereavement support made them feel. **Nicole** said:

> *'We had to go home with this unpacked bag. And that was it. It just felt final.'*

The finality is hard to hear. The full stop and emptiness at the end of someone's life – both a full stop and paradoxically a gap. There is a sense of shock in all the participants accounts of the actual death and immediate aftermath. The loved one was suddenly gone. In most of the accounts the death wasn't sudden at all, but there does seem to be a lack of forward planning on behalf of the ED staff, to ensure the relatives know what is going to happen and then what happens next. **Max** says:

> *'That was it. I did go to see her, to see her dead body, but when it came to it, I felt I couldn't go in the room, and I just left the building and sat in the car. And at that point my engagement with the ED finished'.*

Danisha's experience was very similar:

> *'…even after I was told he had passed you know, that was the end. There was nothing else. That was it. So final'.*

Pete also talks about leaving the hospital with a bag:

> *'… a green plastic bag with her handbag and dressing gown and slippers… I was then allowed to go… that was it'.*

The word 'allowed' is saddening – the participant's close relative had died, but this implies a seeking of permission, which should never happen. His use of the phrase 'that was it' is also saddening. It implies a full stop on the life of his mother -in -law, but also there was no follow up to make sure that **Pete**, who had been up all night, was alright himself. Nobody seems to have really cared about him. And again, both **Patricia** and **Elizabeth** had no follow up either. **Patricia** remembers:

> *'The hospital thing – well that bit ended in a blur. It felt strange really. We left and we never had to get back in touch with them … there was no bereavement support'.*

Elizabeth also describes visiting her husband's body in the mortuary, and then:

> *'So that really is the end … I heard nothing from anybody at the hospital'.*

Bella, because her father had died suddenly, had to endure a coroner's inquest which she found difficult, so in a sense she did have further contact with the hospital, although not in a supportive sense. But she still felt that she had a good experience, and at the end, her thoughts were positive, she actually said it was nice to be able to articulate them:

> *'It's nice actually. Nice to do this. I think it's important not because it's me but because I need to tell people that you can have a good experience even here at the end of life like this. I need to tell my story.'*

The participants lived through the experiences described here and it was the experiences themselves which had long lasting effects on the participants, not, in fact, talking to a researcher about these experiences. The research highlights the aftereffects of the time in the ED.

5.6 Conclusion

This chapter has described the themes that emerged from the data obtained from the bereaved relatives. Although the focus has been on the feelings of the bereaved family members, the participants experiences do shed light on the care given to the dying patient, and hence this study has been about both the care of the dying and the care of the family members. The vulnerable individuals here have been the dying persons, who have not had a voice. The family member participants have spoken out for their loved one and been strong and altruistic in their desire to perhaps improve care for future patients and their families and help them to have a good death.

CHAPTER 6: THE EXPERIENCE OF DEATH IN THE ED: THE PERSPECTIVE OF NURSING STAFF

6.0 Chapter abstract

This chapter describes the findings of the study based on the results from the second data set, the registered nurses.

6.1 Introduction

Eight registered nurses with direct experience of working in the ED shared their experiences of caring for dying people and their family members. Their details are below (again, they were not a homogenous group and the pseudonyms chosen reflect this):

Table 5: Nurse participants:

Name * *Pseudonym	**Approximate years in practice in the ED**	**Transcript number**	**Geographical area**
Georgie	12	1	Manchester
Ed	8	2	London
Samuel	10	3	USA
Kate	4	4	Oxford
Alex	10	5	London
Andy	10	6	Newcastle
Sarah	25	7	Oxford
Martin	8	8	Oxford

The themes that emerged during analysis of the nurses' data are as follows:

The experience of the environment of the ED – subthemes: The busy-ness of the ED/ The layout of the ED

Being with the dying person - subtheme: Being with the dying person in resus

Being with other people- subthemes: Being with family members / Being with other staff members

Feelings about the experience

Figure 6 illustrates how the themes correlate to the concept of the life world (Van Manen, 2003).

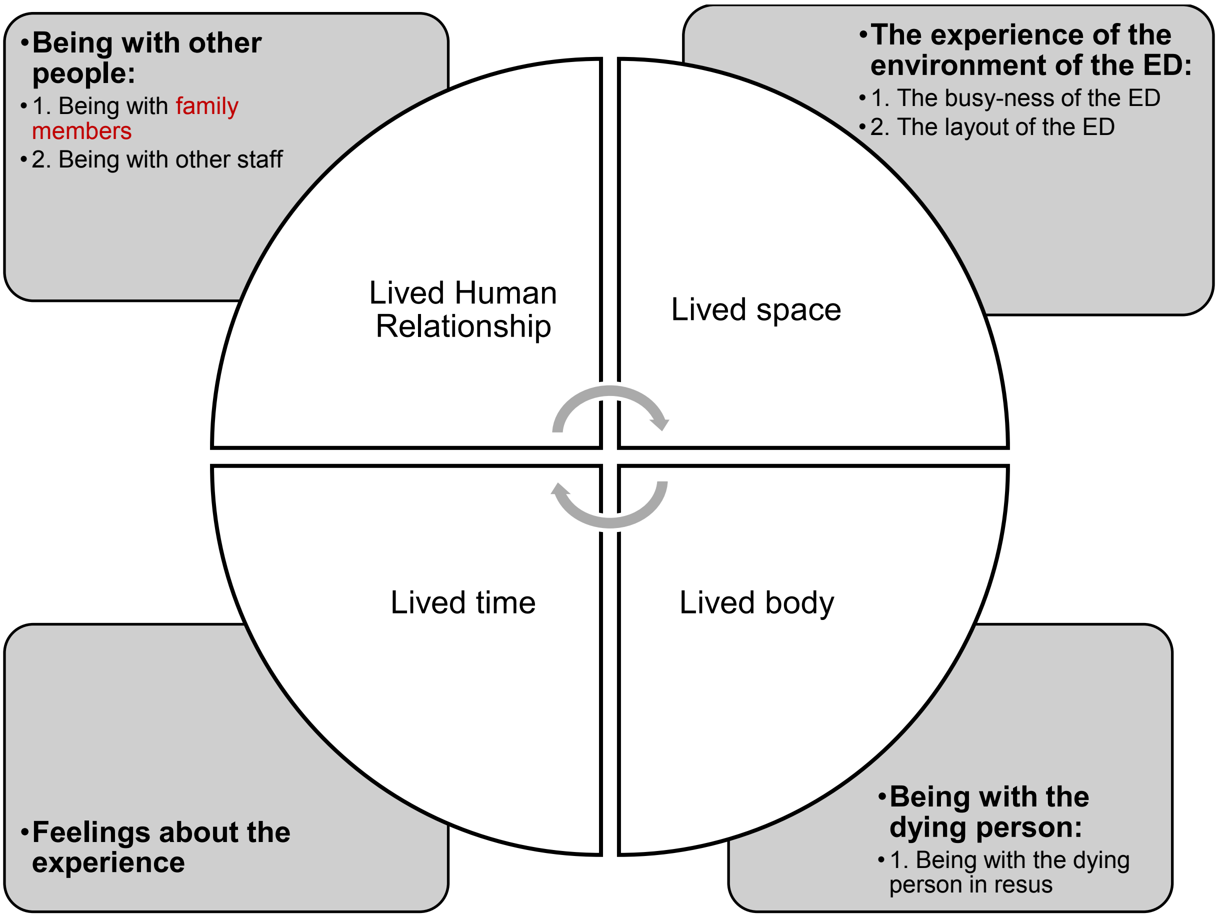

Figure 6: Themes from the nurse participants data

6.2 The experience of the environment of the ED

The environment in which they worked was extremely important to all the participants. There was a collective sense of powerlessness when they discussed this. This theme has two sub-themes: the busyness of the ED and the layout of the ED

The busyness of the ED

Aligning with the bereaved participants' experience, this subtheme illustrates the nurses' feelings regarding the inappropriateness of the ED as a place to die. The 'busyness' of the ED was emphasised by all the participants. It is extremely difficult under these circumstances for the nurse to achieve a sense of 'being with' the patient and family. This was mentioned by all participants as directly affecting patient care at the end of life. **Georgie**, asked what she felt about end of life care in the ED said it was down to the individual staff member:

> *'It depends on the sort of day they're having … if it's busy or whatnot. If you're running around with loads of drunks and people screaming and that sort of thing, it's hard to make sure that every little thing happens properly, you know?'*

Georgie's description paints a picture of an environment, which is more than just busy. This is perhaps the general public's idea of an emergency department, and possibly reflects the values of the ED: to act as a place where people come in an emergency. When asked to expand on the afore-mentioned 'little things', she said:

> *'Well, like making sure that the relatives are properly looked after … making sure they've had tea and making sure that they're comfortable, it's just as important as it is with the patient.'*

The nurses were aware of the detrimental effects of being in such a busy place. **Ed** talked about the recent death of a patient:

> *'It was no way to die, in a noisy, busy environment, lots of bright lights and people coming and going'.*

He feels very strongly that good end of life care in the ED:

> *‘very much depends on the environment, whether it’s calm or busy, you know’.*

In both these quotations **Ed** sounds quite passive – as though he has no control over what is happening to the patients for whom he is responsible. This fits with **Georgie's** opinion that good end of life care depends on the sort of day the staff are having.

Kate, who was a senior nurse at the time of interview, reflected deeply on what it was like to look after a dying patient in such a busy environment:

> *‘I really really easily remember the feeling of looking after a dying person in a very busy unit and obviously you want to give all the care you can… but actually when there’s fifteen other patients who are having life- saving treatments which rely on urgency and timeliness and you can see your colleagues are working as hard as they can and people are going off colleagues are working as hard as they can and people are going off [beginning to die] and getting sicker and more unwell, you can’t be in that room the whole time looking after that dying person … when I was a junior nurse I was probably more able to keep going back and forth to the room, check the family were OK, that sort of thing. But when I was a co-ordinator, it was horrible, the stress was never-ending’.*

This long piece has been quoted here because it expresses the feelings of the staff who want to give good care but are feel they are constrained by time pressures (their perception of lived time) and pressures of seniority, and also the culture of the department. **Kate** goes on to say more about time and how it is perceived by the staff:

> *‘The family would go home, and we would give them the reassurance that we would keep popping in and keep an eye on the patient. But in reality, you know that that nurse is now going to go and run the whole unit and you know you might not be able to achieve it all the time. And that, in itself, increases the stress.’*

The busyness here has taken on a sense of it’s being a concrete fact, in that it is an implacable, immoveable thing, just as much not the nurses’ fault as there not being enough parking at the hospital. This again is the nurses perception of lived time. **Alex** also discussed the busyness of the department:

> *'The ED has got busier over the last 17 years [the amount of time he had been working there]. We used to have more time for people. And that really impacts on patients when they are at the end of their lives…the pace is much more frenetic these days. There is so much stress… the bed managers are constantly at us to maintain patient flow and all that really means is get them processed quickly, get them out of the department if it seems like they're going to be here a long time.'*

'Processed quickly' is quite dehumanising language. The concept of time comes up again and again. **Alex** mentioned that he often feels overwhelmed by this busy-ness, this lack of ever having enough time:

> *'we all care. We do what we can. But there seems to be more people attending the department these days.'*

The lack of time has an impact on the care. The nurses all care, but only to the extent that they 'do what they can'. **Martin** felt very similarly, stating:

> *'I've never met a nurse who didn't want to give good care, but the atmosphere in the ED is very rushed. There are always a lot of calls on our time'.*

Being busy and running around is normalised within the culture of the ED. As in the quote above, they do what they can, they want to give good care - but there is no time. The nurses describe themselves as passive individuals, pushed this way and that by the currents of their working environment, the ED. There is a clear sensation of a lack of control and a feeling that they would love to give good care but are constrained by the nature of their workplace and things they can do nothing about. **Martin** says at one point:

> *'… nobody ever seems to ask nurses what would work for them.'*

This lack of control, even from the fairly senior nurses who made up this sample – the majority of the participants had over 10 years of experience in the ED – is concerning. The nurse participants recognised that good end of life care does not always exist. They described their wish to give good end of life care, and their regret that due to the busyness of the emergency department, the lack of time, it was not always possible, or in fact valued within that particular culture. **Kate** said:

> *'I really want to be good at this you know, to know that I always give good end of life care. But I can't – every day is so busy, it's all I can do to keep on top of everything.'*

This busyness was universally seen as an element that the nurses had unfortunately no control over, and there was even a sense that they should be pitied for having to work in such a busy environment. **Alex** said:

> *'I do think it's difficult, we have a really difficult job. People don't really understand how hard it is, working in such a busy place.'*

The nurses discuss the busyness of their environment as though it can never change, it is just the way it is and always will be. It is important to them and all observations they make are influenced by the fact that they all work in a very busy environment.

The layout of the ED

The layout of the ED was also an important issue which affected the working day of the participants and influenced how they provided care to people at the end of their lives. **Samuel** talked in depth about the geographical environment and how it impacts on end- of -life care:

> *'It [end of life care] kind of depends on the situation and the environment… the layout of the ED is not really conducive to end of life care. I think we are sometimes too focused on saving lives. Because, you know, we all have to die and yet we all pretend we won't die. So, when the emergency rooms were being built, I don't think much thought went into what would happen if this patient didn't survive'.*

This is his perception. He gave a very vivid example:

> *'Where do you put the relatives if they don't want to witness a resuscitation? There should be somewhere easy for them to get to, so a staff member doesn't have to go out of his way to take them there. Because the staff member might be needed in the resus room, right? So obviously it's important that he can get to both the relatives and the patient very easily. I don't think anyone really consulted nurses at all.'*

Because of this, **Samuel** felt that the ability to give good end of life care was again sometimes out of his control. **Martin** also felt this. Many years after the event, he remembers a patient who came in after being badly burned in an electrical fire. He recalls the patient wanting to pass on a message to his wife to say he loved her, prior to being intubated. Sadly, this patient did not survive. **Martin** recalls:

> *'I can't bear the smell [of burning] to this day. It seemed to kind of permeate the whole department, there wasn't a room where we could sort of shut him away, he was in resus, which is a big open area … it took ages to go away.'*

The language is interesting. As in the example above, it is almost dehumanising. The patient had ceased to be an individual and valuable person, just a badly burnt and dying patient who needed to be 'shut away' to protect the other patients and staff from the trauma, the smell of his burnt body. On a purely practical note, apart from the choice of language, it's a good example of the clinical staff not having been consulted when the layout of the department was being designed and constructed. The thought of this poor man dying in such an un-private area and the impact it had on everyone present led **Martin** to say:

> *'The environment is so important in the ED. It's never ideal … you know, the flow and everything. It would be so great if bereaved relatives did not have to walk past other casualties to see their dead loved one.'*

Again, the language is depersonalising ('other casualties') although the sentiment is appropriate. **Martin** does sound as though he cares that people may be distressed by having to observe others in a state of distress.

The 'flow' mentioned above is a commonly used phrase, meaning the movement of patients through the department. It contributes to the stress experienced by staff and as mentioned above can be seriously impeded by the layout of the department. **Sarah** mentioned:

> *'I've had to transfer patients along busy corridors full of people – patients who didn't look like they were going to survive for much longer. There was no privacy. I refused once and it was awful – I said I'm not moving that patient she's going to die any minute. Even though it was so chaotic in the department'.*

This facet of the layout of the department – that there is not enough privacy for seriously ill patients and their families or suitable areas to provide good end of life care, is also mentioned by **Ed**:

> *‘We need to better prepare the environment – there needs to be better relatives’ rooms, quiet rooms, call them what you will.’*

There was a lack of privacy at the end of life for both the patients and families. **Ed** said:

> *‘There’s just nowhere for them to go, where they can be quiet or whatever. Yeah, some units try to have a dedicated room, but often it’s just for the relatives – the relatives’ room, you know? Any room big enough to have a bed in it is always used anyway due to the nature of the unit, the busyness’*

The geographical layout of the ED is clearly an issue for the nurse participants. This reinforces the data from the relative participants (the openness of the ED), and the issues are similar – mainly the lack of privacy. The nurse data adds perspective about the flow through the department and how this affects patient care at the end of life. There is also a sense of the environment being an issue beyond the control of the nursing staff, although the participants quoted did attempt to find ways to work within these constraints.

6.3 Being with the dying person

This study was concerned with what it was like for the nurses to be with the dying patient and it was quite difficult to get them to talk about this, about what it was actually like, away from the challenging experiences and the practical procedures. Possibly this reflects a discomfort around discussing death. Some of the participants felt very strongly that the ED was no place to die, although this stipulation was relaxed for those who came in needing resuscitation. For this reason, there is a sub theme to this category, which is ‘*Being with the dying person in resus*’.

Kate described a terminally ill patient who had died about 10 minutes before his daughter was able to get there. He had come in from a nursing home and there was a DNAR (Do Not Attempt

Resuscitation) order so no resus attempt occurred. Her description shows an example of busyness preventing the nursing team from actually being with the patient:

> *‘We were kind of like phoning her [the daughter] and asking where she was, and she missed him dying by about 10 minutes, and we were so busy trying to get her on the phone that it sort of took our focus away from the patient so it was you know really sad and we all felt really sad and really awful …she came, and we’d removed all the medical stuff at that stage, and I gave her the opportunity to do last offices with me’.*

From this quotation, it sounds as if the nurses were ‘being with’ the phone rather than the dying patient. She admits the focus was on the phone. **Kate** describes how she moved from feeling really sad about the patient to feeling that she was helping the daughter, even after the patient had died. It’s an example of a task-based intervention, rather than a patient-centred intervention. **Kate** and the daughter washed the patient, combed his hair, and changed his gown. And all the while they were talking:

> *‘I mean I never had the opportunity to talk to this patient, he was unconscious the whole time I looked after him, so she was telling me all about his life and career … and for me it felt like a really wholesome experience’.*

Later in the interview, **Kate** talks more about what it is like for her to look after patients who are near death:

> *‘It’s all about seeing the patient as an individual and what they need at that particular time and it’s about giving the nurses the confidence to be like, this patient could die, are we prepared?’*

She was asked to expand more about the confidence issue:

> *‘I think we need to recognise, like, that the ED can be an OK place to die and they [the nurses] do it well. Or can do it well. I think the culture is that no one should really die here and it’s terrible and that sort of gets in the way. And then the nurses just feel kind of stroppy; they’ve got this patient who shouldn’t be there in their opinion. And they don’t know what to say’.*

It can sound as though nurses try to justify what does happen by suggesting that they really care, but again are constrained by factors beyond their control. The data suggests that they struggle with the 'being with' the dying patient.

Alex explained that he found it difficult to be with a dying patient because sometimes he didn't know what words to use:

> *'I think as you get older or more experienced you get better at using the right words to talk to the dying and their families. But we, or I should say I, don't always get it right of course. It can be very painful when families are angry, and we have done everything we possibly could have done – I genuinely think most of us are really just trying to do our best'.*

Asked about 'everything we possibly could have done', **Alex** explained:

> *'You know, kept them comfortable and looked after them and all that'.*

The feeling was almost a sense of irritation – the nurses had done everything they could possibly have done, yet the families were still angry. There seems to be no sense of trying to understand what the families are going through and how they are grieving. Another participant, **Sarah**, recognised the distress and felt that being with dying patients and their families got easier with experience:

> *'I think I manage that [being with dying patients and their families] probably better now. But when you're with somebody and you spend a bit of time with their family and you see how upset the family are – I find that really hard when the families are upset… it's about finding the right time to step away – how much support do they want, what kind of support, do they want an arm round them, do they want a cup of tea? For me it's about knowing what they're asking me to do.'*

What makes caring for the dying in the ED different from perhaps other areas of nursing practice is the sense that the dying itself is, or can be, absolutely unexpected, and this requires a different mindset than for other patients in the ED. **Martin** talks about the fact that the experience of being with the dying person in the ED can be shocking and distressing as a nurse, remembering difficult sights and events that he has seen or experienced over the years:

> *‘I think our minds get fixed on details and we remember the details. That’s a very nursing thing or maybe just a human thing’.*

Asked about these details, he gives many examples that even years later have stuck with him:

> *‘I remember we had a 17- year- old girl brought in …we took her to resus, we wanted to do anything at all to give her a chance… the story was that she had fallen head- first from the top of a multi-story care park… I was trying to stabilise her neck. And I remember the bones of her cervical spine, under my fingers, felt like rice-crispies. The bones were so shattered. She was very very dead. It was terrible’.*

Sarah expands on the challenge of caring for the dying in the ED. As she explains, it is the ‘gear change’ from the intense effort of saving lives to the idea that there is nothing more that can be done, which is so difficult:

> *‘From go go go do everything, to almost feels like everyone else walks away and leaves the nurse just to tidy up and make the patient comfortable. When they have died this is. And it’s really hard in our- in my- head to allow that gear change to happen…and partly it feels like you almost, you’re not walking away because you are the person who’s left there. But it feels as though everyone else is walking away because there’s not much they can do. And as a nurse, that is so hard’.*

There is perhaps some resentment inherent here in the comment about everyone else walking away. It is like somebody has to do the tidying up and laying out of the patient, and that is the nurse. There is no sense here of the importance of ‘being with’ the patient (or family). Everyone else can walk away, but the nurse is faced with the harsh reality of caring for the body which until recently was a person who could not be saved. **Martin**, again, describes similarly:

> *‘[when the person has died] there were three people in this room and now there are two. The person is gone, couldn’t be saved, and it affects everyone, but as a nurse, your job is not finished, not only do you have the last offices to do, you also have the family to look after. I don’t think we get time to grieve’.*

The concept of grieving as a nurse recurs later in this chapter.

Being with the dying person is clearly difficult and there is a definite sense of confusion about how to ‘be with’ the patient if the patient cannot be saved, ignoring the fact that time spent with the deceased patient can also be part of the ‘being with’. Taking refuge in the need to do practical things is a common response in the participants, but it is clear that the nurses remember and are upset or sorry after a death, even if there is perhaps a sense of resentment that it is the job of the nurse to clear up and sort everything out after a patient has died

Being with the dying person in resus

Being with the dying person in a resuscitation situation is very different to being with a terminally ill patient coming in from a care home because there is a chance that the actions of the ED team can save this person’s life. **Alex** felt acutely that the role of the nurse involves a particular kind of powerlessness that he found distressing when caring for dying patients in this environment. He describes a death in the resuscitation area, of a man in his forties after a pulseless electrical activity cardiac arrest, the most common type of arrest; **Alex** explained that there were no ICU beds available, and the patient died before he could receive intensive help:

> *‘The wife was, completely understandably, beside herself …it was truly awful. Such naked grief and anger. He died as a result of failure of intervention by the medical staff. I wasn’t in a position to change that… sometimes it’s hard as a nurse that you can’t change things. Even though you do your best to give high-level care’.*

Andy also talks about a sense of powerlessness, of not being in a position to change things:

> *‘It’s awful when you have to do something you know you shouldn’t …’*

When asked about this statement, he explained that he meant attempting to resuscitate someone who clearly wasn’t going to survive. The person may have been dead already, or so frail that the resuscitation attempt itself may be harmful. **Samuel** felt the same:

> *‘I think we try really hard but at the end of the day we have to do our jobs which are often trying to save lives. Resus is traumatic. We can only do what we can … so sometimes the ability to give good end of life care is out of our control’.*

Samuel seems to be suggesting here that the job of a nurse in the ED is to save lives, a very different position from focussing on end- of -life care, and not in any sense being with the dying person.

Georgie briefly discussed the difficulty of providing patient centred care in a resus situation. She remembered a recent event in which a man in his sixties came into the ED via ambulance with his wife; he was having a heart attack. Unfortunately, he became life-threateningly unwell very quickly and went into cardiac arrest. The team rushed him into resus. His wife was there as well whilst he was being resuscitated:

> *'And she was in a state of shock and I asked the student nurse to take her to sit down and stay with her. But she didn't want to leave, so the student made sure she had a chair a bit back from the area…and when it was called [when the patient had died] his wife was there, you see, and could go up and sit with him whilst we took all the equipment away. So that was good'.*

The wife was with him the whole time with the student nurse supporting her. The experience of caring for the wife despite all the attention being on the dying patient was so important. **Georgie** went on to say:

> *'Resus is so chaotic often and I do worry that if the family are there, they may get – not forgotten, but maybe…ignored but it's not deliberate or intentional'.*

Some of the other participants, making similar points, managed to put the patient at the centre of the events but also really care for the families. **Ed** felt it was vital to look after the relatives as well as the patient during an arrest

> *'Last week we had a patient in resus in cardiac arrest. The team worked really well together, and it was so fluent. It was ultimately a failed resus attempt. The wife was present throughout and afterwards she was thanking me because she felt she had seen that we had done our absolute best for the patient…we took her to the quiet room when she was ready to leave him … of course he was still our patient and we had work to do to make him comfortable. But we try to give people as much time as they need with their loved ones.'*

Ed felt that even after death, the person was still his patient and still needed looking after along with the family. This is what being with the dying person means.

Many of the participants considered good family care during a resus attempt to be incredibly vital to their work as emergency nurses. They were, like those quoted above, quietly satisfied with the care that they had given. Again, **Andy** told a long story about a young man brought in after collapsing on a football pitch and again, sadly, he did not survive:

> *'He was probably dead, on arrival at the hospital, but we treated him as if there was a chance - rushed him into resus and started all the procedures…we worked on him for ages and we didn't get him back and we were not surprised. His wife and 10- year- old son were outside and I had to go and tell them and my god it was horrible. I took them into an empty side room, and she said, he's gone, hasn't he? And I said he has, and I am so sorry, I wanted to let you know that we really tried. Really really tried.'*

Andy goes on to explain that he spoke to the child and took him in to see his father and brought him a coke, and the child and his mother sat there until they were ready to go:

> *'And the kid said, will you look after him now for us? And I said yes but it was heart breaking. I thought about it all the time we were doing the last offices and I talked to the patient about it, about his son'.*

A very eloquent example of 'being with' the patient. The 'being with' carries on after death. **Andy** later saw a letter that the widow had written to the hospital saying that his thoughtfulness really made a difference. He told me this meant a tremendous amount to him. His memories of this are of being with the dying person by looking after his family.

This feeling of having given good, satisfying care to the patient who has died in resus (and to their families) is really interesting because of the sense that it's OK to die in the ED if you come in needing resuscitation. This feeling is inherent in many interviews - **Samuel** mentions it above when he implies that the job of a nurse in the ED is to save lives. **Ed** puts it very clearly:

> *'One thing I would say is that the ED is absolutely not the place to die. Emergency departments are about saving lives. We resuscitate people. We're not geared up for providing good end of life care if the patient doesn't survive…death shouldn't be an emergency medicine thing'.*

Sarah also says:

> *'Those we've resuscitated or who've had a big brain injury and are likely to die very soon – I think we manage those quite well. We prioritise those patients and relatives and look after them and that's because we knew it was going to be fairly short term – I think we do those quite well.'*

Asked to expand about how they manage these patients 'quite well' and about the short- term comment, **Sarah** explained that a resuscitation, being expected, fits in well with their busy day – it fits their skill set, and the patient will either die or go to ICU, and the family do not expect to be in the department for a long time. She goes on to say:

> *'I'm not sure we manage the longer deaths very well, or those who are not likely to die with us but will die very soon – you almost want to see them coming into a separate area'.*

Samuel explains further, in the context of describing a less than optimal episode of care, how vital it is to be aware of the needs of the dying patient in the context of the family. His patient was an older man with a terminal prognosis from cancer, who had come into the ED very sick. The medical team were discussing what treatment, blood tests and scans they were going to do when the patient arrested and needed resuscitation (no 'do not resuscitate' form):

> *'So immediately everyone goes into hyper-emergency mode, right? I was on his chest and I knew he was gone really but we had to do this and then his wife came in and it was so bad, so bad…it was called almost immediately but I can't get out of my head that his last moments were all this panic and fear and his poor wife too, lots of movement and massive stress. That was really not good end of life care.'*

Samuel was with the person at a critical time of his life and reflected that it was not good. Sadly, he could not expound upon what happened next as another emergency occurred. This sort of patient – the frail and ill patient who had a diagnosis of cancer or other life-limiting illness and who wasn't going to survive a resuscitation event, was mentioned by almost every participant. **Ed** was very annoyed (on behalf of the patient) about this kind of situation. He talks about a gentleman who was receiving palliative care for end stage lung cancer:

> *‘The family insisted that he should go into hospital and insisted on calling an ambulance. So, then we had this moribund chap, DNAR already signed by the GP, and they were insisting that he had fluids and imaging etc. Luckily or unluckily, he died before things could escalate further, but it was no way to die … a bad death’.*

Andy agrees:

> *‘[A good example of a bad death] is the elderly dying patient at home or in a care home who is brought in at the end of their life. Often, they will end up dying alone in a cubicle or in the back of an ambulance. It’s particularly grim if they do not have their DNAR with them or if they don’t have one in the first place. Then we end up doing a futile resus attempt, so the patient has a horrible death, and often the family are very upset’.*

Kate had a similar perspective, although she qualifies it by saying that it is OK for some types of palliative care patients to come into the ED:

> *‘If someone is well known to palliative care services, has been very open and wants to talk about their future planning, has an advanced care plan in situ and a DNAR, and they come in appropriately, for example they have a chest infection that may be reversible, so they come in and then deteriorate rapidly and die … their experience and that of their family will probably be OK’.*

This is because they have had forward planning. But there are some patients, like the gentleman mentioned by **Ed** above who are not accepting that they are going to die, or whose family will not accept this:

> *‘There’s this cohort of patients who are known to palliative care services or known to be in the last years of life who come in in a heap because they’ve never talked about what they want, what they would like for their care, and no-one really knows what to do with them and then the team that come and pick them up don’t really want to make decisions and it’s terrible for the family and the staff because often we have to perform resus on a patient when we know it will be futile’.*

There is again a sense that the nursing staff are not in control of this situation, although they may want to 'be with' the patient and family, to provide good care, the system does not allow this and it's not felt to be possible to change it.

Being with the patient in the highly charged situation of a resus attempt, was described as a challenge for all the participants, but ultimately a challenge that they enjoy: it fits their skill set and in some deep way is what they are for. The fact that the patient doesn't survive is less important than the fact that an attempt to save them has been made. If they don't survive, the nurses can draw on the fact that they 'did their best' or that they provided good care to the family, to redeem the situation and allow some satisfaction in their work.

6.4 Being with other people

In all the cases of the nurse participants who were interviewed, the 'being with' the families of the dying patients was an important part of their job and they were all aware, both that it was so important and also that it is often not done well. And nursing is rarely a job that is done in isolation, so being with other people is a part of any nurses working day. This theme has two sub themes: *Being with the patients' family members* and *Being with other staff*.

Being with family members

Being with the relatives has been touched on in the section above regarding resuscitation. All participants felt it was an important, if difficult, part of their work. **Kate** talked about how hard it was bringing up the subject of death:

> *'Some patients and families haven't had the opportunity to explore what is really important to them, that then gets missed and the patients end up dying before anyone's had the bravery to bring it up. I don't like it at all, I feel like the families will be upset'.*

When mentioned that they are going to be upset anyway, **Kate** said:

> *'It's difficult – that's when I feel perhaps some compassion fatigue in myself. Perhaps I am trying to protect myself. The families can be hard.'*

Here **Kate** is being completely honest, but she is coming from a very personal point of view. **Sarah** talks about it from the families' point of view, and described a utopian vision of what good end of life care, really being with the relatives would look like:

> *'…what I think would be lovely is that when someone was really quite close to dying in the department, and the family needed some support, that someone would be able to go and sit with them and offer some support, just be there, someone who was very experienced in this sort of thing and would just keep calm and say this happens, there is nothing to worry about, this is normal'.*

There was no indication about who this 'someone' might be. She also talks about the need to normalise death to help the families:

> *'Society's changed so much, hasn't it? You don't see your granny die so when it comes time for your mum to die, you don't know what it's like or what it's about. So, people are totally unprepared. And in the ED, we focus on the dying patient so much and it's so quick quick quick … I'm very angry that we don't do it [end of life care] well in the ED. For the relatives particularly'.*

Alex described a situation he had been involved in recently where a 94 -year- old lady had come into his ED very unwell, dying from many causes, and she was part of a large church community and many visitors came and sang and prayed, and they put her in the 'nicest' side room:

> *'I remember somebody read a poem and it was about the amount of colour she had had in her life. I thought it was so lovely that her last conscious moments were of all the people around her joyfully praying and talking … there were a lot of tears, but you felt that she had died in the best way possible considering that she was in a very basic side room on a busy unit … all this colour and life around her as she slipped away.'*

It gave **Alex** great satisfaction to have facilitated this good death. And it is a good example of being with the relatives, working with them to give them what they want rather than what the system thinks they want:

> *'Afterwards the granddaughter came to find me and was so grateful. I was like – we didn't do anything. And she said – but you did. You let Grandma be herself. That was precious to me.'*

By actually doing very little, **Alex** and the team were able to help this family say good-bye to their relative in the exactly right way for them.

Ed came over as a very matter of fact interviewee, very clear in his views and very practical. He talks about the being with and giving care to the family members as an integral part of his role but from a very practical point of view. When asked what could improve end of life care in the ED, he said:

> *'There needs to be better relatives' rooms … we need a stash of personal care items for this situation as well, wet wipes, maybe a nice soft blanket, anything to make the situation easier for the family. Perhaps an emergency fund so that we can provide relatives with nicer coffee and sandwiches if their vigil lasts a while.'*

All these things are important and show an understanding of the difficulties facing families in this situation. It is not a classic example of 'being with', but is perhaps mentally, or psychologically being with the families, and equally as important (but perhaps an easier dream to realise) as **Sarah's** idea of ideal family care, above.

The participants did show understanding of the need to look after the families but varied in the interpretation of exactly how this should be done. It feels as though there is much work to do to improve the care given to families so that nurses can truly demonstrate a sense of being with, being alongside the family members of patients who are dying and have died in the ED.

Being with other staff members

In some ways this was an easier topic for the participants to discuss. There was a strong culture of looking after each other, of teamwork. **Martin** described it as being like the forces, there was a sense of camaraderie in the department. Many of the participants used this focus to discuss the importance of mutual support and caring for the junior members of the team.

For **Samuel** it was so integral to his care that his definition of a good death in the ED centrally involved looking after each other:

> *'Last week we had a code [arrest] and I was working with a newly qualified nurse. Sadly, we didn't get the patient back … it was called and the next thing, she was running from the room really upset…so when the patient was OK, I went to look for her and she was in one of the side cubicles, she had been vomiting, she was so distressed. She thought we had failed the patient… I was sad but she was having a bit of a meltdown. I spent time talking to her and she did calm down. I thought that was good end of life care.'*

This account is so interesting on many levels. Firstly, the real importance of supporting colleagues in a distressing situation. But also, because **Samuel** mentions that he made sure the patient was OK before going to look for his colleague. At this time the patient was dead, and the family were not present, but **Samuel** is still putting the patient first, being with the patient. He goes on to say:

> *'I think we need to remember that end of life care involves not only the patient and the family, but also the staff who are involved and I am really passionate about looking after ourselves as nurses as well.'*

This is really the first time any of the participants has made this observation. It is quite profound. It is very much linked to **Kate's** observation about empowering nurses, giving nurses the confidence to know that they can deal well with death even in an emergency setting, in fact **Samuel** uses that word:

> *'If we are going to empower nurses to look after patients well, we need to ensure that the emotional needs of the nurses are being met'.*

As **Kate** points out:

> *'We need to support staff. I think it's the nursing and support staff who probably will have the biggest impact on end- of -life care in the emergency department'*

It's vital to look after them. **Kate** goes on to say:

> *'I think we get very hung up that this [patients dying on active treatment, for example a failed resus attempt] is a bad death and I'm not sure that it is. The lack of recognising that means that we don't support staff at all well in these situations'.*

As discussed in chapter one, there are different interpretations of a good and a bad death; it is not clear that a failed resus attempt could be anything other than a bad death for the person whose death it is.

Martin is also very vocal about this, in the context of what can practically be done to improve end of life care in the ED:

> *'Remember our core nursing skills, remember to treat the patient and family and each other as real people with dignity'.*

It's interesting that these working, practical nurses feel themselves integral to the whole situation, because of course they are, but it is rarely acknowledged. The literature is rich in studies around supporting nurses but acknowledging that the care of the staff is genuinely integral to the concept of a good death is not a common idea. There is a definite need for critical incident debriefing after a death. **Samuel** again was the most vocal about this. He says:

> *'I am haunted by that young nurse I mentioned earlier who was so distressed that she became physically sick. It shouldn't be the case really. We need to get better at it. If I could change one thing that's what I would do – see if I*

> *could get funding for a counsellor for the nurses so you could ask to speak to someone if you needed it. And some dedicated time out in the middle of the shift and that sort of thing.'*

Working as a team – 'being with' other staff members, is important throughout health care settings and as demonstrated here, very important in the ED. Although the participants were asked about 'other staff members' they actually focussed on members of their own profession, with no mention of mutual support of or from the medical staff, for example. Teamwork is important but perhaps the nurses did not feel fully equal members of the team, hence the comments about being unable to change things and feeling powerless.

6.5 Feelings of the participant

Some of the participants felt uneasy about being open in their interviews about their feelings. **Georgie**, when asked if she felt upset when someone dies in the department said:

> *'Well, not anymore. You have to sort of get used to things. I used to get upset, but there are always living people who need us. Sorry if that sounds hard.'*

In answer to the same question, **Ed** said:

> *'I don't get upset at all, is really my honest answer … you see at my level you just have to get on with things'.*

But this was qualified later in the interviews. It came out that in varying degrees, the participants were all affected when someone dies. In the examples above, the participants were given space with the researcher being silent, and **Georgie** went on to say:

> *'If it had been a particularly shocking death, like a young person with a drug overdose or maybe a horrible cancer, I actually would get upset. It's sort of horrific when things like that happen.'*

Ed was the same:

> *'The stab wounds do get to me. Often they are so young and it's such a waste'.*

That these participants perceived that there are degrees of death impact is interesting. There is also often an element of perhaps denial or detachment - having to get on with things and not having time to be upset or express feelings when someone dies, and also perhaps a sense that as the nurse becomes more experienced the death affects them less. **Kate** expresses this very eloquently:

> *'I can't remember the last time I got really upset about a patient dying… but I wonder if that's to do with feeling that I'm doing a better job, now that I have more experience. So, like now, I make more of a difference. And actually, normalising death is a massive thing. It does make a difference to us as nurses.'*

Sarah agreed:

> *'My attitudes [towards death and dying] have changed from when I was a lot younger. I think some of that's experience, you've just seen so much'.*

Many participants mentioned normalising death. **Alex**, when asked about his feelings about how end of life care in the ED could be improved said:

> *'We could allow more people to die at home. We need to do more to facilitate that, but more, we need to talk about it. Talk about how people die and how it's quite normal …talk about death more'.*

It is important to acknowledge however that dying people may have care needs which are more difficult and complex than can be provided at home and that family members may also need support. For this reason, many people are not able to be cared for at home and need the benefit of skilled nursing care at end of life. **Andy** felt very much the same as **Alex**:

> *'Everybody needs to think about their own death and if people have strong views, they need advanced directives and of course DNARs. But we need to talk about death more, be more open as a society. People shouldn't be coming into hospital at the end of their lives.'*

Alex clearly didn't feel that we can help everyone to have a good death:

> *'In the ED, some people will die anyway. Some people will improve. And some people we can help to have a good death. Good deaths affect me least because it was good. I think it would help if we as a society could accept that we're all going to die. Death is universal'.*

Some of the participants felt that they genuinely grieved for their patients. **Samuel**, when asked how it affected him when a patient dies in the ED told me:

> *'It never goes away. It always always affects me. I couldn't do my job if it didn't. I don't always remember everyone's names. But I do remember my patients and I grieve for those who don't make it.'*

And **Martin** said:

> *'We don't get time to grieve and that's important because we do grieve'.*

Sarah talked very openly about her feelings when someone dies:

> *'I've sat there with tears running down my face before and I think I can do that because it's OK for them to know I'm upset … as a society we don't realise, or we underestimate, the impact it [death] has on people. And it's very easy not to get involved. I think it's the getting involved that makes the difference.*

This sadness at the loss of the patient does not altogether align with earlier comments about not getting upset, or only getting upset when someone is particularly young or dies in a particularly tragic way. ED nurses learn resilience, which is more complex than merely relying on experience or holding opinions about the inappropriateness of end-of-life admissions. It is about finding personal strength to cope with and acknowledge difficult situations and learning how to adapt and change positively through these experiences. The participants have shown that they do care about their patients and each other and that their feelings about death can be complex, but there is perhaps also denial and detachment in their responses.

6.6 Conclusion

In this chapter an attempt has been made to show the depth and breadth of the data obtained from the nurse participants and the themes that have emerged from this data. The data reflects what the bereaved family members have said but looks at the issue of end-of-life care in the ED from a different perspective. The environment of the ED which the family members found frightening and confusing is acknowledged by the nurses to be suboptimal when caring for people. The busyness of the area, which the relatives found distressing, is again acknowledged by the nurses to be a major factor in influencing the care of the dying and their families. The difficulties inherent in 'being with' the patient and others at this time, and managing feelings is also demonstrated by both sets of participants. The nurse data builds on the data provided by the relatives, and completes and makes whole the wider picture, allowing greater understanding of what it is like to be with a dying person in the ED and ultimately, therefore, what the experience of death and dying in the ED is actually like.

CHAPTER 7: DISCUSSION OF THE FINDINGS FROM THE STUDY – DEATH AND DYING IN THE ED. A PHENOMENOLOGICAL STUDY OF FAMILY MEMBERS AND NURSING STAFF

7.0 Chapter abstract

This chapter focusses on a discussion of the findings from the study, showing that care in the ED is influenced by the biomedical model of medicine and discussing data-based solutions for improving care, including the creation of a nursing theory focussed model.

7.1 Introduction

In this thesis, the lived experience of family members and of nurses of those dying in the ED has been explored. This chapter will open with a summary of the findings from the study, as described in the previous two chapters. The data from the bereaved family members is summarised first followed by the data from the nurse participants.

The family members experienced a lack of physical and mental privacy whilst they were with their loved ones in the ED. They found the physical environment strange and unfriendly and the area was often very busy. The family members experienced problems in communicating with their loved one due to the seriousness of their condition but also with the hospital staff who often appeared uncaring. Therefore, the deaths of the loved ones took place in the presence of strangers. Death in ED was sudden and unexpected; relatives did not have time to build up a rapport with the hospital staff. This led to feeling of shock on the part of the family members.

Nurses felt that ED is not an appropriate place to die and felt strongly that these patients do not have a good death. However, there was a strong feeling among nursing staff that they are not responsible for the circumstances of a patients' death; the environment not being under their control. Nurses did not feel there was anything they could do to change or improve the physical environment which they felt impacted on the patient and family care, and this added to their feelings of powerlessness. Nurses feel generally powerless and mention that they need to be empowered to provide good end of life care. Despite this they perceived that they paid great attention to the needs of the relatives within the context of ED. The patient admitted to resus was viewed slightly differently by the nursing staff, as an attempt has been made to save the life of the patient and the nurses in these circumstances continue the care even after death and remember when they have been thanked for what they do. However, the data from the bereaved family members did not find any difference in care whether the patient was admitted to resus or not.

In terms of improving care given to individuals at the end of their lives in acute settings, it must be acknowledged that there are several recently published (medically focussed) resources available to guide clinicians. Hospice UK, along with NHS Improvement published in 2018 some guidelines about improving end of life care during acute admissions (UK, 2018). The Irish Association for emergency medicine, the European Society for Emergency Medicine and the Royal College of Emergency Medicine have also recently published guidelines (Irish Association for Emergency, 2020; Medicine, 2017; Medicine, 2020). Additionally, two other recently published studies focussed on nursing care of patients and families and may be useful (Berbís-Morelló, 2019; TSE, 2020), along with studies mentioned in chapter 2 of this thesis.

However, many of those who have studied the working patterns in ED have identified the dominance of the biomedical model and cure orientated care (Aacharya, Gastmans and Denier, 2011; Czaplik *et al.*, 2013; Hwang *et al.*, 2013) . The implications of the biomedical model for those facing the end of life in ED is discussed in the literature review. This study adds the perspectives and experiences of those attending ED with their dying family member which has not previously been explored and reinforces the perspectives of nursing staff.

The experiences of those attending ED with their dying family member endorse the dominance of the biomedical model, and participants described in detail how they felt alone, lonely, ignored, and unable to develop relationships with staff at this most difficult time. Whilst this study did not look at the experiences of the dying, it would be logical to argue that the experiences of their family members are likely to reflect the experiences of those who die in ED. Although nurses felt they were doing their best, they acknowledged but did not question the dominance of the biomedical model. Thus, while the dominance of the biomedical model is acknowledged, the experiences of those attending ED with their dying family member illustrates the limitations of this model and provides evidence that an alternative model of care for those who cannot be saved needs to be developed, even if this is not recognised by the nurses who participated in this study.

The results have to an extent validated work that has already been done by other nurse scholars who have studied nurses' experience of looking after end-of-life patients in the ED (Gloss, 2017; Mughal and Evans, 2020; Scott, 2020). However, this is the first study to have examined the experiences of both relatives who have been bereaved in the ED and nurses caring for patients who have died in the ED. The study has highlighted the uniqueness of the physical and cultural environment of the ED, which emerges as a clinical area strongly influenced by the biomedical model. This chapter will examine initially the biomedical model within the culture of the ED, and then proceed to discussion of the difficulties inherent in providing care for dying people and their family in this environment.

7.2 The biomedical model of medicine

The biomedical model of medicine is the prevailing model of illness used in Western settings and is developed from the perspective that health is defined purely by an absence of sickness or disease (Rostosky and Travis, 1996; Wade and Halligan, 2004; Willis and Elmer, 2007). It is an ancient idea, first defined by Hippocrates (Robson and Baek, 2009). Prior to the age of science, broadly speaking, patient care was influenced strongly by religious principles and folk / cultural ideas (Cora-Bramble, Tielman and Wright, 2004), but the ideas of Hippocrates managed to survive (Cantor, 2017) and were revived during the 19th and 20th centuries with the rise of science in medicine (Glenn, 1988). . The biomedical model focusses purely on the suffering body, reducing this body to a collection of cellular abnormalities (Johansson, 1998).

It is a reductionist model (Wade and Halligan, 2004). Willis and Elmer (2007) defined several features of the biomedical model, including the view that the body is a machine and therefore fixable (by medicine), and treatment is generally preferred above prevention or no treatment. In order to provide this treatment, knowledge belonging to the physical sciences (anatomy, physiology, pathology, pharmacology amongst others) is drawn on (Şanlı and Platin, 2015).

Within the biomedical model, an individual is therefore perceived as a physicochemical machine or purely as an illness diagnosis. This idea will be very familiar to hospital workers particularly in the UK ('Mrs B? She's the new pancreatic ca'). As discussed throughout this thesis, the emphasis is on the body's structure and malfunction, the mind is completely separate. In terms of practising medicine, the overarching principle of the biomedical model is the treatment imperative – patients must be treated at all costs (Willis and Elmer, 2007). This does not mean ignoring the life processes and denying death, but it does mean that everything that can be done must be done (Wade and Halligan, 2004). It is worth mentioning that the hospice movement was started as an attempt to move away from this model; the biomedical model is not necessarily relevant in a hospice setting (Mino and Lert, 2005).

The biomedical model is important, all the advances in medicine from the development of surgical techniques to the discovery of anaesthesia, antibiotics and indeed palliative care, are framed by the biomedical model as described by Virchow, the father of modern pathophysiology, whose work emphasised that every pathology arises from a damaged cell (Rocca and Anjum, 2020). As an example, without an understanding of the body as a collection of cellular structures, pioneering techniques such as the first renal transplant in 1954 would not have occurred (Schillace, 2021). However, reading about this transplant makes it clear that the biomedical model is only part of the whole picture. The names of the transplant surgical team are documented as are the names of the patients, a set of identical twins. The nursing team are not named and there is no indication of what it was like for the patients to undergo this procedure (Schillace, 2021). The biomedical model describes only a small, albeit important, part of this story. The model can be described, thus, as a reductionist model – where reductionism is the philosophical idea that all higher-level phenomena (psychological, spiritual, social, or medical) can be explained at, or reduced to a lower level – such as biology, chemistry, or physics.

7.2.1 The biomedical model in the ED

The ED is run on a very biomedical model. The purpose of the ED, as discussed elsewhere is to save lives. People come into the ED as broken, hurt, bodies and the expectation is that the ED will fix these problems (McGuinness, 1988; Chan, 2011; Cypress, 2014). The care is very fast-paced, technology-dependent, and goal-focussed. Death is not denied, but the preference is that it belongs somewhere else. The staff operate under pressure to quickly move the patients through and find solutions and all within a 4 hour period (in the UK) before the patient ‘ breaches’ and the Trust is liable to be fined (Glen, Constanti and Brohi, 2016). This model of care in the ED works well according to the literature (Cooper and Grant, 2009; Calvello *et al.*, 2013) and ensures safe practice, with staff working within hierarchies and known, established roles (Hassan, 2018). The top of the hierarchy is the ED consultant who is the decision-maker (http://www.rcem.ac.uk, 2015).

7.2.2 Nursing and the biomedical model

From the nursing point of view the biomedical model can be problematic. One of the first nurse scholars to question the model was arguably Nightingale (Nightingale, 1992), who argued that nursing is much more than ‘the administration of medications and the applying of poultices ‘ ; advocating an early holistic model and suggesting nurses should be supporting the patient to recover from disease through attention to the world around the patient. Therefore fresh air, good sanitation, attention to the importance of sleep and diet and crucially, stimulation of the patients' mind are very important (Nightingale, 1859). Her model concentrates on holistic care of the whole person rather than just focussing on the disease. Unfortunately, writing in the nineteenth century, she still asserts the superiority of (bio)medical knowledge and the need for nurses to obey their physician colleagues.

The history of nursing demonstrates how influential the biomedical model was and continues to be. In a seminal paper, Menzies (1960), describing the state of nursing in a large London hospital, perfectly demonstrates the challenges of nursing within the biomedical model. She (correctly) identified that nursing is a difficult and complex activity which exposes the nurse to many distressing and upsetting experiences. She identified behaviours used by nurses to cope with the experiences which included distancing themselves emotionally from patients and reducing their interest and sense of responsibility to patients. Nurses also felt resentment at their perceived lack of importance to the general public and the medical staff and compensated by a complex hierarchy depicted by differing uniforms for each stage of their careers (third year students having an extra stripe, fourth years having a different cap etc). Deference to the medical staff was a given. Menzies (a psychologist) posited that these behaviours infantilised the nursing staff and prevented their professional growth and development (Menzies, 1960). Whilst actively resenting it, according to the author, the nurses in Menzies' study were perpetuating the biomedical model of care and were seemingly unable to see any way to move forward as an independent profession.

Fortunately, at around this time work was being developed by various nursing theorists which provide an alternative parallel way to give care, of which more later. Nursing theorists were beginning to carve out a distinct role for nurses, beyond the traditional task-orientated model. Models for nursing were developed and pioneered which emphasise the unique contribution nurses bring to patient care, demonstrating that nursing is far more than a mere 'doctors helper' role.

Essentially, focus on the biomedical model obligates nurses working within areas such as the ED (even today) to see an individual as a collection of malfunctioning cells within a body. The task of the nurse within this model is to focus on the patients' physical requirements and nursing itself is reduced to a series of routine tasks carried out according to various policies or procedures. Technical skills such as phlebotomy or suturing are seen as more valuable than communication with a stressed person (Şanlı and Platin, 2015). Another example: the lingering importance of the biomedical model of medicine could be argued to be responsible for the higher salary afforded to Physicians' Associates – a UK profession allied to medicine. Physicians Associates (PAs) generally start in practice at a pay band far higher than newly qualified nurses, after a two year course (Brown *et al.*, 2020).

A focus on the physical body of the patient does not automatically equate to focus on the biomedical model, however. Nursing assessments, of necessity focus on the patient's body – taking observations, observing the condition of the skin, managing accoutrements such as catheters, wounds, syringe-drivers. Despite the view of the body as a machine, object, or thing, it is important to note that to a patient it is never experienced like this. To a patient their body is everything, it is far more complicated than a machine, an object, or a thing. The nursing profession has had for many years a specific focus on holistic care (Brooker and Waugh, 2013; Papathanasiou, Sklavou and Kourkouta, 2013) ; nursing assessments are therefore centred on the care of the entirety of what a person is (Thomas and Pollio, 2002). Merleau-Ponty, whilst acknowledging that we are our bodies in the most earthy way – we weep, we eat, we excrete – nevertheless spent his career emphasising that we are much more than this, we are sacred, whole and complex beings (Merleau-Ponty, 2005).

However, the environment of the ED is such that the dominance of the biomedical model makes it difficult for nursing to demonstrate a unique contribution. Holistic nursing care, whilst valued by staff, is overshadowed by the dominant biomedical culture, and not valued enough. The data from the nurse participants in this PhD study did not show consistent holistic perspectives. Holistic care can perhaps be seen as mainly a nursing concept and less important than medical care (Corner, 2003); it has always been central to nursing values. This is not a new debate, the concept of the multi-disciplinary team was developed to ensure that every speciality had a voice and contributed equally to the care of the person (Corner, 2003). However, there is a danger that this approach can lead to a disconnected framework of highly expert individuals providing fragmented care, and because care is headed up by a medical consultant , who has ultimate responsibility for the patient, the focus remains very medical (Broom, 2016; Rocca and Anjum, 2020). In the very medically dominant world of the ED, uniquely (in healthcare) constrained by time factors and the need to save lives, nurses are having, in looking after dying patients who cannot be saved, to move between two paradigms – the caring, holistic nursing-values driven model and the biomedical model. It is questionable whether this is even possible; the nurses who participated in this study definitely adhered to the biomedical model.

7.3 Death in the ED

The challenge of saving lives equates to the challenge of defeating mortality. The role of overseeing death has moved in the Western world from the religious to the medical authorities during the past 100-200 years due to both technological advances and the rise in secularisation (Winnington, Holroyd and Zambas, 2018). The philosopher, Michel Foucault, interested in the relationship between knowledge and power, and how they are used in society, coined the term ‘medical gaze’ (Figlio, 1977) to signify the dehumanising aspect of medicine, with its focus purely on the body whilst ignoring the self-identity of the individual. The medical gaze reduces the body to a collection of potentially malfunctioning cells and infers the notion of power in the patient-doctor relationship. Furthermore, the patient, understandably attracted by the belief that technological advances such as CPR and defibrillators , or mechanical ventilation, can actually delay or even prevent death, becomes a faithful and willing follower of the powerful medical icon (Winnington, Holroyd and Zambas, 2018), thus contributing to the idea that death can and should be 'put off' (Zimmermann, 2007). If this idea is prominent in a culture, it is understandable that death, when it does occur, is seen as a failure of the system. The lack of understanding about DNAR orders which was highlighted during the initial stages of the covid-19 pandemic illustrates this well (Iacobucci, 2020b; Iacobucci, 2020a; Sutton *et al.*, 2021).

This attitude is prevalent in the ED, both among service users and staff (Gamlin, 2002; Bailey, Murphy and Porock, 2011d; Decker, Lee and Morphet, 2015; Hogan *et al.*, 2016) , demonstrated in the findings from this PhD study (chapters 5 and 6), and might contribute to poor experiences at the end of life in the ED, again as the data from the previous chapters shows. Patients and their family members are bewildered and lack understanding of the processes at the end of life, and staff, if it is clear that there is no lifesaving treatment that can be delivered, feel that the ED is an inappropriate place to die. It could be argued that one unintended consequence of the commitment to the biomedical model is the relegation of those who cannot be saved, as indeed has been illustrated throughout this study.

Worldwide, this problem has been realised for many decades (McCallum *et al.*, 2018). The most common solution has been to ensure increased specialist palliative care staff presence in the ED (Gloss, 2017; Dawood, 2019; Carlin, Dubash and Kozlovski, 2020) and also to educate ED staff about the principles of palliative care (Beemath and Zalenski, 2009; Cheng and Teh, 2014; Mierendorf and Gidvani, 2014). In this thesis it is suggested that the problem is more complex than this.

7.3.1 Palliative care in the ED

It is generally globally acknowledged that end of life care in the ED has room for improvement (see above and chapter 2). Chapters 5 and 6 demonstrate this specifically. As above, one solution has been to increase the presence of palliative care clinicians in the ED alongside improving the education given to ED clinicians regarding palliative care (Gisondi, 2009; http://www.rcem.ac.uk, 2015; Gloss, 2017; del Mar Díaz-Cortés *et al.*, 2018). This, although an apparently straightforward and elegant solution has been worked on for several years and there is little evidence that it has actually improved care of the dying though it has undoubtedly increased the knowledge of clinicians working in the ED around the principles of palliative care (Meo, Hwang and Morrison, 2011; Mierendorf and Gidvani, 2014). One of the relative participants in chapter 5, had contact with the hospital palliative care team and did not find it particularly helpful.

One of the central tenets of palliative care is the acknowledgement that the patient is the best situated person to decide whether care approaches offer adequate relief from their suffering. Where the patient is too unwell to be able to indicate their feelings, the principles of palliative care indicate that the family should be able to express their views for the patient (Monroe, 2003; Hinkle, Bosslet and Torke, 2015; Cowan, 2018). The findings from this study indicate that the patient and family do not always feel included in the decision making at the end of life. Many of the relative participants did not feel listened to and were not given time to allow them to make decisions for themselves or their relative. The prevailing memory of the ED was how busy everyone was all the time. This comes out in both participant groups. The nurse participants were always busy and felt that changing things, for example to prioritise care for the dying, was not possible. Indeed, the idea that someone else – not counted in the workforce numbers – should be provided to care for the dying. There was certainly little effort made to provide palliative care to patients at the end of life, and to their relatives.

Even if the palliative care model is applied in the ED, this still refers to the biomedical model. It is unsurprising that palliative care itself conforms in some sense to the biomedical model – implying that the 'medical gaze' extends even to the area of specialist palliative care. Medical practitioners naturally continue to take decisions about what is best for their dying patients –

in some cases, for example complex symptom management, this is of course highly appropriate - (Clark, 2002; Heyland *et al.*, 2006; Fukuzawa and Kondo, 2017), and there is acknowledgement that palliative care is not exempt from this medicalisation of death (Clark, 2002). However, there exist policies and procedures designed to improve care at the end of life which attract criticism even from palliative care professionals, such as Juth et al's (2010) paper looking at the ethics of the European Association for Palliative Care's framework for palliative sedation (Juth *et al.*, 2010), which is echoed by the concern expressed by the Royal Dutch Medical Association (Koper *et al.*, 2014).

Participants who took part in this study all referred to the lack of control and lack of involvement in the care of the patient; how they were separated from care delivery. Control theory acknowledges that a sense of belief in control over one's life may be the most important defence against the experience of distress for an individual (Redding, 2000), and by extension, their loved ones. Fear of loss of control may be the most important concern for patients at the end of their lives and for their families (Caruso-Herman, 1989; Borgsteede *et al.*, 2006; Holdsworth, 2015; Mah *et al.*, 2019). Allowing and promoting control at the end of life is essential for the patient to have a good death; decision-making in palliative care therefore needs to be with the patient and not for the patient (Winnington, Holroyd and Zambas, 2018). However, this is still not the case in the current socio-political climate (Winnington, Holroyd and Zambas, 2018) and was clearly missing from the care described by participants in this study. Palliative care, even in the hospice setting continues to be under the jurisdiction of medical professionals (Lynch *et al.*, 2011), which may prevent the patient and family from being involved in decisions about care, thus perpetuating the biomedical model. The participants in this study certainly did not feel they had any control as their family member or in fact their patient approached the end of life. The nurses felt powerless and unable to change anything and the families felt that everything that was happening was out of their control. Even when things went relatively well, the memories are framed in such a way that one participant felt grateful to the hospital staff who allowed her to visit her own mother and allowed her sister to see her own mother's body – there is no actual sense of control. It is quite clear that the hospital staff are in charge, and in the case of the nurse participants this presumably means the medical staff or the managers - whoever it is who enforces the rules, designs the environment, and sets the culture. It is certainly not seen (by the participants) as under the control of the nurses.

7.3.2 Palliative care vs palliative nursing

Palliative care exists as a medical speciality (Grudzen, Stone and Morrison, 2011; Lutz, 2011; Quest *et al.*, 2012), but it is recognised that it is designed to expand the traditional disease-focussed medical treatments to include other goals such as enhancing the quality of life for patients and family members, helping with decision making and providing opportunities for personal growth (Ferrell *et al.*, 2018). These goals require interdisciplinary working, and palliative care teams generally consist of a wide spectrum of professionals including nurses, medical practitioners, social workers, chaplains and pharmacists (Salins *et al.*, 2016), with each professional group contributing to comprehensive care of the patient and family. However, there is evidence that healthcare and organisational areas that are dominated by a cure-oriented, medically focussed culture, can obscure the interdisciplinary aspect of palliative care (Dahlborg-Lyckhage and Lidén, 2010; Lynch *et al.*, 2011). This makes it essential for each discipline to define its unique contribution to palliative care.

Nursing as a discipline has much in common with the general ethos of palliative care. Nursing nurtures a caring, ethically based, culturally sensitive nurse-patient relationship that encourages healing (focussing on wholeness rather than cure) through compassion, empathy and support (Lynch *et al.*, 2011), knowing that one aspect of this relationship is intimate care of the body (Lynch *et al.*, 2011), something which is particularly unique to nursing as a discipline . This emphasis on holistic care, dignity, the relief of suffering and promotion of the quality of life are very much basic and easily recognised tenets of palliative care (Lynch, 2014). As one US nurse scholar wrote, from the point of view of the nursing profession, hospice care is the epitome of good nursing (Friedrich, 1999). The nurse participants in this PhD study, whilst caring to the best of their ability within the environment of the ED, were not able to care in a palliative nursing way, which they recognised and regretted, but felt powerless to change.

7.3.3 Nursing care for end -of -life patients in the ED

When discussing nursing, the concept of 'caring' typically arises. The feminist nurse scholar Falk Rafael divides caring into three categories, ordered caring, assimilated caring and empowered caring (Rafael, 1996). In her work, ordered and assimilated caring are based on medical science. Ordered caring as its name implies refers to care being given on the orders of others. Assimilated caring refers to an integrated yet subordinate approach to caring – an example might be a nurse following a doctors' ward round and using their caring behaviour to explain to the patient what the doctor has said. The nurse has assimilated some medical knowledge which they use to explain or repeat what they have heard the doctor say to the patient. Falk Rafael posits that nurses' adaptation of medical knowledge makes nursing care invisible (Falk-Rafael, 2001). Empowered caring, however, intertwines power and caring in such a way as to use the unique knowledge that nursing has, to enhance the life of the patient. Empowered caring emphasises the importance of nursing research as the creation of nursing knowledge, thus leading to nursing expertise (Falk-Rafael, 2001).

In the study on which this thesis is based, the nurse participants did not feel empowered. They describe many feelings of powerlessness. Powerlessness is not an uncommon complaint within nursing (Billeter-Koponen and Fredén, 2005; Boswell, Cannon and Miller, 2005; Anne Kornhaber and Wilson, 2011) and is known to cause stress and even burnout (Olofsson, Bengtsson and Brink, 2003). Nurses are often subjected to the demands of others which may conflict with what they how they wish to provide patient centred care (Karlsson *et al.*, 2010), an example would be relatives bringing the patient to the ED for the nurses to look after when the patient was dying, rather than letting the patient die at home (Karlsson *et al.*, 2010). The nurses who participated in the study on which this thesis is based felt strongly that these patients should not be in hospital - but were unable to do anything about it. Another example might be medical staff deciding that a patient should undergo a procedure even though, from the perspective of the nurse, it will not necessarily be in their best interests (Clanchy, 2021). In these circumstances and reflected in the data from the nurse participants, nurses may feel inadequate or feel dependent on their medical colleagues which can increase a sense of powerlessness (Plant and White, 2013), perhaps being forced by their professional body and the team culture to attempt resuscitation because the patient has arrived without a ‘Do not resuscitate’ order (DNAR) even though they are clearly suffering from a life- limiting condition with no further options for life- prolonging treatment (Tíscar-González *et al.*, 2020).

Effecting change in a healthcare setting requires the change agents to feel empowered (Falk-Rafael *et al.*, 2004). There is little written in the literature about nurse empowerment in the ED. One study from the USA looked at ED nurses’ perceptions of their empowered status and found that the majority of the participants claimed to feel empowered – however caring and the patient were not mentioned. Empowerment in this context was defined as access to leadership training, self- management of work rotas, and sufficient time to do paperwork and other allocated tasks (DeVivo *et al.*, 2013). The nurses who participated in this study did not feel empowered to change the delivery of nursing care within the ED. Further research in this area is recommended (DeVivo *et al.*, 2013).

It appears that nursing needs to rediscover its own value within ED. Palliative nurses are fortunate in that they can nurse in a truly holistic way, at least in palliative settings (Lynch *et al.*, 2011), but palliative nurses do not work in the ED. ED nurses, as demonstrated in the data presented in Chapter 6, work within the biomedical-model culture of the ED and are not empowered to care in a way that promotes a good death in such an environment.

7.4 Peplau's Theory of Interpersonal Relations – a solution

In 1952, and the years following, the nurse scholar Hildegard Peplau , influenced by phenomenology (Brunero, Jeon and Foster, 2015) developed a deductive theory of nursing which she called the interpersonal relations model (Peplau, 1997). The model innovatively moved away from the idea that nursing meant assisting the medical staff; Peplau felt that the nurse instead should work with the doctors and other health professionals to promote the patients' wellbeing (Gastmans, 1998). This included an understanding of the patient experience.

Peplau did not consider her research to be an end in itself, her feeling was that the results should be used for the advancement of the patient's wellness (Gastmans, 1998). In this she was influenced by her reading of Husserl and other phenomenologists, who believed that theory in and of itself was of secondary importance, what matters is the understanding of the experience and life world of the individual (Gastmans, 1998; Nyström, 2007). Her experience as a psychiatric nurse led her to the work of Rogers, who was interested in applying phenomenological ideas in a therapeutic context (Rogers and Murray, 1943). Peplau's model put the nurse-patient relationship, and hence the importance of the patient experience, firmly in the centre of nursing work, ensuring that a collaborative relationship exists to allow the patient to achieve their goals and experience optimum care.

The model explains the nurse-patient relationship as developing through four overlapping stages : orientation, identification, exploitation and resolution or termination(Peplau, 1997). The stages are fluid and the progress though them may be non-linear. The genius of the model is that it recognises that a therapeutic relationship has to develop and grow between the nurse and patient, thus ensuring a focus on the experience of the patient. The nurse has to consciously (vicariously), enter the lifeworld of the patient, to attempt to understand what they are experiencing, to allow this growth (McGuinness and Peters, 1999). The model implicitly accepts that a patient is someone who has something wrong; the orientation phase takes place when the patient accepts this and seeks help from the nurse. The identification phase is about the patient selectively working with the people who can offer help, solutions to the identified problem are sought and the therapeutic relationship grows, with the nurse deliberately using his or her skills to identify with the problems of the patient and understand their unique experience. The exploitation phase is concerned with the patients' use of the nurse-patient relationship amongst other nurse-identified resources to move forward towards resolution, and the resolution/ termination phase results from the successful completion of the other phases – the nurse-patient relationship can then be dissolved, and the patient can move forward (Peplau, 1997; Gastmans, 1998; McCrae, 2012). In many cases sadly, the moving forward element means moving forward to the end of life. Peplau's emphasis on patient experience makes her model an example of the practical use of existential phenomenology in nursing and in nursing research, hence the choice to use this model to complement the methodology used in this thesis.

Therefore Peplau (1997) was interested in the meanings of the interaction between nurse and patient/ family and recommended that nursing staff attempt to put themselves in the place of the patient in order to fully understand what the patient is experiencing (Peplau, 1997; D'Antonio *et al.*, 2014; Brunero, Jeon and Foster, 2015). Peplau felt that healthcare systems are networks of relationships and relationship behaviour tends to depend upon how each person thinks of self and their place in the lifeworld (Peplau, 1997). Building up a relationship thus necessitates hearing the patients' story and considering the patient as a whole, within their current lifeworld, including the relationships that they may have with their significant others.

When it comes to giving care to a patient who cannot communicate because they are too unwell, it is particularly important to look at the patient as an individual living their life and perhaps coming to the end of that life, having made relationships with loved ones and friends (Peplau, 1997). The key to this thesis is death and dying, specifically death and dying in the emergency department and, importantly, how this is experienced, therefore the question needed to be asked: ‘what was it like to experience death in the ED from the perspective of bereaved relatives and nursing staff? ‘. Nurses are used to developing relationships with patients in the context of delivering nursing care, and this approach can also be used when researching nursing care. Linking to nursing theory demonstrates how existential phenomenology can be an illuminating methodology for a nursing research study.

7.4.1 The importance of Peplau’s theory

Nursing is notoriously difficult to define – it is essentially a practice primarily concerned with the frontline delivery of health care to individuals and communities (Pearson, Vaughan and FitzGerald, 2005). This practical imperative means that the hands-on side of nursing can sometimes be seen as the only part that ‘matters’ (Risjord, 2010). It is the visible part, certainly, not helped by the public stereotypes of nursing (Takase, Kershaw and Burt, 2001; Cleary *et al.*, 2018; Gill and Baker, 2021; van der Cingel and Brouwer, 2021). Despite nursing’s advances throughout the 20th and 21st centuries, nurses are still perceived by the public through a variety of unhelpful stereotypes either angels, sexualised uniformed workers, or battle-axes (Hoeve, Jansen and Roodbol, 2014; White *et al.*, 2019; Rabie, Rossouw and Machobane, 2021), and as existing purely as doctors helpers, rather than professionals in their own right. Hoeve et al (2014) conclude that nurses need to work hard to communicate their professional worth to the general public as their professional image is so outdated – they suggest nurses themselves need to show their importance through more engagement in clinical research, engaging with the media, and social media, though monitoring and reacting and learning to speak for themselves (Hoeve, Jansen and Roodbol, 2014). There is evidence in this thesis that nurses’ worth has been consumed, or lost within the biomedical model that operates within ED.

One example of a way in which nursing can show it’s worth as a profession is by a greater attention to the essence of what nursing is, the area of practice that is specifically nursing rather than any other discipline (Andrews, Ashmore and Rosewell, 1991; Pearson, Vaughan and FitzGerald, 2005; Butts and Rich, 2018). Models and theories of nursing are therefore very important – they do not in themselves provide a knowledge base for nursing care, rather they act as a framework in which knowledge can be synthesised into effective nursing care (Butts and Rich, 2018). Models map out the boundaries of nursing as a profession, and allow nursing to defend itself from threats of de-skilling and accusations of poor practice (Ahtisham and Jacoline, 2015). It is only possible to defend something when boundaries are known (Andrews, Ashmore and Rosewell, 1991). Nursing theories and philosophies can defend against rigid thinking and allow nurses to open their minds and think creatively (Butts and Rich, 2018), thus contributing to the body of literature that defines the uniqueness of nursing itself. Theories and philosophies are therefore essential for practice as they provide the foundations of the profession and demonstrate the value of what nursing is. Without such a foundation and a unique body of knowledge behind it, nursing really is in danger of being reduced to a series of practical tasks carried out by well-meaning people.

Parse et al (2000) published a critical paper in which they argued nursing theory-guided practice encouraged a deeper , constantly seeking ,nursing knowledge, encompassing philosophical perspectives, ethical perspectives and an always- developing sense of what it means to be human (Parse *et al.*, 2000). The authors contrast this knowledge with what they call traditional nursing practice which is nursing practice based on (bio)medical knowledge and a set of unwritten rules which cannot be changed (‘we’ve always done it this way’), as demonstrated in the data from this study, presented in Chapter 6.. This point of view challenges nurse writers who feel that nursing theories are no longer relevant to day-to-day nursing practice (Warelow, 2013; Brandão *et al.*, 2019; Mudd *et al.*, 2020). One criticism in modern terms has been that nursing should concentrate on evidence based practice rather than theory (McCrae, 2012); however a recent integrative review found that nursing theory-guided interventions improved patient outcomes in every case (35 studies examined) indicating that nursing theories can be used alongside evidence based practice to achieve positive patient outcomes (Younas and Quennell, 2019). The latter study also reports that they found a decrease in the number of studies using nursing theories in recent years and recommend that nurses should re-discover and continue to develop theory-guided practice (Younas and Quennell, 2019). This thesis supports this argument.

Peplau's interpersonal relations theory (Nyström, 2007), has been introduced in the section above (7.4) . Peplau summarised her model /theory by explaining that nursing is an interpersonal process that must deal with the client's felt, or perceived needs (McCamant, 2006). Peplau describes the nurse-patient relationship in terms of four, or possibly three distinct phases. The first is the orientation phase, this occurs when the patient first accesses the healthcare system. The nurse is responsible for orientating the patient, trying to help them understand what is going on, interpreting the environment, and attempting to ensure they are in a state where they can benefit from care. In this thesis, this stage – however brief- would take place with the patient and their loved one. Following on from this, the nurse and patient enter the identification phase which occurs when the patient can recognise the need to receive care. Even if the care is perceived to be minimal such as making the patient comfortable, it should be recognised as care. The nurse continues to provide reassurance and education including clarification of expectations. Originally this was followed by what Peplau called the exploitation phase; later the identification and exploitation phases were condensed to form the working phase. This phase focusses on the acknowledgement from the patient of the need for care and the recognition that the nurse is uniquely able to provide it. The power shifts from the nurse to the patient, allowing greater emphasis on independence if the patient is getting better, or allowing greater focus on the holistic needs of the patient as they approach death. The final phase is the termination, or resolution phase – this occurs when the patient either recovers or dies and can separate from the dependency of nursing care. In all cases, the ending of the relationship requires some reflection by the nurse. Thus, the nurse patient relationship has a distinct form, beginning, middle and end.

Findings from this PhD study can be related to the model that developed from this theory. Peplau was convinced that, in the development of nursing knowledge, emphasis must be placed on the meaning and relational links between persons, and that human experience lies at the source of all knowledge (Peplau and O'Toole, 1991). The theory was revolutionary at the time as it focussed on the development of a therapeutic relationship including give and take between the nurse and the patient / client , rather than the patient passively accepting treatment and the nurse passively carrying out the doctor's orders (Gastmans, 1998). Peplau felt the interactive phenomena that occurred between a nurse and a patient had a qualitative impact on outcomes for that patient , thus making nursing a complex and growth-provoking process (Nyström, 2007). She was a great devotee of the concept of nursing being a complex profession composed of both art and scientific elements, where the artistic side is the 'caring' part and the scientific side the growing quantitative evidence base for nursing interactions (Peplau, 1997). Peplau's theory placed greater emphasis on both forming and terminating the nurse- patient relationship and thus she is sometimes called the 'mother' of the concept of the clinical nurse specialist, a role designed to nurture and focus on the importance of the nurse-patient relationship , embedding clinical expertise firmly within the holistic interpretation of the nursing role (Haber, 2000). As mentioned above, Peplau's theory revolutionised nursing when it was first published. The data in this thesis indicates that it could revolutionise care in the ED.

Ultimately in Peplau's view the nurse is a facilitator (Fite *et al.*, 2019), helping the patient to fulfil what the patient themselves perceives to be their needs. The theory places an enormous importance on communication and Peplau was very ahead of her time by declaring that the orientation phase is basically the 'make or break phase' '…it is during this time period that the nurse's behaviour signals a pattern of receptivity and interest in the patient's concerns, or fails in this regard' (Peplau, 1988). She thus foretold the 'hello my name is' movement - an initiative in the UK to improve patient -healthcare professional interaction by attempting to ensure that the relationship gets off to a good start (Kmietowicz, 2015).

In the study on which this thesis is based, the bereaved participants who had the best experiences had care from nursing staff who followed Peplau's phases to some extent from the beginning. They reported clear and responsive communication from those caring for their family member, and also felt to some extent supported by the nurses and listened to - one testimony is a good example of this, where the participant mentions that the nurses allowed the family to have some sanctuary in the side room after her father's death and how they provided gentle care to the father after death. However, many bereaved participants did not describe this communication or care, they felt largely left alone in an environment that was alien to them. Even the family members who had the best experiences, however, had no sense of closure. None reported being followed up after the death of their loved one, and their experiences ended very ambiguously. Peplau's insistence on the termination phase of her model / theory was again ahead of its time, and significantly Peplau states that the termination phase requires reflection on the part of the nurse (Peplau, 1988).

One criticism of Peplau's model is that with its strong focus on the nurse-patient relationship, this implies direct interaction between the nurse and the patient and that therefore the model is un-usable in the context of an unconscious patient (D'Antonio *et al.*, 2014). However Peplau herself countered this criticism by the adoption in later years of the word ' client' alongside the term 'patient' (Forchuk, 1991; Stagg, 1992). The model has been successfully used in palliative care settings with the family / relative as the 'client' (Fowler, 1994; Mok and Chiu, 2004; Okon, 2005; Nyström, 2007) and is considered to be a direct influence on the person-centred care model, which may also be used with the family unit as well as the individual patient (McCormack and McCance, 2006; McCormack, 2016).

Rediscovering nursing theory, particularly Peplau's easy to use and very nursing focussed theory may aid nursing staff in using their innate nursing resources to reclaim their professional identity, and thus be empowered to provide excellent care at the end of life in the ED or other similar environment. The focus on facilitating care, being alongside the patient and family, ensuring that the episode of care itself is respected as important, so that each patient and family feel secure, because they know what is going on at each step of the journey, including the difficult end of the journey – these things are really the essence of nursing. Human beings are simple creatures, needing to know rules and boundaries, who to trust and who can help in need. Peplau's theory simply formalises a framework which can only help the nurse to help the patient and family.

7.5 Introducing the theory of the Peaceful End of Life

The theory of the Peaceful End of Life is an example of a further concept that could be used by ED nurses to aid them in providing the care that they would like to give, as described by the participants from the study on which this thesis is based and empowering them as nurses. The theory of the Peaceful End of Life is a mid-range nursing theory which was developed in the 1990s (Ruland and Moore, 1998). Its authors, both practising nurses, sought to address the perennial problem of the theory-practice gap in nursing by developing a theory from an unpublished set of standards of care for the dying patient in an acute setting (Ruland and Moore, 1998). They chose to develop this as a mid-range theory so that it was therefore succinct, brief, and easily usable by practising nurses, unlike the original standards of care document, which was too detailed, unstructured, and unable to be rigorously tested. The theory involves five concepts - not being in pain, experience of comfort, experience of dignity / respect, being at peace, and closeness to significant others / persons who care. The theory very much correlates with the idea of a good death as discussed in chapter one.

The authors (Ruland and Moore, 1998) state this should be considered an initial theory that should be further developed and refined, and indeed there is very little literature relating to the theory. A recent paper described a case report showing how the theory had been successfully applied when nursing a unviable neonate and family in an intensive setting (Agudelo, Romero and Gualdrón, 2020). A Brazilian paper from 2017 examines the theory very positively according to Fawcett's criteria, but tests it in a palliative care environment rather than an acute setting (Zaccara *et al.*, 2017). The strength of the theory is that it is a nursing theory, designed to support non-specialist nurses to provide good end of life care (Jaffer, 2012). The sub-concepts of the theory provide easily accessible guidelines for nursing staff. Its use in the ED has not been tested, however.

The theory of the peaceful end of life depends on the nurse proactively acting as a facilitator to enable the patient to gain benefit from all concepts of the theory. Peplau’s interpersonal relations theory ‘fits’ with the peaceful end of life theory, if, during the ‘working’ phase of Peplau’s theory, the nurse proactively works with the patient to ensure the five concepts are addressed:

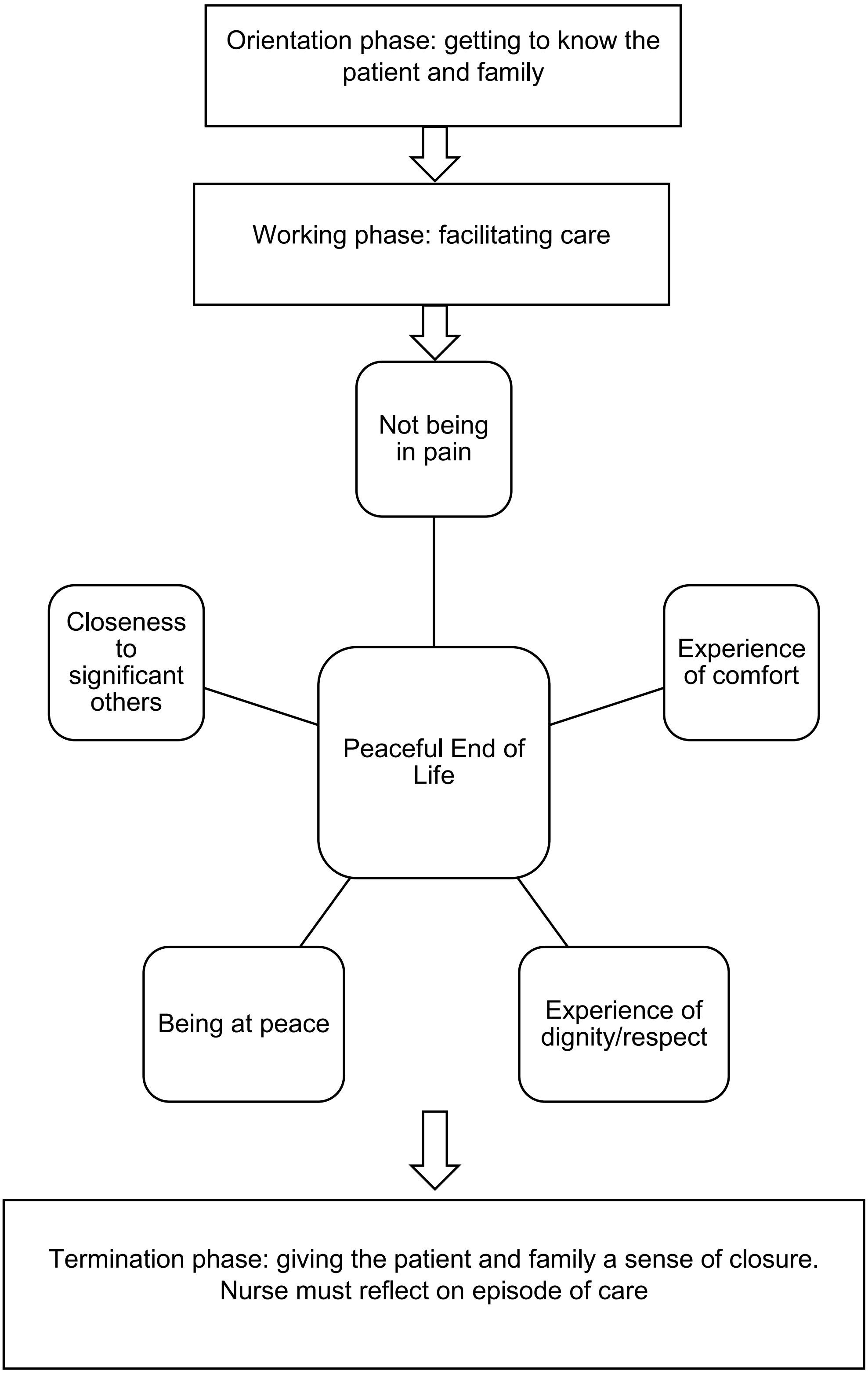

Figure 7: A proposed nursing model for end-of-life care in the ED

Merleau-Ponty’s phenomenology has been used to understand the perception of the family members and nursing staff regarding the experience of the death of a patient in the ED: in a specific attempt to move beyond a simple dichotomy between mind and body and to understand the perceptions and experiences of those involved in the death of the patient in ED from a holistic point of view. Even though family members could not identify missed care as such, they could identify the lack of connection from staff, the isolation, the ‘being with’ that never was and the effect that this had on the final few hours of the patients life. When there is no more to do from a biomedical model, this study demonstrates that there is still much work to do and that this is currently not attended to. It has been argued that the dominance of the biomedical model leads to overshadowing of the dying patients needs within the ED.

The above model attempts to show how the theory of the peaceful end of life can correlate with Peplau’s theory of interpersonal relations to improve care at the end of life. In Chapter 1, five principles for good end of life care were discussed, which came out of work done following the demise of the Liverpool Care Pathway : recognising that someone is dying, ensuring sensitive communication takes place, involving the dying person and their loved ones in any decisions made, respecting and caring for the friends and family of the dying person and ensuring individualised care planning (Wise, 2014). Whilst the wording is slightly different, these five principles correspond with the theory of the peaceful end of life. The principles of the Nursing theory can thus be applied to provide a framework for care within the ED which nurses can use when the default biomedical model can no longer be applied. The key is excellent communication between the patient/family and the nurse and a commitment to the nurse proactively working with the patient and family to facilitate all five of the elements of the peaceful end of life theory. The nurse must accept responsibility for ensuring that attention is paid to all elements and, as per Peplau’s theory, must use self-awareness and reflection at all stages. Care therefore becomes fully patient/family focussed, within the environment of the ED, and simultaneously the nurse is empowered to work ‘with’ the patient/family rather than doing things to / for the patient and family. It is hoped that this approach may bring better satisfaction with the care episode for all concerned. The model above showing the integration of the Peaceful end of Life theory with Peplau's theory of interpersonal relations could also help with the unique problem in ED of the nurse not having much time to establish a caring relationship with the patient and family. End of life care is difficult in such a high-pressured environment; the above model gives nurses a succinct framework through which to practice.

7.6 Conclusion

This chapter has outlined the unique contribution this PhD study has made to the literature around end-of-life care in the ED – and has argued that the renewed application of nursing theory within the ED can facilitate the unique role of the nurse within the ED when the dominant biomedical model can no longer be applied. This thesis has demonstrated the need that exists to improve end of life care in the ED, through the testimony and stories from relatives and nurses and provided a response through the application of nursing theory.

The PhD study has achieved the aims and objectives set out in chapter one and repeated here. Specifically, this research aimed to create new knowledge by describing the priorities and needs of dying patients who end their lives in the emergency department. Further, the research sought to generate new knowledge regarding the nature of the experience of family members of dying patients and the nurses who care for them by describing their priorities and needs. Finally, the study was designed to contribute new knowledge regarding the potential for improvement in the care for the dying in the ED which might be used in future research.

To meet these aims three research objectives were set:

1. To review and examine the literature surrounding the experience of death in the emergency department (chapter 2) from the perspective of bereaved family members and nursing staff.

2. To describe the experience of death in the emergency department from the perspective of bereaved family members and nursing staff (chapters 5 and 6).
3. To discuss the experience of death in the emergency department from the perspective of bereaved family members and nursing staff in such a way as to provide material for education and future research (chapters 7 and 8).

The study provides a detailed description of the experiences of family members (and by logical extension those of the patient) who have been alongside the dying patient in the ED and have experienced the care given during the dying process and beyond. As the study also includes the experiences of nursing staff, the study serves to highlight the inadequacy of the biomedical model in the ED. This chapter has explored the problem here and introduced some solutions which will be expanded upon in the following chapter.

CHAPTER 8: CONCLUSIONS AND RECOMMENDATIONS

8.0 Chapter abstract

This chapter outlines the conclusions drawn from the programme of evidence-building research described in this thesis. This is followed by the presentation of evidence-based recommendations for education, clinical and research practice, policy, and future research. The chapter closes with some reflections on carrying out this PhD research.

8.1 Introduction - The study and findings

This qualitative study, underpinned by the tenets of existential phenomenology, focused on the lived experience through observation of death and dying in the emergency department. Two groups of participants were chosen to discuss their lived experience: bereaved family members and qualified nursing staff.

Lived experiences can be described as those experiences that make plain the immediate, pre-reflective consciousness a person may have regarding events in which he or she has participated. They are used as the basis for recalling how individuals have lived through the event and by doing this, transform them into objects of consciousness (Kleiman, 2004). The actual act of recollecting implies that what one recollects must have been meaningful (Kleiman, 2004). Lived experience is therefore the starting point of phenomenological research (Hultgren, 1990).

The philosophy of Merleau-Ponty is situated in the actual physical world. We exist, according to Merleau-Ponty as embodied creatures, indistinguishable from the real world (Merleau-Ponty, 2012). It could be argued that Merleau-Ponty's philosophy has only one question at its core: how can we, as human beings, make sense of the world in which we are present? (Seamon, 2014). We are enmeshed in the world and the world is simultaneously enmeshed in us (Seamon, 2014). We communicate with the world through the perception of our embodied selves; the body is the channel, the opening through which all experience can take place (Kelly, 2005).

Merleau-Ponty's phenomenology, focussed as it is upon the body as an indistinguishable part of the whole individual, makes it an appropriate approach to look at the experience of death and dying within the ED. The unique point of this study is not so much the experience of the death of an individual from the perspective of family members and the nursing staff, but the experience of the death of an individual in the emergency department. The ED is a world in which death is and can be very close, due to the emergency nature of the care undertaken there. The participants lived through the hours they describe, being in the world of the ED. Although some of the bereaved participants were either health care personnel or had attended the ED previously in some other capacity, to all of them, the experience was new and fresh because of the circumstances of that experience. And as Merleau-Ponty describes, how we experience the environment very much depends on the circumstances in which we find ourselves and our characteristics and unique needs and abilities (Sanders, 1993).

The nursing theorist, Hildegard Peplau produced a model in the mid to late 20th Century which built on phenomenological ideas and showed how nurses can work with the patient / family to enhance their experiences during the unique circumstances of their episode of care, no matter how long or short this episode is. Her focus on the patient/family experience allows the findings from this study to be presented in a way in which the relevance to nursing as a distinct profession can be demonstrated. The data from both groups, the bereaved family members and the nursing staff showed that due to the environment and culture of the ED, it is a challenging place to experience end of life care, either as a nurse, a family member or as a person at the end of their life. In chapter 7, the reasons for this were discussed at length and a nursing framework for end -of -life care, based on the work of Peplau, was tentatively introduced.

It could also be argued that this research study has demonstrated the importance of paying attention to detail – the importance of small things. For much of nursing's history, it could be argued that attention has been paid to the wider picture rather than small details (Nelson, 2003). The history of nursing is about politics, famous figures, wars, and education. Nelson (2003) argues that the profession has ignored the everyday, perhaps mundane stories of the lives of the women and some men who through the years have looked after patients in every possible setting from the drawing room to the prison, to the battlefield, to the operating theatre and to the Emergency Department. The experiences of patients and their nurses are very important. The history of nursing has been overshadowed by the history of medicine, so famous surgical techniques are known about, and breakthrough treatments are discussed, but not enough attention has been paid to the skilled nursing and the experience of the patients who underwent these revolutionary surgical procedures or who were the first to be given world-changing medications such as penicillin or etoposide. This research study has attempted to shed light on the skilled nursing of the dying in the ED and how this has been experienced by the loved ones of the dying patient.

The literature around the experience of death and dying in the ED has found that the culture of the ED is very medically led as discussed in Chapter 7 (Bailey, Murphy and Porock, 2011b; Gloss, 2017; Dawood, 2019; Hendin *et al.*, 2020b). The nurses are conditioned to follow the medical lead and focus on saving lives. It is unsurprising that they look at the situation from this point of view. However, if their narratives are unpicked, there is real genuine caring and pride in this caring. Despite this, there is little, or no attention being paid to an alternative paradigm of care delivery

8.1.2 Limitations and strengths of the study

The study was designed to examine the experiences of family members who had been bereaved through death in the ED and the experience of nurses caring for the dying in the ED. It aimed to be as comprehensive as possible, but it naturally has some limitations which may affect the relevance of the findings.

Recruitment to the study was challenging as described in Chapter four. The participants were self-selecting, social media users, coming forward of their own volition, therefore a group of people who both had a story to tell and wanted to tell it. Possibly therefore, people who do not use or who are uncomfortable with technology were excluded, along with people who did not wish to tell their story. It is questionable whether these are significant limitations. However, more seriously, the study did exclude two specific groups: non-English speakers and those who die in the ED and have no friends or family.

The exclusion of non-English speakers is due to the very prosaic fact that the researcher does not have skills in languages other than English. From the literature, it is possible that in English-speaking countries the experience of those who are unable to speak English is significantly worse than those who can speak English.(McGrath, Vun and McLeod, 2001; Garrett *et al.*, 2008; Burton and Shaw, 2015). Solutions other writers have found include the use of interpreters, specific focus groups with other non-English speakers and surveys in different languages (Crosby, 2013). Research with linguistically diverse populations has classically been challenging; it is hugely important to find ways of including these groups in research studies (Murray and Wynne, 2001). This is relevant to both the participant groups in this research study, which also marginalised nurses who were not able to speak English or who were not confident in English.

There are some people in any society who live solitary lives for any number of reasons. The evidence from the literature shows that this population have generally poorer health outcomes ('Do Terminally Ill People who Live Alone Miss Out on Home Oxygen Treatment? An Hypothesis Generating Study,' 2008; Cavalli-Björkman *et al.*, 2012; Aoun and Skett, 2013), and it may be extrapolated from this that their experience of death in the ED is equally poor. Researching the experiences of death and dying in the ED without being able to talk to bereaved family members would require a different methodology, perhaps observational research, or ethnography, but would be possible and would add greatly to the knowledge around this topic. People without relatives or friends are a truly marginalised group and there is much to do from a research point of view.

The strengths of this study include the in-depth data from the phenomenological interviews which guided the findings. Phenomenology never purports to uncover absolute truth; Merleau-Ponty's phenomenology is concerned with the understanding of people as beings in a situation, individuals anchored to the shared lifeworld by their experience of themselves as embodied , and embedded in that world (Sadala and Adorno, 2002). Everyone's experience is therefore unique to themselves, and this is what this study has uncovered through the phenomenological interviews. Uniquely the bereaved carers and the nurses have been given a voice and allowed to talk about what was important to them at a very stressful time.

Another strength is that this is a strongly nursing-focused study, rooted in nursing practice with findings which have a practical application aimed to directly improve patient care. Findings from this PhD study will support nurses to fulfil their duties according to the NMC code of conduct (Glasper, 2015) when caring for a patient at the end of their life. The inclusion of the nursing perspective strengthens the study and allows focus on the improvement of care rather than simply describing the experience of the relative participants. The inclusion of participants from different geographical areas also strengthens the study and makes the findings more relatable than if the study concentrated on one particular area or hospital Trust. The participants were diverse, reflecting the diversity of the global population within the realms of possibility and taking into account the weaknesses described above.

8.1.3 The covid pandemic

The data collection for this study had just been completed when the Covid-19 pandemic struck. There have been many changes to society, not least in the way hospitals and particularly emergency departments have functioned. Many non-specialist nurses were being asked to work with critically ill and end-of-life patients in unfamiliar areas (hence the Theory of the Peaceful End of Life could have been helpful). The pandemic has been a global emergency and has affected every country in the world. This short section will briefly outline the differences that have been experienced by both patients and families and by hospital staff and make recommendations for future research.

The biggest and most disruptive change that patients and families have experienced during the pandemic has, arguably, been the isolation that very sick patients have felt due to visiting restrictions (Bear *et al.*, 2020; Carr, Boerner and Moorman, 2020; Gesi *et al.*, 2020; Hendin *et al.*, 2020a; Miller, 2020; Rosen, 2021). Real-time data collection for the study on which this thesis is based would not have been possible. Research into relatives experience of death and dying in the ED during the pandemic will almost certainly focus on the fact that they were not allowed to be with their loved one at the time of death. At the time of writing, visiting is still restricted in hospitals throughout the UK to at most one visitor for one hour a day, although the rules are now slightly relaxed in most places for the dying patient (Rose *et al.*, 2021). The writer Michael Rosen shares how difficult it was for his wife not to be able to visit whilst he was very sick in ITU (Rosen, 2021).

Another big difference is the fear and anxiety that became ‘normal’ throughout the world particularly pre-vaccine (Miller, 2020), so that even if visiting was permitted even after death, sometimes the very act of considering visiting a loved one was so fraught with distress that the decision itself was unbearable (Morris, Moment and Thomas, 2020; Rose *et al.*, 2021). This means that the family may not see their loved one at the point of death or afterwards, thus disrupting the natural grieving process. Due to social distancing measures, it has also not been possible to have more than a handful of people at a funeral (Sowden, Borgstrom and Selman, 2021). Silva et al (2021) writes that disruption to the grieving process and funeral rites can corrupt the therapeutic processes of these rites, causing emotional scarring and the potential to develop complex grief (Silva *et al.*, 2021). During the pandemic, nursing in the ED has been particularly hard because of these issues (An *et al.*, 2020; García-Martín *et al.*, 2021) and patient experience has also been affected (Quah *et al.*, 2020).

Being a nurse in the time of the pandemic has not been easy. Nurses have endured a variety of pandemic-related issues from being hailed as heroes (Kenny, Simmons and COL, 2020; Mohammed *et al.*, 2021; Różyk-Myrta, Brodziak and Kołat, 2021) to coping with the aftermath of Covid and the possible public shift of attitude and satisfaction towards the Health Services post Covid (Association, 2020; Marlow *et al.*, 2020). Along the way, nurses have had to cope with the fear of their own death or that of their colleagues (Maben 1 and Bridges, 2020), or fear of bringing the virus home to relatives and loved ones (Hu *et al.*, 2020; Labrague and de Los Santos, 2020). The virus has brought huge amounts of grief and stress– nurses grieving for life pre-covid, for their lost colleagues, relatives, friends and patients and also for the unavoidable changes in their working lives (nurse educators having to deliver high level programmes online, ITU nurses looking after several patients at a time, oncology nurses having to deliver the worst of news to patients through PPE and without the patients family with them) (McCallum *et al.*, 2021).

Perhaps there have been some positives, however – it is possible that the aforementioned effect of infantilisation of nurses through insistence of identifying uniforms particularly in the UK (Timmons and East, 2011; Brien and McAllister, 2019) has been lessened by the fact that all frontline personnel including medical staff were dressed in some version of scrubs due to infection control(Sorrell and Ibrahim, 2020; Wang *et al.*, 2020).

Research into the experiences of ED nurses looking after dying patients during the pandemic may highlight further issues and it is recommended that particular focus should be on the experience of patients who have been unable to have loved ones with them. This may help in understanding of the group discussed earlier who have no relatives / friends. The experience of cardio-pulmonary resuscitation during the pandemic is another area to be studied.

8.2 Recommendations

This study is just the first step. The findings have sparked many ideas and thoughts about effecting changes as a result of the study. Nursing research exists to add depth to the body of professional knowledge that defines what nursing actually is and therefore needs to be as relevant, as creative and as innovative as possible whilst remaining firmly rooted in the values of nursing (Horton, Tschudin and Forget, 2007).

The various ideas which have led to recommendations are grouped into five categories: recommendations for education, for clinical practice, for research practice, for policy and, importantly, for future research. This is the beginning, not the end.

8.2.1 Recommendations for Education

The pre-registration nursing curriculum in the UK is extremely full (Clarke, 2021; Kumah *et al.*, 2021) and much emphasis is placed upon technical and practice-based nursing (Duncan and Johnstone, 2018; Seah *et al.*, 2021). Formal post-registration education in nursing is not currently compulsory in the UK, but every nurse is expected to complete 35 hours of continuing professional development every three years in order to revalidate – this may be informal work-based learning (Galletly, 2021).

Based on the findings from this study, two recommendations for nurse education are made. Firstly, pre-registration student nurses should have dedicated teaching about death and dying. This does not currently happen. As discussed in chapter one, more open discourse is needed to normalise death and to prevent the taboos currently surrounding death and dying. Death needs to be prepared for, acknowledged, and openly discussed throughout life, so that people's wishes around death are known and preparations can be made. Without acknowledgement of death as a normal part of life, life cannot be lived fully and openly (West and Glynos, 2016; Wynton, 2019). Importantly, for the subject of this thesis, people need to be supported to realise that their elderly, frail relative is going through a natural process when they begin to come to the end of their life, and that these individuals do not need to come into the ED where they are likely to have a less than optimal death.

Death and dying education is more than education about palliative care. There is a wealth of material in the arts and humanities that may be used to educate students about death and dying and that may broaden their minds and spark creative thought (Darbyshire, 1994). This leads on to the second recommendation around education: student nurse, and post registration nurses should be encouraged to discover more about their own body of professional knowledge including nursing theory. Based on the findings from this PhD, nurses need to be empowered to challenge 'norms' and evidence from the literature suggests that one way of empowering nurses is to rediscover their unique nursing knowledge (Falk-Rafael, 2001; Horton, Tschudin and Forget, 2007; Younas and Quennell, 2019). Exploring and developing nursing knowledge through career-long practice-based learning has been shown to reduce stress and the potential for burnout through improving career satisfaction (Billeter-Koponen and Fredén, 2005; Chang *et al.*, 2005; Modaresnezhad *et al.*, 2021).

8.2.2 Recommendations for Clinical practice

Based on the findings from this study it is recommended that every emergency department should have a team of dedicated end of life care nurses whose remit would be to work within the nursing teams to improve end of life care and empower nurses to develop the skills needed. These nurses would also provide post death debriefing and support for staff, and follow-up from hospital for bereaved family members. Emergency Department end of life care nurses would ideally have post registration training in both ED nursing and palliative care nursing and preferably an advanced clinical practice qualification and would be expected to work autonomously with both the ED and palliative care team's input. Optimally they would be independent prescribers and have excellent communication skills. Ultimately this model would lead to all staff members having good basic end of life care skills.

However, in practice this will not be easy, and departments may find it difficult to recruit into these roles, partly because of the global shortage of registered nurses (Nardi and Gyurko, 2013; Johnson *et al.*, 2016; Haddad, Annamaraju and Toney-Butler, 2020). Another recommendation for clinical practice is that nurses/ departments explore the use of death doulas in the ED.

The role of the death doula has emerged in recent years , following the successful and well known implementation of the birth doula as a professional friend to support women giving birth (Spiby *et al.*, 2016). Birth doulas are not health professionals and do not provide any clinical care; rather they provide social, emotional and practical support (Spiby *et al.*, 2016). Birth doulas roles are expanding globally and they are now being used to address inequity as advocates for women with differing needs and in non-mainstream circumstances (Cidro *et al.*, 2018). The literature describes the death doula movement as having developed in response to gaps in current health and social care systems that lead to less-than-optimal care for the dying (Rawlings *et al.*, 2019; Rawlings *et al.*, 2021).

Death doulas are not yet registered and have no regulatory body. There is common assent that they need to be trained; currently in the UK there are several bodies offering training, a quick google search shows this can vary from a basic 6-week online course to a very intensive 120+ hours course with blended learning and placements included. However, the literature shows that there is a place for death doulas as a bridge between lay people and professionals (Mannix, 2020; Murphy, 2021). Some of the bereaved participants, in the research study on which this thesis is based, had never seen death before and did not understand what was going on. The nurses did not understand that the family members did not understand. The role of the death doula is to interpret the process of dying for the loved one – this cannot be underestimated, the families need to be aware that the sights and sounds of the deathbed are not abnormal, but part of the natural process of dying (Mannix, 2020). More research is needed but it is anecdotally suggested that the presence of a knowledgeable lay person may be more comforting as a continual at the bedside than a uniformed professional (Mannix, 2020).

Society as a whole needs to be more comfortable with discussing death and dying. The death café movement is a further global initiative designed to help people become more confident when talking about death (Miles and Corr, 2017). The first death café started in Switzerland in 2004 and the concept was developed further by Jon Underwood, who started the first death café in London in 2011 (Morgan, 2017). There are now death cafes around the world. A death café is a pop up event with strict rules to facilitate support for the participants (Morgan, 2017). It is a compassionate and safe space to openly discuss death and dying. Since the start of the Covid-19 pandemic, death cafes have been running virtually (Chang, 2021) and there has been research about using the death café technique to help reduce burnout in ICU staff (Bateman *et al.*, 2020). Again, this is potential concept that may be useful for ED staff.

8.2.3 Recommendations for Research practice

8.2.3a Research with so-called vulnerable groups

It is possible that one reason for the lack of research into the needs of dying patients and their relatives in the emergency setting is that these groups are felt to be vulnerable. There is some justification for this, particularly when working with dying patients – time is very short and many may not wish to spend it talking to a researcher (Henry and Scales, 2012; Gibbins *et al.*, 2013); those that do may not be typical of the population, being a self-selected group of individuals who are feeling well enough to participate (Henry and Scales, 2012). Researching the experience of sudden death in the ED is unlikely to ever to involve patients due to the nature of the situation (death in the ED is unplanned, unlike hospice or even intensive care), however, the study on which this thesis is based demonstrates that it is possible to research the experience of grieving family members.

Grief can be hugely overwhelming and very isolating (Arizmendi and O'Connor, 2015). It has long been observed that one of the most isolating things about grief is that bereaved people feel others do not know what to say and therefore avoid them out of embarrassment, making the isolation even more acute (Whitaker, 1984). This issue is particularly important when considering undertaking research related to end-of-life care. Such research is necessary to assess and improve the quality of care given to individuals and family members at the end of life and to monitor the success or otherwise of any innovations or interventions (Stiel *et al.*, 2015); however there is a sense that research into end of life care situations is intrusive and even potentially unethical (Casarett and Karlawish, 2000; LeBlanc, Wheeler and Abernethy, 2010). The presumption is often made that any research with bereaved families following a death is unduly burdensome and therefore not ‘appropriate’ (LeBlanc, Wheeler and Abernethy, 2010; Bentley and O'Connor, 2015).

However, when the evidence is examined, it becomes clear many bereaved individuals actively want to take part in research. Colin Murray Parkes, writing in Agnes Whitaker's anthology (1984) states: 'anyone who turns towards the widow and the widower and gives confidence that they do have something to offer at moments of utter despair helps to reassure them that all is not lost' (p xi) (Whitaker, 1984). Supporting bereaved people to use their experiences in ways that can help others adds dignity and shows they are valuable as a person, and their experiences are important (Monroe, 2003; McLoughlin, 2010).

It has been suggested that participating in research, particularly qualitative research, can help individuals who are grieving, not just by demonstrating they and their experiences are helpful, valuable and of use (Monroe, 2003), but also because of the therapeutic effects of sharing their experiences with a researcher (Bentley and O'Connor, 2015). East et al (2010) write that personal stories gained through research , particularly healthcare research, may portray sad and potentially traumatic experiences, the exploration of which can lead to healing and the building of resilience (East *et al.*, 2010) .Bereaved people talk about the importance of someone listening (Klass, 2013), and in a research situation, the researcher is that person listening to the bereaved individual (Norberg, Bergsten and Lundman, 2001).

Grief comes from the loss of someone important to the grieving person, and is an expected reaction following a death (Nyatanga, 2018); it is also known that experiences of grief are individual to each person and that over-broad generalizations about grief should be challenged (Rosenblatt, 2017). In a world respectful of cultural diversity, it is important to understand that there is no 'normal' standard of grieving (Rosenblatt and Bowman, 2013; Neimeyer, 2014; Rosenblatt, 2017; Schwartz, Howell and Jamison, 2018). Grieving is not a pathological process that requires medication (although it may do), but a fluid process which changes with each person and can alter throughout the person's life without ever completely disappearing (Stroebe and Schut, 1999; Rosenblatt, 2017). Rosenblatt (2013) writes that in working with bereaved people it is important to move away from any sort of preconceived ideas or theories and just be open to the realities for individuals; therefore, self-doubt and caution on the part of the researcher are more important than certainty (Rosenblatt and Bowman, 2013).

The study on which this thesis is based showed that grieving people are glad to have the opportunity to take part in research which is also backed up by the literature (McCallum *et al.*, 2019). It is also important to be aware that consideration needs to be given to the feelings of nursing staff as research participants, who also suffer from feelings of grief, something which has been highlighted during the covid-19 pandemic (McCallum *et al.*, 2021). Recommendations from this study include the recommendation for researchers to be unafraid of working with grieving individuals. Such individuals may have important things to say and should not be excluded from participating in research.

8.2.3b Self-care when carrying out research into sensitive topics

As discussed in chapter four, it is essential that consideration is given to the effects on the researcher of carrying out research into sensitive topics such as death, dying and bereavement. In emotionally-laden research, the researcher is vulnerable to harm (Cotterill, 1992) (Dickson-Swift *et al.*, 2008); (Liamputtong, 2007) because s/he is attempting to understand someone else’s experience, crucially without having shared the experience. Use of a reflective diary, support from the supervisory team and being aware of one’s own feelings are highly recommended, as discussed in Chapter four of this thesis.

8.2.4 Policy

There is evidence that in general nurses are policy implementers, rather than policy makers (Arabi *et al.*, 2014; Turale and Kunaviktikul, 2019; Rasheed, Younas and Mehdi, 2020; Hajizadeh *et al.*, 2021). To effect change – for example in the provision of better end of life care in the ED – it is essential that nurses are involved at all levels of service development and are empowered to prioritise the nursing agenda (Chan, 2006a). Education and culture change as above can encourage more nurses to get involved in service development and policy making; without this, changes in education, clinical practice and nursing research will not have a far enough reach. Nurses should be seen as essential members of the policy-making team rather than purely service implementers or users.

8.2.5 Future research

Further research into family experiences of death and dying in the ED is needed. The marginalised groups mentioned earlier deserve research into their experiences so that recommendations for improved care can be made – these are non-English speakers and persons who die without any family or friends with them. Further research is also needed to explore the experiences of staff who care for dying patients in the ED. Research into beliefs and attitudes about death would also be helpful to determine ways to improve the quality of care provided.

Specifically, in order to inform healthcare practice, this study raises a number of questions for further research:

1. What are the experiences of non-English speakers who have been with a loved one who has died in the ED?
2. What were the experiences of people who have died in the ED without friends / relatives?
3. What are the experiences of nursing staff who care for non-English speakers in the ED, or who work in non-English speaking areas themselves?
4. What are the attitudes and beliefs around death amongst nurses working in the ED?
5. How can ED staff who care for dying patients and their families be best supported?

It is by understanding how individuals make sense of these experiences that healthcare services in the ED, including both acute and palliative care, will be more able to meet the needs of the people they support and provide better care both before and after death occurs.

8.3 Some final thoughts

In 1968, Glaser and Strauss published their monograph Time for dying, the culmination of a research study into dying in hospital in the San Francisco Bay area (Glaser and Strauss, 2017). Their aim with this study was to reform care of the dying, to make management of dying by health care personnel, patients and families more compassionate and rational (Small and Gott, 2012). Much of their work focused on what they termed '*awareness contexts'*, specifically the context in which the patient and healthcare worker could communicate about death and dying (Glaser and Strauss, 1964; Glaser and Strauss, 1965). They describe four contexts, closed awareness, suspected awareness, mutual pretence, and open awareness; there is a trajectory from the first (only the healthcare worker is aware that the person is dying) to the last (everyone is aware that death is approaching). They posit that there is a general reluctance to discuss the process of dying, specifically a reluctance to tell the person and family that death is near (Glaser and Strauss, 2017).

It is 53 years since this study was completed and it remains highly relevant. Findings from the study on which this thesis is based suggest that communication around the processes of death and dying needs much more work. The general reluctance to discuss the processes of death and dying was translated in this study into busy-ness and difficulties in understanding what was going on. Glaser and Strauss themselves suggested that much more research was needed in this area (Glaser and Strauss, 1968). The study on which this thesis is based builds therefore on much more illustrious beginnings.

From a phenomenological point of view, this study has offered a unique insight into the lifeworld of the family members who have been with their loved one who has died in the ED and also the lifeworld of the nursing staff whose job it is to look after these people. As the researcher, the journey described in the pages of this thesis was one of adventure, allowing a different (to clinical practice) experience of patient and colleague care, and also of insight and change. It was amazing to hear these experiences, not as a clinical nurse, or even as a patient

/ relative, but as an independent recorder of the experiences. The insight given, through these stories has been both enriching and challenging, enriching because they are important insights into the patient and nurse experiences, and challenging because now it is clear that things need to change and a way has to be found to make this happen. The findings have shown that there is much room for improvement in end-of-life care in the ED and it was an enormous privilege to be allowed to listen to and ultimately tell these stories; it could be argued that there is a responsibility to ensure these stories reach a wider audience. There are plans to publish the findings in academic journals and to present at conference(s), also teaching in the workplace and at the University is planned.

Ultimately this is a nursing thesis written by a nurse. The findings, whilst universally interesting, will be of great relevance to practising nurses. Some thought has been given to how to use the findings to improve care on a practical level. A paper from 2017 discusses the use of experience based co-design (EBCD) to improve the care given to palliative patients in the ED (née Blackwell *et al.*, 2017). The authors found that the approach was useful for promoting collaborative working between vulnerable patients, families, and staff. EBCD is typically a quality improvement technique and can reach those individuals not usually reachable through QI projects as the approach is flexible and encourages reflection on the part of all the participants (Donetto, Tsianakas and Robert, 2014). It is planned to explore this idea at a local level to engage nurses and service users, and possibly the wider academic community through dissemination at conferences and publications.

Nurses are extraordinarily privileged to be present at the end of life and to care for the patient's body and everything that makes up who that person was, including their relatives and friends. This ultimate care is unique amongst health care professionals and must be owned by nurses. To give someone a peaceful death is a great gift and something that all nurses can aspire to. The Indian polymath, Rabindranath Tragore, who died in 1941 wrote:

Peace, my heart, let the time for the parting be sweet.

Let it not be a death but completeness.

Let love melt into memory and pain into songs.

Let the flight through the sky end in the folding of the wings over the nest.

Let the last touch of your hands be gentle like the flower of the night.

Stand still, O Beautiful End, for a moment, and say your last words in silence.

I bow to you and hold up my lamp to light your way. (Enright, 1983)

It is hoped that this work will play a tiny part in helping ED nurses realise how important a good, peaceful death is and help them to understand how to achieve this for their patients.

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APPENDICES

Appendix 1: Ethics Approval Oxford Brookes University

OXFORD
BROOKES
UNIVERSITY

Professor Debra Jackson
Director of Studies
Oxford School of Nursing and Midwifery
Department of Sport, Health and Social Work
Faculty of Health and Life Sciences
Oxford Brookes University
Headington Campus

7 August 2018

Dear Professor Jackson

UREC Registration No: 181211
Exploring the quality of death and dying in the Emergency Department

Thank you for the email of 4 August 2018 outlining the response to the points raised in my previous letter about the PhD study of your research student Kay McCallum and attaching the revised documents. I am pleased to inform you that, on this basis, I have given Chair's Approval for the study to begin.

The UREC approval period for the data collection phase of the study is two years from the date of this letter , so 7 August 2020. If you need the approval to be extended please do contact me nearer the time of expiry.

Should the recruitment, methodology or data storage change from your original plans, or should any study participants experience adverse physical, psychological, social, legal or economic effects from the research, please inform me with full details as soon as possible.

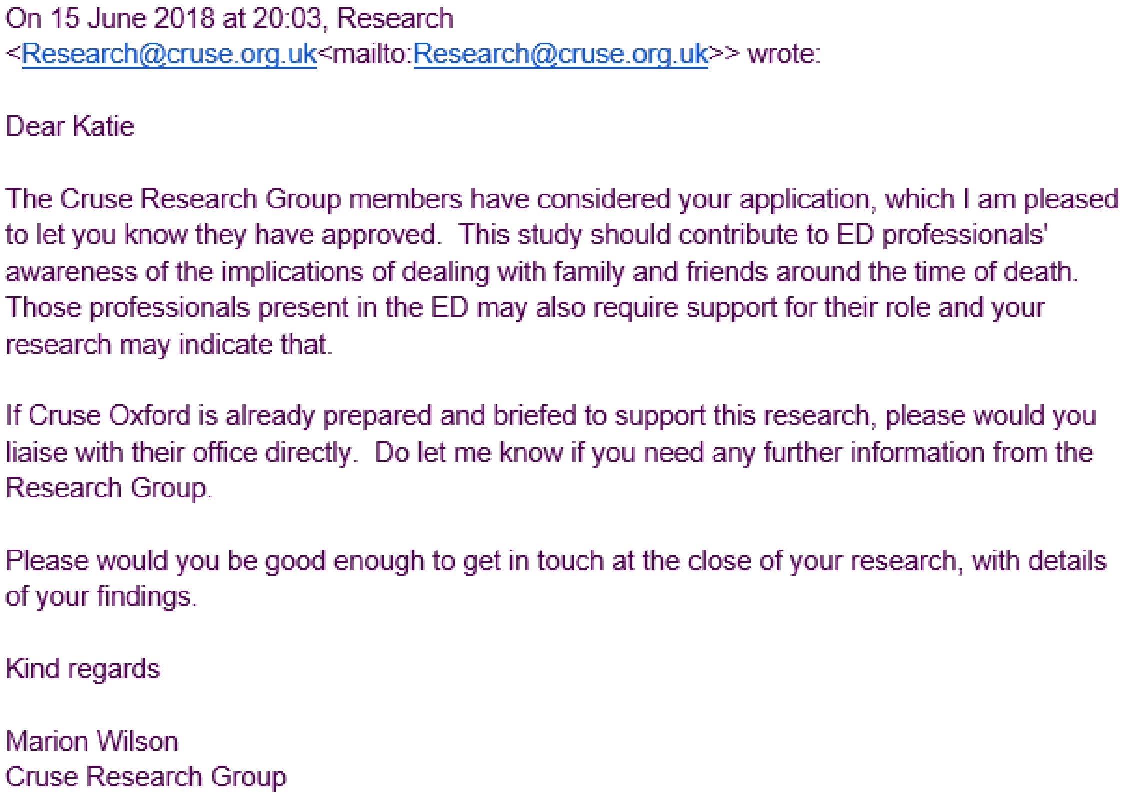
Yours sincerely

Dr Sarah Quinton
Chair of the University Research Ethics Committee

cc Helen Walthall and Helen Aveyard, Supervisory Team
Kay McCallum, Research Student
Kellie Tune, Research Ethics Officer
Jill Organ, Research Degrees Team
Louise Wood, UREC Administrator

www.brookes.ac.uk

Appendix 2: Ethics Approval Cruse Bereavement care



On 15 June 2018 at 20:03, Research
<Research@cruse.org.uk<mailto:Research@cruse.org.uk>> wrote:

Dear Katie

The Cruse Research Group members have considered your application, which I am pleased to let you know they have approved. This study should contribute to ED professionals' awareness of the implications of dealing with family and friends around the time of death. Those professionals present in the ED may also require support for their role and your research may indicate that.

If Cruse Oxford is already prepared and briefed to support this research, please would you liaise with their office directly. Do let me know if you need any further information from the Research Group.

Please would you be good enough to get in touch at the close of your research, with details of your findings.

Kind regards

Marion Wilson
Cruse Research Group

Would you like to take part in PhD study?

Have you lost a loved one in a hospital emergency department (ED)?

We are researching the experience of death in the ED. You may be asked questions about the care your loved one had in the emergency department and what the experience was like. All information will be anonymised for your protection.

You can help us improve care.

Please contact Katie McCallum
email: 16113566@brookes.ac.uk
call: 01865 482603

Appendix 3: Information sheet and consent form – relative participants

Participant Information Sheet

'Exploring the experience of death in the emergency department: a phenomenological study'

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please feel free to ask questions if anything you read is not clear or would like more information. Take time to decide whether or not to take part.

What is the purpose of the study?

This project will aim to find out about the experience and feelings of informal carers (husbands / wives / partners /loved ones) and nursing staff who have been with a person who has died in an Emergency Department (ED).

Why have I been invited to participate?

You have been invited to participate because you have experienced the death of a loved one in the emergency department of a hospital or have looked after such a patient in the context of your nursing role. You may have been recruited via Cruse Bereavement Care. Whether you do decide to take part or not will have absolutely no impact on your current or future support from Cruse bereavement care or from the NHS.

Do I have to take part?

No. It is up to you to decide whether or not to take part. You do not have to take part if you do not want to. If you do decide to take part I will ask you to sign a consent form at the meeting. Taking part or not taking part will have no impact on any care or access to support now or in the future.

What will my involvement be?

You will be invited to an interview of approximately 30 - 45 minutes at a time and location that is convenient to you. This maybe by telephone or skype as well as in person.

You will be asked to tell the researcher, in your own words, about your experience when your loved one died in the Emergency Department. It is very important that you feel comfortable when talking to the researcher and we would like to stress that you can stop the interview at any time, or ask the interviewer to change the subject.

How do I withdraw from the study?

You can withdraw at any point of the study, without having to give a reason. If any questions during the interview make you feel uncomfortable, you do not have to answer them and you can withdraw from the interview at any time without giving a reason. Withdrawing from the study will have no effect on you. If you withdraw from the study we will not normally retain the information you have given thus far, unless you are happy for us to do so. Please just inform the researcher of your desire to withdraw from the study. She will then ask if you would like your data to be destroyed and will do so if you so wish. Just so that you are aware, if you decide to withdraw from the study after you have given the interview, information that has already been de-identified or analysed may be difficult to withdraw.

What will my information be used for?

The collected information will be used for a research project leading to a PhD degree. The information you give will be analysed alongside information from other participants. Data will be written up as part of a thesis and will be published in an academic journal. You will be able to have a copy of the summary of the results if you wish. Please be aware that this will require you to give the researcher a postal or email address, which will be destroyed after use.

Is there any benefit to me in taking part?

There will be no direct benefits to you from taking part in this research , which will ultimately aim to improve the experiences of carers when a person dies in the Emergency Department.

Will my taking part and my data be kept confidential? Will it be anonymised?

The records from this study will be kept as confidential as possible. Only myself and my supervisory team will have access to the files and any audio tapes. Your data will be de-identified – your name will not be used in any reports or publications resulting from the study. All digital files, transcripts and summaries will be given codes and stored separately from any names or other direct identification of participants. Any hard copies of research information will be kept in locked files at all times. Data will be kept for 10 years.

However, we do need to inform you that the confidentiality of the information you provide can only be protected within the limitations of the law - i.e. it is possible for data to be subject to subpoena, freedom of information claims or mandated reporting. Due to the nature of the study, the fact that only a small number of people will be interviewed may also make it difficult to maintain confidentiality.

Who is organising and funding the research?

The research is being conducted by K McCallum as a research student at Oxford Brookes University, in the school of nursing, faculty of Health and Life Sciences .

Who has reviewed the study?

The research has been approved by the University Research Ethics Committee, Oxford Brookes University.

What if I have a question or complaint?

If you have any questions regarding this study please contact the researcher, K McCallum on ***16113566@brookes.ac.uk or 07773280426.***

The supervisory team can be contacted as follows:

Helen Aveyard, Director of Studies: ***haveyard@brookes.ac.uk***

Helen Walthall, Supervisor : ***hewalthall@brookes.ac.uk***

Debra Jackson, Supervisor : ***Debra.Jackson@uts.edu.au***

Concerns regarding the conduct of the study should be addressed to the UREC Chair at ethics@brokes.ac.uk .

To request a copy of the data held about you please contact 16113566@brookes.ac.uk.

If you are happy to take part in this study, please sign the consent sheet attached.

Many thanks for reading this information sheet.

Appendix 4: Consent form

CONSENT FORM

Full title of Project: ‘Exploring the experience of death in the emergency department: a phenomenological study

Name, position and contact address of Researcher: Kay McCallum, doctoral researcher , OxINMAHR, Collonade Building, Oxford Brookes University.

16113566@brookes.ac.uk

07773280426

Name of Researcher:

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated **06.10.19** (version **4**) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my future medical care or legal rights being affected. ☐

3. I understand that I will be audio-recorded during this interview ☐

4. I understand that all efforts to maintain confidentiality will be made, however there may be a risk of what I say being leading to identification of myself or my loved one. I also understand that confidentiality can only be maintained within the limits of the law . ☐

5. I agree to the use of anonymised quotes in publications

   Yes / No (*please indicate)*

6. I agree that my data gathered in this study may be stored (after it has been anonymised) in a specialist data centre and may be used for future research.

   Yes/No (*please indicate)*

7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent.	Date	Signature

K J McCallum

161113566@brookes.ac.uk

07773280426