Death, Dying and End-of-life Care Provision by Doctors and Nurses in the Emergency Department - a Phenomenological Study

by

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List of Abbreviations

ACEM	The Australasian College for Emergency Medicine
ACP	Advance Care Planning
CENA	College of Emergency Nursing Australasia
CP	Constitutive Pattern
EN	Enrolled Nurse
EOLC	End-of-Life Care
EOL	End-of-Life
GOC	Goals of Care
GOPC	Goals of Patient Care
ICU	Intensive Care Unit
NHRMC	National Health and Medical Research Council
PC	Palliative Care
RN	Registered Nurse
SBREC	Social and Behavioural Research Ethics Committee
WHO	World Health Organisation

Glossary of Terms

Eidetic	Ability to recall an experience in exact detail so that when the experience is retold, it re-awakens a sense of commonality with the other.
Heresy	Historically, heresy is a criminal offence often punishable by death. An individual is believed to be guilty of heresy when they go against the fundamental beliefs of a religious group or if they display behaviour that opposes a religious doctrine.
Medicare	A health benefit scheme that Australian residents and citizens are entitled to. It allows Australians to access healthcare at an affordable cost or free of charge. It also covers the cost of screenings, tests, scans, and some medications. Medicare does not cover ambulance services, dental costs, cosmetic surgery, glasses, contact lenses, and hearing aids.
Medieval	A period also known as the Middle Ages. It was also called the age of faith because religious beliefs were prominent and attached to every incident, including one of the major occurrences of the time, The Black Death.
Pathic	To understand another person’s experiences and empathise when a deeper understanding is gained.
Taboo	Actions and words that are prohibited based on cultural and societal norms. In the context of death and dying, death as a taboo is culturally hidden away and silenced.

Abstract

Background: Prior to the first half of the 20th century, death, dying, and end-of-life care was very much a family and community affair. People died within their own home, often surrounded by family, and loved ones. In later years, death and dying was classified as a social problem, and like most social problems of the time, institutionalisation was believed to be the gold standard of treatment. Death, dying, and end-of-life care have now been brought into institutions such as hospitals. At the same time, there have been significant advancements in the fields of medicine, demography, and pathology. These disciplines have contributed to the classification and control of death and dying. People are now living longer with numerous co-morbidities and there is a significant ageing population. Consequently, there have been increases in the numbers of people who present to emergency departments across Australia seeking access to care at the end of life. Emergency department staff must have the knowledge and skills required to provide end-of-life care in a setting that traditionally contradicts the goals of comfort care. With the increase in demand for end-of-life care in emergency departments, a gap exists in the experiences of how staff provide such care in this setting. As a result of this gap, it is important to understand the lived experiences of emergency department doctors and nurses who provide end-of-life care.

Aim: The aim of this research is to understand the lived experiences of emergency department doctors and nurses concerning death, dying, and end-of-life care provision.

Methodology: A phenomenological research method is used in this thesis. A qualitative methodology has been employed using Han-George Gadamer’s hermeneutic phenomenology. The use of Gadamer’s hermeneutic phenomenology has assisted the researcher to establish an understanding and create meaning out of emergency department staff experiences. Data were analysed using Diekelmann’s seven step analysis to support Gadamer’s phenomenological approach. Gadamer’s key phenomenological concepts of constant dialogue, fusion of horizons, language, experiences, truth, prejudices, and hermeneutic questioning were used.

Findings: An analysis of the 16 interviews resulted in the identification of 4 major themes and 14 sub-themes: (1) ‘providing care with respect and dignity’, with the associated sub-themes of ‘dignifying deterioration and death’, ‘respecting culture, beliefs and values’, and ‘the meaning of the participants’ culture, beliefs, and values’; (2)

‘ethical dilemmas’, with the associated sub-themes of ‘treatment decisions’, ‘relinquishing care’, and ‘experiencing dilemmas’; (3) ‘providing for end-of-life care in an emergency department and the role of the participants’, with the associated sub-themes of ‘role perceptions’, ‘the intensive nature of the role’, ‘emotional burden’, and ‘emergency department-end-of-life role integration’; and (4) ‘experiencing conflict’, with associated sub-themes of ‘time and environment’, ‘family’, ‘advance care planning’, and ‘resolving conflict’.

Conclusion: From the findings, the complexities of decision-making as an overarching theme across all four major themes emerged as a constitutive pattern. This constitutive pattern showed that this study has provided an in-depth interpretation of how emergency department staff navigate the difficulties experienced in balancing complex decisions about treatment options. Gadamer’s fusion of horizons was widely integrated into the study. The findings of this study have significant implications for medical practice, nursing practice, and the overall emergency department governing bodies that focus on improving end-of-life care outcomes for patients, families, and emergency department staff.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed..

Oluwatomilayo Omoya

23 February 2021

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Prologue

I belief death, dying, and end-of-life care (EOLC) within the emergency department (ED) is a vital aspect of ED work. My preunderstanding of the topic is also that providing quality EOLC to patients and their families in a setting that often opposes EOLC is a challenge. However, for some patients and their families, when quality EOLC is provided to meet their needs, the experience becomes a positive one. Even so, death, dying, and EOLC occurs at a difficult time, so I always strive to make the experience a positive one for patients and their families. Due to my experiences, and the challenges I have faced in ED when attempting to provide EOLC, I am interested in other ED doctors' and nurses' subjective meanings of death, dying, and EOLC.

My experiences of the same phenomenon mean that the experiences of the participants and my own can connect, as we become co-constructors of meaning. In the end, every participant in the project described the same phenomenon from different viewpoints making meaning through discourse (Moustakas 1994). Contrary to quantitative methods where distance is created between the participants and the research question, qualitative research is participatory. In my use of Gadamer's hermeneutic inquiry, the participants are co-researchers and I was one of the participants (Gadamer 1975; Moustakas 1994).

Guided by Gadamer's hermeneutic philosophy and Diekelmann's hermeneutic analytic approach, the constructs of the participants' experiences of death, dying, and EOLC often resonated with mine, and I was able to better understand what these experiences were like for the participants; in this way, new understandings were formed (Gadamer 1975; Diekelmann et al., 1989). As a result, I have learnt to be open and sensitive to the life worlds of others and to explore how the meanings I take for granted contribute and enrich our everyday lives. I have discovered Gadamer's key concepts of experience, language, truth, questioning, and fusion of horizons, which are woven throughout the thesis.

Chapter 1: Introduction

1.1 Synopsis of the study

This thesis presents the experiences of emergency department (ED) doctors and nurses concerning death, dying, and end-of-life-care (EOLC), using Gadamer's hermeneutic phenomenological underpinnings. Gadamer's main aim was to reveal how humans come to an understanding of truth that is impossible to access using the scientific method. In Gadamer's *Truth and Method*, the discovery of understanding of any phenomenon does not belong to a set of meanings (Gadamer 1975).
Nevertheless, differences within meanings need to be acknowledged because there is a cultural/historically affected consciousness that shapes individual experiences (Gadamer 2004). Therefore, Gadamer argued that understanding cannot be established without knowledge of past historical experiences. For Gadamer, the interpretation of text needs to be undertaken through a fusion of horizons (Gadamer 2001), in which the text and the interpreter's horizons need to come together to establish a single horizon, each informed by the other's historical context. Language is the medium through which each horizon produces understanding (Gadamer 2004). Gadamer acknowledged that understanding is subjective, and that individuals will have various interpretations of subject matter. These various interpretations result in a richer understanding of the phenomenon (Fairfield 2012). In this chapter, the historical context of hospice and palliative care in Australia is explored to understand current practices around death, dying, and EOLC.

1.2 History and current practices of Hospices

In the sixth century, the Benedictine monks were popular for their hospices. These began as places of refuge and comfort, especially for pilgrims who were fatigued and exhausted (Abu-Saad & Courtens 2001). Gradually, the hospices also began to provide refuge for the weak and sick (Milicevic 2002). Consequently, this increasingly led to care of terminally ill patients (Abu-Saad & Courtens 2001), who found a resting place in the hospices. However, medical practice was very basic as it was not the key focus of the hospice; instead, the care provided was based on the philosophical underpinnings of palliative care such as the provision of comfort, food, warmth, and kindness. Specifically, spiritual, and religious services were offered when cure was impossible (Abu-Saad & Courtens 2001).

Early hospices were founded on Christian religious beliefs, and despite the number of hospices that had been established, the majority continued to adhere to Christian values and traditions (Abu-Saad & Courtens 2001; Currow & Phillips 2013). However, of central concern for modern palliative/hospice care specialists is how problematic it is to adhere to Christian traditions for those of non-Christian faiths and for people from minority ethnic communities who need hospice care (Abu-Saad & Courtens 2001). Despite this criticism, the overarching principles of the hospice, to facilitate a good death and to develop ideas through research and practice, sole devotion to the care of dying people and their loved ones remains the priority (Allen 2008). Thus, a hospices' narrow focus enhances better provision of EOLC in comparison to other institutions such as hospitals and nursing homes (Becker 2001; Abu-Saad & Courtens 2001).

1.3 Palliative Care (PC) in Australia

In Australia, about 40 years ago, palliative care began from the modern hospice and has since rapidly evolved (Currow & Phillips 2013). Such care began in Australia due to the recognition of the poor quality of care for people who were dying, and to better improve the care provided to terminally ill patients and their families (Howarth 2007). By the early 1970s, the major hospice providers in Australia were the Little Company of Mary, the Sisters of Charity, and the Deaconess Society (Currow & Phillips 2013). Approaches to care for the dying patient were centred on the traditional model of care from the hospices of the early-middle ages which aimed to ensure that the dying, who were often stigmatised, had a place of refuge and shelter (Howarth 2007). In later centuries, hospitals increasingly became focused on curative medicines which had a negative impact on the provision of holistic care, which was the focus of the earlier hospices and hospitals (Abu-Saad & Courtens 2001).

Palliative care emerged to shift the focus away from the institutionalisation and medicalisation of death of the late 19th century. The term 'palliative care' was gradually introduced as a synonym for hospice care (Johnston 2005). Palliative care originates from the Latin word to *pallium*, which means to cloak or cover (Johnston 2005). Symbolically, the word means to cover up an end of life care patient with a cloak for warmth, comfort, and protection (Becker 2001). In other words, symptoms are cloaked and covered with care and appropriate treatments. Thus, the sole aim is to promote patient comfort.

Remarkable growth in palliative/hospice care took place in western societies in the late 20th century. In Montreal, Canada, the first palliative care service was opened in the Royal Victoria Hospital in 1975 (Scott et al., 2016). The period of the 1970s through to the 1990s saw a remarkable expansion of palliative /hospice care programmes in countries such as Australia, the UK, Europe, and North America (Furst & Radbruch 2016). Within a few years of the first hospice to open in Australia, the number of hospices/palliative care programmes increased to over 240 (Noble & Winslow 2016; Abu-Saad & Courtens 2001; Howarth 2007).

In contemporary times, palliative care as an approach to providing EOLC is not without its own challenges, especially around inequalities in access to palliative care when the disease is not cancer (Mitchell et al., 2010). Misconceptions exist that palliative care is mainly for cancer-related diagnoses; however, Australia has an ageing population, and more people are dying of expected deaths due to chronic co-morbidities than they are of non-malignant or cancer-related conditions (Wiseman 2016). The Australian Institute of Health and Welfare report on the leading causes of death for the years 2005-2007 highlights the underestimation of the contribution of chronic diseases to mortality (Bishop & Tyas 2007). Chronic diseases such as cardiovascular disease, chronic obstructive pulmonary disease, renal failure, musculoskeletal conditions, and mental and behavioural disorders were all major causes of mortality in Australia. According to Mounsey et al. (2018), patients with non-cancer illnesses who are also at the end stage of their disease process, have similar needs to patients with cancer and thus require palliative care. Therefore, the social justice notion of palliative care that covers those with a burden of disease other than cancer in palliative care needs greater attention, and services need to be extended beyond cancer.

To further develop the field of palliative care, international congresses on palliative care are held to share experiences and research findings. Thus, international, and national organisations such as the European Association for Palliative Care, Palliative Care Australia, and the National Hospice Organisation in the USA have been established. These organisations collaborate through shared knowledge and experiences of palliative care. At the same time, palliative care (and its principles) is now a major field of knowledge as evidenced by its range of published journals, textbooks on palliative medicine and palliative care, and the establishment of palliative medicine as a field of its own at universities across Australia, Canada, and the UK.

1.4 Principles of palliative care

The guiding principles of palliative care are embedded within the numerous definitions of palliative care provided in this section. In the 16th century, the first definition of palliative care was used firstly in medicine to describe the alleviation of suffering. Over the centuries, this definition has remained the stem from which all other definitions have been built, broadened, and established. As the modern palliative/hospice movement was ushered in, its definition and principles broadened. Palliative care was originally defined as:

> *The management of patients in whom death is almost certain and not too far off, where the control of symptoms is the prime clinical objective and the emotional and spiritual preparation of both patients and family is given high priority (Abu-Saad & Courtens, p. 6).*

From this definition, palliative care can be seen to focus on symptom control rather than cure, with due consideration being given to the psychological and spiritual aspects of care. At the same time, palliative medicine has been gaining ground and is now seen as a formal medical specialty of its own (Noble & Winslow 2016; Abu-Saad & Courtens 2001). Stemming from the first definition from the 16th century, in which the alleviation of suffering was the major focus, the principles of palliative medicine were broadly defined as:

> *The study and management of patient with active, progressive and far-advanced diseases for whom the prognosis is limited, and the focus of care is quality of life (Abu-Saad & Courtens p. 6).*

Both definitions provided in the preceding paragraphs place emphasis on the concept of care rather than cure. Within both definitions, the fundamental principles of palliative care are highlighted. However, the definition provided by the European Association of Palliative Care and the World Health Organisation (WHO 2020) has been significantly broadened to recognise the remarkable impact of an interdisciplinary team (doctors, nurses, pharmacists, social workers, therapists, clergy, volunteers etc.) required to provide quality end-of-life care (Higgins 2010). First, the definition of palliative care by the European Association of Palliative Care states that:

> *Palliative care involves the provision of active total care when disease is not responsive to curative treatment. Palliative care neither hastens nor postpones death; provides relief from pain and other distressing symptoms; integrates the psychological and spiritual aspects of care and offers a support system to help*

> *the family cope during the patients' illness and in bereavement (Abu-Saad & Courtens p. 6).*

Further broadening the above definition, the WHO (2020) defines palliative care as an approach to care that:

> *Improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social, or spiritual. The quality of life of caregivers improves as well. Palliative care involves a range of services delivered by a range of professionals that all have equally important roles to play including physicians, nursing, support workers, paramedics, pharmacists, physiotherapists, and volunteers in support of the patient and their family.*

Arising from the above definition, the WHO (2020) provided guiding principles to further define palliative care. Some of these guiding principles are provided below:

Table 1. 1: Principles of palliative care

Principles of Palliative Care	1.) Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness.
	2.) It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.
	3.) Addressing suffering involves taking care of issues beyond physical symptoms
	4.) Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.

In summary, the principles guiding palliative care are rooted in its various definitions beginning from the 16th century till the present day. One common theme, however, is the significant emphasis placed on the provision of holistic care (Buckley 2008).

Holistic care not only attends to the physical (biological) comfort of the terminally ill patient, but also gives due care to the psycho (emotional), social, and spiritual aspects of dying. Indeed, all the definitions and principles put forward have emphasised the alleviation of suffering and the provision of comfort, with less of a focus on curative therapies. As previously stated, EOLC is increasingly prevalent in EDs, which is an area of healthcare that strongly focuses on life-saving or life-prolonging measures. Despite its opposing aims, patients who require EOL and palliative care will present to an ED to access services. Thus, it is important that ED doctors and nurses can care for patients who require EOL and palliative care, even in the ED setting.

1.5 Death, dying, and EOLC in the ED

In western industrial societies, during the 20th century, as science increasingly gained ground, death and dying were increasingly viewed as a break with life rather than a part of life (Backer et al., 1982). Death and dying both became frightening and fascinating (Backer et al., 1982). Death was associated with uncertainty and disorder. In line with the scientific view of the time, the resolution to the uncertainty of death and dying was to control these processes (Howarth 2007; Backer et al., 1982). In attaining control, death and dying gradually became medicalised; hence, the increase in presentations to EDs.

The ED is generally the first point of contact for patients who need healthcare services, serving as a specialty for critical conditions and traumatic events, with the primary aim of providing curative treatment. There is a misconception by the general public and ED staff that death is often not expected within the ED, and that people who seek medical intervention from EDs are primarily seeking curative measures (Smith et al., 2009; Beckstrand et al., 2012). On the contrary, people who have chronic illness trajectories often know that death could happen at any moment, and yet, also seek medical intervention from the ED. Patients with incurable chronic illnesses and EOLC needs access EDs because they are an important mode of entry to accessing EOLC and symptom management. Therefore, EOLC still needs to be given in an area designed to save lives.

EDs have evolved over time and now serve as a gateway to accessing medical treatment for diverse patient presentations that include those who will die in the ED from various causes. As a result, emergency staff work hard to identify and stabilise the presentation of acute conditions with an emphasis on urgent interventions and the initiation of treatment and procedures in a timely manner. Many people come to the ED with life-threatening conditions, or for the control of symptoms at the EOL. According to the Australian Institute of Health and Welfare (2018), of the 7.5 million presentations to EDs in 2015, approximately 16% either died in the ED or were dead on arrival. People at the end of life often have an acute crisis, and admission to the ED is a common pathway to accessing EOLC (Kenen 2010). Despite the significant amount of contact with the dying patient, accepting death and the provision of quality end-of-life care within the ED remains difficult (Kenen 2010; Chan & Malone 2006). ED doctors and nurses still lack the knowledge and skills required to adequately care for people at the end of life (Grudzen et al, 2012; DeVader et al, 2012). One reason for this is the focus of emergency education on saving lives, with little or no emphasis on EOLC (Smith et al, 2009).

1.6 Research Aim

The aim of this research is to understand the experiences of ED doctors and nurses concerning death, dying, and EOLC, and to further interpret these experiences as described by the doctors and nurses who work in the ED setting.

1.7 Research Question

Guiding the research aim are the broad questions that this study will answer:

- *What are the barriers and facilitators to providing quality EOLC within the emergency department?*
- *What are emergency doctors and nurses educational and formal training needs for EOLC and palliative care skills?*
- *What is the role of palliative care within the emergency department and is it clearly defined?*
- *What are the attitudes, experiences, and beliefs among emergency care doctors and nurses regarding the provision of EOLC in the emergency department?*

1.8 Significance of the study

Death and dying is inevitable; everyone will eventually die. Even though this is an indisputable fact, the topic of death is still viewed as taboo (Kirshbaum et al., 2011). It remains an issue that is likely not up for discussion within the social arena (Zimmermann 2007; Zimmermann 2012). Generally, the society we live in (especially western society) is one in which we fight against death (MacArtney et al., 2014). The reason for this is due to the medicalisation of health that allows interventions that prolong life (Tieman et al., 2018; Koksvik et al., 2020). Over the past 20 years, the percentage of older adults in

Australia has grown from 300,000 to over 3 million (ABS 2010). In most cases, advances in healthcare mean that there are new technologies and life-saving medications readily available to prolong life and to temporarily stave off the inevitability of death (Tieman et al., 2018). In addition, as people are living longer, there is a significant ageing population also living with many comorbidities (ABS 2010). All these reasons have led to an increase in presentations to EDs (Beckstrand et al, 2012; Smith et al, 2012).

Patients who present to the ED seeking EOLC are considered as a low priority, as emergency care and staff are directed towards more acute and critical situations (Smith et al., 2009). Once a patient's 'do not resuscitate' (DNR) order has been agreed upon, both medical and nursing attention declines rapidly (Chan 2005). This declining attention should not be the case because patients and their families at the EOL do need holistic care (Bailey et al., 2011). The holistic care needed at the EOL requires a different set of medical-nursing skills and knowledge (Bailey et al., 2011).Time needs to be spent with both the patient and their families to develop rapport, establish a relationship, and promote comfort (physical, emotional, mental, spiritual, and psychological comfort) (DeVader & Jeanmonod 2012). Also, pain management, symptom control, and palliative care specialist referrals are required for the patient (Crossno 2004).

The research has shown some of the challenges that ED nurses and doctors encounter, including high workloads that may restrict the time and attention needed to provide quality EOLC (Chan 2004; Heaston et al., 2006; Smith et al., 2009; Beckstrand et al., 2012). In addition, the setting and design of most EDs does not allow for privacy for the dying patient and their families, especially when providing sensitive information at the EOL (Chan 2004). Most have cubicles demarcated by curtains, and information can be heard by people within proximity. Emergency staff not knowing the patient's wishes, and the holding of unrealistic expectations of care by both the patient and their families, all make EOLC provision highly challenging (Beckstrand et al., 2012).

Death can be expected or unexpected in the ED. Therefore, when there is impending death, the life-saving model of treatment is not beneficial and EOLC becomes crucial. Emergency nurses and doctors may need to abandon their knowledge and skills of aggressive and life-saving treatment to promote comfort and EOLC. Traditionally, ED nurses and doctors are not trained in providing EOLC (Schears 1999). Emergency departments are known for their life-saving measures, as medical treatment is tailored to the prevention of death and the prolonging of life. However, death is not an uncommon occurrence within the ED. Despite the aggressive treatments and life-saving measures that are provided to patients, death still occurs and there is a lack EOLC knowledge and skills in such settings (Devader & Jeanmonod 2012; Chan 2004). Emergency nurses and doctors need to be well-equipped in providing symptom management, identifying patients with palliative care needs, and initiating palliative care consultations.

Emergency nurses and doctors may personally feel uncomfortable with discussions about palliative care (providing comfort care and avoiding aggressive treatments), because they may want the patient to live. This wish could be due to a lack of confidence in the assessment and prognosis of the patient, fear of litigation, and lack of information about the goals of care (Devader & Jeanmonod 2012). Therefore, exploring these areas is crucial for informing EOLC practices of ED staff. The findings of this study will assist ED staff to identify areas of care that need improvement, so that quality EOLC can be provided to patients and their families.

1.9 Overview of Chapters

Chapter 1 has provided a brief overview of the background and significance of the study. These components have been explored to establish the foundation for the remaining chapters. In this chapter, a brief introduction to the methodology used has been given. In addition, a brief exploration of the literature has been introduced to establish the significance of the issue. The gap identified in the research literature provided the justification for the present study, and finally, the historical basis of hospice/palliative care and its principles were explored as well as how these have had an impact on current ED EOLC practices.

An historical account of death, dying, and EOLC practices will be undertaken in Chapter 2 by exploring thanatology. In this chapter, the historical practices, the socio-cultural factors, and contemporary theories around death and dying will be examined to enable an understanding of current practice, and whether historical practices around death and dying are still present in contemporary societies today or otherwise. This chapter will contribute to the theoretical basis of the study.

A review of the literature will be presented in Chapter 3 by identifying the current research literature that addresses ED doctors' and nurses' experiences of death, dying, and the provision of EOLC. Relevant literature will be selected based on the inclusion criteria. The findings of the literature review will be presented using a thematic analytic approach. Any limitations of the review will be identified as well as the implications for ED staff EOLC practices.

Chapter 4 discusses the methodological and theoretical underpinnings of the study. This chapter will explore the key concepts of Gadamerian hermeneutic phenomenology and will use these to address the experiences of ED staff. The contributions made by other phenomenologists and how these have shaped Gadamer's approach to phenomenology will be discussed in detail. The use of Gadamer's phenomenology in conjunction with some elements of phenomenology, as described by Van Manen, will be justified.

Chapter 5 presents a detailed discussion of the hermeneutic research analysis method. Diekelmann et al's (1989) interpretive hermeneutic method will be used to analyse the data. Details of the ethics approval process, the research participants, data collection, and the data interpretation and analysis will be explored in depth. Issues around ethical considerations and trustworthiness will also be addressed.

Chapter 6 will explore Part A of the major findings of the study. Through the use of Diekelmann et al's (1989) approach to data analysis, Part A will discuss the first two major themes: 1) Providing for respect and dignity, with three sub-themes of: a) *Dignifying deterioration and death; b) Respecting culture, beliefs, and values;* and *c) The meaning of the participants' culture, beliefs, and values;* and 2) Ethical dilemmas, which will be explored through three sub-themes: a) *Treatment decisions; b) Relinquishing care;* and *c) Experiencing dilemmas.* These sub-themes will be discussed under each major theme to provide greater depth and understanding of the major theme.

Chapter 7 presents Part B of the findings and will explore the remaining two major themes: 1) Providing for EOLC in the ED and the role of the participant, and four sub-themes: *a) Role perceptions; b) The intensive nature of the role; c) Emotional burden; and d) ED-EOLC role integration.* The second major theme is: 2) Experiencing conflict, through four supporting sub-themes: *a) Time and Environment: Barriers to EOLC; b) Families; c) Advance care planning;* and *d) Resolving conflict.* This chapter will provide an understanding of the challenges that EOLC poses in the ED setting.

Chapter 8 interprets the findings in the context of the available evidence on the experiences of ED staff to refute or support the findings of the study. This is where the new findings will be presented. The code of ethics statements, Gadamer's philosophical concepts, and thanatological principles will be used to discuss the findings. Gadamer's key concept of fusion of horizons will be used as the researcher discusses personal experiences to affirm common understandings. In this chapter, the constitutive pattern as a requirement of a hermeneutic analysis will be addressed in detail.

Chapter 9 summarises the main points discussed in the study and provides a concluding analysis of the thesis. The significance of the findings and recommendations for future research will be addressed. The findings will be summarised and implications for the relevant fields of knowledge will be discussed.

This chapter has introduced the hermeneutic phenomenology of Gadamer as the philosophical underpinning of this thesis. It has also presented the context of hospices and palliative care in Australia and how this has led to the current practices of EOLC in EDs, the research aim, the significance of the thesis, and an overview of the chapters. Chapter 2 will present a diverse historical underpinning of death, dying, and EOLC practices, and its significance for current EOLC provision by ED staff in Australia.

Chapter 2: Thanatology

This chapter presents the topic of thanatology, which is the scientific study of death and its associated practices, including the study of the needs of the terminally ill person and their family (Kastenbaum, 2009). Firstly, aspects of death and dying will be presented through a historical lens. Secondly, the current major causes and mechanisms of death are discussed, as these trends inform current thinking around death and dying. Thirdly, the socio-cultural aspects of death and dying are discussed and how these shapes the norms and traditions surrounding the death and dying process in western society. Finally, the chapter will discuss how these theories, both past and present, provide a theoretical basis for the study of doctors' and nurses' experiences of death and dying in the ED setting.

2.1 An historical perspective

Death, dying, and EOLC practices have their roots in history, both in the western and non-western world. This aspect of the chapter addresses beliefs, attitudes, and before and after death practices. This section explores the changes in death rituals and beliefs over the centuries. Death practices from countries in Africa, Asia, Europe, Indigenous and non-Indigenous Australia, South America, and early Melanesian society will be explored as a basis for comparison. The historical perspective explored in this chapter presents the practices and attitudes exhibited towards death and dying from primitive times, through the eras of ancient civilisations, into the Middle Ages, and through to the 21st century.

2.1.1 Primitive times (4000 BC-3000 BC)

In primitive times (4000 BC-3000 BC), illness, disease, and death were believed to be inflicted by supernatural causes in the form of unseen spirits and gods, even though death was often caused by famine, attacks from wild animals, and from rudimentary medicinal practices (Clements 1932; O'Gorman 1998; Helman 2007). Superstition, myth, religion, and magic were used to explain death (Malinowski 1948). At the time, primitive people believed that spirits, which were mischievous and vengeful, were the main cause of death in individuals who had done wrong (O'Gorman 1998).

Similarly, illness, disease, and death were a form of punishment from the gods (Clements 1932). Therefore, tribal witch doctors treated illnesses with ceremonies (ritual chanting), and sacrifices were often offered to appease the gods and avoid death as a punishment (O'Gorman 1998). However, in some cases, confessions and the acknowledgement of sin was recommended as treatments for recovery from illness and disease, and thus, could avoid the ultimate punishment of death (Clements 1932). Additionally, herbs and plants were used as medicines (morphine and digitalis) by witch doctors (Clements 1932). The primitive treatments of the time significantly resulted in many deaths (Gorman 1998). Life for humans was brutal, traumatic, and short, with the average lifespan being 20 years of age (Malinowski 1948).

Regarding attitudes to death in primitive times, early humans did not flee from death (Moore & Williamson 2003). Nevertheless, recurring confrontation with the death of others often stirred up a range of emotions from horror at the sight of a corpse, to feelings of fear and loss for the dead (Malinowski 1948). To deal with the fear of death and dying, the living used religion and magic. Again, religion was also used to appease the gods and the ancestors (Malinowski 1948). Supplications and prayers were directed to a god to gain power of life over death (Helman 2007), while magic was believed to be a means of transferring power from the hands of death into the magician's hands and, in turn, to gain control over the spirits and forces that caused death in humans (Moore & Williamson 2003). It appears that from the earliest of times, humans have used beliefs (religion) and control tactics (magic) to overcome their fear of death.

Even though early humans instinctively feared death, they also believed that another way to gain control over death was to perform human sacrifices to the gods (O'Gorman 1998). The intentional killing of another human was a way to confront death and the fear associated with it (Rivers 1926; Moore & Williamson 2003). Human sacrifices can be described as a way to show death that they had no fear of it. Often, ceremonies and magic practices to alleviate anxieties and fears were performed before a killing was carried out (Moore & Williamson 2003). The people (priests and witch doctors) who performed ritual killings and sacrifices were esteemed within societies and viewed as powerful, because they had power over death (Malinowski 1948). In the same way, participation in the killings by other people allowed them to identify themselves with death and to understand what the mystery of dying looked like (Moore & Williamson 2003). Thus, witnessing and performing the killings made the power behind death recognisable and not mysterious or fearful after all.

Further to this, in early primitive societies, death was understood as a gateway to the afterlife (Rivers 1926). The reason for this was that primitive societies at the time were intellectually incapable of grasping death as the total extinction of a being (body, soul, and spirit) (Moore & Williamson 2003). Even though their imagination was deep and sustaining, they tended not to be elaborate (Kerrigan 2007). In other words, the ability to view the body as just a vessel that would never exist after death was unfathomable at the time. Another reason for this was due to the experience of day, night, sunshine, rain, summer, and winter which suggested to early humans, the existence of a dualism i.e. two kinds of reality: material (physical) and immaterial (spiritual) (Malinowski 1948; Meixner 2017). This concept was also used to explain that there is a part of humankind called the soul (spiritual) which existed in the afterlife even when the body (physical) decayed (Malinowski 1948). The experience of dreams by individuals at the time, further consolidated the belief that there was an unseen spiritual aspect to death (Rivers 1926; Moore & Williamson 2003). The figures of the dead seen in dreams and visions were believed to be the surviving souls of the dead, thus confirming the existence of the soul after death in early human societies (Tylor 1871). In present times, some cultures such as Indigenous Australians believe in ancestral visitations. Aboriginal Australians believe that the spirit of the deceased and the spirit of the ancestors often communicate and reveal messages to the dreamer (Glaskin 2005).

To the primitive human, life after death was just as real as the existence of life here on Earth (Rivers 1926). For example, the primitive culture of death in early Melanesian society (Vanuatu, Solomon Islands, Fiji, and Papua New Guinea) used the word *Mate,* meaning dead, to address an individual who was seriously ill and likely to die, as well as someone who was healthy but very elderly, with the belief that if the individual was not dead, they were meant to be dead ‘by now’ (Rivers 1926). This belief illustrates that death was not viewed as unique or as a catastrophic event that stood out more than any other event. Instead, death was seen as a mere condition of passing into another life, or as a transition from one existence (life on Earth) to another form of existence (the afterlife), much like any other transition at the time (Rivers 1926). For example, ceremonies held for the transition of a boy to manhood were no more or less unique than afterlife ceremonial transitions (Rivers 1926; Kerrigan 2007). In the same way, an elderly individual who was considered dead enough would have ceremonies and burial rites performed for them while they were still very much alive (Rivers 1926). Therefore, the living was celebrated as if they were dead; hence, the practice of burying the living in the belief that a person could both be living and dead at the same time. These practices show that life and death were believed to co-exist together and that death was not unique in itself. The quote below further explains the view that an individual who was dead was very much like the living:

> *The dead come to him and he sees, ears and talks with them; he goes to visit the dead in their home and returns to tell his fellows what he has seen and heard and done, and his story is believed, and he believes in it himself, just as fully as if it had been an account of a journey to some country of the living (Rivers 1926, p. 48).*

From the above quote, the primitive human believes the spirit of a dead individual (a ghost) to be like any other living person (Rivers 1926). A ghost in the primitive era could eat, drink, cultivate the land, and go to war like any other living human, and the intriguing part of this, is that they could also die again (Rivers 1926; Tylor 1891). Hence, life after death existed as life before death, and this belief was very real to the primitive individual (Kerrigan 2007). In the same manner, it was believed that whatever happened to the living on Earth also happened to the dead in their afterlife existence. From there onwards, primitive people began to form ideas and beliefs about the afterlife, and the soul and its destination. Primitive ways of comprehending death began to build the basis for ideas about death and dying as the era of the ancient civilisations approached. Overall, in primitive times, the existence of life after death was established and, as the ancient era approached, the dominant phenomenon in relation to death and dying was the importance of performing rituals and rites of passages for the deceased.

2.1.2 Ancient times (3000 BC-AD 410)

In the ancient era (3000 BC-AD 410), life after death increasingly became a fascinating phenomenon that was accompanied by numerous rituals and rites of passage (Kerrigan 2007). At the time, death was not perceived as a single incident, but involved a process through which the spirit of the deceased was transferred slowly from the land of the living to the land of the dead (O’Gorman 1998). However, the successful transfer to the land of the dead had to be marked by crucial rites and rituals of passage, otherwise the spirit of the dead was said to be in limbo (Fonseca & Testoni 2011). In the ancient Zoroastrian tradition (in parts of Central Asia), it was believed that the soul did not ascend to heaven at the moment of death, but that it hovered in the vicinity for three days waiting for the completion of a particular ritual (Toynbee 1968; Kerrigan 2007). The ritual involved allowing time for crows and vultures to eat the flesh of the deceased, leaving the skeletal remains to be buried (Toynbee 1968). Only then could the journey to the afterlife begin.

Ancient societies however had their own ways of living, and hence, a range of different rituals for death. In many ancient cultures, the deceased were not considered to be truly dead until a complete decomposition had occurred; thus, the practice of reburial found in the Madagascan tradition of *famadihana,* where the body was exhumed and the bones reburied for a final burial (Kerrigan 2007). It was believed that death had occurred only when the body became a mere carcass after which the soul could take flight (Kerrigan 2007). For example, the people of several outlying islands of Indonesia waited to hold second funerals of skeletal remains when the body had become completely bare of flesh, because this was when death was believed to have finally occurred (Toynbee 1968). Similarly, some ancient Australian Aboriginal tribes and the North American Lakota Sioux have been known to expose the dead on trees until they had been picked clean by birds and animals before they were deemed ready for a proper burial in a skeletal form (Toynbee 1968). Again, it was only after this ritual that a successful afterlife journey could be guaranteed.

The ancient world placed rituals of death and rites of passage at the core of public life (Di Domenico 2009). The most celebrated example was found in Egypt. Ancient Egyptians' distinctive practices in death and dying were shown through the pyramid structure, the Valley of the Kings, the tomb of Tutankhamun (a king), death masks, and mummies (the paraphernalia of pharaonic death) (Kerrigan 2007). Within the majestic structures of the pyramids lie the tombs of various pharaohs, where there was comfort and protection. Another common trend in most of these ancient cultures was that the dead were equipped and buried with what they needed for their afterlife journey (Kerrigan 2007). This was popularly known as *grave goods (Di Domenico 2009).* For example, the tomb of Tutankhamun, a young popular pharaoh who died, was buried in the pyramids. The young ruler's tomb was adorned with gold, statues, flowers, furniture, exquisite vases, precious caskets, and chariot parts (Kerrigan 2007). Burial with valuables was crucial, so that the dead could journey into the afterlife with comfort (Di Domenico 2009). Other items such as food, drink, spare clothing, and money were also buried with the dead to have enough supplies during their journey to the afterlife (Kerrigan 2007; Di Domenico 2009). In another ancient culture, *Benin* chiefs and rulers (*known as obas)* in Nigeria, were often buried with their wives, members of their household, and slaves as human sacrifices to accompany them in a smooth transition to the afterlife (Di Domenico 2009; Odejobi 2014).

Another ritual in ancient Egypt was the mummification of bodies, which was crucial for preserving the soul through the afterlife. After the dead were mummified, death masks painted with love and care were worn over the face to give the dead a human face (Di Domenico 2009). Egyptian rulers, while still alive, had their tombs already built in splendour to ensure a comfortable resting place in the afterlife (DeSpelder & Strickland 1987; Kerrigan 2007). Some pyramids were built with staircases towards the sky which would be used to journey into the afterlife. Some were buried in a foetal position so that reincarnation in the form of a new birth would be guaranteed (DeSpelder & Strickland 1987). Only when all these rituals were completed would a funeral be possible. Funerals were celebrated as grand occasions with feasts, ritual dances, prayer, and spells being chanted. After all the formalities, the body was placed into the tomb to await reincarnation (DeSpelder & Strickland 1999). This discussion shows that death at this time was essentially a public affair. Furthermore, there was a significant awareness of one's own death, with preparations being made accordingly for the time of death in the future.

Like ancient Egypt, ancient Greek rituals and rites of passage were crucial aspects of funeral practices (Spellman 2014). When rituals were not performed, there were fears of remaining on Earth as ghosts with no resting place (DeSpelder & Strickland 1987). Ancient Greeks also believed in an afterlife, but they didn't see it as something to look forward to because of the loss of life, and its joys and pleasures here on Earth (Kerrigan 2007). However, an unburied or un-cremated corpse would be unable to journey into the afterlife, hence the spirit of the dead would remain on Earth (DeSpelder & Strickland 1987; Kerrigan 2007). The ancient Greek ritual of death was a three-stage process which typically began with the laying-out of the corpse, known as the *prosthesis.* The body was washed, anointed with oil, covered with a shroud, and then exhibited on a bier sometimes for several days (Kerrigan 2007). Families, friends, and important community members all came to visit the dead (DeSpelder & Strickland 1987). Again, this shows that death was very much a public affair at this time.

The next stage of the ritual for the ancient Greeks was the procession to the cemetery where the body was placed in a cart which was followed by mourners wailing and crying (Kerrigan 2007). Of importance was the amount of people in the procession, therefore, it was not uncommon for mourners to be hired for crying, wailing, tearing of clothes, and head slapping in a histrionic show of grief (Kerrigan 2007). The last stage occurred as the dead was laid to rest in the grave or placed in a pyre and burned. The ashes were then generally placed in a jar or urn and buried. Graves were placed in family plots so that the departed could be buried with their loved ones.

Death ritual practices for ancient Romans were similar to that of the ancient Greeks. It was also crucial for the dead to be buried so that their spirits were not left roaming around as ghosts with no resting place. Individuals who had received the necessary rituals before death were classed as deities, and had their gravestones inscribed with *di manes*, meaning the ancestral spirits of the gods (DeSpelder & Strickland 1987). In other words, it was believed that they were resting within the spirit of their ancestors rather than wandering around in limbo. Real life is said to begin when all burdens had finally been laid down and the soul was free to join its ancestors. The early era discussed above demonstrated that death and dying were a punishment by a higher power; hence, the belief in the existence of an afterlife seen in the ancient times that followed. From there onwards, rites and rituals were crucial for the spirit of the deceased to journey through the afterlife into a peaceful space.

2.1.3 The Dark Ages, Middle Ages, and the Renaissance (AD400-AD1650)

As the Dark Ages, Middle Ages, and the Renaissance (AD400-AD1650) approached, the belief in the afterlife was sustained. However, in addition throughout this period, death and dying were now very much more a public affair. During this time, the attitude exhibited was one of acceptance and resignation to death (Aries 1974). These attitudes to death and dying occurred both before (in ancient times, BC3000-AD410) and during the Middle ages (AD800-AD1400) (Aries 1974; Backer et al., 1982). During this time (the Dark Ages, Middle Ages, and the Renaissance, AD400-AD1650), death and life were thought to co-exist (Backer et al., 1982). Death evoked no great fear or awe in people, as it was familiar and unhidden (DeSpelder & Strickland 1987; Backer et al., 1982). Hence, there was a collective resignation by society at the time that death was inevitable and universal.

During the Middle Ages (AD800-AD1400; the Medieval period), isolation from death was impossible due to the religious teachings and the effects of the Black Death (The Great Plague) (Backer et al.,1982; Howarth 2007). The mediaeval times (the Middle Ages) are seen by some researchers as “The Age of Faith”, hence the noticeable influence of religious teachings at the time on any phenomenon, including death and dying. Death was familiar, and anxieties about the afterlife were not prominent because of the rudimentary religious teachings of the time. From these religious teachings, the dead were believed to be asleep in Christ until the day they would be resurrected at the apocalyptic return of Jesus Christ on the last day (DeSpelder & Strickland 1987). At the time, salvation was believed to have been achieved through the church, and not only by doing good works or through freedom from sin (DeSpelder & Strickland 1987). Overall, the character of death was so familiar to the extent that there was a sense of collective destiny and death as a common fate for all people during this time.

Further to this, the Middle Ages (the medieval era) was fraught with numerous dangers due to travel, famine, childbirth, violence, and heresy (Olsen 2015; Wood & Williamson 2003). Heresy in particular was dangerous because of how religious teachings were esteemed. People who spoke against the theological or religious teachings of the Christian church were heretics in medieval Europe (Olsen 2015). The heretics such as the Jews, Muslims, and medieval Christians whose beliefs were considered to be unorthodox, were often punished, persecuted, and killed (Olsen 2015). In accordance with the religious mentality of the time, a forewarning was believed to be given before death was experienced (Aries 1974). Religious forewarning was believed to come through the prophets. For example, when Jews were warned of their impending death, they turned to the wall in an act of remorse to either avert death as a judgement, or to accept death as recorded in the old testaments of the Bible (Aries 1974).

Accordingly, death remained a public affair in such a way that the forewarning given allowed everyone, including non-family members and friends, to know that the individual would die (Werlang & Mendes 2014). All were welcome to enter the dying person’s house where they would lie awaiting death silently with acceptance and resignation (Aries 1974). In addition, the openness and familiarity of death and dying at the time brought about the popular name “tamed death”, coined by Philippe Aries (1974), a prominent early researcher in the field of death and dying. The tamed death of the Middle Ages found its meaning in acceptance and collective resignation to death and dying. In some other traditions, death was resigned to, and impending death was waited for, in the ritual position of lying down with no fear (Aries 1974). Also, some of the forewarning was through the body’s natural signs and intuition, rather than through a supernatural or magical premonition which were predominant in death and dying during primitive times (Aries 1974; Aries 1981; Malinowski 1948). Once the body showed signs of impending death, the dying person would acknowledge and anticipate their death.

In contrast to other eras (primitive and ancient), in the Middle Ages, it appeared as if there was a real sense of knowing when death was imminent by the individual who was dying, and there were no particular fears associated with knowing that death was near.

Often, most people would use their knowledge of the imminence of their death to prepare for the important act of rites and rituals (Werlang & Mendes 2014). The dying person would often organise a public ceremony to be coordinated how they had specified. Like the ancient era, rites and rituals were considered to be very crucial (Spellman 2014). Rites and rituals were religious acts conducted by a priest. Final prayers of forgiveness were offered to God to grant paradise and save the soul from the perils of hell. But when rites and rituals were not prepared for, and not performed, because death was sudden or unexpected, this was considered a bad omen just like in the ancient era (Spellman 2014). Sudden death was feared because it meant that the individual did not have the chance to turn their back on worldly ventures and focus on the divine and heavenly journey (DeSpelder & Strickland 1987).

However, during the Middle Ages, rites and rituals were often not performed, especially due to the prevalence of the Black Death, also known as The Plague, which caused a lot of sudden and unexpected deaths (Wood & Williamson 2003). The Black Death resulted in the deaths of an estimated 75 to 200 million people in Eurasia, peaking in Europe from the year 1347 to 1351 killing over 25 per cent of the European population (Backer et al., 1982; Kelly 2006; Howarth 2007). The Black Death of the Middle Ages has been marked by historians as a major turning point in history due to the significant loss of life (Coulton 1929; Martin 2001; Aberth 2005; Lenz & Hybel 2016). Uncertainty remains as to where The Plague started; however, the majority of the literature suggests that it began in Central or East Asia and was believed to have been spread by rats and their parasitic fleas, with the spread being aided by the transport of grains by sea through to Europe (Coulton 1929, Ziegler 1969; Lenz & Hybel 2016). However, death was a phenomenon that was associated with religion at the time (the Middle Ages), therefore people living in the medieval Middle Ages related the Black Death to an act of punishment and chastisements from God for the wickedness and sin committed by humans (Aberth 2005). Comparisons were often made with the Old Testament plague that was sent by God to the Egyptians for their disobedience, and the New Testament plagues in the Book of Revelation (Martin 2001).

The plague was described as an atrocious calamity attacking men and women, the rich and the poor, and the old and the young (Coulton 1929; Lenz & Hybel 2016). In other words, no-one seemed to be spared and numerous homes were left uninhabited due to the deaths. Help could not be rendered to others, because most were struck down by the plague (Aberth 2005). The plague not only attacked humans, but also animals living within the household were not spared (Aberth 2005); for example, horses, dogs, birds, and even the rats which inhabited the walls of the houses (Kelly 2006; Lenz & Hybel 2016). Some of the notable signs and symptoms of the plague which indicated an early death, were enormous tumour-like growth at the roots of the thighs and the arms and, at the same time, uncontrollable bleeding of ulcers (Ziegler 1969; Aberth 2005).

Again, in line with the religious theme of this period, medical practitioners stated that the plague could not be cured or controlled, because it was the will of almighty God (Coulton 1929; Lenz & Hybel 2016). As opposed to the prestige and power ascribed to doctors in the current modern age, due to advances in medicine and control over death, physicians at the time of the Black Death were viewed as ineffective and accused of incompetence (Coulton 1929; Ziegler 1969). Physicians became the object of jokes and were often scorned because the remedies they gave during the plague brought no relief (Aberth 2005). However, it is important to note that several of the physicians at the time contracted the disease which resulted in their deaths. The medical profession at the time also attributed the cause of the plague to astrological influences and misalignment within the universe (Aberth 2005).

Subsequently, the significant death rates lead to the co-existence of the dead with the living (Werlang & Mendes 2014). Burial sites were not located on the outskirts of the cities or along the roads (Aberth 2005). Rather, burial grounds were often inside the cities and in the residential areas where people lived (Werlang & Mendes 2014). The sight of the dead no longer seemed strange to the living. For example, burial grounds were left uncovered despite the pungent smell and multiple corpses being added and would only be covered over when full (Aries 1974). In some cases, when decomposition was completed, the bones were removed, and another individual buried in the same place (Lenz & Hybel 2016). The exposure of corpses and bones from the soil caused no surprises or discomfort, and was not looked upon with disgust, which is the opposite of what happens in the 21st century (Werlang & Mendes 2014).

From this information, it can be said that the co-existence of the dead and the living was so normal, despite the unbearable smell of exposed corpses in the burial grounds (Lenz & Hybel 2016). This revealed a situation where there was a level of intimacy between the dead and living. The intimacy expressed for the dead during this time has also been directly linked to the strong religious teachings of the Middle Ages about the resurrection (Despelder & Strickland 1999). The resurrection teachings suggested that those who had died would again be resurrected, and that families and their loved ones would eventually be reunited with each other (Despelder & Strickland 1999; Werlang & Mendes 2014). From this belief, it can be said that the living exhibited no fear because they already had a strong conviction about the certainty of what would eventually happen, the resurrection and the seeing of the dead again someday. Hence, these teachings brought comfort to the living.

As the Middle Ages came to an end and the Renaissance era (16th century) began, one-fifth of London's population in 1603 had already died from the Black Death (Backer et al., 1982). In total, over 50 per cent of Europe's population had now died (Coulton 1929; Aberth 2005). As the 17th century approached, the cause of most diseases was still unknown, and even the cause of the perilous Black Death during the Middle Ages remained unknown and many people continued to die from infections (Aberth 2005). However, death was still very much in the public arena, so much so that the living would wait among the dead to experience their own death (Howarth 2007). Evidently, people were surrounded by death, so this not only made them resign themselves to the death of others, but also helped them to accept the inevitability of their own death (Howarth 2007). An example of the acceptability of death at the time was recorded in one of Mozart's remarkable letters to his father. Mozart was a prolific and prominent music composer of the classical era from 1750 to 1820 (Bloom 1956). Towards the end of his life, in one of his many letters to his father, he wrote:

> *As death, when we come to consider it closely, is the true goal of our existence, I have formed during the last few years such close relation with this best and truest friend of mankind that death's image is not only no longer terrifying to me, but is indeed very soothing and consoling! And I thank my God for graciously granting me the opportunity (you know what I mean) of learning that death is the key which unlocks the door to our true happiness. I never lie down at night without reflecting that — young as I am — I may not live to see another day. Yet no one of all my acquaintances could say that in company I am morose or disgruntled (*Bloom *1956*; Mersmann 1972; Anderson 1996; Melograni 2007).

Wolfgang Amadeus Mozart, letter to his father, April 4, 1787.

The above quote encapsulates the general view of death and dying at the time which was characterised by a sense of resignation towards one's own death. There was a resolution expressed in the quote by Mozart that death was looked forward to with no fear. The writer had come to accept the imminence of his own death. In keeping with the religious theme of the time, Mozart believed in God and went on to further acknowledge God as the one who gave him the grace to accept death. This can be attributed to the final rites of appeasing God, so that all the worries of life would be left behind, and a place in paradise would be granted by God. Furthermore, death was close to the author like any other event, in that there was no discomfort or unease expressed. Instead, it was total acceptance.

Before the end of the 17th century, the microscope was invented by Anton van Leeuwenhoek (1632-1723), thereby allowing physicians to see disease-causing organisms for the first time (Karamanou et al., 2010). Following this discovery, the very first vaccination against smallpox was developed by Edward Jenner in 1706, which caused a direct increase in the average lifespan from 20 years during the primitive era (BC4000-BC3000), to an average of 35-45 years (Riedel 2005). As the 18th century approached, the cause of the Black Death remained uncertain, but by the time the third modern plague pandemic of 1894-1930 came about, scientists had the opportunity to gain insight into the symptoms and transmission of disease (Aberth 2005). Thus, the symptoms of Black Death were found to be similar to the modern plague, which scientists attributed to a bacterium (Aberth 2005).

The discovery of penicillin in 1928 by Sir Alexander Fleming (1881-1955) was one of the most crucial discoveries of the 20th century (Tan & Tatsumura 2015). Many people were saved from infections that had previously caused the death of thousands of adults and children each year (Mourits 2017). As a result, by the end of the 19th century, the average lifespan had significantly increased to 40-50 years (Mourits 2017). In the same way, the end of the 19th Century brought significant medical advances. Wilhelm Roentgen who discovered roentgenograms (X-rays) in 1895, allowed doctors to view the inside of the body and the internal organs (Rontgen 1895). Subsequently, the polio vaccine was discovered, saving thousands of people from the virus that caused paralysis (Aberth 2005). Another breakthrough was the culture plate method, which was used to identify pathogens (Sandle 2011). In addition, the first major complex surgeries were performed, with the first successful heart transplant being undertaken by Dr.

Christian Barnard in 1968 (Cooper 2018). Robert Jarvik then went on to create the first artificial heart, and on the 2nd of December 1982, it was implanted into Barney Clark, who lived for the next 112 days (Khan & Jehangir 2014).

All these medical advances helped prevent many of the more familiar causes of death within society, and as the 20th century came to an end, the major causes of death had significantly changed. The average lifespan had increased to 40-60 years. In the 21st century, we have seen further significant advances through a range of innovative medical technologies. New life-saving advances are now readily available to prolong life. Medicine in the 21st century can determine, to some extent, when death will occur. This has resulted in a change in the attitudes of healthcare professionals (doctors and nurses), when dealing with death in the ED. This represents a change in beliefs from primitive times, when death was not a force to be stopped, to now, when death is often avoided. In some cases, death can be seen as a failure.

2.2 Past to current major causes and mechanisms of death

As previously discussed, in past centuries, death occurred rapidly due to the major pathology of the time (infectious diseases), as illustrated below in Table 2.1 (O'Gorman 1998; AIHW 2018). Acute infectious diseases such as the Black Death, tuberculosis, typhoid fever, diphtheria, streptococcal septicaemia, syphilis, and pneumonia were the main causes of death (Despelder & Strickland 1999). As illustrated in Table 2.1 below, infectious diseases (starting from the Black Death of the Middle Ages) were the main causes of death for approximately one-third of the male and female populations (AIHW 2005). For males, injury and poisoning accounted for a further 1 in 5 deaths, and approximately 10% of deaths were accounted for by respiratory and circulatory diseases (AIHW 2005). In comparison, female deaths from injury and poisoning were one-fifth less than that of males (AIHW 2005). The historical changes in the major causes of death has been termed as an *epidemiologic transition* (Despelder & Strickland 1999).

Table 2.1 below illustrates this transition and the changes in the leading causes of death over the centuries in the male and female populations:

Table 2.1: **Leading underlying causes of death by sex, years 1907 and 2000**

Males			
Causes of death 1907	**% deaths**	**Causes of death 2000**	**% deaths**
1. Infectious disease	33.8	1. Injury and poisoning	51.8
2. Injury and poisoning	19.7	2. Circulatory	13.1
3. Circulatory	11.8	3. Cancer	12.4
4. Respiratory	10.5	4. Digestive	7.6

Females			
Causes of death 1907	**% deaths**	**Causes of death 2000**	**%deaths**
1. Infectious disease	31.0	1. Cancer	33.2
2. Circulatory	11.9	2. Injury and Poisoning	31.5
3. Respiratory	9.0	3. Circulatory	12.0
4. Cancer	6.5	4. Mental	4.2

Source AIHW 2005; GRIM Books

As can be seen, the causes are no longer the same, as now, the major causes of death in the 20th century for western countries can be prolonged by advancement in technologies. The approach of the 20th century saw major advances in pathology which shaped the understanding of infectious disease. Now, there are numerous antibiotics (not only penicillin) available to combat most infections. The significant shift over the course of the centuries is the result of changes in the manner of death and how long it takes before death is ‘allowed’ to now occur (Kiernan 2010). Hence, most people now die gradually rather than suddenly (Howarth 2007). Now in Australia, coronary heart disease (CHD) is the leading underlying cause of death for both sexes (AIHW 2018). Dementia and Alzheimer’s disease is ranked a close second, especially in females. The reason for this is that women now live approximately 4.2 years longer on average than males (ABS 2019). Dementia and Alzheimer’s disease is more likely to occur at an older age, hence resulting in a higher proportion of females with dementia and Alzheimer’s disease.

Further to this, “cerebrovascular disease (CVA, which includes stroke), lung cancer, and chronic obstructive pulmonary disease (COPD) make up the top five leading underlying causes of death in Australia for both males and females of all ages combined” (AIHW 2018). Also, technological advancement means that more people survive birth, childhood, and adolescence, thereby increasing their chance of reaching an older age

(AIHW 2018). Accordingly, the top five leading causes of death in Australia today are chronic diseases that eventually require EOLC. CHD is a chronic disease that can be managed with medications through which life can be prolonged for a lengthy period, as opposed to past eras in which cardiac diseases, even though as yet medically unestablished, could lead to instant death. Therefore, people are no longer suddenly dying from these chronic diseases (CHD, dementia, CVA, lung cancer, and COPD), because they are manageable over the long-term, and treatments that prolong life are readily available (Despelder & Strickland 1999). Consequently, people often present to the ED repeatedly seeking emergency care treatment for the management or control of symptoms (Pauls & Ackroyd-Stolarz 2006). However, care provision eventually comes to a point where EOL and palliative care is needed for management after life-prolonging measures finally fail. It is important to note, however, that while some patients will present to the ED seeking the normal ED goal of curative treatment, others will present to access end-of-life and comfort care measures.

Others with established end-of-life care measures may present due to an acute crisis, seeking management and control of symptoms. However, when care goals are not adequately established, ED doctors and nurses may be compelled to provide treatment that is medically futile. According to Crossno (2004), futile treatment provision in the ED often occurs due to the conflict that arises between the traditional role of saving lives against the provision of comfort care. At this point, it is crucial for ED doctors and nurses to thoroughly and effectively assess the patient in order to determine whether the management of symptoms or the treatment of reversible causes rather than a life-saving approach is required (Crossno 2004). The changes in the leading causes of death from incidents that cause rapid death to chronic morbidities that can be managed by significant technological advances, have contributed to a significant ageing population, as people are now living longer (ABS 2014). These changes (technological advances, the increase in the ageing population) have directly led to an increase in presentations to the ED (Chan 2004; Bailey et al, 2011; ABS 2014). More importantly, as death and dying are increasingly becoming part of the ED doctors' and nurses' role, and being brought into the hospital setting, medical and nursing staff need to understand when care provision is futile, so that a good death experience can be provided for patients and their loved ones.

In addition, advances in medical technologies and sciences during the 19th century increasingly led to the control of the death and dying processes (Howarth 2007). The increasing desire to control, classify, measure, and predict social phenomena, including death, was presumptuously used to restore patterns of social order lost in the move from rural (primitive era) to urban societies (19th century onwards), as previously discussed (Howarth 2007). With the intention to classify and control the death and dying process, disciplines such as demography, pathology, and sociology were developed and established (Prior 1989). Demography was established as a discipline to identify trends in the causes of death (see Table 2.1) across various groups and populations, with consideration of the social, economic, behavioural, and environmental factors that arise from these patterns (Howarth 2007).

The discipline of pathology was established in the 19th century to scientifically study disease. Pathologists constructed scientific links between causes of death and diseases within the human body. Also, the new discipline of sociology at the time was concerned with illuminating the systemic social and cultural factors that shaped our contemporary attitudes to, and experience of, death and dying (Howarth 2007). The one common aim of the three disciplines (demography, pathology, and sociology) was to investigate, explain, classify, and ultimately control the death and dying process (Howarth 2007). Similar to the discipline of demography and pathology, sociology saw death and dying as a measurable phenomenon.

Emile Durkheim was one of the first sociologists and was known as the principal architect of modern social science (Howarth 2007). Emile Durkheim’s ground-breaking work on suicide in 1897 measured the occurrence of death using quantifiable data to show that modern societies were more able to control death than were traditional societies. Durkheim’s findings specifically acknowledged death as a social problem that could be measured and then controlled. Subsequently, Durkheim set a precedence that shaped the sociological approach to death for the next half century (Durkheim 1897). Hence, the study of death and dying became a measurable entity that was determined by individual social factors. For example, the occurrence of death was correlated with social factors such as occupation, social and economic status, wealth, and housing status. This scientific approach of identifying, categorising, and measuring the causes of death through the lens of quantifiable data such as age, birth cohort, gender, and socio-economic status have been the basis of studying death and dying within the discipline of sociology (Howarth 2007).

As the 19th century progressed, death and dying was now increasingly classified as a social problem as opposed to the previous view of death being like any other event. Subsequently, as with any other social problem of the time, (19th -20th century), institutionalisation (hospitals, asylums) became the gold standard solution (McNamara 2001). In the same way, the need for control over mortality, and the belief that death could be cured lead to the institutionalisation of the dying (Backer et al., 1982), as opposed to primitive times, the ancient era, and the Middle Ages, where death was more of a public affair and not hidden away behind a hospital door. People no longer died in the comfort of their homes with their families and loved ones, but rather, they died in hospitals (McNamara 2001). This remains the case today. According to the AIHW (2017), 82 per cent of total deaths for the year 2014-15 occurred in the public hospital system.

A consequence of the move to institutionalisation was the requirement for professional skills and expertise (Backer et al., 1982; DeSpelder & Strickland 1987). Consequently, the 20th century saw the significant development of professional medical and nursing skills, and the organisation of expertise. Official formal training for nurses began during the 19th century and kept advancing into the 20th century. Another example is the field of medical science, as medicine is now relied upon to assist with the battle between life and death (Backer et al., 1982). As more advanced treatment and diagnostic skills have been developed, hospitals and particularly EDs, have increasingly become a place designed and organised for the purpose of controlling death and dying. Today, this is evident in EDs where doctors and nurses are increasingly required to provide aggressive life-saving treatments to prevent death, even when death might be the best outcome for the patient.

In the same manner, this approach of viewing death as being controllable by measuring and quantifying its causes and impact continues to shape modern western societies' understanding of death and dying (Howarth 2007). This is reflected in current contemporary society where there is an emphasis on producing data tables and graphs detailing the leading causes of death (as previously shown in Table 2.1 above). In western societies, the leading causes of death are coronary heart disease, respiratory diseases, and cancer. Such data act as a mechanism to identify the major causes of death so that they can be better controlled and, in turn, reduce the number of people dying from these causes (AIHW 2005). Therefore, a move to institutions such as hospitals that can provide acute and critical care was required so that these diseases could be better controlled (McNamara 2001). Overall, in the contemporary era, death is categorised into differing causes, all of which can be cured or avoided; thus, the move into institutions such as hospitals.

2.3 Medicalisation of death and dying

The attempt to control death lead to the creation of a new way of dying, known as the medicalised/biomedical model of dying. The medicalisation of death refers to the process by which death and dying is seen through the lens of medicine (Helman 2007; DeSpelder & Strickland 1987). Modern medicine has now come to define health and illness and has effectively become a mechanism of control that determines who is healthy and what is normal (Backer et al., 1982; DeSpelder & Strickland 1987). Howarth (2007) argued that the medicalisation of death has dehumanised the dying process, because death in medicine is seen as a failure, leading to a situation in which people who are dying are subjected to a range of technological indignities in the attempt to keep them alive at all cost. Often, the medicalisation of death can be seen in the ED setting where doctors and nurses are focused on cures and treatment.

According to Howarth (2007), the medicalisation of death and dying has disempowered dying people and their families. Medical science's commitment to saving lives, with little attention being paid to when EOLC would have been crucial, can have a distressing effect on the dying and their families. Maintaining the illusion of hope for survival and, in turn, not allowing the dying and their relatives to make adequate preparations to come to terms with imminent death can cause a negative death experience for the patient, the staff, and the relatives (O'Connor et al., 2011). It appears as if dying people are discouraged from focusing their attention on death. Relatives and friends often feel it necessary to maintain the illusion of survival with the hope that modern medical technologies will save them (Beckstrand et al., 2008). Again, sociologists have criticised this modern model of treating the dying (Backer et al., 1982; Beckstrand et al., 2008). They believe that treatment occurs in a resounding conspiracy of silence in which doctors, nurses, and dying people and their relatives are not able to speak about death (Backer et al., 1982; Beckstrand et al., 2008). Therefore, it is crucial that ED doctors and nurses maintain effective, open, and honest communication to facilitate a good death experience for patients and their families. As a result of the illusion being created, sociologists have begun to challenge the culture of silence in death and dying, and to explore the nature of the medicalised model of dying (Howarth 2007).

Sociologists argue that in contemporary western societies, death has been removed from the public sphere. The institutionalisation of, and culture of silence around, death has given way to a new discourse for the need to give voice to the dying. Notable studies such as Sudnow (1967), who explored the social organisation of death in a hospital setting through an ethnographic approach, and Glaser and Strauss (1967), who worked on the awareness and timing of death, have challenged the culture of silence in death and dying. The findings of these studies at the time gave rise to a new construction of death and dying. Death and dying was no longer constructed merely as a static state that can be measured and controlled, but rather, the focus shifted to the individual dying in a hospital setting (for example in an ED setting) surrounded by doctors, nurses, and relatives.

The construction of death and dying began to mainly focus on the meanings and experiences of death and dying of the individual (Glaser & Strauss 1965). What this meant for ED doctors and nurses is that they began to understand that even if a patient presented to an ED setting where aggressive treatment to prevent death was the norm, the medical and nursing staff needed to ensure that they individualised the assessment and communication with the patient to ensure that the patient who may be seeking end of life/comfort care was not assumed to be seeking the “normal” life-saving measures of an ED (Crossno 2004). Sociological researchers employed these new approaches to examining death and dying by focusing on the individual (Glaser & Strauss 1965). Their new approaches essentially explored how the individual constructs their own experiences and meanings of the world around them (Sudnow 1967; Elias 1985). Hence, there has been a shift in the social approach to death and dying, from a culture of silence to the exploration of the individual’s own meanings.

Critics of the modern medicalised model of dying, such as Glaser and Strauss (1965), Sudnow (1967), and Elias (1985), have concluded that institutionalisation is the major problem of dying in modern societies along with the focus on curative tendencies rather than palliation. They argue that death has been medicalised, institutionalised, and most of all, hidden away and often occurring in hospitals, primarily in the ED setting. It is important to note that these curative tendencies are more prevalent in the ED setting where advances in medical technologies have led to the belief that death can be controlled or even postponed (Young 2008). In some cases, when death occurred in an area such as ED setting where life-saving is the aim of the day, it can be seen as a medical failure (Schears 1999). Other critics such as Gorer (1955) and Aries (1981) believed that the problem of mortality in modern societies is associated with the loss of tradition. Historically, death was closer to people when it occurred at home in the midst of family and friends, including the youngest members of the clan (DeSpelder & Strickland 1987). In an act of care and love, family members would wash and prepare the body after death. In the same way, family members had the responsibility of building a coffin, or in some cases it would be built by the local carpenter, for the body to be laid out in the front parlour for everyone (friends, family, acquaintances, and community members) to view and show their final act of love (Toynbee 1968; Aries 1974). Adults and children often held vigil to watch over the body and would sleep in the same room with the corpse (DeSpelder & Strickland 1987). Hence, it was clear that community members both old and young came together in communal sharing for the ritual of mourning.

In contrast, modern societies have generally been described as death-denying, where the focus is to avoid the reality of death and dying (Gorer 1955; Aries 1981). But more current evidence exist which suggest that societal views around death and dying might be changing (Dees et al., 2011; Roset et al., 2019). The introduction of advance care planning (ACP), the increase in awareness that life-saving technologies has its limitation and the increased momentum gained by the movements of assisted dying shows that our current society is more accepting of death and dying than in previous years (Roset et al., 2019). It appears that health care institution and its professionals especially ED health care providers still tend to provide life prolonging measures (Wang 2018; Wong et al., 2019). The literature has shown that health care providers often had inadequate ACP knowledge and felt uncomfortable more than the patients and families in discussing EOLC measures (Evans et al., 2012; Adam & Carlee 2016; Osman 2020). Again, the denial of death in the hospital sector can be seen in the location of the morgue which is often on the ground floor and designed in a way that is inaccessible to the public (Backer et al., 1982). They have been designed to have a private loading unit and exit hidden away from other hospital patients and the general public (Backer et al., 1982).

Current practices have altered the significant family involvement with the death of their loved ones, which used to be the norm in earlier times (Fonseca & Testoni 2011;

Larkins 2007). As previously stated, death traditionally occurred in the home where the body was prepared by family and friends, and then kept in the home until the funeral (Toynbee 1968). However, death has now been far removed from society and taken over by the funeral industry in an attempt to avoid the visual confrontation of death (Larkins 2007).

The consequences can be seen in the shift of the funeral process from a family-oriented approach to an industrialised one (Young 2008). Family and friends are now simply given the role of consumers, as opposed to a time in which the control and power of the final acts of love (as discussed above) belonged to family and friends (Larkins 2007). Now, the bodies of the dead are taken away by funeral directors for a life-like presentation that is more visually appealing to the public; hence, shielding the true face of death and fostering the removal of death from the public sphere (Young 2008). Ceremonies are often private, open expressions of emotions tend to be discouraged, and in some cases, children are guarded against viewing the dead body (despite the rampant exposure to violence and death through media), and some adults may also avoid this (Larkins 2007). This demonstrates the remarkable changes in attitudes towards death compared to the past.

Similar to the chronological and geographical changes in funeral practices, grave site inscriptions have also changed over time. Inscriptions on graves have always been part of the ritual practice of dying. The words were often carefully chosen to ensure that they reflected and honoured the deceased accurately. More so, they were heavily influenced by the social norms and beliefs of the times. Early societies carved the initials of the deceased on rocks and stones, as the tomb was seen as a temporary residence, only holding nothing more than the body (Walter 1999). Hence, most inscriptions from early times were as simple as *‘Here lies the body of …’,* as it was believed that the spirit of the deceased (which was considered to be the most important part of the human) had departed and would be reincarnated again (Fitzpatrick 1997).

However, over the centuries, grave site inscription practices have changed from the view of the body in the tomb to providing a commemoration that embodies the totality of the deceased, sometimes even being humorous. In our current society, a gravestone inscription might read, ‘In loving memory of …’, or even something humorous such as, ‘I told you I was sick’ (Fitzpatrick 1997). The reason for this is that the more secular a society becomes, the less association there is with religiosity and myths (Fitzpatrick

1997; Walter 1999). As society becomes more secular, there is a significant absence of religion-related themes, and generally, death is conceptualised as a natural event rather than the notion of a religious or transcendent encounter (Fitzpatrick 1997). In the same way, in line with current western practices associated with death, humour might be used as a tool to hide away from the reality of death and to cope with loss.

Death and dying in western societies have essentially become a private affair (Charmaz 1980; DeSpelder & Strickland 1987). Even when death is imminent and there are interactions about the dying process between friends and family, death is often treated as a guarded secret (Charmaz 1980). Friends and family tend to create an air of mystery around the process of dying (Charmaz 1980). Despite all the ongoing interactions between everyone (family, friends, doctors, and nurses), the individual experiencing the dying process is often left out of these interactions (McManus 2013). The reason for this is believed to be the direct result of the nature of individualised western society (Backer et al., 1982). In view of this, the death and dying of an individual is seen as their own responsibility and something that one does alone (Backer et al., 1982). In other words, one is an individual unto death. Particularly in the elderly, there are expectations from doctors, nurses (including ED doctors and nurses), and families that the individual accepts death (McManus 2013).

The dying individual often tends to be encouraged by family, friends, doctors, and nurses to deal with their feelings and concerns independently (Backer et al., 1982; McManus 2013). As opposed to when death was a public affair that involved family, friends, loved ones, the old, the young, and community members (Glaser & Strauss 1965). Again, the ability to handle one’s own death is now seen as an achievement of the societal value of independence. As a consequence, independence is often achieved at the cost of loneliness, fear, and despair (Leishman 2009; Charmaz 1980; Backer et al., 1982). Thus, of central importance to 20th century thanatology and sociology of death and dying is to break down the societal norm of silence and the individualisation of death and dying, rather than calling on elements in society to normalise the expression of feelings and concerns by individuals, family, and friends (Leishman 2009; Backer et al., 1982), but also, allowing for a more public acceptance and increase in interactions between the dying individual, family, friends, doctors, and nurses as each one navigates the dying process.

2.4 Contemporary Theories of Death and Dying

The late 20th century saw one of the most important psychological theories on death and dying emerge from the work of Dr. Elisabeth Kubler-Ross. Kubler-Ross's research on death, life, and transition (to the afterlife) drew attention to an area that had been neglected and hidden away. At the time when the denial of death was well embedded in society, her work led to an open discourse that provided a deeper understanding of how the imminence of death affects the patient, healthcare professionals, and loved ones. Her five stages of the dying process – denial and isolation, anger, bargaining, depression, and acceptance – helped to improve the care of the dying (Kubler-Ross 1989). However, critics of Kubler-Ross's stages of dying have argued that one of the significant problems with the framework is the way in which doctors and nurses view these stages. Healthcare professionals, including ED doctors and nurses, may have a tendency to fit the patient into a particular stage, believing that the patient must pass through each of the stages one at a time (Kastenbaum 2009). Although most thanatologists agree with the stages described in the work of Kubler-Ross, they do not necessarily believe that the process of death and dying occurs in linear stages, with one following the other.

Further to the work of Kubler- Ross, another philosopher who shaped the understanding of death was Martin Heidegger (1889-1976). Heidegger has been acknowledged as one of the most notable philosophers of the 20th century. His famous concepts of being-towards-death explained that death is not simply something that occurs at the very end of life, but rather, it cannot be separated from life, neither does it suddenly creep up on us at a future moment. He used the concept of *finality* to further explore the conception of being-towards-death. Heidegger believed that all humans are beings *("Dasein")* moving towards death, because everyone will experience death one day. One of Heidegger's quotes summarises the concept of *Dasein* (moving towards its death):

> *'As soon as man comes to life," he says, "he is at once old enough to die' (Heidegger 1962, p. 289).*

For Heidegger, death is always with "Dasein" and, as a result, every individual needs to be aware of death as it is central to the understanding that death is finite. Heidegger stated that 'Death is something that stands before us – something impending' (Heidegger 1962 p. 294). However, when there is a lack of death awareness as a finite entity, Heidegger referred to this as the 'constant tranquilization about death' (Heidegger

1962, p. 298). This tranquilization occurred through the evasive concealment of the face of death in everyday life, when society, individuals, neighbours, and friends, including healthcare professionals (and ED doctors and nurses) give each other hope that death will be escaped and that the individual will be able to carry on. This can be linked to the ED, where doctors and nurses work in a setting where death avoidance is often the goal of care. Consequently, care provision tends to prevent the occurrence of death, even when death would be in the best interests of the patient. Hence, the avoidance of death, as stated by Heidegger, can occur. It is crucial for ED doctors and nurses to be aware that death is a natural occurrence and does not have to be medicalised and prevented.

Further to Heidegger's theory of being-towards-death sociological theorists; Emile Durkheim (1858 –1917) attempted to deconstruct how death and dying were seen within society and the individual using the structure-agency divide. The structure-agency debate stems from a concern with the way in which society is both produced and maintained (Howarth 2007). This framework emphasises the significance of the structure of society or of the individuals within it, or a combination of the two. Some sociologists such as Karl Marx (1818 –1883) and Friedrich Engels (1820 –1895) believe that it is the structure of society that requires investigation, while others; Gary Becker (1930 –2014) and George Stigler (1911 –1991) consider that it is the individual who is central to the construction of society. Another perspective by Pierre Bourdieu (1930-2002), Peter Berger (1929-2017) and Thomas Luckmann (1927 –2016) argues that structure and agency need to be brought together so that a full understanding of social phenomena can be obtained. In relation to the ED setting, when a patient presents seeking treatment, they do not simply come as they are, but rather, they present with their societal norms, culture, traditions, and individuality, all of which directly influences the care provided. In the same way, death is a culturally driven phenomenon in relation to the attitudes, traditions, and rituals that go with it (Barnett 2008). Hence, the culture of the society in which the individual lives will influence their behaviours, expectations, and attitudes when they present to the ED. Most importantly, ED doctors and nurses need to be aware of these unique cultures and norms to provide a good death experience for the patient and their loved ones.

For ED doctors and nurses, understanding what is socially acceptable for a patient's culture around death and dying allows for modification of their own behaviours to suit the patient and their family to be able to better care for them. Furthermore, the early sociologists (Emile Durkheim) believed that society defines the standard of what is acceptable and otherwise. In relation to societal standards and expectations of EDs, the general public may expect that deaths in the ED are preventable and other members of the public may access the ED as a gateway to seek EOLC services that are not necessarily available within the community. Therefore, ED doctors and nurses need to thoroughly assess each patient regardless of the structural norms of the ED which tends to provide life saving measures. Overall, ED doctors and nurses, can often be influenced by societal norms rather than what is believed by individual doctors and nurses to be of value to the patient (Howarth 2007; Walter 1999). For these early sociologists, no matter how individuals perceived their society, its structures constrained them to behave in certain ways (Howarth 2007). For example, in the ED setting, the culture is one that requires ED doctors and nurses to potentially lean towards life-saving measures because of societal expectations, even when it might not be required.

Sociologist: Gary Becker (1930 –2014) and George Stigler (1911 –1991) who focused on agency (individual), believed that individuals can act in meaningful ways in the social world. An increase in the quest for understanding and meaning was established as people were not simply seen as passive receptors of social structures, but instead, were active in the social construction of their own lifeworld (Howarth 2007). Hence, death and dying began to shift from a definition based on social structure to a growing interest in the individual construction of meaning and understanding of one’s own life-world (in their experiences of death and dying). For ED doctors, nurses, and their patients, it is important that they assess each individual, regardless of the general societal norms and culture surrounding death and dying. Each patient’s EOLC preferences need to be individualised and tailored to meet their own definition of a good death.

Furthermore, the growing interest in individual meaning and construction of social phenomena (such as death and dying) brought about another perspective in the structure-agency debate. New era sociologists such as Pierre Bourdieu (1977) and Anthony Giddens (1984) stated that structure (society) and agency (individuals) are inextricably linked. They defined structure as a virtual reality that relies on individuals to retain its existence. For example, their approach was that some of the societal rituals and practices around death and dying continue not because of pre-existing structures and constraints in society, but because individuals perceive them as a meaningful ritual and therefore continue to perform them. This sociological perspective indicates that the practices of ED doctors and nurses are not only influenced by societal expectations, but also by their own personal beliefs and attitudes around death and dying, which can therefore have an impact on the care provided to patients and their relatives. Healthcare professionals' own attitudes are a significant factor which can either facilitate or inhibit the provision of quality EOLC (Adesina et al., 2014). Evidence has shown that healthcare workers who have negative attitudes, such as fear of and anxiety towards the dying process, have a negative impact on the provision of EOLC (Keegan & Drick 2011). On the other hand, healthcare professionals who have no apprehension and resolved thoughts about death and dying tend to show an increase in comfort in providing EOLC to the terminally-ill, and as a result, provide a good experience for patients and their families (Iranmanesh et al., 2008; Braun et al., 2010).

The death and dying literature often use "fear of death" and "death anxiety" interchangeably (Backer et al., 1982; Leishman 2009). Today, the major fear associated with death and dying is the fear of the unknown (Leishman 2009). The uncertainty of how, when, and where death occurs, what happens to the loved ones left behind, and what it means to be non-existent are major factors that drive and feed into the fear of death and dying (Backer et al., 1982). Consequently, healthcare professionals such as doctors and nurses need to firstly identify if they also have any of these fears around death and dying. Only then can they potentially assist people to identify and express their fears so that comfort and relief can be offered. Overall, dying is a shared experience due to its impact on others; not only on the individual experiencing death, but also on family members, carers, healthcare professionals (including ED doctors and nurses), loved ones, and other members of society.

According to Hayslip and Han (2009), culture is central in preparation for death, and clarity about the culture of the individual is crucial for healthcare professionals, including ED doctors and nurses, to provide EOLC. To do this, ED doctors and nurses must be culturally competent (Rosenblatt 2009). Cultural competency is achieved when healthcare professionals are able to do away with their own prejudices and assumptions, have a good knowledge base about the culture of the other, and learn what is not known, including modifying their behaviours to suit the etiquette and propriety of other cultures (Rosenblatt 2009). For this reason, it is important that healthcare professionals such as ED doctors and nurses are aware of these traditions and practices, especially in a multicultural country such as Australia, and act to assist patients and loved ones through the process involved before and after death, so that a good death experience can be achieved.

2.5 Present day perspective

Healthcare professionals, including ED doctors and nurses, have been increasingly given the role of providing EOLC. Doctors and nurses are expected to provide quality EOLC while ensuring that the spiritual, emotional, physical, and psychological needs of patients and their families are met (Backer et al., 1982). However, when there is a lack of fulfilment in these expected roles, disagreement and conflict may arise between all involved (the patient, family members, doctors, and nurses). For example, when caring for a patient at the end of life, doctors in any setting, including the ED, are now expected to assume the leadership role of coordinating care, providing direction, and giving medical orders (Backer et al., 1982).

The role of the nurses is central to achieving good EOLC (Beckstrand et al., 2008). Nurses must possess skills in symptom management and psychosocial care and should also have the learned intuition that comes with the experience of caring for dying patients and their families (Bailey et al., 2011). Physicians also need to have the skills and competence to manage complex symptoms as well as to communicate bad news (Bailey et al., 2011). When healthcare professionals lack adequate skills and knowledge, the death and dying experience can have a negative impact on the patient and their families (Bailey et al., 2011). Skills such as symptom control and management, excellent communication, advocacy, and rapport-building are vital in the ED setting (Buckley 2008). Yet, it is important to note that conflict may arise when one of the parties involved disagrees with the expected role. In turn, this can lead to a negative experience of death and dying when there is miscommunication about role expectations (Backer et al., 1982).

Looking back to the times when death occurred in the comfort of the home with significant family involvement, it was very much a family and community affair (DeSpelder & Strickland 1987). However, as we moved into the modern era, the experience of death became more isolated and institutionalised. Death now occurs in the hospital setting, particularly in the ED where doctors and nurses can exert their professional knowledge and control to determine if a death experience will be either positive or negative (McNamara 2001). Another issue today is the organisational influences that have an impact on care. Healthcare professionals, such as ED doctors and nurses, work in an arena where they are exposed to both professional and bureaucratic systems of control (Backer et al., 1982). In other words, doctors have the authority to make professional decisions that can over-ride other decisions, but at the same time, bureaucratic systems exert control on performance through KPIs and timeframe rules (Glajchen et al., 2011). Once task completion becomes the focus, the dying patient and their family may just become another set of tasks that need to be carried out, so the art of care becomes lost. At this point, patients, loved ones, and family members do not always have the control to determine how EOLC will be managed and provided (Backer et al., 1982).

Additionally, the negative effects of the shift of death and dying into the hospital system represents a power imbalance that can leave patients and family members feeling a loss of control over care management (Backer et al., 1982; McManus 2013). Another way in which medicine exerts control over death is through its authority to verify and certify death (McManus 2013). This is one of the very first crucial legal processes and can only be carried out by a medical professional (McManus 2013). The certification process is required before any other event can occur (McManus 2013). In view of this, medicine also has an influence on death, as it is the only profession that is relied upon to state causes of death (McManus 2013).

Additionally, over the centuries, the growth of Catholicism, Protestantism, and other religions from their rudimentary teachings to a supposedly more advanced knowledge based on faith, has also brought about a change in the attitude of acceptance of death towards that of fear and a fascination with death (Backer et al; 1982; Adams 1993). As a result of these religious teachings, death has moved from a phenomenon that was accepted as part of life to one viewed as a form of justice (heaven or hell) (Walter 1999). These teachings suggest the existence of life after death, and that in order to achieve a good life after death, it is important that the dying person had undertaken ‘good works’ and behaved well before meeting their creator (Backer et al., 1982; Spellman 2014). It also appears that there is a form of Christianity that focuses on sin and punishment without a balanced view; thus, neglecting the Christian message of love and forgiveness (NIV 2011).

As a result, it is often believed that dying people who are not prepared to meet their creator in the right manner will face justice and retribution rather than reward (Walter 1999). People were taught that they must prepare to meet their creator in the right manner (Backer et al., 1982). The right manner is attained through true salvation from God and this can only be found once all mortal desires are not yielded to; humanity was now only to rely solely on God. In contrast to the more current teachings, the religious teachings of the Middle Ages suggested that salvation could be achieved through the church (DeSpelder & Strickland 1987). Through these religious teachings, life after death gradually became a source of terror, rather than consolation (Backer et al., 1982; DeSpelder & Strickland 1987).

Further to this, the cultural changes in the language used around death and dying emphasise the current attitudes of western societies. The portrayal of death in the media and in everyday conversation can be seen in the words and expressions used. For example, euphemisms such as ‘passed on’, ‘kicked the bucket’, ‘laid to rest’, ‘was a goner’, ‘pushing up daises’, ‘left us’, ‘bit the dust’, and ‘no longer with us’ are used (DeSpelder & Strickland 1999). Accordingly, the word ‘burial’ is commonly replaced with ‘laid to rest’, while dead or dying is replaced with ‘passed away’ or ‘called home’, and the undertaker is now a ‘funeral director’ (DeSpelder & Strickland 1999). As a word, death itself appears to be too jarring and direct; consequently, words that are supposedly less confronting are chosen to hide away death while talking about the facts of death itself.

It is believed that these euphemisms provide solace, even though they are vague and not seen as harsh or blunt. Although direct contact with the dead is not as common as it once was, death still has a significant place within society, and people including health professionals have great difficulty talking about death, despite its inevitability (DeSpelder & Strickland 1999). The research has shown that the language an individual chooses to use around death can reveal their attitudes towards death (DeSpelder & Strickland 1999). For people who have unresolved fears about death, euphemisms will commonly be used as opposed to an individual who has no fears about death and dying and can confidently use the expression ‘death’ as it is. For example, in relation to ED doctors and nurses, when honest and open conversation surrounding death and dying cannot be directly articulated, it brings into question their own attitudes towards death (DeSpelder & Strickland 1987).

In addition, our current society emphasises the need for control. However, dying can directly result in a loss of consciousness, loss of control over bodily functions, and dependence on others (Backer et al., 1982). Death in our current times is seen as a frightening concept (Fonseca & Testoni 2015). Moreover, part of the fear experienced lies within the goal-oriented culture we live in where self-esteem is directly related to productivity (Lerner 1970; Backer et al., 1982). In such a culture, fear will occur if an individual believes they have not achieved their goals. The research has shown that people who had completed their life work and achieved most of their life goals had a lesser fear of death and dying (Adesina et al., 2016; Costello 2006), as opposed to individuals who felt they had not completed their life goals and were therefore not ready to die.

Also, according to Walter (1999), western societies have a significant fear of social death prior to physical death. For example, social death occurs in a confused geriatric individual who is confined to 24/7 nursing home care (Walter 1999). In situations where there is a significant cognitive decline, family members and loved ones might start to grieve the loss of the individual they used to know, even though their bodies linger on (Walter 1999; Greenwood et al., 2018). Often, people aim to have their social death coincide with their physical death to prevent an end of life that is lonely and withdrawn (McManus 2013). In relation to the ED setting, social death often occurs when dying patients are neglected due to the chaotic setting of the ED and because of the physical separation of the dying person (McManus 2013).

There is a significant neglect of the patient who is already expected to die, and social death is further experienced due to the segregation of the dying, often due to the time pressures and workload of ED doctors and nurses (Bailey et al., 2011). The segregation and act of removing the dying from the main areas of care directly inhibit regular interaction with the dying patient. Therefore, the dying can often feel as if death has occurred already due to the isolation experienced. Research has shown that as soon as a patient has been declared as dying in the ED setting, they are moved into a secluded area and were often not included in the discussion of their own care (Bailey et al., 2011; Bradley et al., 2013; Borgstrom 2017). Hence, leading to the social death experienced by the dying patient while they are yet to be declared physically dead (Kastenbaum 2009; McManus 2013).

Overall, initial attitudes towards death, as previously discussed, represented acceptance, but there has been a loss of the previous tradition of acceptance of death which appears to have been replaced by fear and the denial of death at all cost. The reason for this appears to be the change in mortality patterns and the institutionalisation of death and dying. Death no longer occurs in people’s homes, but instead, has now moved into the hospital setting. Hence, the ceremonial tradition that often occurred between the family and the dying person has been eliminated. Essentially, it is very important that healthcare professionals (ED doctors and nurses) have the skills, attitudes, and knowledge required to care for patients needing EOLC (Bailey et al., 2011). Also, death and dying needs to be brought back into the public sphere. The taboo surrounding the discussion of death needs to be eradicated, considering that death and dying is inevitable for everyone. Open discussion needs to begin with healthcare professionals who provide EOLC. In particular, ED doctors and nurses must also have the skills to navigate complex issues and dilemmas that will be encountered in the provision of EOLC. Chapter 3 presents the current literature on the perspectives of doctors and nursing regarding death, dying, and EOLC in the ED and its implications for ED staff.

Chapter 3: Literature review

This chapter explores the current available literature that addresses death and dying in emergency department (ED) settings. A thematic analysis approach was used as the process to structure the literature review. This chapter will discuss the findings of the review, presented within the context of the broader literature, with consideration of the identified research gap.

Medical and nursing practice is driven by the concept of ensuring the total well-being of patients and their families, and more than in any other area of practice, this notion is crucial in end-of-life care (Schears 1999). ED doctors and nurses agree that care of the dying must be delivered in such a way as to enhance comfort and dignity, and to ensure that the person is as free as possible from any form of pain (be it psychological, physical, emotional, mental, social, and/or spiritual) (Schears 1999; Quest et al., 2011; Norton et al., 2011). Within the ED, there is often resistance to the idea that death has occurred. Death is perceived by the general population, doctors, and nurses as something to be prevented, and appears to go against the principles of emergency care which includes the aggressive saving of life at all cost and the four hour rule policy of timely diagnosis and swift discharge (Chan 2004).

The literature has shown that ED doctors and nurses may feel a sense of guilt and defeat if death occurs (Schears 1999; Chan 2004). Another reason for resistance to the concept of death and dying in the ED is due to the conflict which frequently occurs between the traditional role of life-saving and the goals of EOLC. Often, there are instances when the inevitability of death is so close that providing life-saving treatment should no longer be the main aim, with comfort and EOLC becoming essential (Crossno 2004; Norton et al., 2011). The conflict experienced is evidenced in the growing number of patients at the end of life admitted to the ED who increasingly receive futile and invasive treatments rather than comfort care (Forero et al., 2012). Reasons for this could be due to the lack of having access to advance care plan information, a lack of discussion of goals of care by the primary care provider/ General Practitioner (GP) which are needed to make critical decision at the EOL (Le Conte et al 2010; Lowery & Quest (2015).

The aim of this literature review is to critically analyse, synthesise, and appraise the available literature on the provision of EOLC by ED doctors and nurses. The findings present an integrated evaluation of previous theory and research on the issues under investigation. An exploration of this issue is critical because it has the potential to identify barriers and facilitators to the effective implementation of EOLC in the ED setting, and in turn, to inform the practice and education of ED doctors and nurses. In addition, exploring this issue has the potential benefit of increasing competency, skills, and knowledge in the provision of EOLC in the ED setting for clients and their families.

3.1 Review question and aim

The aim of the literature review is to explore death, dying, and EOLC provision within the ED setting. Guiding the literature review is the specific statement of “End of life care provisions within the ED”. To begin the literature review, the framework used to structure the review is explained, followed by the search strategy and the article selection process. This will be followed by a critical appraisal of the included primary research studies. Finally, the thesis will discuss the major findings of the review giving consideration to the limitations of the review and the identified research gap.

3.2 The process used to structure the literature review

The process used to structure the literature review is the traditional approach of an integrated/narrative/thematic analysis due to its advantages in relation to flexibility (Braun & Clarke 2006). A thematic analysis allowed the presentation of the themes that arose from the literature, and the identification of trends, including relevant theories (Braun & Clarke 2006). Other types of literature review were considered before choosing this process. For example, the theoretical review method consisting of an analysis of theories relating to the issue was not appropriate to the literature review question (Yuan & Hunt 2009), because the review question topic was broad in scope and the sources and searches required were not aimed to be from a specific theory (Yuan & Hunt 2009). Consequently, an integrated/narrative/thematic analysis was used by searching the literature for both qualitative and quantitative studies to answer the review question and gain a sound overview of the topic.

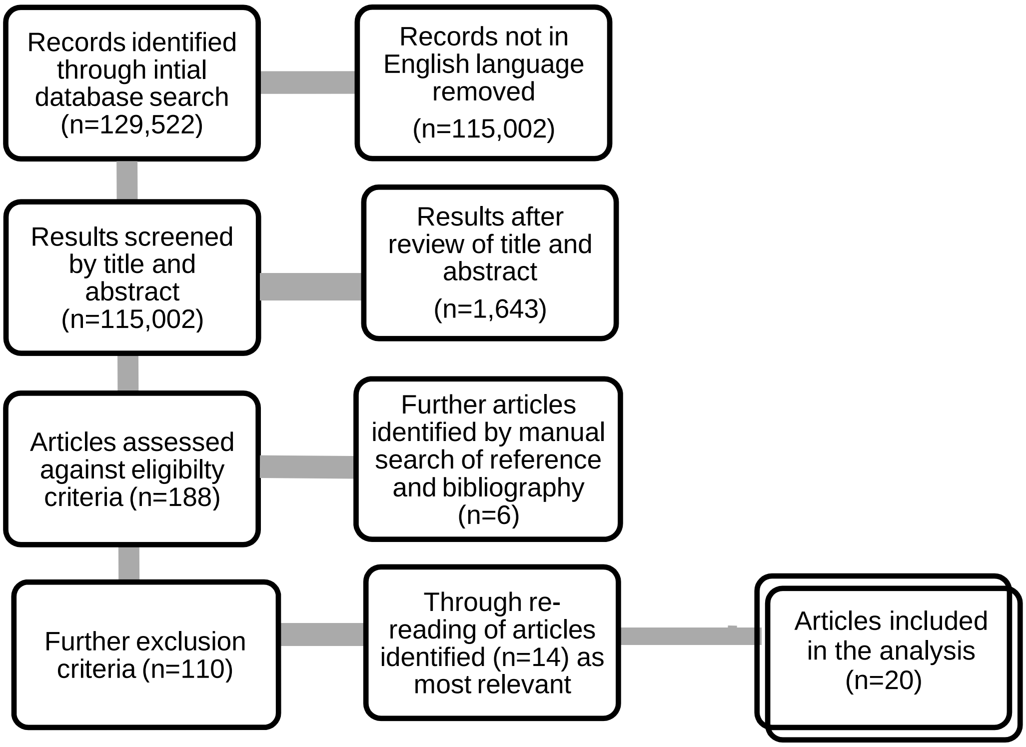
Thematic analysis moves beyond the explicit counting of words and phrases; rather, it is a method for identifying, analysing, and reporting both implicit and explicit patterns (themes) within data or text (Guest & MacQueen 2008; Braun & Clarke 2006). In this case, the data that were analysed were the primary research studies included in the literature review. The selected articles were sorted and collated to identify clusters of ideas that were similar, and then different potential themes (Braun & Clarke 2006). To find implicit and explicit themes within the primary research, the articles were read and re-read to become familiar with the arguments and ideas presented (Braun & Clarke 2006). The initial ideas that were generated across the relevant primary research studies were sorted into potential themes (Braun & Clarke 2006). Ideas for themes were recorded as the articles were read, and when similar themes were encountered again, they were documented by adding the author, date, page, and line number where the information was found in the data to the relevant theme. Some themes were collapsed into each other, while other themes were broken down into separate themes (Braun & Clarke 2006).

After an initial review of the research studies, a summary table was constructed to provide the key characteristics of the individual studies (Appendix 1). The incorporation of these research articles into a summary table facilitated an effective critique of the studies and helped to identify the gaps in the literature (Elliot 2007). The summary table allowed a visual representation of the major findings of each article and how they related back to the aim of the study. It also provided a visual analysis of the recurring themes present in the findings.

3.3 *Search Strategy*

Once the gap in the current literature had been identified, in this case, the inadequate representation of the experiences of Australian ED doctors and nurses providing EOLC, a clear strategy was used to search for the most relevant literature. The key concepts within the research question were highlighted. A list of synonyms, acronyms, scientific terms, and medical subject (MeSH) headings were generated, and the most appropriate keywords identified. Multiple databases were searched, including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline (Ovid), SCOPUS, ScienceDirect, Web of Science, Medline, Journals@ovid Full Text, Google Scholar, and a number of academic websites to identify the relevant literature. The following keywords were used singly and then in combination: "*emergency department", "ED", "death and dying", "EOLC", "end of life care", "terminal care", "medical", "nursing", "Palliative care", "education", "experiences", "attitudes", "knowledge", and "barriers and facilitators".* The initial search of the literature (see the PRISMA flow chart in Figure 3.1 below) was conducted with no inclusion or exclusion criteria being applied. These results were then screened by title and abstract. Other inclusion criteria that were subsequently applied included articles written in the English language with an abstract and a bibliography. Further articles from websites were included based on having an author and date.

Figure 3.1: PRISMA Flow Chart:



The articles were then included based on the following inclusion criteria:

- Primary research studies written in the English language
- Studies that examined the perspectives of ED nurses and doctors on EOLC, death and dying, and palliative care in the emergency department
- Studies on Advance Care Planning (ACP), surrogate decision-making, and ethical issues in end-of-life care within the ED setting
- Research studies focusing on the common causes and incidence of traumatic and non-traumatic deaths within the ED

Additionally, studies on the experiences of nurses and doctors in paediatric emergency departments were included. Although, these studies were not necessarily targeting the population under investigation, they provided information that was relevant to the issue (i.e. death and dying or end-of-life care). The review aimed to explore death, dying, and the provision of EOLC within the ED setting; therefore, articles were excluded based on the following criteria:

- Research studies not written in the English language, the grey literature and secondary research studies
- Research studies focusing on coping skills and strategies that healthcare professionals use when providing EOLC, because these do not address the aim of the literature review
- Research studies that explored the perspectives of other allied health professionals
- Studies that explored the experiences of nurse educators and lecturers involved in teaching EOLC

With the application of these inclusion and exclusion criteria, 110 articles were selected. From a further reading of the 110 articles identified, 14 articles were selected as the most relevant. A manual search of the reference lists and bibliographies of these articles was also conducted, which provided another 6 primary articles relevant to the study. In the end, 20 primary articles were deemed most relevant to the study.

The grey literature, review studies, and personal opinions written by experts in the field were accessed and used to provide background information and enhance the knowledge about the issue being investigated. Palliative and EOLC websites were also accessed for additional current information on the most recent relevant publications. Three websites were used: *Palliative Care Australia*, *CareSearch*, *Hospice UK*, *WHO Europe* and *Palliative Care Nurses Australia.* These websites provided useful synopses of EOLC provision with statistical information on the occurrence of death in palliative care; however, information specific to EDs was not provided by these sites.

3.4 Critical appraisal and analysis of the studies

The primary articles identified consisted of quantitative studies, qualitative studies, case control studies, non-randomised and randomised control trials (RCT), and mixed-methods articles. Therefore, the critical appraisal tools used to critique each of the primary research papers were: The Critical Review Guidelines in Schneider and Whitehead (2013) and the qualitative research checklist by CASP (2006 a, b, c). These tools were used individually, and in combination where relevant, to critically appraise the contents of each research report (Schneider 2013). In addition, they also determined the validity and reliability of the research articles in the literature review to ensure that the evidence was rigorous enough to identify research gaps and for application in both theory and practice (Schneider 2013). All the critical appraisal tools mentioned above were also used in combination with the National Health and Medical Research Council-NHRMC levels of evidence tool to assess the quality of each included study (NHRMC 2009).

The critique process began by undertaking an evaluation of the methods and research design used in each study. The studies employed methods and designs such as focus groups, semi-structured and structured interviews, randomised control trials, non-randomised prospective trials, single group pre-test post-test designs, descriptive, non-experimental and experimental, and post-test comparisons for intervention and control groups. All the included research articles clearly described and identified the designs and methods their authors used.

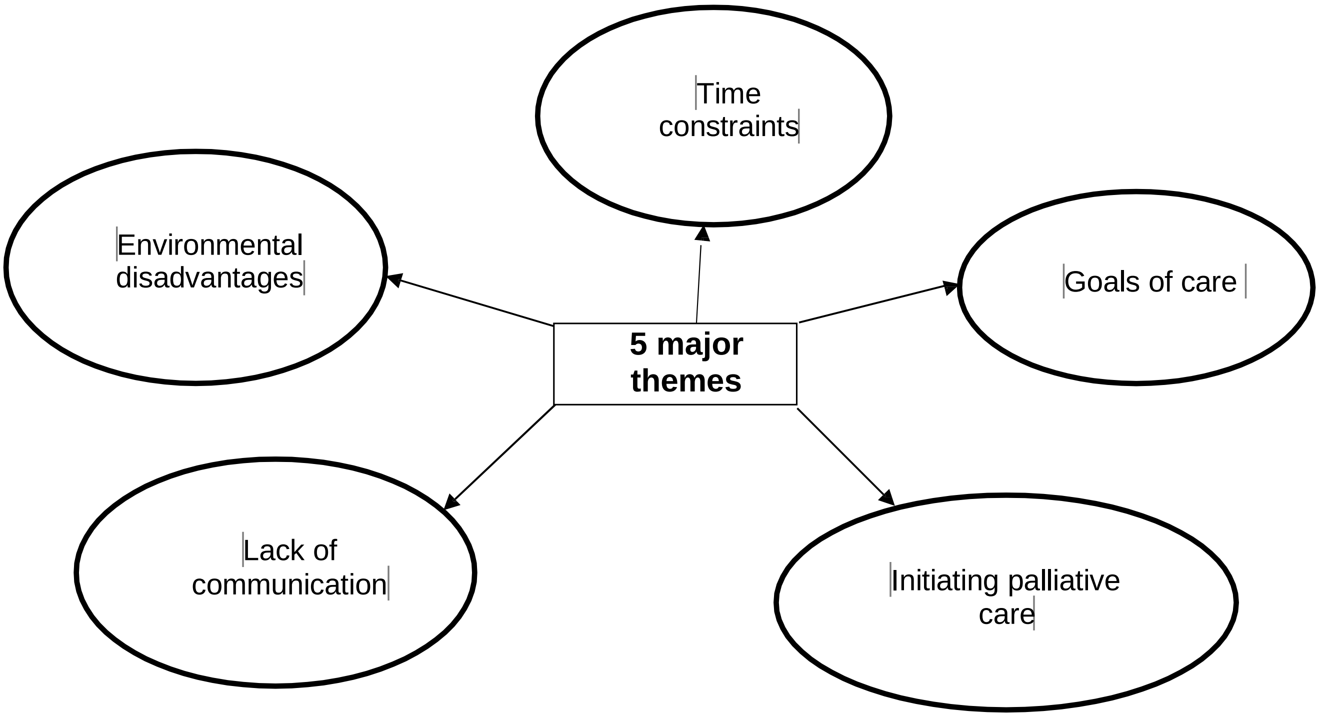
The reliability and validity of the instruments (surveys and questionnaires) used for data collection in each article were assessed. Five of the research articles (Le Conte et al., 2010; DeVader and Jeanmonod 2012; Smith et al., 2012; Lamba et al., 2012; Fulbrook et al., 2005) did not meet the criteria for validity and reliability of the instruments used; however, they were included because their findings were supported and confirmed by other research findings where the validity and reliability of the instruments was identified. According to Parahoo (2014), the quality of the tools used determines the validity and reliability of the findings. Hence, it was important to expose the instruments used to a proven developmental process so that the consistency and accuracy of how each instrument measured attributes could be obtained (Kermode & Roberts 2007; Polit & Beck 2008)**.**

Seven of the research articles were conducted in Australia, eight were conducted in the USA, and one each from UK, Europe, Canada, and France. The participants in the studies were ED doctors and nurses who either worked in a metropolitan or rural setting. Four of the research articles included EOLC patients and their relatives. Articles who included patients and their families were used because it added an in-depth discussion that provided some comparison and differences within the experiences of the participants. All 20 research articles selected for the literature review were considered rigorous enough to be included.

3.5 Findings

This literature review has identified that ED doctors and nurses were key players in the provision of EOLC, even though their primary focus was on curative/life-saving measures. With the aim of identifying emerging themes from the literature, the research articles were collated and sorted according to their aims, objectives, and findings. The findings that emerged were organised and grouped into five major themes (see Figure 3.2 below).

Figure 3.2: Literature review themes



3.5.1 Time constraints

Time constraints referred to the limitations in the time available for a set of tasks that were required to be undertaken. EDs are highly pressurised environments in which one of the major barriers faced is the high workloads that do not allow time for adequate EOLC (Heaston et al., 2006; Beckstrand et al., 2008; Grudzen et al., 2012; Bradley et al., 2013; Decker et al., 2015). Similarly, according to Bradley et al. (2013), the highly stressful workloads were a result of overcrowding, poorly designed EDs (lack of privacy, cubicles demarcated with curtains), noise, alarms, buzzers, unruly, intoxicated, aggressive, and agitated patients, all making the ED environment unconducive for end-of-life and palliative care (Bradley et al., 2013). In addition, ED staff (nurses and doctors) were expected to make rapid diagnoses and provide treatment in a timely fashion; hence, any delays could be seen by colleagues as a form of incompetence (DeVader & Jeanmonod 2012; Lowery & Quest 2015). However, an Australian study by Jelinek et al. (2013) found that patients at the end of life who had been cared for in the ED required more time because diagnosis and treatment plans were not always straightforward.

Similar results were reported in two USA studies by Glajchen et al. (2011) and DeVader and Jeanmonod (2012), with both studies identifying time constraints as a major barrier to providing quality EOLC within the ED. The results revealed that patients and their families needed time to process the often sensitive information that the emergency staff had delivered, especially information about the termination of treatment and the severity of the disease (Glajchen et al., 2011; DeVader et al., 2012). However, due to the time constraints in the ED setting, emergency staff may be unable to provide the additional time required to thoroughly discuss end-of-life issues and palliative care options with patients and their families (Glajchen et al., 2011). Therefore, the time required to provide effective EOLC in an emergency setting, where time is often not available because of the high volume of patients that need to be attended to within the ED, remains a major barrier (Glajchen et al., 2011; DeVader et al., 2012)..

Furthermore, having considered the perceptions of ED doctors and nurses in metropolitan areas in the previous paragraphs, it was also reasonable to consider the experiences of ED staff in rural settings. Beckstrand et al. (2012) focused on rural nurses' perceptions of EOLC in a USA ED. Similar to their counterparts in urban/ metropolitan areas, time constraints had a negative impact on the provision of quality EOLC for the dying patient (Heaston et al., 2006; Beckstrand et al., 2009). However, peculiar to rural settings was the lack of resources (Beckstrand et al., 2012). Emergency nurses in rural settings reported a significant lack of personnel (doctors, a palliative care team, social workers etc.) compared to their counterparts in metropolitan areas (Beckstrand et al., 2012).

Another recent study from 2017 by Beckstrand et al., echoed the same findings as their 2012 study. The findings from the more recent study indicated that nurses in rural settings do not always readily have the input of an emergency physician when providing EOLC. As a result, they remained as the frontier care givers, and had to initiate medical treatment and provide life-saving treatments (Beckstrand et al., 2017). Overall, for rural emergency nurses, the challenges of time constraints when delivering EOL and palliative care to patients in the ED were even further compounded by the lack of resources (Beckstrand et al., 2012). Both metropolitan and rural EDs were faced with chaotic and highly stressful environments within the ED, which did not allow the time and effort needed for appropriate EOLC (Glajchen et al., 2011; DeVader et al., 2012; Beckstrand et al., 2012). Indeed, there exists an environmental disadvantage to dying in an ED.

3.5.2 Environmental factors

In any ED, the provision of good EOLC is often hindered by the nature of the environment. The ED environment is characterised by such factors as noise and busyness, rarely providing calm, comfort, or any form of privacy for patients and their Families (Bailey et al., 2011; Beckstrand et al., 2012; Decker et al., 2015). Similar to time constraints, environmental factors were reported by ED staff as one of the major barriers that inhibited the provision of optimal EOLC (Bailey et al., 2011). According to a UK study by Bailey et al. (2011), similar findings were reported by Heaston et al. (2006)'s study in the USA, showing that the high levels of activity together with the lack of space and privacy to deliver sensitive information made the ED a less than ideal environment for EOLC for patients who were dying and their families.

To determine how an ED environment caused disadvantages for the dying, Beckstrand et al. (2012)'s study from the USA examined ED nurses' perceptions of the design of EDs as an obstacle to providing EOLC. The findings revealed that one of the major concerns was the lack of privacy in the design of the ED (Beckstrand et al., 2012). Similar concerns were found by other studies from the UK and USA, with findings showing that the basic ED layout was over-crowded and that cubicles were separated by curtains between patients, with no provision for private conversations (Bailey et al., 2011; Beckstrand et al., 2012; Decker et al., 2015). Smith et al. (2012) also reiterated this finding by stating that the design of most EDs did not maintain the privacy of patients, especially when passing on sensitive information at the EOL, and that most had cubicles demarcated with curtains, and information being able to be heard by people within close proximity.

This point was also sustained in Beckstrand et al's (2009) study of ED nurses' perceptions of obstacles to EOLC in the ED. The findings revealed that environmental disadvantages were the main factor negatively impacting on EOLC in the ED (Beckstrand et al., 2009). ED nurses in the studies reported that the design of the ED did not promote the privacy or comfort needed at the end of life, and did not allow privacy for the patient and their grieving family (Beckstrand et al., 2008; Beckstrand et al., 2012; Smith et al., 2012). For these reasons, it appears that the ED environment is a barrier to the provision of comfort and end-of-life care for patients and their families.

While the discussion in the preceding paragraph revealed the perspectives of ED staff in regards to the ED environment (Beckstrand et al., 2009; Bailey et al., 2011; Beckstrand et al., 2012), of central concern, however, was the silent voice of the patient in the literature. Basically, there was a gap about the perspectives of patients' experiences of receiving EOLC in the ED setting. Among the few studies that have explored the experiences of the patient in the ED was one by Rosenwax et al. (2011), whose study supported the argument of other researchers who had explored the perspectives of ED doctors and nurses – that the ED environment was not an appropriate setting for providing EOLC (Beckstrand et al., 2009; Beckstrand et al., 2012; Smith et al., 2012).

Similar to the opinions of ED staff, EOL patients in the study described their experiences in an ED environment as a setting of windowless light, unpleasant smells, noise, long waits, continued sounds of screaming, ambulance sirens, and dependence on strangers for symptom management (Rosenwax et al., 2011). The sentiment expressed in these descriptions embodies the emergency department's rescue-oriented model of care, rather than providing dignity through care (Strote et al., 2011). The rescue-oriented model of care is the norm in the ED while end-of-life and comfort care are not frequently addressed (Grudzen et al., 2012). Another significant factor that contributed to the environmental disadvantages was that the focus of ED resources was to aggressively save lives, often without preserving dignity (Rosenwax et al., 2011). Again, it appears that ED care was priority-driven with the aim of resuscitation and the prolonging of life.

Several research studies have investigated some of the environmental obstacles and barriers to providing EOLC in the ED (Heaston et al., 2006; Beckstrand et al., 2009; Smith et al., 2009; Glajchen et al., 2011; Beckstrand et al., 2012). One of these studies investigated the obstacles to care, and supportive behaviour as perceived by nurses in the ED while providing EOLC, using a 70-item questionnaire (Beckstrand et al., 2009). The results emphasised that the highest-ranking obstacles were the lack of privacy in the ED due to the poor environment and design (Beckstrand et al., 2008). This point was also supported by other studies (Smith et al., 2009; Beckstrand et al., 2012; Jelinek et al., 2013; Glajchen et al. 2013), in which the researchers concluded that the emergency environment, due to its lack of privacy, was not conducive or comfortable enough to provide the type of care needed for dying patients and their families.

Having considered how the environment of the ED does not accommodate appropriate EOLC provisions, it was also considered reasonable to look at the organisational barriers of the ED that might impact on the ED environment. From this literature review, gaps exist within the literature on the impact that organisational barriers had on EOLC. One of the few studies conducted by Glajchen et al., (2011) in the USA found that organisational barriers stemming from the managerial or administrative level caused low prioritisation and a sense of ageism, which threatened the delivery of good quality EOLC in the ED setting. These barriers included a shortage of nursing and medical staff, overcrowding within the ED, the pressure to discharge patients, and the financial burden and associated cost-cutting (Glajchen et al., 2011).

Given the current high costs of healthcare, it was not surprising that situations such as these applied unnecessary pressure on ED staff to be productive, with an emphasis on results rather than on caring and spending time with patients (Bailey et al., 2011). Therefore, the art of care often became lost with little or no time to provide emotional or psychological care (Heaston et al., 2009; Bailey et al., 2011). Overall, the ED environment appears to pose a barrier to quality EOLC, and people with terminal illnesses who presented to the ED were often caught in the drama of the emergency care where the goals of EOLC were rarely addressed due to the low priority associated with death and dying (Bailey et al., 2011). In addition, there existed a lack of end-of-life care coordination and communication that occurred in the ED (Smith et al 2010).

3.5.3 **Lack of communication**

The lack of communication between patients, their families, ED staff, and the palliative care specialist often lead to conflict between all parties. Smith et al’s (2010) USA study of EOLC patients’ experiences in the ED revealed that conflict occurred when palliative care providers communicated orders that were time-consuming for ED staff. Although the orders would benefit the patient, the lack of time and attention caused care to be compromised (Smith et al., 2010). In the same manner, another USA study by Glajchen et al. (2011) examined the experiences of family members who accompanied a loved one to the ED at the end of life. Family members in this study acknowledged that they experienced a lack of communication, attention, and segregation (Glajchen et al., 2011). However, they believed that this was not the fault of the ED staff, instead blaming this on the busyness of the environment and the high workload of the emergency staff members (Glajchen et al., 2011).

Similarly, Marco et al's (2005) study of family members showed dissatisfaction with the care provided due to understaffing in a high workload environment, but that overall satisfaction was reported to be high by family members when communication was effective (Marco et al., 2005). Effective communication was an important component of end-of-life and comfort care provision (Glajchen et al., 2011). In order to achieve a holistic model of care that was patient-focused and individualised, excellent communication was required between all parties involved (patients, loved ones, emergency doctors, and nurses) (Glajchen et al., 2011).

Furthermore, Bailey et al. (2011) interviewed EOLC patients' experiences of care within the ED largely based on the level of communication/ attention they received. In contrast to Glajchen et al's (2011) study, in which families stated that the lack of communication and attention was due to the busyness of ED staff, patients blamed the lack of communication and attention on ED staff focusing on machines and technical aspects rather than on caring (Bailey et al., 2011). The patients in the study (Bailey et al., 2011) agreed that more attention was given to the technical aspects of care and less was given to the physical, emotional, psychological, and spiritual aspects of care. Technological developments have greatly increased life expectancy, life-saving treatments, and more advanced care, but its detrimental effects must not be discounted (Tieman et al., 2018). One of the major detriments, according to Bailey et al. (2011), was that the focus on the technological area of care contributed to the lack of time to develop a good doctor/nurse- patient relationship, which was considered especially important for the dying patient and their family.

Nevertheless, this variation in the perspectives of patients and family members can be explained by the family members not being involved in Bailey et al's (2011) study, which only explored the experiences of the patients. The interviewed patients believed that having good communication to develop the doctor/nurse-patient relationship determined the quality of EOLC they received (Bailey et al., 2011). Similar to the patients, nurses in Bailey et al's (2011) study also recognised the importance of investing the therapeutic self in the nurse-patient relationship. In other words, the art of caring was conceptualised as a therapeutic alliance that developed between the nurse and the patient. Also, the nurses in the study recognised that a therapeutic relationship founded on effective communication was required to provide optimal EOLC.

Correspondingly, Heaston et al’s (2006) study of nurses’ perceptions of obstacles and supportive behaviours in EOLC, reported that good communication was a significant supportive behaviour. Good communication between the ED staff, the patient, and family members was found to be important, as was ED staff taking the time to communicate with family members after the patient’s death. However, Bailey et al. (2011) showed that ED staff in their study had anxieties about talking to EOLC patients and their families. They also reported anxieties related to managing their own emotions during the care of a patient at the end of life who was suffering or had any discomfort. Another study of emergency physicians’ experiences with patient death revealed that 95% of physicians in the study often witnessed death, and that there was a significant need for training in communication around death, and coping with death-related anxieties (Strote et al., 2011).

The issue of communication was also explored by Bailey et al. (2011). The findings showed that the standard of EOLC in UK hospitals has been brought into question, with the major concerns being associated with inadequacies in communication and in the quality of EOLC provision (Bailey et al., 2011). According to Bailey et al. (2011), good communication between doctors, nurses, social workers, and specialist palliative care was required in an ED for comfort care to be successful. Similar findings were reported for EOLC patients. Smith et al. (2010), argued that for EOLC patients, effective communication of expectations and reassurance were important and they highlighted the need for effective communication between the patient, caregivers, doctors, nurses, and palliative care specialists (Smith et al., 2010). For example, communication about expectations of care such as prognosis, communicating how long waiting times would be for investigations, where things were up to, what needed to be done, and how far things were moving, were all important (Smith et al., 2010).

Further to this, the literature has suggested that breakdowns in communication often lead to the revolving door and a cycle of treatment of the terminally-ill patient from one acute service to another without properly addressing EOLC needs and goals of care (Glajchen et al., 2011). Overall, determining the goals of care required effective communication with the patient and their family members (Crossno 2004).

Communication breakdowns caused significant disparities between the patient's wants and desires at the end of life compared to the reality of care (DeVader et al., 2012). DeVader et al. (2012) found that many patients desired a 'good death', with a good death for patients being defined as a death free from pain, a well-prepared death, the presence of loved ones, not dying alone, and having a good relationship with the healthcare providers (Adesina et al., 2016; DeVader et al., 2012). However, according to DeVader et al. (2012), the patient's desires and the reality experienced at the end of life were very different. For example, patients may initially be resuscitated or intubated before a DNR (Do Not Resuscitate) order is discovered (DeVader et al., 2012). Events such as this were associated with poor communication and lack of documentation (DeVader et al., 2012).

The consequences of poor communication were revealed in a study conducted in the USA (DeVader et al., 2012). The statistics showed that 40-70% of patients suffered unnecessary significant pain, 10-30% of patient's EOLC wishes were disregarded by doctors and nurses, and in 25-35% of patients, poor communication imposed significant financial and personal burdens on families and loved ones (DeVader et al., 2012). This glaring contrast between the patient's desires at the end of life and the reality of what was experienced means that ED staff need to examine their communication skills and clinical practices to ensure that the provision of EOLC aligns with the end of life desires of all patients and their families (DeVader et al., 2012). Even though there were inadequacies in the end of life and comfort care communication skills of ED doctors and nurses (DeVader et al., 2012), it appeared that the ED was still a setting that served to initiate end-of-life and palliative care.

3.5.4 Initiating end-of-life and palliative care

Initiating end-of-life and palliative care referred to the process of identifying and referring patients who will benefit from palliative care services in a timely manner using a holistic assessment approach. Findings from the available studies suggested that ED staff have found that the difficult discussions about initiating end-of-life and palliative care has often been left for them to undertake, rather than the GP or the long-term specialists (Chan 2004; Bailey et al., 2011; Bailey et al., 2011; Grudzen et al., 2012; Lamba et al., 2012;). Similarly, emergency staff in these studies felt frustrated with the responsibility of having to openly discuss EOLC with patients whom they had not had a long-term relationship with (Chan 2004; Bailey et al., 2010; Bailey et al., 2011 Grudzen et al., 2012). The feelings of frustration reported by ED staff were also discussed by Grudzen et al. (2012), who suggested that this frustration was because ED staff were often just meeting their patients and families for the first time during the ED presentation. Therefore, they believed that it was not their responsibility to address the goals of care, and that it was in the best interests of both the patient and their families to have the initiation of end-of-life and palliative care discussed by their primary care physician due to the already established rapport and relationship before presenting to the ED (Grudzen et al., 2012; Lamba & Mosenthal 2012).

Grudzen et al. (2012) and Lamba and Mosenthal's (2012), two studies form the USA suggested that ED staff felt that initiating palliative care was not their responsibility. Similarly, numerous other studies from the UK, have concluded that it was not the responsibility of the ED staff to initiate end-of-life and palliative care (Chan 2004; Bailey et al., 2010; Bailey et al., 2011; Grudzen et al., 2012; Lamba et al., 2012; Detering et al., 2014). However, DeVader et al. (2012) suggested that initiating palliative care fits into emergency care work, but that emergency staff still lacked the necessary end-of-life and palliative care skills; hence, the main reason why ED staff did not initiate end-of-life and palliative care. Some situations in which end-of-life and palliative care skills were required by emergency doctors and nurses included the effective management of patients at the end of life in the ED, assessment of the illness trajectory, the formulation of a prognosis, effective communication of bad news, and Advance Care Planning (ACP) (Bailey et al., 2011). Other areas where skills were required included the resuscitation of a dying patient with their family being present, managing pain and other symptoms, withdrawal and with-holding of care, ethical and legal issues, and spiritual and cultural care competence (Bailey et al., 2011).

Similarly, ED staff in Beckstrand et al's (2012) study reported that they did not know enough about the available EOLC options to enable them to initiate end-of-life and palliative care, and to guide patients and their families to make an informed decision. Others stated that there was a need for more education within the curriculum (DeVader & Jeanmonod 2012). Studies by Grudzen et al. (2012), DeVader et al. (2012), and Meo et al. (2011) showed that emergency staff possessed only limited understanding and knowledge of palliative care because they had little or no training in this area. Subsequently, they felt unprepared to deal with the emotional investment needed to tackle sensitive end of life information, which lead to poor end-of-life care provision (Meo et al., 2011; Grudzen et al., 2012; DeVader et al., 2012).

DeVader et al. (2012) also showed that fewer than 18% of the medical students and residents in their study had received formal education on EOLC. On further exploration of the medical textbooks, the findings indicated little to no information on EOLC provision (DeVader et al., 2012). Similar to medical textbooks, Beckstrand et al. (2012) revealed that nursing textbooks and curricula also lacked adequate information on EOLC. The results indicated that 50 of the top-selling medical books only had 2% of content dedicated to EOLC (Beckstrand et al., 2012). As a consequence of the lack of quality educational resources, ED staff felt inadequately prepared to provide or initiate end-of-life and palliative care (DeVader et al., 2012; Beckstrand et al., 2012). The literature has clearly identified that significant education was required in end-of-life and palliative care and its role in the ED (DeVader et al., 2012; Beckstrand et al., 2012).

The evidence from the literature has shown that education on EOLC improved ED staff knowledge and skills (Devader & Jeanmonod 2012; Shearer et al., 2014). Studies that have examined the effects of pre/post education effects on end-of-life and palliative care skills showed a significant increase in knowledge and managing end of life symptoms, discussing end of life issues, and an increase in hospice referral after the education was provided to ED staff (Lamba et al., 2011; Lamba et al., 2012). Therefore, training of future ED staff must be aimed at improving EOLC with an emphasis on the available end-of-life and palliative care resources. However, gaps still exist within the current literature as to the benefit of education compared to experiences where ED staff are exposed to the physical care of a dying patient. An Australian study found that both education and exposure to EOLC were suggested by participants as a potentially effective approach to training health professionals (Adesina et al., 2014)

Furthermore, results from a range of research studies has indicated that there were significant benefits of timely initiation of end-of-life and palliative care within the ED (DeVader et al., 2012; Lowery & Quest 2015). For example, the initiation of the right treatment modalities from the beginning of the presentation was found to significantly determine symptom control, quality of life, improved access to hospice and palliative care, and decreased hospital and Intensive Care Unit (ICU) stay (Lowery & Quest 2015). Overall, despite the widely held belief by some ED staff that end-of-life and palliative care did not fit into ED work, there was overwhelming evidence suggesting that patients who were identified in the ED as needing palliative care services appeared to have increased symptom control as well as a high survival rate (Chan 2004; Bailey et al., 2010; Bailey et al., 2011; Grudzen et al., 2012; DeVader et al., 2012; Lamba et al., 2012; Lowery & Quest 2015; Solberg &Hincapie-Echeverri 2015).

Jelinek et al's (2013) findings revealed that even when primary physicians had initiated end-of-life and palliative care prior to ED presentations, ED doctors and nurses still reported inadequate understanding of the prognosis by patients and their families. The lack of understanding by both the patient and family members were attributed to the poor communication skills of the primary or usual care provider (the palliative care specialist, GP, or oncologist) who may not have informed the patient about the extent of the severity of their illness, and thus would leave the emergency staff who had only met the patient a few minutes before, to do what was termed in the literature as the "dirty job" (Lamba & Mosenthal 2012; Jelinek et al., 2013;).

The “dirty job” involved truthfully disclosing the severity of the prognosis and discussing the need for comfort, end-of-life, and palliative care (Grudzen et al., 2012; Lamba & Mosenthal 2012; Jelinek et al., 2013). The literature review has suggested that an ED might not be the ideal place for initiating difficult conversations and decisions about withholding treatment (Lamba & Mosenthal 2012; Jelinek et al., 2013). However, decisions on medical treatment and the extent of life-prolonging interventions made in the ED often determined subsequent interventions, despite the goal or pathway of treatment the usual doctor or specialist might have followed (Lamba & Mosenthal 2012). Therefore, it appears that the ED was crucial in initiating end of life/comfort care communication and treatment, even though it was traditionally aimed towards life-saving treatment.

End of life care encompasses the control of pain, management of distressing symptoms, the ability to break bad news, helping patients and families make clear and wise decisions while simultaneously coping with their grief and loss (Kenen 2010; Limehouse et al., 2012). As previously discussed, in most EDs, delivering good EOLC is greatly hindered by the chaotic, busy, and highly stressful environment (Olsen et al., 1998). However, there is a growing body of interest in the integration of palliative care as a speciality into emergency medicine and nursing, particularly in the USA (Kenen 2010; Lawson 2012; Solberg & Hincapie-Echeverri 2015). In some cases, palliative care, and the ED work collaboratively to seek out ways of improving ED care for patients with chronic life-limiting illnesses who will benefit from palliative care (Lawson 2012). For example, in 2006, the America Board of Emergency

Medicine announced palliative medicine as a sub-specialty of emergency medicine due to the increase in EOLC needs within the ED (Kenen 2010; Lawson 2012).

Although some progress has been made in the integration of EOL and palliative care into emergency medicine in countries such as the USA, there is a significant gap in the Australian literature as to how EOLC is delivered within the ED. Much of the Australian literature has focused on assessing, describing, and addressing EOL and palliative care needs within the ED. However, a review of the literature has identified that the available research does not adequately represent the experiences of Australian ED doctors and nurses in the delivery of EOLC in an area that is designed to primarily cure and prevent death. The literature has also shown that patients often presents to ED not necessarily seeking death prevention measures but as a means to access EOLC symptom management (Smith et al, 2009; Bailey et al, 2011; Beckstrand et al, 2012; Lowery & Quest 2015). There are gaps within the literature on studies that examines EOLC health care services in Australia and in particular those addressing reasons why patients at the EOL have to present to the ED setting for their EOLC services to be met.

The findings in this theme has identified end-of-life and palliative care as an area that needed improvement in the curricula of ED nurses and doctors (DeVader et al., 2012; Beckstrand et al., 2012). Education can improve the ability to initiate end-of-life and palliative care, and also to assist in providing adequate information to inform patients and families about the treatment options (DeVader et al., 2012; Beckstrand et al., 2012). Notwithstanding, the culture of emergency work conflicts with that of end-of-life care (Smith et al., 2009). The conflict arises when the need to provide stabilisation of acute medical emergencies is at odds with the culture of end-of-life and palliative care, which aims to balance quality of life with the burdens of invasive treatments (Smith et al., 2009). Role conflict occurred due to incompatible components and differing expectations required within the same role (Seal 2007). ED doctors and nurses often expressed the conflicting emotions they encounter in their role of saving lives and the care expected for a patient with a terminal illness (Smith et al., 2009). Overall, emergency staff need to have the skills to understand when treatment becomes futile and EOLC needs to be initiated as the primary aim, so that the patient and their family can experience a good death.

3.5.5 Goals of care

The goals of care refer to the planned outcomes of care, and in the context of EOLC, it can either be aimed at comfort or life-prolonging care. Discussions and understanding of care goals is a crucial component in the context of a serious/ terminal illness, as it allows ED staff to align the care provided with what is most important to the patient and their family (Detering et al., 2014; Levinson et al., 2019). Lowery and Quest (2015) suggested that there was often a misalignment between the goals of care of the patient, and those of the ED staff. ED staff may focus on the provision and stabilisation of an intervention for an acute occurrence (Lowery & Quest 2015). However, the patient's own goals of care may solely be the palliation of their occurring symptoms (Thomas et al., 2014; Lewis et al., 2016; Levinson et al., 2019). It was concluded by Lowery and Quest (2015) that the recognition of this disconnect by the healthcare provider is the first step in providing quality care to patients and their families.

Similar to Lowery and Quest (2015), Beckstrand et al. (2009) found that a disconnect often occurred not only between the ED staff and the patient, but also with family members. Beckstrand et al. (2009) found that family members' understandings of the meaning of 'life-saving measures' were poor. As argued in this study, family members do not understand that the insertion of multiple intravenous access points causes pain and bruising (Beckstrand et al., 2008). Again, an endotracheal tube will cause the patient to not be able to speak. In addition, chest compression in cardiopulmonary resuscitation (CPR) can lead to fractured ribs and, in turn, discomfort and pain (Beckstrand et al., 2009).

Nevertheless, the number of patients who access the ED at the end of life has continued to expand at an exponential rate (Smith et al., 2009). Within this group of patients are hospice care patients with a definite goal of care (Lowery & Quest 2015). According to Lowery and Quest (2015), the goal of care for most hospice patients is to be provided with comfort with no aggressive medical intervention to save their lives. Consequently, emergency staff need to carefully assess and establish the reasons for presentation. In short, emergency staff should not assume that a hospice patient presenting to the ED wishes to have new investigations, interventions, and treatments.

Smith et al. (2010) explored the reasons why hospice patients with a definite goal of care presented to EDs. The results revealed that patients and their families were unable to manage the symptoms at home (Smith et al., 2010). They also felt unprepared to face the challenges of EOLC at home (Smith et al., 2010). Even in cases with an advance directive in place that was clearly understood by the family members and the patient, it became daunting when family members and carers (in the home) were faced with the actual situation of the patient being unable to breathe or experiencing a sudden exacerbation of their symptoms (Smith et al., 2009).

Correspondingly, Bailey et al. (2011) found that once these symptoms had occurred, there was fear and hesitation which then led to presentation to the ED. However, Bailey et al. (2011) went on to suggest that patients and their loved ones had been advised to report to an ED when they had contacted their private palliative outpatient specialist. On the other hand, some patients and loved ones immediately requested an ambulance to the ED rather than contacting their hospice care management (Bailey et al., 2011). Therefore, it could be argued that as the prognosis changes, presentation to the ED may be required to re-establish further goals of care, even for patients with a well-documented goal of care. Therefore, goals of care need to be assessed, determined, and prioritised.

Patients who presented to the ED seeking EOLC were considered as a low care priority (Smith et al., 2009). According to Bailey et al. (2011), once patients had been confirmed as receiving comfort care, resources and staff were no longer directed towards them. Other critical conditions and life-saving interventions were believed to require more attention and resources than a dying patient (Bailey et al., 2011). Similar to other studies (Smith et al., 2009; Bailey et al., 2011), DeVader and Jeanmonod (2012) indicated that at this stage, when the dying patient was declared to be receiving comfort care, from the perspective of ED staff, there was nothing much more to be done. The patient and their family did not receive the time and attention needed to provide physical, emotional, psychological, and spiritual comfort (DeVader & Jeanmonod 2012). Smith et al. (2009) concluded that the main reason for categorising dying patients within the ED as a low priority was due to the general belief that the ED does not offer EOLC.

On the contrary, Bailey et al. (2011) found that ED staff paid a great deal of attention to young patients who die because of an unexpected traumatic death experience. In comparison, there was significant neglect of patients who were elderly and already expected to die (Bailey et al., 2011). Another of Bailey et al’s (2011) findings showed that when a patient was younger and declared as being in comfort care, abundant attention was still given to the patient and their family, and yet as soon as an elderly patient had been established as receiving comfort care, segregation of both the dying and the bereaved occurred immediately. In the same way, Lamba et al. (2012) and Lee et al. (2015) found that emergency staff were more likely to involve the palliative care team in a timely manner when patients were young and had traumatic and critical sudden events compared to their elderly counterparts. Hence, Lamba et al. (2012) explained that the reason for young people's timely care and intervention as opposed to that of elderly patients was due to the expected high level of bereavement/ emotional support for distraught and unprepared families of younger patients.

Bailey et al. (2011) highlighted that in addition to neglecting the care of dying elderly patients, ED doctors also immediately relinquished their care with the unspoken rule that it was the primary role of nurses to provide EOLC. According to Smith et al. (2009) and Beckstrand et al. (2009), there was an assumption made by both the public and other health professionals (especially doctors), that nurses were solely responsible for the care of the dying within the ED. However, although Beckstrand et al. (2009) supported the argument that nurses have a vital role in providing EOLC, she acknowledged that an interdisciplinary team (doctors, nurses, the pharmacist, the palliative care team etc.) was still required to achieve the best possible outcome for dying patients and their families. Similar to doctors relinquishing their care, some nurses were also found to pass on their care duties to student nurses and nurse assistants due to their own high workloads (Beckstrand et al., 2008). These studies highlighted that patients who needed palliative rather than curative care were segregated and given no priority within the ED.

On the contrary, ED nurses with an understanding of the importance of quality EOLC viewed their involvement in caring for a patient and their family at the end of life as a privilege (Smith et al., 2009; Marck et al., 2014). Furthermore, proponents of EOLC in EDs have also suggested that nurses who valued EOLC faced tension in relinquishing of care (Chan 2005). Tension occurred as a result of the understanding that EOLC was important at this stage of life, but due to environmental and time constraints, they were unable to efficiently provide the needed care (Chan 2005). According to Chan (2005), when nurses were unable to turn their own moral choices, and what they believed was the right thing to do for a patient into action, this led to distress. Nurses with a special interest in EOLC reported that once it was certain that the only end result for a patient was death, they were motivated to care for the patient in a way that was comfortable and peaceful by advocating to ensure that futile treatments were not provided (Chan 2005).

ED doctors also believed that they were at times faced with resistance from nursing staff in regard to the goals of care for dying patients (DeVader & Jeanmonod 2011). Similar studies have reported that conflict was experienced when nursing staff perceived that good EOLC had not been provided for the patient, and assumptions were made that the patient must be seeking aggressive treatment (Jimenez-Herrera & Alexson 2015; Pauls & Ackroyd-Stolarz 2006; Jacobs & Jacobs 2010). Suggestions were made by an Australian study that advance care planning (ACP) could be the solution (Detering et al., 2010; Detering et al., 2014). However, a USA study by Smith et al. (2009) found advance care planning and directives to be too general to be useful, because translating general ACP into specific treatment plans was challenging, partly because of the differing views of what comfort measures meant.

ACP was reported as an important component of EOLC provision within the ED (Rhee et al., 2011). It was a major determinant of the EOLC model and goals of care provided within the ED. ACP enhanced autonomy by ensuring that patients could express their future preferences for care (Silvester et al., 2012); hence, it was about giving decision-making control to the patient rather than to their family members or the health practitioner (Detering et al., 2014). In addition, ACP ensured the provision of quality EOLC for patients (Detering et al., 2014). It improved communication within families, and between patients and ED staff, and provided a high probability that the patient’s wishes about EOLC were known and granted (Shanley et al., 2009). Furthermore, it reduced the potential for an individual to receive unwanted burdensome treatment and improved patient and family satisfaction (Detering et al., 2014). Therefore, ACP was reported to have a significant benefit in terms of shorter hospital stays and it eliminated the provision of futile treatments (Silvester et al., 2012; Detering et al., 2014).

The points in the above paragraph have also been supported by the work of Detering et al. (2010), who conducted a randomised controlled trial. In this study, patients were randomised to ACP. The intervention group with ACP had their EOLC wishes met and followed, while the control group had no ACP in place (Detering et al., 2010). In the intervention group, family members of patients who died had significantly lower stress ($p<0.001$), lower anxiety ($p=0.02$), and lower depression ($p=0.002$) than patients in the control group who had no ACP (Detering et al., 2010). Overall, patient and family satisfaction were reported as being higher in the intervention group (Detering et al., 2010). Correspondingly, ACP alleviated the stress and anxiety that accompanied the time of dying, as the already documented plans and wishes of the patient who was dying removed the burden of decision-making from the relatives and loved ones (Detering et al., 2010).

Accordingly, the role of nurses in patient advocacy in the ACP process was significant. In the acute hospital setting, when the patient loses their capacity to make decisions in the absence of ACP for medical treatment, life-sustaining treatment, including CPR and intubation, were routinely implemented (Seal 2007). In situations such as this, it was found that nurses who were unable to advocate for the patient were distressed when the patient was frail, dying, and wished to avoid any aggressive measures (Seal 2007). The nurses in Seal’s (2007) study felt powerless to advocate for their patient on the EOLC treatments provided. In recent years, it appears that nurses have become increasingly confident in advocating for their patients, as they can now act legitimately and be ethically comfortable about their advocacy role at the end of life. All the same, ED staff must ensure that ACP provides the needed guidance for the goals of care to be achieved.

3.6 Discussion

The literature review has set out to address death, dying, and the provision of EOLC within the ED from ED staff perspectives. The findings indicated that death and EOLC were a common occurrence within the ED (Crossno 2004; Beckstrand et al., 2012; Smith et al., 2012). Globally, there is a significant ageing population with more co-morbidities; over the last 20 years, the percentage of older adults in Australia has grown from 300,000 to over 3 million (ABS 2010). More recently, there has been a rapid increase in the number of people aged 65 years and over has from one in every seven people in 2011 (14%), to nearly one in every six people (16%) in 2016” (ABS 2016). In most cases, advances in healthcare have meant that there are new technologies and life-saving medications readily available to prolong life and postpone the inevitability of death. All these reasons have led to an increase in presentations to the ED. However, there is a significant gap in the literature in relation to the experiences of Australian ED doctors and nurses in the delivery of end-of-life/comfort care**.**

From the literature review, the lack of time and the design of the ED were perceived as major barriers to providing quality EOLC (Heaston et al., 2006; Beckstrand et al., 2009; Bailey et al., 2011; Bradley et al., 2013; Decker et al., 2015). The busy, chaotic, and highly stressful environment of the ED did not allow the time and effort needed for EOLC

(DeVader & Jeanmonod 2012). Despite the enormity of the workload, ED staff must make decisions regarding diagnosis and treatment very quickly, as time is needed when providing EOLC and sharing sensitive information with the patients and their families (Redley et al., 2003). However, due to the high workload and fast-paced setting, the needed attention and time may not be given to patients at the end of life. Overall, EDs are places where urgent decisions are made, and end of life decisions cannot be made quickly because patients and their families need time to process information regarding impending death (Redley et al., 2003). Consequently, there are deficiencies in providing quality EOLC to patients who present to the ED (Heaston et al., 2006; Beckstrand et al., 2009; Bailey et al., 2011; Bradley et al., 2013; Decker et al., 2015).

In addition, other studies such as Devader and Jeanmonod (2012), Seow et al. (2014), and Bailey et al. (2011) suggest that the quality of EOLC provided within the ED setting is poor due to the lack of education. Other research studies also show that inadequacies are evident in the professional and continuing education of ED doctors and nurses (Chan 2004; Bailey et al., 2010; Bailey et al., 2011; Grudzen et al., 2012; Lamba et al., 2012). Therefore, lack of time cannot only be said to contribute to the inadequate EOLC provided in the ED, but also ED staff's lack of communication, and EOLC skills and knowledge are also significant factors. A report by Olsen et al. (1998) identified that one of the major issues that arose on a regular basis in the ED was that doctors and nurses lacked effective end-of-life and palliative care communication skills. Similar to Olsen et al. (1998), Shears (1999) reported that ED staff had great discomfort discussing the imminence of death with patients and approaching family members after death. Shears' (1999) report found that ED staff frequently cast aside opportunities to discuss meaningful EOLC options with patients and their families and did not honestly provide information about patient prognoses.

The reason for avoidance of discussions surrounding death was reported by Bailey et al. (2011) as being related to anxiety. Bailey et al's (2011) study found that ED staff were anxious about talking to a dying patient and their families. They reported feeling anxious about managing their own emotions during the care of a dying patients who were suffering from pain (Bailey et al., 2011). Beckstrand et al's (2009) study also highlighted the negative effects that nurses who feared the experience of death had when caring for patients at the end of life. The findings revealed that nurses who had unresolved fear about death felt uncomfortable in providing EOLC. DeVader and Jeanmonod (2011) found that, like ED nurses, the quality of EOLC provided by ED doctors was dependent on their own personal comfort with discussing EOLC. According to DeVader and Jeanmonod (2011), the reason for the discomfort experienced by ED staff was a direct result of their deficiency in knowledge and their lack of information about palliative care resources.

Despite these criticisms, the popularity of the notion that the primary physician outside of the ED was responsible for initiating end-of-life and palliative care remained largely undiminished (Smith et al., 2009; Bailey et al., 2010; Smith et al., 2010; Grudzen et al., 2012; Lowery & Quest 2015). O'Connor et al. (2011) refuted this argument and stated that ED was the ideal place for difficult conversations and decisions about with-holding treatment, and that these conversations should begin in the ED and, most importantly, be initiated by ED staff. It was suggested that decisions about medical treatment and the extent of life-prolonging interventions made in the ED often determined subsequent interventions, despite the goal or pathway of treatment the usual doctor or specialist might have followed (O'Connor et al., 2011). Therefore, it appeared that the role of ED staff was crucial in the initiation of communication about, and treatment for, EOLC even though the ED was traditionally aimed towards life-saving treatment.

Studies by Grudzen et al. (2012), Beckstrand et al. (2012), and DeVader and Jeanmonod (2011) provided insight into the place of EOLC in undergraduate nursing and medical curricula. These researchers suggested that the need for clinical exposure to patients at the end-of-life needed to occur throughout educational programmes, so that ED staff can be competent and educated in identifying and providing end-of-life and palliative care needs to patients and their families (Meo et al., 2011; DeVader & Jeanmonod 2011; Beckstrand et al., 2012; Grudzen et al., 2012). Although these studies did not specifically evaluate the effects that professional experiences could have on skills and knowledge, they did indicate that the formal education that occurred during training sessions increased comfort and the ability to provide EOLC (Meo et al., 2011). Overall, there was a significant gap within the current available literature as to the evaluation of the effects of EOLC education on Australian ED doctors and nurses.

The main aim of EOLC is to promote comfort and pain management, and to alleviate symptoms that will improve quality of life. It is important to note that there were occasions when a dying patient would arrive at the ED seeking EOLC. At this stage, the patient would no longer require any curative approach to care but wanted comfort and relief of symptoms (Crossno 2004). However, ED staff were trained to provide life-saving treatments and reported experiencing tension and conflict with patients and family members, especially if there were differences in the goals of care (Bailey et al., 2011). The tension and conflict were especially evident when ED staff believed aggressive interventions were still required as opposed to the comfort care wishes of the family (Jimenez-Herrera & Alexson 2015). Discussions around ACP and goals of care were needed to ensure that the care provided would be tailored to meet the needs of the individual patient (Jimenez-Herrera & Alexson 2015). The findings revealed that ED staff may feel compelled to provide futile treatment when there was no ACP in place (Vollman 2001; O'Connor et al., 2011; Beckstrand et al., 2012).

An unexpected finding within the literature was the unspoken rule of doctors relinquishing the role of care to nurses once a patient was deemed suitable for comfort care only or a DNR order (Chan 2005; Beckstrand et al., 2008; Bailey et al., 2011). However, significant attention and care were provided to young patients at the end of life compared to elderly patients (Smith et al., 2009). Overall, these studies significantly highlighted that patients who needed palliative rather than curative care, were segregated and given less priority within the ED (Chan 2005; Beckstrand et al., 2008; Bailey et al., 2011). This discrimination should not be the case because patients and their families at the end of life, whether young or old, need holistic care (Bailey et al., 2011). The holistic care needed at the end of life requires a different set of medical-nursing skills and knowledge (DeVader & Jeanmonod 2012). Diverting resources and attention away from patients at the end of life has been found to have a negative impact on the EOLC that the patient and their families receive in an ED (DeVader & Jeanmonod 2011), In relation to the time needed to be spent with both the patient and their families to develop rapport, establish a therapeutic relationship, and promote comfort (physical, emotional, mental, spiritual, and psychological comfort) (Bailey et al., 2011). Also, pain management, symptom control, and palliative care specialist referrals are required for the patient at this time (Bailey et al., 2011; DeVader & Jeanmonod 2012). Despite these significant needs, patients and their families who require EOLC appears to be isolated and were transferred away from critical areas.

In summary, death and EOLC will continue to occur within the ED. Death will occur because of chronic illness, sudden deterioration, and at the terminal phase of a life-limiting illness. Deaths that are anticipated and expected will also occur within the ED. Subsequently, the ED will be required to cater to the needs of patients and their families at the end of life. The findings from this literature review have revealed and highlighted the significant gaps within the research literature. These gaps are around the major barriers to providing EOLC in an Australian ED setting. Consequently, there is a need to explore death and dying in the Australian ED setting from the perspective of doctors and nurses.The literature suggests that there is still a significant gap in knowledge about how Australian ED doctors and nurses deliver EOLC in an emergency Australian setting. Using a thematic analysis approach, the main findings showed that there were barriers that existed which had a negative impact on the delivery of quality EOLC within the ED. The literature suggested that traditionally, EDs were designed to provide aggressive life-saving treatment to patients. Among these patients were those seeking comfort care, who did not require any form of life-saving treatment. Hence, EOLC provisions needed to be attended to within the ED.

The literature reviewed herein has examined how end-of-life and palliative care needs are assessed, described, and addressed within the ED. A significant gap has been identified in the current literature in relation to how ED doctors and nurses provide EOLC to patients and their families. This gap is even greater for Australian ED doctors and nurses. As a result, an exploration of Australian ED doctors and nurses is required. The information gained from exploring these issues will be useful for ED doctors, nurses, educators, and cooperating bodies to better understand the difficulties encountered in providing EOLC in an ED setting along with identifying specific areas of EOLC within the ED that require improvement and/or change. Finally, the information obtained will improve EOLC skills and knowledge so that emergency staff can provide competent EOLC to patients and their families. The next chapter will discuss the chosen methodology that has been used to explore the identified research gap of the current experiences of ED doctors and nurses in providing EOLC.

Chapter 4: Methodology

Guided by Hans-George Gadamer's phenomenological interpretive underpinnings (hermeneutics), this phenomenological study explores the lived experiences of ED doctors and nurses concerning death, dying, and EOLC using qualitative methods of data collection. Phenomenology was chosen because the goal of this type of research is to fully understand people's lived experiences, in this case ED doctor and nurses, and the insights that arise from those experiences (Polit & Beck 2008). Other qualitative methodologies such as ethnography, which concerns itself with the exploration of a particular social or cultural setting, did not fit the aims of this research study. Grounded theory, which aims to construct theories, was not applicable because the objective of this study is not to conceptualise a theory for ED staff. Action research, which is often initiated to solve a problem, and case studies, where a participant or situation is focused on in detail, were all considered, but none of these methodologies suited the topic being investigated (Atkinson et al., 2001). Below, I provide a discussion of my use of qualitative research, the researcher's position within the project, and the phenomenological hermeneutic approach and its justification.

4.1 Qualitative research

Qualitative research is a research approach used to discover how human beings understand, experience, and interpret their social world (Hammersley & Traianou 2012). Qualitative research also provides a deeper understanding and rich insight into the phenomena under investigation. This approach aims to answer questions about meaning. In the context of this study, a qualitative research approach has been used to explore ED doctors' and nurses' experiences of a phenomenon (death, dying, and EOLC), and also what the experience of providing EOLC means to them (Polit & Beck 2008). According to Lincoln and Guba (1985), subjective experience is gained through information constructed by individuals as they give meaning to a social phenomenon, which in this case was the experiences of ED staff concerning death, dying, and EOLC. In order to interpret these subjective experiences, I employed a hermeneutic phenomenological methodology guided by Gadamer (1989).

Phenomenology gravitates towards meaning and reflectivity, and it is a way of accessing the world as we experience it pre-reflectively (van Manen 2014). Pre-reflective experience explores the ordinary day-to-day experience of our lives (van Manen 2014). From a philosophical point of view, phenomenology is a method that gives meaning to our everyday experiences (van Manen 2014). The quote below by van Manen summarises what Gadamer's phenomenology entails as a method of inquiry:

> *Phenomenology is primarily a philosophic method for questioning, not a method for answering or discovering or drawing determinate conclusions, but in this questioning there exist the possibilities and potentialities for experiencing openings, understandings and insight- giving us glances of the meaning of phenomena and events in their singularity (van Manen 2014, p. 25).*

From the above quote, it can be seen that, like Gadamer, van Manen shows that good phenomenological lifeworld studies always provide meaningful interpretations of lived experiences and present insightful reflections into the meanings of those experiences. It also demonstrates that the experiences of human cannot be accurately captured with concepts based on the laws of logic, abstractive theories and categories of scientific methods (van Manen 2002). Instead, phenomenology aims to convey in meticulous and deep language, the phenomenality of an experience as they are with the origins and conditions surrounding these phenomena and events (van Manen 2014). Like Gadamer, it is believed that the researcher's past experiences and knowledge must be embedded into the research.

4.2 The researcher's position within this project

Qualitative research requires constant reflection and awareness of the researcher's own personal preconceived experiences and understanding of the issue being investigated. The subjectivity of the researcher and the participants are all part of the research process (Gadamer 2004; Flick 2009). "The researcher's own past and present experiences, including personal feelings and reflections, observations of activities within the field all become data, forming part of the overall interpretation" (Flick 2009, p. 92).

The researcher for this thesis is currently practicing as a Registered Nurse (RN) in an ED of a major metropolitan hospital. My interest in the topic has been ignited in response to current practices of EOLC within the ED. As an RN with current experience in the topic of investigation, I undoubtedly have preconceived knowledge, notions, and ideas that have been shaped by my own experiences.

Epistemology poses the question of the relationship between what is known by the inquirer (myself) and by the knower (the participant) (Guba & Lincoln 1994). It is a process through which the knower and the known are inseparable and shape one another (Guba & Lincoln 1994). However, to be able to make new meanings and understandings, as suggested by Gadamer, the tradition of transcendental phenomenology and epoche (openness) was employed for this investigation (Gadamer 1975; Moustakas 1994). According to Moustakas (1994), epoche allows the researcher to disclose their own personal experiences and feelings. The art of examining one's experiences is crucial to avoiding bias throughout the course of the research (Moustakas 1994). Being transcendental in this context allowed me, as a researcher, to examine the experiences of ED staff with a fresh eye and an open mind by acknowledging my own knowledge, and my preconceived ideas and notions, in order to obtain new knowledge derived from the essence of these experiences (Moustakas 1994).

Further, my practice as an ED Registered Nurse (RN) has provided me with the lived experience of providing EOLC, including the complete death and dying process, within the ED. My journey into investigating the experiences of ED staff concerning death, dying, and the provision of EOLC was because of my own personal experiences as an ED nurse. My knowledge of the topic under investigation was initially formed by my participation in a selective palliative care topic during my undergraduate study and working as an RN in an ED setting. These experiences have given me insight into EOLC nursing that I felt unprepared for and working in an ED where the goals of care to prevent death were the opposite of those of EOLC, which often made care provision quite difficult.

4.3 Ontology

Ontological assumptions are concerned with what constitutes reality and truth (Scotland 2012). According to Guba and Lincoln (1994), ontology questions the nature of reality and what can be known about it. In relation to this study, my use of ontology questions how things really are and how things really work in relation to death, dying, and EOLC within the ED from the perspective of ED doctors and nurses (Guba & Lincoln 1994). Lincoln and Guba (1985) state that reality is individually constructed; there are as many realities as there are individuals i.e. relativist/naturalist ontology. Relativist ontology assumes that there are multiple realities as opposed to a positivist form of ontology that believes any phenomenon has a single reality (Denzin & Lincoln 2005).
Therefore, my inquiry is guided by the relativist form of ontology where there are no right or wrong truths, as different people may construct meaning in different ways. However, truth emerges as a consensus formed by co-constructors (the participant and the researcher) (Gadamer 2004; Scotland 2012).

Phenomenological hermeneutics required that I, as the researcher, needed to take a position regarding my perceptions of how things really are and how things really work in the search for truth. From my perspective, in the ED, various patients presented including those seeking end-of-life and palliative care, but I felt that EOLC in the ED was often challenging. Through these experiences, my research journey to investigate ED staff experiences of death and dying, including EOLC, was given birth. My initial proposal was to make use of a traditional qualitative phenomenological approach using interviews and bracketing my experiences away from the research, but this began to seem inappropriate because the main reason for undertaking the research journey stemmed from my personal experiences of providing EOLC in an ED.

Therefore, hermeneutic phenomenology guided by Gadamer was chosen, because this approach explores and interprets the lived experiences of individuals within their own lifeworld (Polit & Beck 2008). In addition, this approach suggests that critical truths about reality are grounded within people's lived experiences, including those of the researcher (Polit & Beck 2008). The following table summarises my use of the research paradigm, including the ontology, epistemology, and methodology:

Table 4.1: Methodology Outline

Paradigm	**Methodology** (what procedure can I use to acquire knowledge?)	**Theoretical framework** (what approach do I use to gain knowledge?)	**Method** (what technique do I use to find out?)	**Epistemology** (how do I know what I know?)	**Ontology** (what is reality?)
Interpretative	The use of a phenomenological hermeneutic approach	Hermeneutic Interpretive approach by Gadamer (reality/truth for ED staff will be interpreted using hermeneutics)	Qualitative interviews	Reality/truth will be interpreted to discover the underlying meaning of death, dying, and EOLC as experienced by ED staff	There is no single reality. Reality is created by each individual ED staff member

(Guba & Lincoln 1994; Guba & Lincoln 1985; Patel 2015)

4.4 Husserlian and Heideggerian phenomenology

Phenomenology was initially developed by Edmund Husserl (1859-1938), and then extended upon by Martin Heidegger (1889-1976). This philosophical tradition is rooted in an approach to understanding people's everyday life experiences (Macann 1993). A phenomenological study can either be descriptive or interpretive (hermeneutical). Descriptive phenomenology was developed by Husserl (Heidegger 1962). This descriptive form of phenomenology was primarily interested in describing what people knew. Its philosophical underpinnings were rooted in the careful description of everyday life as people experienced it. The other form of phenomenology is the interpretive approach, which is employed in this study. Interpretive phenomenology was developed by Heidegger (1962), who was a student of Husserl. Heidegger moved away from his professor's philosophy of descriptive phenomenology into hermeneutics, also known as interpretive phenomenology. Heidegger's form of hermeneutic phenomenology was then further developed by Hans-George Gadamer, into the form used in this study. According to Gadamer, the term hermeneutics refers to "understanding" (Gadamer 1975).

The philosophy of phenomenology is to investigate human experience and meaning as they emerge in its originality (van Manen 2014). It aims to uncover and bring to light the suppositions and ideas that form our understanding of the world as we live it (van Manen 2014). This methodology prioritises how the human being experiences the world; for example, how ED staff experience the provision of EOLC in an ED. The basic idea of phenomenology is to constantly question the assumptions and pre-assumptions that inhibits an adequate understanding and to bring to expression the immediate experiences of the day to day moment (van Manen 2014).

Phenomenologists assume that there is an *essence* that makes a phenomenon what it is (Polit & Beck 2008). This essence is described as an essential "invariant structure that can be understood" (Polit & Beck 2008, p. 227). In the same way as ethnographers assume that cultures exist, the phenomenologist assumes that there is an essence. An essence is a phenomenon experienced by a group of people and a phenomenologist asks what this essence means to those who have experienced it (Polit & Beck 2008). In this study, phenomenology allows the question of what the essence of death, dying, and EOLC experiences is for ED staff, to be captured.

Lived experience encompasses the ordinary and the extraordinary, the quotidian and the exotic, the routine and the surprising, the mundane, the dull, the ecstatic moments, and aspects of experience as we live through them in our human existence (van Manen 2014). This is not just human experience; it is the concept of lived experience; the intent to explore directly the originary or pre-reflective dimensions of human existence: life as we know it (Heidegger 1962; van Manen 2014).

The phenomenon to be uncovered are generally hidden in the lived meaning and its appearances (Heidegger 1962). The appearance of a phenomenon can be covered up in numerous ways since it is yet to be discovered (Heidegger 1962). Phenomenology aims to unconceal the hidden and the covered-upness within any phenomenon (Heidegger 1962). Therefore, "phenomenology does not primarily produce a doctrine or body of knowledge; instead, it generates "body-knowledge" (Heidegger 1962, p. 60). A related intent of phenomenology is to investigate the circumstances, restraints, and assumptions of how a phenomenon portray itself as it is rather than through a theory (Heidegger 1962). Phenomenology has a distrust of theory and aims to question the assumptions and abstractions of theory (Heidegger 1962). According to Heidegger (1962), people's experiences cannot be related to a theory, as one does not see their experiences through the lens of theory. The difference between phenomenology and most other forms of research is that phenomenology studies the world as we experience it, or become aware of it, before we theorize it (Heidegger 1962). For example, as a researcher who wishes to study EOLC within the ED using a hermeneutic phenomenological approach, I would give a direct interpretation of the ways in which the experience of death, dying, and providing EOLC within the ED presents itself in its various modalities and aspects. It is the experience itself as described by ED staff that is the hermeneutic bearer of the meaning, not any theory or abstract construction (Heidegger 1962).

In terms of a phenomenological approach, hermeneutics is the art of interpreting the meaning of a phenomenon, i.e. the understanding and interpretation of ED staff members' experiences of death, dying, and EOLC, rather than only describing the experiences. In contrast to descriptive phenomenology, which attempts to only describe human experience, interpretive phenomenology (hermeneutics) not only describes human experience, but also emphasises interpretations, understanding, and meanings of individual experience. The goal of Gadamer's interpretive phenomenology is achieved by entering the world of another individual to discover the "practical wisdom, possibilities, and understandings" found in their experiences (Polit & Beck 2008, p. 229).

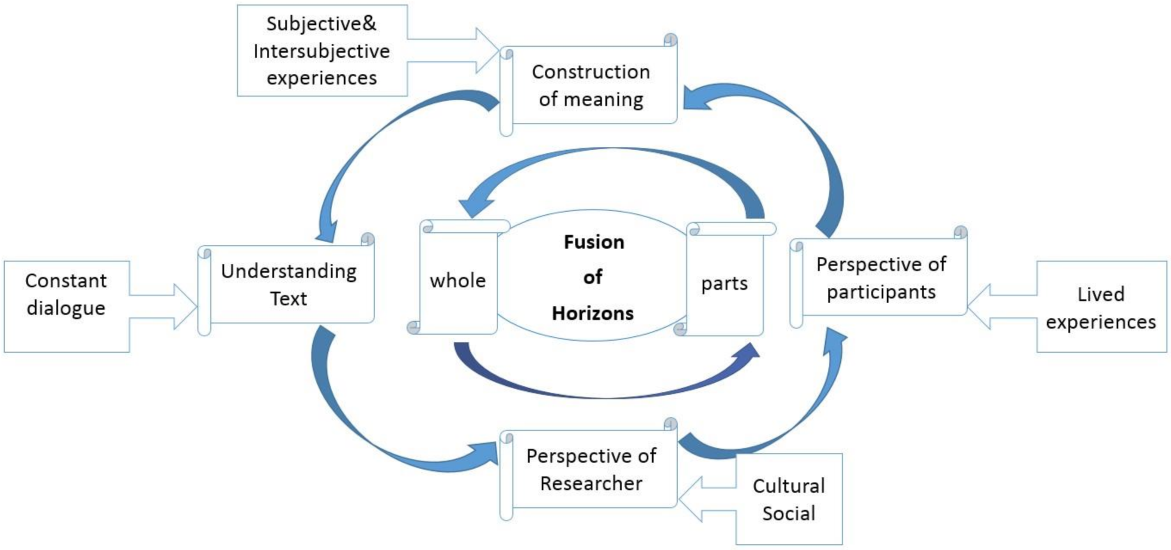
4.5 The Gadamerian phenomenological (hermeneutics) approach

Like Heidegger (1962), Gadamer (1976) was also an interpretive (hermeneutic) phenomenologist. Building on the work of Heidegger (1962), Gadamer (1976) further described the interpretive process as a circular relationship known as the hermeneutic circle. The hermeneutic circle was used so that the researcher could understand the text/ data as a whole. Importantly, understanding the whole requires an understanding of the parts and vice versa (Gadamer 1976). Understanding of the text is gained through constant dialogue with the text, and by continually questioning its meaning. Attention is focused on the analysis of the construction of meaning within the subjective and intersubjective experiences of ED staff.

4.5.1 Hermeneutic Circle

Research studies drawing on the idea of the hermeneutic circle involve cultivating the skill of appreciating experience from the perspective of others. At the same time, significant consideration is given to the cultural and social forces that may have shaped the perspective of the individual i.e., the fusion of horizons. In my use of the hermeneutic phenomenological approach, the hermeneutic circle has been established through the coming together of two interpretive horizons (ED doctors and nurses, and my own experiences as an ED nurse) to create a fusion of these horizons into one (Gadamer 1976). The following diagram shows my use of the hermeneutic circle throughout this study, to understand the lived experiences of ED staff concerning death, dying, and EOLC.

Figure 4. 1: Gadamer's Hermeneutic circle



Adapted from Gadamer (1976)

My use of Gadamer's hermeneutic circle is apparent throughout the thesis. Within the hermeneutic circle, the process of understanding represents a movement away from my first pre-judgement of what I believed were the major challenges of EOLC provision in

ED (my understanding in parts) to the meaning of the whole (combined with the participants' own experiences) (Gadamer 1975; 1976). In doing so, I was confronted with the meaning of the whole through which a change in my sense of meaning was developed once I had understood the detailed parts of the text (Parse 2001).

Furthermore, a major distinction between descriptive and interpretive (hermeneutics) phenomenology is that in interpretive (hermeneutics) phenomenology, bracketing does not necessarily occur (Gadamer 1976). In interpretive (hermeneutics) phenomenology, both Heidegger and Gadamer believe it was not possible to bracket one's own being-in-the-world, but also remain open to new meanings/ understandings (Heidegger 1962). The researcher's own prior understanding was described as a tool for hermeneutical inquiry (Gadamer 1975; van Manen 2014; Polit & Beck 2008). Therefore, the researcher has identified these prior understandings as explained above. Gadamer's interpretive (hermeneutics) phenomenology suggests that, ideally, the researcher must approach each interview and dialogue with an openness, to hearing exactly what the text (transcribed interview) is saying (Gadamer 1975).

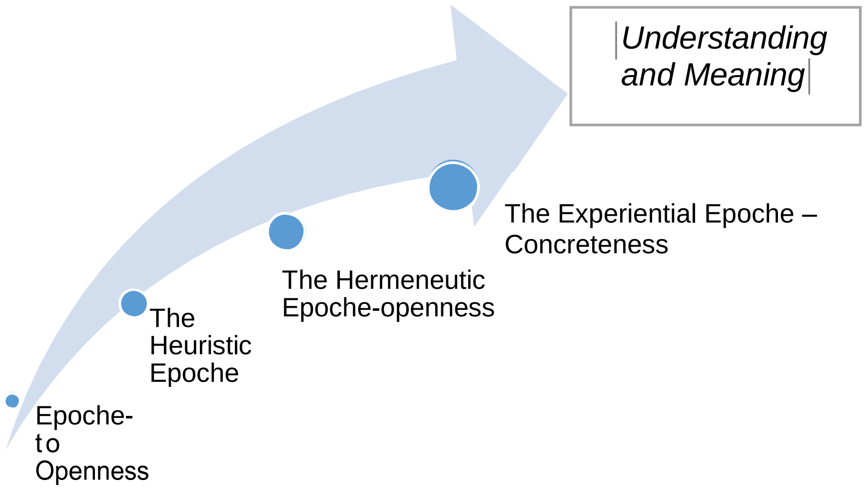
In applying Gadamer, a true understanding of ED staff members' experiences will only be gained by adopting an openness to their world without any objectivity. In order to gain an understanding, and to make meaning of ED staff members' lived experiences of death, dying, and EOLC, a constant state of openness was maintained by employing the philosophical act of epoche, meaning openness. As an act of openness, the concept of epoche supports Gadamer's philosophical approach. The act of epoche was taken further by a contemporary phenomenologist, Max van Manen, a Dutch-born Canadian scholar who specialises in phenomenological research methods. According to van Manen, epoche means that as a researcher, I need to be open and aware of my own preconceived ideas and prejudices concerning the issue being investigated. As a result of my awareness, I allow openness, and focus on the analysis of the lived experiences of ED staff concerning death, dying, and EOLC.

4.5.2 van Manen in support of Gadamer

Max van Manen's (2014) epoche reduction technique was used to elaborate Gadamer's approach to the use of openness, which guided this inquiry and helped to bring a true understanding of the phenomena. The use of van Manen's epoche technique to investigate ED staff led to a deeper understanding and meaning. This technique was used by immersing myself into the act of epoche (openness) using four key points:

epoche-reduction to openness; the heuristic epoche; the hermeneutic epoche: openness; and the experiential epoche: concreteness, as illustrated below:

Figure 4.2: van Manen's Act of Epoche (Openness):



4.5.2.1 Epoche-to Openness

The idea of epoche calls us back to understanding and returning to the world as we live it; (van Manen 2014). Epoche-to-Openness of phenomenology does not attempt to conceptualize ideas or establish a predetermined notion, with a reductive approach to its reflections on lived experience (van Manen 2014). My attitude to using epoche-to openness is to explore the experiences of ED staff as they have lived them. To achieve this requires that I position myself to be open. This openness is the fundamental meaning of epoche (van Manen 2014). My supervisors were also instrumental in the data analysis stage by keeping me accountable and ensuring that my interpretations remained objective and were not tainted by my preconceived ideas and notions.

4.5.2.2 The Heuristic Epoche

This method repels the attitude of taken-for-grantedness (van Manen 2014). Its main aim is to awaken a sense of wonder about the phenomena being investigated (van Manen 2014). This heuristic epoche with a sense of wonder is a technique that allows me to voluntarily carry thorough a sense of astonishment so that a cognitive responsiveness can be maintained throughout by deliberate analysis, thus bringing the "knowing" of astonishment into the lived experiences of ED doctors and nurses (Cogan

2016). A phenomenological quote that explains epoche states:

> *Phenomenology is much more than a suspension of assumptions. The phenomenological reduction is a change of attitude that throws suspicion on everyday experiences* (Crotty 1996, p. 4).

From the above quote, this stage of epoche required that I employ an abstemious method of reflection on the fundamental constructs of the lived experiences of death, dying, and the provision of EOLC by ED staff (van Manen 2014). Abstemious reflection must be open and should abstain from theoretical, critical, and sentimental intoxications, instead reflecting on pre-predictive and pre-reflective everyday existence (van Manen 2014).

4.5.2.3 The Hermeneutic Epoche-Openness

In this stage of epoche, all personal feelings, subjective preferences, inclinations, and expectations that might tempt the researcher to come to a premature understanding of a phenomenon must be overcome so that the experience can be understood as it is lived through (van Manen 2014). As explained by Gadamer, understanding must be created as a combination of the parts and the whole and vice versa (Gadamer 2004). I applied this stage of epoche by being aware of my own personal interpretations of the issues being investigated and, on all assumptions, addressed in writing as stated above, while performing an explicit reflection. As previously stated in this chapter, an awareness of one's own prejudices, agendas, and concepts regarding (psychological, political, and ideological) justification and the nature of the question is vital. For this to occur, vested interests and pre-understandings were reflected upon and a practice of radical openness to the phenomenon was employed.

In this hermeneutic epoche, the pre-understandings, assumptions, and interests were spelled out in previous paragraphs to eliminate any bias and to let the phenomenon 'speak for itself' (van Manen 2014). This does not mean that one arrives at an absolute point of view, because such a pure gaze is impossible. However, it requires that the numerous sources and levels of meaning that are been generated are investigated for their various dimensions of lived meaning rather than being overlaid with an individual's structure of thinking (van Manen 2014).

4.5.2.4 The Experiential Epoche – Concreteness

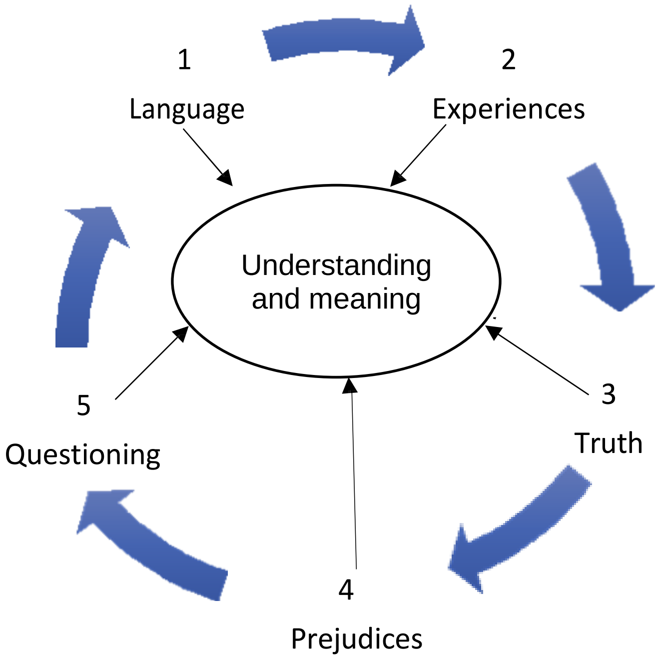
Eidetic reduction in phenomenology attempts to grasp essential insights in assessing the meaning of a phenomenon or event (van Manen 2014). My use of this experiential epoche did not only ask how ED staff experienced caring for someone at the end of life, but also what the eidetic (accurate recall of experience) nature of the experience of end of life care was (thus I can better understand what this specific experience may be like for ED staff). The phenomenological eidos (eidetic nature) of providing EOLC in the ED would be adequately described if the ED staffs' description brings back the lived meaning and significance of the experience of care (van Manen 2014). Achieving understanding of, and providing meaning to, ED staff members' lived experience of death, dying, and the provision of EOLC was the main objective of using this methodology. The use of Gadamer's epoche, as described by van Manen (2014) using the four points above, answers Gadamer's central questioning of establishing understanding and meaning.

4.5.3 The nature of 'understanding'

The nature of understanding is the central question of Gadamer's investigation (Gadamer 1989). Instead of a two-way mode of understanding where an individual simply understands a phenomenon, Gadamer pushed towards a three-way relationship through which individuals comes to an understanding with another and then they both come to a mutual understanding (Gadamer 1989). In relation to this study, Gadamer believed that when the participants and the researcher understand each other about something, we do so with respect to that something.

Gadamer explained that when we understand another individual's perspective, we not only understand what they have communicated nor just their view, but we ponder whether their perspective of the phenomena has any validity for us too (Gadamer 1989). In this regard, even self- understanding does not, equate to not having a personal opinion, but instead, for Gadamer, the understanding of one's way around the particular phenomenon (Gadamer 1989). Other elements that make coming to an understanding and meaning possible include language, experience, truth, prejudices, and questioning. This is illustrated in the diagram below:

Figure 4.3: Gadamer's creation of understanding and meaning



4.5.3.1 Language

Language makes coming to an understanding possible because it is the medium through which understanding is created (Gadamer 1975; Gadamer 1989). This understanding rests on the joint willingness of the participants to allow themselves to uncover a subject matter that presents through conversation (Gadamer 1989). According to Gadamer (2004), a conversation must be allowed to emerge as every conversation carries a spirit of its own and the language used carries its own truth within it (Gadamer 1989). In this study, language has been used as the medium in which substantive understanding and agreement take place between the ED staff members and I. Language was not just a mere tool, it is was used to construct and communicate ED staff members' experiences of death, dying, and EOLC provision.

4.5.3.2 Experiences

An experience constitutes memory, and it is a persevering meaning that is carried for the individual who has had the experience (Gadamer 1989). According to Husserl, all knowledge begins with experience (Husserl 1970). The primary data for this study are units of ED staff members' lived experiences/ meanings of providing EOLC (Gadamer 1989). ED staff members' perceptions of death, dying, and EOLC provision come together to produce a unity of experiences as individual experiences are retained. These units of experience are themselves units of meaning that contribute to the formation of concepts (Gadamer 1989; 2004). The experience produces a better knowledge of the phenomenon and questions all pre-assumptions (Gadamer 1976; 1989). In other words, one's experience changes one's entire knowledge (Gadamer 1975). This is a journey that allows a holistic understanding of events, removing the condition and obligations of everyday life as it ventures out into uncertainty, but at the same time, each adventure is exceptional as a subjective truth (Gadamer 1989).

4.5.3.3 Truth and Prejudices

Gadamer believed that meanings cannot be understood in an uninformed way, as we cannot adhere carelessly to our own pre-understanding concerning the phenomenon if we seek to understand the meaning of another (Gadamer 1989; 1994). Of course, we do not forget our fore meanings but all that is asked is that we remain open to the meaning of the other person or text. In this study, this openness was carried out by situating ED staff members' own meaning in relation to the whole of my own meanings. To do this, an awareness of my own prejudices was required, and this was carried out by reflecting on past preconceived ideas and notions so that true knowledge and meaning could be obtained (Gadamer 1975). Along with all the mentioned components, Gadamer's priority of hermeneutic questioning was employed. According to Gadamer (1989), the essence of the question is to make sense; when a question arises, it brings to light the nature of the idea as it were. Questioning makes the object and all its possibilities fluid.

4.5.3.4 The hermeneutic priority of questioning

The hermeneutic priority of questioning lends itself to the realisation of a phenomenological question that may arise at any instance when a particular experience causes us to pause and reflect (van Manen 2002). This quote explains the priority of a hermeneutic phenomenological mode of questioning:

> *Even the most ordinary experience may bring us to a sense of wonder. Perhaps we suddenly think back to an event that struck us or someone made a comment about something we experienced. And now we wonder what this experience is like? How do we live through an experience like this? and thus it may happen that an ordinary experience may suddenly appear quite extra-ordinary. We become more aware of the phenomenal phenomenality of a phenomena!*
>
> (van Manen 2014, p. 31).

Guided by the above quote, questions were asked to uncover the experience of providing EOLC, rather than about EOLC itself (van Manen 2014). Hence, these phenomenological questions inquire into the meaning of the lived experiences of ED staff when providing EOLC.

4.6 Justification of the chosen methodology

The focus of this inquiry is not simply to describe ED doctors’ and nurses’ experiences concerning death, dying, and EOLC, but also to interpret subjective data that are accessible to subjective consciousness, and to concentrate on the lived context within which those actions evolve and become meaningful. The use of a descriptive approach, such as Husserl’s phenomenology on its own would not satisfactorily answer the research question. Husserl’s phenomenology was strictly cognitive and intellectual; for Husserl, all preconceived ideas and judgements must be suspended, but Gadamer’s phenomenology of hermeneutics saw this as a shortcoming (Gadamer 1975). An interpretive approach was needed to discover associations, relationships, and patterns within the phenomenon that is being described. Therefore, an interpretive descriptive approach guided by Gadamer’s hermeneutic phenomenology has been employed.

The Gadamerian hermeneutic interpretive phenomenology approach best fits as the method of inquiry for this study because his phenomenology was not only based on the knowledge of phenomena, but also on the meaning (Gadamer 1975; 1989). Hence, the aim of this research project is to understand, and give meaning to the lived experiences of ED doctors and nurses concerning death, dying, and the provision of EOLC. Gadamer’s hermeneutics concerns itself with the phenomenon of understanding, and of the correct interpretation of what has been understood. However, for meaning and understanding of a phenomenon to be achieved, all preconceived ideas and knowledge must be embedded into the research, as discussed in the section on the researcher’s position within the project. Therefore, an interpretive (hermeneutics) phenomenology was used as the qualitative method of inquiry for this project. The next chapter discusses the data analysis methods and processes in line with Gadamer’s phenomenological approach.

Chapter 5: Methods

This chapter discusses the research methods used to analyse the data obtained through the semi-structured interviews with ED staff concerning death, dying, and EOLC. In this chapter, ethical processes are discussed, the recruitment of the research participants, the data collection process, and the assessment of rigour in qualitative research are explored. There is an extensive range of phenomenological analytic methods. Diekelmann et al's (1989) research method has been chosen because it fits with Gadamer's interpretive hermeneutic phenomenological approach. Diekelmann et al's (1989) method is used for interpreting and exploring the lived experiences of people. This analytical method has been used extensively in nursing research. The technique is used to interpret the meaning of an experience through identifying themes (Diekelmann et al., 1989). For this reason, Diekelmann et al's (1989) seven interpretive stages of analysis have been chosen because the aim of this Gadamerian interpretive project is not simply to describe phenomena, but to interpret the lived experiences of ED doctors and nurses.

Central to the data analysis in this hermeneutic study is the use of the hermeneutic circle, as previously discussed. The use of the circle is a methodological process that requires a continual movement between the parts and the whole of the text being analysed, so that understanding and meaning can be reached (Gadamer 1976). In applying Diekelmann et al's (1989) seven stage interpretive analysis, Gadamer stresses that the researcher cannot separate themselves from the meaning of the text and must strive to be open to what the text reveals. Therefore, this technique is complementary to Gadamer's approach for this project. The use of Diekelmann et al's (1989) seven stages of analysis as it applies to this thesis will be discussed in this chapter.

5.1 Ethical considerations

Ethics approval to conduct the research was sought from the Social Behavioural Ethics Committee (SBREC) of Flinders University, Adelaide, South Australia on the 17th November 2017. Conditional approval was initially granted on the 21st February 2018, with a number of issues needing to be addressed and clarified. Once these issues had been clarified, final approval (project number: 7909) was obtained on 5th April 2018 (see Appendix 3). Ethics approval to access Australian ED doctors and nurses was sought and obtained from the Australasian College for Emergency Medicine (ACEM) and the College of Emergency Nursing Australasia (CENA) (see Appendices 4 and 5 respectively).

The two organisations (ACEM and CENA) distributed the email to members inviting them to participate. As such, the researcher was not provided with participant email addresses. Participants who were interested in the study then contacted the researcher through a phone number used specifically for the purposes of the study, hence indicating consent to participate in the study. To maintain confidentiality, pseudonyms were given to all participants. All the participants remained anonymous and confidentiality was maintained. While the participants' identities were known to the researcher, no identifying information was published, thus ensuring that the anonymity of the participants was ensured. The participants who volunteered to participate in the interview chose a location suitable for them, while those who lived interstate were interviewed over the phone.

The study aimed to investigate death, dying, and EOLC. Therefore, the researcher understood that the topic could be sensitive and had the potential to cause distress for some participants, although none of the participants became distressed due primarily to the notion that doctors and nurses deal with death and dying on a daily basis. Nevertheless, they were made aware that if they became distressed or upset during the interview, the contact details of, and information about, the free counselling services tailored specifically to both participant groups (ED doctors and nurses) were provided and made available for use. In addition, a general free counselling service was also provided if needed.

5.2 Research participants

Participation in phenomenological inquiry requires individuals to have a lived experience of the phenomenon under investigation (Speziale & Carpenter 2007). According to Speziale and Carpenter (2007), choosing appropriate participants in a phenomenological study is pivotal to achieving a successful research study. Individuals are selected based on their first-hand experience of a culture, social process, or phenomenon of interest (Speziale & Carpenter 2007). Therefore, the participants for this study were ED doctors and nurses with first-hand experiences of providing EOLC. ED doctors and nurses with experience of EOLC voluntarily responded to emails sent by ACEM and CENA for the purposes of describing their involvement, with the aim of obtaining a clear understanding of their experiences. Hence, purposive sampling was employed for this study. According to Speziale and Carpenter (2007), purposeful sampling is commonly used in phenomenological inquiry, because participants have specific characteristics (specifically ED doctors and nurses in this case) that fits the purpose of the study. Due to the use of purposive sampling, the participants were able to provide rich and in-depth knowledge of the phenomenon for the purposes of sharing this knowledge.

5.3 Participant recruitment

The initial recruitment focused on ways to access ED doctors and nurses who had good knowledge of the issue under investigation. Organisations for ED doctors (Australasian College for Emergency Medicine: ACEM) and ED nurses (College of Emergency Nursing Australasia: CENA) were approached to advertise the study and recruit participants across Australia via email. Ethics approval from Flinders University was provided as requested by the organisations (ACEM and CENA) before the request for recruitment of participants was sent via email or advertisement. The purposeful recruitment of participants was performed so that the data obtained would allow the objectives of the study, and the relationship between the concepts to be confirmed (Wuest 2007). Participants were made up of ED doctors and nurses who were able to describe their experiences, attitudes, and knowledge in relation to providing EOLC in an ED setting.

Following the advertising, six doctors and two nurses expressed an interest to participate in the study. Due to the low response rate, the previously approved recruitment method was requested to be modified to a snowball technique, because more participants were needed. As a result of the significantly low response rate for the ED nurses, it was necessary to change the recruitment process to snowball sampling. The reason for a low response rate especially among nurses appears not to be a new phenomenon. A study by MN et al., (2003) reported that nurses may not view research as an essential part of nursing practice and hence not engage in the practice. Other factors that tend to hinder nursing participation in research were attributed to lack of management support, heavy workload, lack of knowledge and training (Cooper & Brown 2017).

A request for modification was submitted to SBREC on the 27th July 2018 to change the recruitment process to a snowballing technique, and to use a transcription service due to the time constraints caused by the delay in recruitment. Approval for modification was granted on the 13th August 2018, so the snowball technique was employed whereby existing participants in the ED doctors' and nurses' network gave information out to colleagues about the study who were then free to contact me. This form of sampling is also known as referred sampling, whereby participants refer other people to the study. According to Polit and Beck (2012), snowball sampling is a method used whereby early informants or participants (existing participants) refer the study to other potential participants. This form of sampling is also known as network sampling (Polit & Beck 2012).

Further, this technique helped capture nurses and doctors outside of CENA (College of Emergency Nursing Australasia) and ACEM (Australasian College for Emergency Medicine). The advertising flyer was redistributed to potential participants. More importantly, without any coercion, any potential participants were free to recruit other potential study participants who were willing to also share their own experiences. The researcher also requested existing study participants to recruit future participants among their colleagues by telling them about the study. The previously ethics-approved advertising flyer was used. In the end, the snowball technique assisted us to recruit 7 more nurses and 1 more doctor, resulting in *n*=9 ED nurses and *n*=7 doctors, for a total of n=16 participants.

The number of participants in phenomenological research typically amount to 10 or less, as such studies often rely on small samples. However, the crucial principle that guided the sample size as an inclusion criterion in this study is that the participants must have had first-hand experience of the phenomenon under investigation (Muecke 1994; Polit & Beck 2008). Also, the participants had to be over 18, could speak conversational English, and needed to have the capability to give quality accounts of their experiences (Polit & Beck 2008). In this study, ED doctors and nurses who had experience of providing EOLC were deliberately sought out while being open to the differences in each individual experience. Although, the ED doctors and nurses in the study were from a range of diverse demographics, they still had a common shared experience of providing EOLC.

5.4 Interviews

Interpretive (hermeneutics) phenomenology goes beyond the traditional approach to gathering and analysing data. Similar to descriptive phenomenology, interpretive (hermeneutics) phenomenology relies on in-depth interviews with individuals who have experienced the phenomenon of interest. Interviews are regarded as the best method for qualitative data collection and are commonly used in nursing research (Whitehead & Annells 2007). However, the structure and conduct of the interview are crucial because a poor interview will result in poor quality data. Also, where a novice or experienced researcher conducts an interview, there are prerequisites that must be met. These include a warm and non-judgemental approach that needs to be established towards the participants throughout, with an unbiased, clear, and non-threatening form of questioning that needs to be maintained. As a novice interviewer, I was guided by these prerequisites.

In the interview process, semi-structured interviews were used to elicit data. A set of open-ended questions were used as a guide (see Appendix 6). The purpose of this list of questions was to provide clarity to the participants when they were unsure of the questions being asked. Further questions were then asked to prompt or clarify the comments and answers provided by participants. The interviews began with a general broad opening question, such as "Can you please begin by describing what it is like to care for someone who is dying in an ED"?, then narrowed down to topics specific to the inquiry as the interviewed progressed. Questions were asked to encourage story-telling and to provide more elaborate answers. For example, "Tell me about your own values and beliefs about death and dying – your own personal perspective"? Probing was then used to elicit further detail and to seek clarification. Finally, paraphrasing was used without changing the meaning of what the participants had said to facilitate understanding and clarity, and to act as a further prompt.

Also, researchers should ensure that they guide and provide direction as the participants share their experiences, without leading the discussion (Speziale & Carpenter 2007). In this study, this process was facilitated by using open-ended and clarifying questions. For example, questions such as "what comes to mind when you think about end-of-life care?" was asked, thus, allowing the researcher to follow the participants' lead, ask clarifying questions when required, and facilitate the expression of the participants' experiences of death, dying, and EOLC in the ED setting. Again, it was important that the researcher did not guide the participants down a pre-determined path, but instead would assist them to describe their individual experiences authentically and fully (Crotty 1996). This was ensured through a critical act of self-reflection on any preconceptions and presuppositions of the topic being investigated.

According to Speziale and Carpenter (2007), it is important that researchers consider the social and cultural context of the participants. Interviewers bring with them their own historical and cultural belief systems (Speziale & Carpenter 2007). Both the interviewer and the participants come with their own expectations; hence, affecting what is said and what is heard (Speziale & Carpenter 2007). In this study, the researcher considered the social and cultural context in which the data was collected before entering the field to conduct the interviews by ensuring reflexivity. Reflexivity was ensured by being open to the influence that the researcher had on the inquiry through their self-reflection.

Primeau (2003, p. 36) stated that “reflexivity enhances the quality of research through its ability to extend our understanding of how our positions and interest as researchers affects all stages of research”. Therefore, as researchers, it is our role to reflect on our influence, analyse it critically, and use it to enhance our project. This was done using a personal research journal as a place to record feelings, attitudes, values, and beliefs that relate to the interview and its processes. According to Speziale and Carpenter (2007), once a researcher has a method of recording and maintaining their self-reflections, which in this study was undertaken through journaling, then they are ready to enter into the field to conduct the interviews.

5.5 Data collection

Data was collected over a period of 7 months. Interview times ranged from 30 minutes to 2 hours. A suitable location for the participant e.g., a university room or private meeting area was used. Participants who resided interstate were interviewed via telephone. In this study there were no indications that the interview process was affected because the interview was conducted face to face or over the phone. Although research studies have explored whether potential differences exist in the quality of data obtained between telephone versus face- to-face (Novick 2008; Vogl 2013). Vogl (2013), examined the effects of telephone versus face-to-face interviews; results were similar to other findings which showed very little difference between the two styles, except participants were more likely to feel relaxed over the phone and disclose more information in comparison to face-to-face (Novick 2008). After each interview, the data were transcribed verbatim by the researcher and de-identified. Pseudonyms chosen by each participant were used.

Due to time constraints caused by the unforeseen slow pace of participant recruitment, a transcription service was later employed to transcribe some of the already obtained data. Confidentiality was maintained throughout the transcription process. The researcher and the thesis supervisors only had access to the transcribed de-identified interview data for the purpose of the analysis. The data were stored in writing (hard copy) and on audiotape on the Flinders University computer server, according to the Flinders University data storage protocols. All data were stored in a de-identified form, while the recordings of the interviews were safely stored within the university facilities on a password-protected computer and university server.

5.6 Rigour or Trustworthiness in data analysis

The goal of rigour or trustworthiness of qualitative research is to present an accurate representation of the participants' lived experiences (Speziale & Carpenter 2007). Lincoln and Guba (1985) suggested five criteria for the trustworthiness of qualitative research: credibility, dependability, confirmability, transferability, and authenticity. To ensure trustworthiness, consistent use of the chosen method was vital and adhered to throughout the study (Polit & Beck 2008). Also, when the findings were recognised as a true reflection of what was said by the participants, the trustworthiness of the data was again established (Speziale & Carpenter 2007). However, if there were any elements of the data that were unclear, the researcher returned to the analysis and reviewed the participants' descriptions guided by Gadamer's hermeneutic process (Gadamer 1975). The criteria for trustworthiness as applied in this study are described below under credibility, dependability, confirmability, transferability, and authenticity.

5.6.1 Credibility

Credibility is demonstrated by activities that result in producing findings that are credible (Lincoln & Guba 1985). A lengthy engagement with the subject matter is one of the other most reliable ways to create credibility (Speziale & Carpenter 2007). Lengthy engagement with the data was ensured using Diekelmann's seven stage process. Also, credibility can be confirmed by allowing the participants to see if the findings from the study were true to their own experiences (Speziale & Carpenter 2007). This is referred to as member checking (Speziale & Carpenter 2007).

In this study, ED staff were not given the final themes, because of the time constraints caused by the initial low response rate. In addition, it helped to avoid any potential for obtaining spontaneous data. According to Mero-Jaffe (2011), one of the major disadvantages of allowing participants access to transcripts were the changes in opinions of participants due to a change in circumstances and views that were true at the time of conducting the interview, but has now changed when presented to participants for member checking. But participants in this study were made aware that publications from the thesis would be available.

5.6.2 Dependability

According to Speziale and Carpenter (2007), once the credibility of the findings has been confirmed, the researcher then needs to question whether the results are dependable. Dependability questions whether the same findings would be produced if the study was replicated with the same participants (Polit & Beck 2008). In this study, dependability was enhanced by ensuring that the data analysis process was clearly documented for easy replication. The entire research process, including the difficulties experienced with participant recruitment and how this was resolved, was detailed so that transparency could be maintained.

5.6.3 Confirmability

Confirmability establishes that the findings truly represent the experiences of the participants, and that the results are not motivated by the bias and prejudices of the researcher. In this study, throughout the data interpretation and analysis process, the researcher established confirmability by recording personal biases and prejudices in a separate journal. The objective of confirmability is to thoroughly illustrate the evidence, including the thought processes that lead to the conclusions (Speziale & Carpenter 2007). Critical acts of reflection were undertaken throughout the data analysis process to ensure that the findings were not creations of the researcher’s imagination. This was also evident in the chapters in which I have described my own pre-understandings to avoid any potential for bias.

5.6.4 Transferability

Transferability refers to the generalisability of the data. In other words, it is the extent to which the findings are applicable to other groups and contexts. To ensure transferability, Lincoln and Guba (1985) stated that a detailed description and interpretation of the data should be provided so that researchers can determine whether it is applicable to other groups and settings. The data were interpreted so that a clear representation of the characteristics of the participants would be represented. In this study, the participants' demographics were detailed, and the inclusion criteria were provided so that the generalisability of the findings to other settings could be ensured. Overall, the two detailed findings chapters have been presented in such a way that they provide meaning to others in similar situations.

5.6.5 Authenticity

Authenticity refers to the extent to which the researcher acknowledges and demonstrates the different realities and worldviews of the participants within the study. Authenticity is established when the various lived experiences of the participants have been shown. In this study, the participants were from different Australian cities and territories, identifying themselves as being from different cultural backgrounds and traditions relating to death, dying, and EOLC. This diversity was well represented within the findings, so that an authentic representation of each participant experience could be represented. When authenticity is established, it has the capability of drawing the reader into the experience being described; hence, giving the reader a better understanding of the lived experiences being interpreted (Polit & Beck 2008).

5.7 Data analysis using Diekelmann et al. (1989)

The data analysis process was guided by Diekelmann et al's (1989) hermeneutic interpretive approach based on Gadamer's hermeneutic circle and processes. As previously discussed, Gadamer's hermeneutic circle was used to begin the interpretation of the data obtained from ED staff. Also, the researcher was aware of their own place within the hermeneutic circle, which was based on my background knowledge from my experience of providing EOLC within the ED setting. Data gained from my own experiences, and the experiences of ED staff members brought together two interpretive worlds to provide meaning and understanding.

Gadamer's interpretive hermeneutic circle was engaged with by constantly interpreting the whole of the data and the constituent parts. The data gained through the interviews was interpreted by understanding the data as a whole with consideration of the parts, with each part being understood with reference to the whole of the data. Thus, the continuous cycle of movement between the parts and the whole made the interpretation of the data one that emphasised how meaning was gained within the cultural and historical context of the participants. Gadamer (1975) stated that, to hermeneutically interpret a text, the researcher cannot separate themselves from the meaning of the text and must be open to the new possibilities that the text can uncover. To hermeneutically understand the data, the ED staff members' understandings, along with those of the researcher were merged together, analysed, and a new understanding established. The text was hermeneutically interpreted throughout the interview process, as well as in the data transcription and analysis processes.

Diekelmann et al. (1989) developed a seven-stage hermeneutic method to identify categories, themes, and patterns arising in text. The intent of this approach is to reveal frequently taken-for-granted shared practices and common meanings. Diekelmann et al's Gadamerian style of data analysis seeks to find meaning and understanding of practices and experiences (Porter & Cohen 2013). As the participants describe their lived experiences, the researcher seeks commonalities in meaning, experiences, and practices. In conjunction with the interpretation of the whole text to the parts and the parts to the whole. Gadamer's fusion of horizons, as previously discussed, within the hermeneutic circle suggests that during the data interpretation phase, understanding and meaning emerge from the researcher's *fore-knowing* (any anticipated data result due to the researcher's own previous knowledge, bias, and/or prejudices), which continually changes with the dialogue and text. In the fusion of horizons, the researcher's *fore-knowing* and the participants' experiences come together for new meanings to emerge (Parse 2001).

Diekelmann et al. (1989) stated that the ability of the researcher to recognise their own experiences as being similar to the participants reinforces their shared meanings and experiences. Diekelmann et al's (1989) seven stage process supports the hermeneutic method of inquiry used in this study. Since its first use by Diekelmann in 1988, numerous phenomenological studies have applied Diekelmann's seven stages, finding that it provides a richer depth to the findings compared to other analysis methods. It has been commonly used in nursing and midwifery research, teacher education, and in interactive learning environments to understand experiences, knowledge, language, and socio-cultural significance (Kuiper 2012). The summary of the stages of Diekelmann's analysis (Appendix 2), as used in this study, is presented below:

Table 5.1: Diekelmann et al's (1989) seven stages of data analysis:

Stage	
1	All the interviews or texts are read for an overall understanding
2	Interpretive summaries of each interview were written, and excerpts provided
3	A (team) of researcher(s) analyses selected transcribed interviews or texts
4	Any disagreements on interpretation are resolved by going back to the text
5	Common meanings and shared practices are identified by comparing and contrasting text
6	Relationships among themes emerge
7	A draft of themes and exemplars from texts are presented to the team. Responses or suggestions are incorporated into the final draft

5.7.1 Stage 1: Interviews are read for an overall understanding.

At this first stage, the purpose was to read the whole of the 16 transcribed interviews entirely. All the texts (the doctors' and nurses' data) were read for overall understanding. Sentences and phrases that produced a general understanding were highlighted in the document. During this first stage, the general theme and feel of each individual document was determined. For example, some participants tended to have a general theme of adhering to the patient's wishes throughout their responses, while some gave an understanding of advocating for patients. Overall, the general understanding obtained from the text was that of *patient-family-centred end-of-life care.*

5.7.2 Stage 2: Interpretive summaries of each interview were written, and excerpts provided.

This involved an interpretive summary of each section of the document and then categories were identified. In accordance with Gadamer's interpretive hermeneutics in this stage, the data were not just described, but an initial interpretation was provided. The transcribed interviews (with the doctors and nurses) were grouped into 13 sections. The nurses' data was summarised and categorised initially, after which the doctors' data was completed as separate analyses but were eventually analysed for their similarities and differences. Once the sections were identified, an interpretation of each participant's responses in each section was undertaken. After each section was interpreted and summarised, categories within the summary were identified and excerpts were attached to each category.

5.7.2a. Stage 2 Extended: Excerpts to serve as supporting data were attached to each individual category that was interpreted.

Each summary was re-read to ensure that the categories captured what the summary was saying, and more categories were added as required. During regular meetings with the thesis supervisors, written interpretations of each summary were read as a team, along with the chosen excerpts from the data to support the interpretation of the categories. This provided greater clarity in the analysis. At this stage, comparisons of the team members' interpretations were undertaken to come to a consensus in each meeting.

5.7.3 Stage 3: A team of researchers analyses selected transcribed interviews.

A team approach with the supervisors was employed at this stage of the analysis. Further analysis of each document was undertaken, and the interpretations given to the categories were discussed within the team for clarification. Any discrepancies in interpretations within the team were clarified by referring to the original text. For example, the investigator originally interpreted an excerpt by a participant as a '*Bad Death'.* However, the interpretation of the category was changed to '*Feelings of Sadness'* after further analysis was undertaken with the expert supervisors. This led to stage four where there was a back and forth process using Gadamer's hermeneutic circle.

5.7.4 Stage 4: Disagreements on interpretation are resolved by going back to the text.

Once the appropriate category had been interpreted with its excerpts, this stage required the identification of a relational theme. The relational theme was identified by using the text generated in stages two and three. The text generated was re-read and studied for similarities and contradictions. Similar themes were grouped together so that a link between multiple themes could be generated. Once the themes emerged, an overarching relational theme of "Experiences of providing EOLC in ED" was generated.

5.7.5 Stage 5: Common meanings and shared practices are identified.

In this stage of interpretation, common meanings and shared patterns were identified for a constitutive pattern that cut across all the texts. The constitutive pattern of 'The complexities of decision-making' emerged by comparing and contrasting parts of the text, and further expressed the relationships between the previously identified relational theme of 'Experiences of providing EOLC in ED'. The identified constitutive pattern of 'The complexities of decision-making' at this stage, was the highest level of hermeneutical analysis.

5.7.6 Stage 6: Relationships among themes emerge.

At this stage, relationships among the themes emerged (see Appendix 2). Potential themes were presented to the research team for validation. This stage provided an opportunity for the research team to review the entire analysis.

5.7.7 Stage 7: A draft of themes and exemplars are incorporated into the final draft.

The responses obtained from the ED doctors and nurses were thematically analysed for common meanings and shared practices. Parts of the text were compared and contrasted to establish relationships among the themes. The themes were initially generated using the hermeneutic process of understanding pre-judgemental notions of the whole text. A change from the initial meaning and understanding of the whole text was gained as the text was explored in detail. In other words, it involved the constant moving from parts of the text to the whole text, and then back to the parts of the text again, with consideration of any preconceived ideas until a conclusive interpretation of the text was obtained.

In summary, this chapter has described the chosen methods used in this phenomenological study. Ethical issues that applied to the study were discussed. Issues of credibility, dependability, confirmability, transferability, and authenticity, and their application within this study were discussed. A description of the research paradigm established what participants considered to be their own truth/reality, while the researcher's own previous knowledge about the topic of inquiry was outlined. Guided by Gadamer's phenomenological interpretive approach (the hermeneutic circle), Diekelmann et al's (1989) interpretive phenomenological analytical seven-stage approach was used to analyse and interpret the participants’ lived experiences of providing EOLC. The next chapter presents the findings of the first two major themes and associated sub-themes that arose from the data analysis process.

Chapter 6: Findings, Part A

This chapter presents the findings from the interviews with the selected ED doctors and nurses. The two findings chapters (Chapters 6 and 7) have been divided into two parts; the first part (A – Chapter 6) explores the first two major themes: 1) Providing for respect and dignity; and 2) Ethical dilemmas; together with their associated sub-themes (see Appendix 7). The second part (B– Chapter 7) explores the two remaining major themes: 1) Providing for EOLC in the ED, and the role of the participants; and 2) Experiencing conflict; and associated sub-themes (see Appendix 7). In both chapters, the findings are presented through an initial introduction of the major theme and its sub-themes, which is explored using quotes from the participants. The interpretation of each quote has been guided by Gadamer's interpretive philosophical approach.

The data were obtained through semi-structured interviews that explored the lived experiences of death, dying, and the provision of end-of-life care (EOLC) in an emergency department (ED) setting. The open-ended interview questions (Appendix 6) were analysed using Diekelmann et al's (1989) seven stages, as discussed in Chapter 4. The hermeneutic analysis was conducted using Gadamer's phenomenology as the philosophical underpinning, with the relational themes being identified leading to an overarching constitutive pattern (CP) (Gadamer 1976; Diekelmann et al., 1989). The constitutive pattern that was identified will be discussed in-depth in Chapter 8, along with the researcher's perspective. According to Gadamer, the perspective of the researcher is a hermeneutic tool in itself.

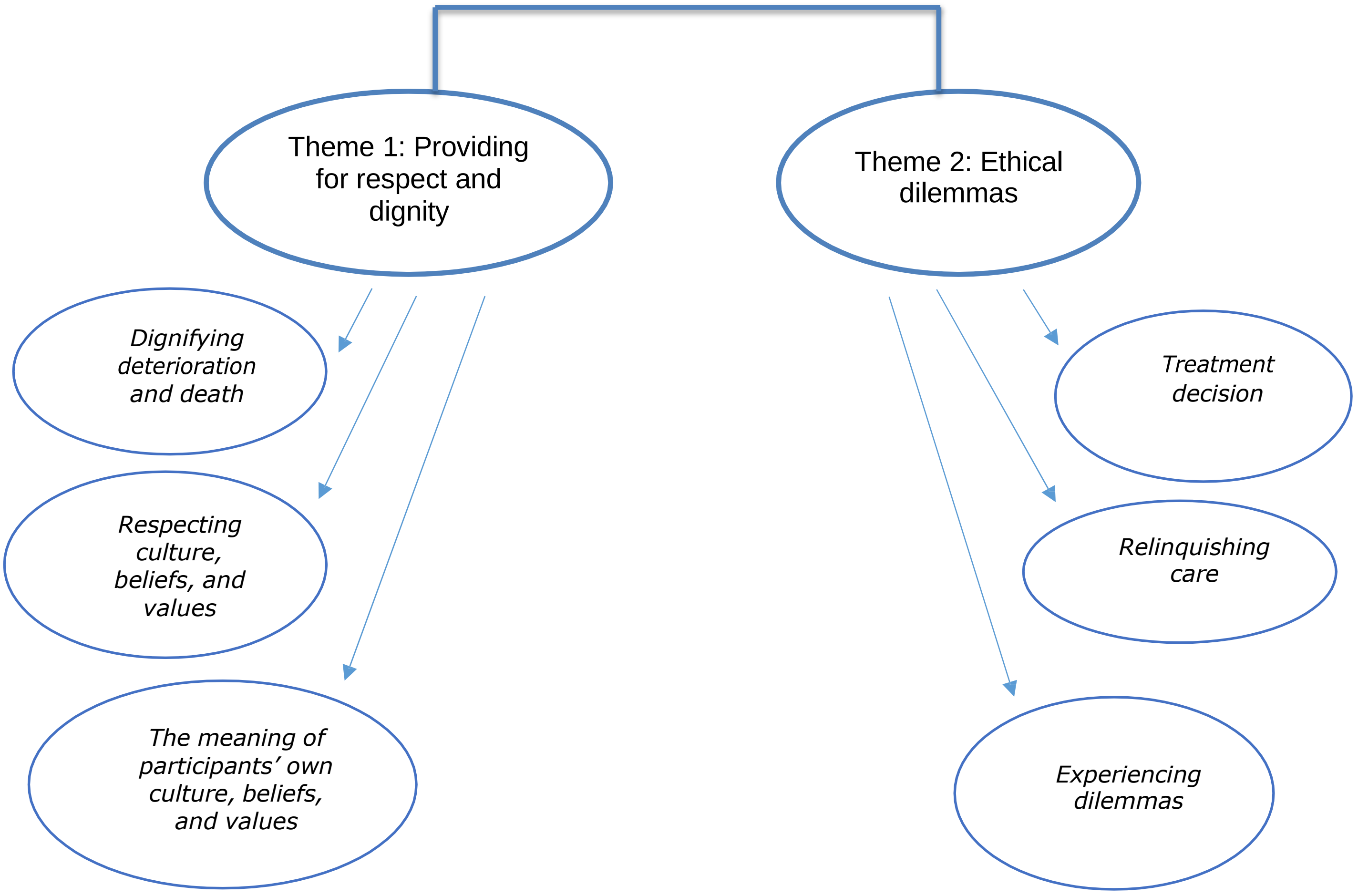
The participants in the study were ED doctors and nurses with current experience of EOLC provision within the ED setting. The ED settings were a mixture of rural and metropolitan locations. Some of the ED where participants worked were the major ED within the cities which provided critical care with major trauma service centres and some were smaller in terms of the services provided.   A total of 16 participants (7 doctors and 9 nurses) provided first-hand accounts of their experiences. Of the 16 participants, 11 had worked in an ED for 10 years, while 4 had worked in an ED for over 10 years. Many of the participants had engaged in postgraduate education and training after their university degrees. In addition, 13 of the participants had undertaken senior roles, including ED consultants, triage roles, resuscitation roles, and team leading (TL). Table 6 below provides further demographics and characteristics of the participants.

Table 6.1: Overview of Participants

	Nurse	Doctor
Total 16	56%	44%
Gender		
Male	4	2
Female	5	5
Age		
18-29	4	1
30-49	5	4
50-64		2
Education		
University Graduate	2	2
Graduate Diploma	6	
Master's Degree	1	1
Doctoral Degree		1
Professional Degree		4
Years of working in ED		
Less than 5 years	1	1
6-10 years	8	2
Over 11 years		4
Roles in ED		
Senior Nursing Roles (Triage, Resus, TL)	5	
Consultant		6
Intern		1
Registrar		1
Low Acuity Team Leaders	4	
Education on Death and Dying		
Yes	4	3
No	5	4

From the data obtained, the first two major themes to be discussed are: 1) Providing for respect and dignity: 'Deterioration and progression to death should occur in a dignified fashion', including three major sub-themes, and 2) Ethical dilemmas: 'And so I was in a really tight spot … we are caught in the middle', including three sub-themes, as illustrated in the diagram below:

Figure 6.1: First two major themes and sub-themes



6.1 Theme 1: Providing for respect and dignity: 'Deterioration and progression to death should occur in a dignified fashion'

The participants believed that the provision of EOLC must be founded on both respect and dignity. They described respect and dignity in EOLC as strictly adhering to the dying patient's wishes (life-saving or comfort care) and ensuring that all needs were met in line with what was of utmost importance to the dying patient themselves. Dignity was upheld when patients' wishes were respected and a death that represented the dying patient's own definition of what a good death meant to them was able to be provided.

The participants highlighted that the common ways that respect and dignity were conveyed to the patients and their families were via the art of caring to meet any and every need of the dying patient and their family. In addition, respect and dignity were shown when honest and open communication about the extent of the true prognosis was communicated with patients and their families as soon as EOLC was identified. The participants believed that honest communication about the prognosis contributed to the acceptance of death and allowed the focus of care to shift to promoting dignity and comfort, as well as to fostering respect for the wishes of the patient and their family.

Common issues for the participants throughout the data included the provision of a good death and dying experience for the patient and their family; the participants' own understandings of respect and dignity; and maintaining respect and dignity throughout the dying process as a duty of care. More specific issues that the participants identified included maintaining respect and dignity in a chaotic ED setting, lack of privacy, the nature of ED work (saving lives as opposed to comfort care), and the time constraints that inhibited the provision of a respectful and dignified death.

According to the participants, respect and the enhancement of dignity did not fit onto a one-size-fits-all approach. Only an individualised approach to care could take into account the physical, emotional, spiritual, and psychosocial needs of the dying patient. The participants' understandings of respect and dignity were different for each individual dying patient, as this was highly subjective, and each patient's needs were unique. According to the participants, when the patient's wishes were respected, they had been given a voice in a situation in which they could easily become voiceless and disrespected and could end up having an undignified experience of death and dying.

The sub-themes explore how the provision of respect and dignity throughout the deterioration process leading to death was provided. The context surrounding the provision of EOLC, as well as how the participants were able to provide respect and dignity based on the needs of the dying patient were explored. Respecting culture, beliefs, and values to foster a respectful and dignified death was described and how the participants' own culture and beliefs impacted on their provision of EOLC.

6.1.1 Dignifying deterioration and death

The participants reported that the vital aspects of respect and dignity for the dying patient and their families included ensuring that their deterioration (despite having been in an ED setting that was 'chaotic, busy and lacked privacy'), was dignified. As deterioration occurred, the participants reported that the dying person became increasingly dependent on the ED doctors, nurses, and family members for their basic needs. Because of this, they reported that an increase in dependency for care resulted in a significant loss of control for the person. Most of the participants believed that the provision of comfort to the dying patient was a crucial criterion for respectful and dignified EOLC:

> *The focus always should be on comfort and dignity of the patient and respecting them primarily, but also their family (Dr Nnea p. 3, L 7-13).*
>
> *I think you can still pass away in a dignified way … {in ED}, I like to see people pass away naturally and comfortably … In emergency department, you find it difficult to see patient deteriorate … and it's an ongoing frustration (Nurse Callij p. 1, L 26-31).*

The participants found deterioration in the ED to be difficult due to the nature of the care context which aimed to save lives and prevent death. When deterioration occurred, it was frustrating, but they believed that the death and dying process could still be dignified. They also stated that ED staff were effective in recognising deterioration of the patient that was either sudden or gradual. In situations where deterioration was gradual, the participants mentioned that other healthcare professionals, such as the GP and the specialist, might not be able to diagnose the deterioration because they were too close to the case to be objective. ED staff were often able to diagnose deterioration, so that goals of care could be put in place for the patient. The participants illustrated the recognition of the deterioration process in the following quote:

> *Often we are the first ones to tell them that we have this window of opportunity quite different to their long-term providers who sort of even can't bear to tell them that {they are deteriorating}, or because the change have just been very slow or haven't recognised the deterioration. We are often the ones who look with the fresh pair of eyes to go "it's not going well". So, let's say you know someone arrives moribund and they have clearly only got a day or a couple of days to live, that's a difference. The vast majority of our patient sort of recognising that they are within the last 12 months of their lives (Dr Turtle p. 2, L 21-31).*

The participants emphasised that the recognition of deterioration was crucial, so that measures to provide a dignified deterioration and dying process were established to ensure comfort care needs were met. Comfort was identified as one of the main ways respect and dignity was achieved.

According to the participants, a respectful and dignified death needs to ensure that EOLC for the patient included the well-being of their family. They described the importance of family members and loved ones in relation to respect and dignity. For example, one participant stated that:

> *For the patient, obviously it's maintaining their dignity, so I would, before bringing the family in, especially if it's from a patient from a tragic circumstance, make sure blood is washed off, a new gown is placed on the patient, clean sheets, things like tubes and lines are removed where possible, sufficient pain relief is given so the patient does not look like he or she is in pain, especially when the family members are in there. Yes, so just making sure that the patient looks presentable before we bring family members in … the patient is then moved to a quieter area … again the family members have the ability to take as much time as they need to … I guess, things that we try and do to accommodate the patient's family members (Nurse Abigail p.11, L 12-38).*

Respect and dignity were ensured for families by making the dying patient comfortable, and thus dignified and presentable before family members were brought in to see the dying patient. Despite the ED setting and the time pressures, the participants understood the value of providing respect and dignity. This was achieved by giving family members a quiet area in which to sit, and time to sit with the dying patient for as long as possible so that their last moments were spent together. An understanding of the participants' views of how respect and dignity were provided established the concept of comfort as a defining attribute for quality EOLC. To further explore the notion of respect and dignity, the following sub-theme presents how respecting the culture, beliefs, and values of patients and their families affected the provision of EOLC.

6.1.2 Respecting culture, beliefs, and values

The participants reported that respect for the culture, beliefs, and values of patients and their families was an important component of providing EOLC in the ED setting. Respecting the wishes and dignity of the dying patient meant that any traditional obligations or wishes of the patient were supported and provided. All the participants believed that they must accommodate the dying patient's requests with regards to their culture, beliefs, and values, as illustrated in the quote below:

> *I can think of one case two or three days ago in the emergency room, an elderly dying person from a Japanese background … died. There was a request by the family to return to the Buddhist ritual for the coming hours and there was reference to that lasting for about six to eight hours in terms of prayers and gathering of family …, so that the values and traditions of the patient can be respected and accessed by the patient and his or her people … there were concerns about space and resources being available to accommodate the ritual at the place of death … But after discussions … I understand the ritual was allowed to happen in the viewing room and there wasn't any further difficulty described (Dr Seamus p. 6, L 8-21).*

They also recognised there were various cultural beliefs and values that were encountered in the ED, but all needed to be respected. Respect for others' beliefs was regarded by the participants as 'ethical' and the right thing to do. They believed that doing anything the dying patient required was more important than the difficulties that ED as a setting may present, such as the lack of ED space and resources. Even if it was inconvenient and held up ED bed space, the person's beliefs and values were considered of utmost importance.

The participants' believed that respect for the dying patient included doing 'whatever' the dying patient required, and in doing so, control was given to the dying patient and that this was respectful and dignified. According to the participants, control was not only given to the dying patient, they also ensured that family members had control. They identified that families often did not realise the control they had regarding end-of-life decisions for their loved ones. They stated that when family members mentioned that their loved one had a good death, the participants used this to define a positive experience of death. The concept of family control in relation to dignity was reported in the excerpts below:

> *Letting the family members feel like they are in control, so people always feel helpless when a loved one is passing away, that's quite natural, they are not able to help, they are not able to have an input, they lose control I think, so something I do for a patient{'s} family when the patient is passing away, say it's an imminent thing and you've got PRNs, morphine, midazolam written up for them, I might think the patient looks perfectly comfortable; however, I really stress and I always make the family understand that I don't know this person, I don't, they know them, if they are concerned, if they think the patient is uncomfortable … that the patient needs anything, they should call, I will be there to listen, I will be there to provide whatever you guys need. It's just giving them that little bit of empowerment, even though it's almost superficial empowerment, but they feel like they are involved in the end of the patient's life, and they can have some input, and rather than taking all the control away from the family and us just doing what we do, putting some of that control back to the family I think is really beneficial … and you can see as soon as you do that, the family pays a little bit closer more attention to the patient, they become that little bit more involved. I feel you can always see that bit of a difference in the family just bringing them in and involving them a little bit more, that's how I feel about it anyway! (Nurse Callij p. 6, L 30-50).*

> *I personally respect that time for them {the dying patient and family members} … If the patient has any family members, we try to include them and tell them what's going on … I make sure I include them …, so I let them know what am doing, how am doing it, what's going on, so I make sure they're part of the process, for them to say what they are experiencing … or if they've had a positive {experience} – I would hope so, because I try to make sure it's a positive experience for them, and let the family be involved**,** so {I tell the family}*

> *if you think she {the dying patient} is distressed, let us know … just make them more comfortable, and explain things to them (Nurse Abebs pp. 7-8, L 36-45, 1-2).*

The participants stated that the inclusion of the patient and their family members in decisions and interventions about the dying process was valuable. They believed that involving families was beneficial because the nature of the high workloads in the ED can hinder the provision of a respectful and dignified death. According to the participants, asking the family to request help for the dying patient made the ED staff appear as if they were more available. Overall, respect for the dying patient was highlighted as a priority, regardless of the ED setting and the nature of ED work. Cultural background, religious beliefs, and family traditions were often viewed as positive and as needed for dignity. The participants also provided accounts of their own personal cultural beliefs and values, and how they impacted on their provision of EOLC.

6.1.3 The meaning of participants' own culture, beliefs, and values

The participants revealed that their own personal culture, beliefs, and views influenced death, dying, and EOLC in the ED. ED doctors, and nurses' beliefs and views ranged from Christianity to atheism, and a range of other beliefs and views. Participants who had Christian views were represented in the following excerpt:

> *Personally, I'm a Christian, so death and dying, I would say, means different to me than it would to someone who isn't a Christian … yes, personally as a Christian, for me there's hope after death and dying, … and that makes this whole process, I guess, not necessarily easier, but it does bring comfort, and the kind of comfort and peace that you would not otherwise know unless you had that hope that this person, if he or she was also a Christian, would be someone you would see again in heaven after … Personally, there is hope when it comes to death and dying, if that person whom you're about to lose is someone that you know is also a Christian (Nurse Abigail p. 5, L 10-28).*

Participants with Christian views believed that, as a Christian, the meaning of death and dying was significantly different to what it would be for someone who was not a Christian. Even though death brought sadness and being a Christian did not take away from the sadness of the loss, it appeared to make coping with death and dying easier. However, if the person who had died was not a Christian, the participants believed that the hope of resurrection (a part of the Christian belief) was not possible. When the deceased was a Christian who believed in God, the participants were assured of the dying patient going to heaven.

Some participants viewed death and dying through the lens of atheism. The participants with an atheist approach to death and dying often used a reasoning and thought process that logically analysed death and dying using the inevitability of eventual biological cell death. The participants who held this belief about death and dying categorised themselves as individuals who believed that death was a natural process, and that there was no God or after-life:

> *My belief in death and dying is that it is what it is, it is quite black and white. You are alive and then you are dead, you are here to pass on your gene, that's what I believe. {We are} just a biological matter. Humans and life are just created in a way for us to pass down our genes and we are just a vehicle for the genetics to pass it down so the {human} species will go on multiplying … I believe it has helped me cope (Nurse Chu p. 1 L 27-28; Chu p. 2 L 18-24).*

For these participants, their belief about the inevitability of death and dying for every human being was clearly defined. Death was seen as a natural end that everyone will experience because it was only natural for body cells to biologically deteriorate and die. Generally, the participants, whether Christian or atheist, expressed that their beliefs were used as a coping mechanism when providing EOLC.

The participants reported various ideas and beliefs that enabled them to cope with death, dying, and the provision of EOLC. They coped with providing EOLC knowing that death was inevitable, that it was part of nursing, and when caring for individuals with similar values. The views and beliefs they used as coping mechanisms were illustrated in the following quotes:

> *This is part of nursing and people are gonna die … I think initially for me it was a bit confronting to have to do that, but I think we can, and learn to cope with it. I developed some strategy, like, to look after a person like that, that is dying, but – yes, it can be a bit confronting, but I think you get used to the idea ... I think sometimes there is a reassurance, personally for myself, that they are old people, and hopefully they've lived a good life, and I think it makes it a little bit better for myself to think that they've really grown old and had a really long life (Nurse Abebs pp. 3-4, L 38-41, 1-4).*
>
> *Personally as a Christian, for me there's hope after death …, and that makes this whole process, I guess, not necessarily easier, but it does bring comfort … Whereas, to someone who is a Christian, I have had one or two situations where the family were Christians, then it's very different, because you're able to sit there and grieve with them, but at the same time, share the hope that this family will see their loved one again, you know, when they get to heaven. So, it's very different outlooks. And, for me personally, I guess the sadness you feel for a family who's not a Christian is a lot deeper, because you know that their separation is forever, as compared to a family who is a Christian (Nurse Abigail p. 5, L 18-28).*
>
> *I think those situations were easier maybe because I felt like they{the dying patient and families}were behaving the way I would behave maybe that's why it was easier so I felt like this person had a really good death in the emergency department (Dr Nnea pp. 4-5, L 59-60, 1-6).*

The above quotes by the participants represent the effects of various beliefs and views on providing EOLC. Some believed that when an individual died at a much older age, it was easier to cope knowing that they have had a long life. Most of the participants reported an initial unease about caring for someone who was dying, but this got better over time as they started to develop various coping mechanisms. They mentioned that some of their coping mechanisms were knowing that death, dying, and EOLC were part of nursing and that death was inevitable.

The participants believed that care was easier when the dying patient and their family held the same beliefs and views as them. They reported that the context of care provision was smooth because it was easier to care for dying patients and their families who ‘behaved the same way as they would’. They also reported that the death experience in such cases was good because rapport and trust had been readily established. Another participant also expressed a personal view that death is natural and “something that can be celebrated”:

> *{Death} is something that can be celebrated … My favourite aunty had breast cancer … {it} spread to her lymph nodes and metastasised … few years ago … it was something that we saw happening … over a long period of time ... she was one of the last people to get one of the suicide kit … but she actually ended up using the {suicide kit}, but before she {used the suicide kit}, we had a celebration for her … So we ended up getting the whole family together and having a big goodbye party. It was just a death; death is a normal part of life and it doesn’t have to be a time where everything has to be terrible and bring everyone down (Nurse Callij p. 1, L 36-39).*

Another participant discussed her personal belief that death was a relief, especially when the dying patient was suffering from pain:

> *Often, {death} is more {of a} positive outcome, the way I view it, than negative one. Often when especially the patient is suffering, when they are dying like battling a cancer or anything. When they eventually pass away, I feel like the family is more relieved that the patient is no longer suffering and in a better place … there is also a sense of relief that a weight has been lifted, that the person has finally been relieved of their suffering. The good is often what I felt more than the bad (Nurse Chu p. 2, L 31-36).*

Personal beliefs also included the belief in euthanasia and the prevention of futile treatment, the belief that life can still be celebrated in death (a planned death as a result of self-euthanasia), the view that every death was positive in the end, especially if the dying patient had battled a long-standing chronic illness that caused pain and suffering. Death was often seen as a welcome relief for the patient, and even more for the family who were witnessing the distress of their loved one. This aspect of the data highlighted that the participants held a range of beliefs, but one common one was the need to provide comfort. Their responses revealed that culture, beliefs, and views did not have to conform to a religious or popular belief system, but that they held opinions that served as a coping mechanism when providing EOLC.

In summary of this major theme, the participants regarded respect and dignity for the dying patient as a crucial element of EOLC. A respected and dignified death and dying process was provided by the participants when comfort (spiritual, physical, emotional, cultural, and psychosocial) needs were met. The participants also held cultural beliefs and views that were used as a coping mechanism when providing EOLC. The dying patient and their family members had various cultural beliefs and views that were important to them. When those needs were provided for by the participants, the dying patients received quality EOLC, regardless of the setting. The participants still upheld the ethical principle of respect and dignity, even when it was difficult because of the ED setting, and when the patient's beliefs went against their own beliefs. Consequently, it was necessary to delve deeper into the specific ethical dilemmas that the participants encountered during the provision of EOLC in the ED setting.

6.2 Theme 2: Ethical Dilemmas: 'And so I was in a really tight spot … we are caught in the middle'

Ethical dilemmas occurred when the participants were presented with situations in which the available choices did not resolve the dilemma itself. Dilemmas were identified when there was ambiguity surrounding the choices between two or more available complex decisions, neither of which was acceptable nor preferable. Thus, decisions about which one to choose were never clear-cut because both decisions came with their own advantages and disadvantages.

The participants expressed that these dilemmas whether ethical, moral, or legal were often complicated; for example, when the dying patient and their family requested interventions and treatments that they believed added no quality to the care of the dying patient. They felt that this went against their own moral or ethical beliefs, describing being in a 'tight spot', or feeling 'that their hands were tied', and being 'forced to provide treatment' that was against their own ethical or moral judgement. Careful consideration when making the best decisions involved selecting the better of the two evils. According to the participants, when such dilemmas occurred and decisions were difficult to make, a legal approach was often required to provide guidance to choose the best decision for the patient.

The participants acknowledged that everyone’s morals or ethics are different, so it was important to be aware of those differences because what an individual believed to be morally or ethically wrong would be different from what another believed to be right or wrong. The differences in moral or ethical understandings often caused ethical dilemmas and conflicts. The participants reported breaches of ethical, moral, and legal obligations due to the setting and nature of the ED, which is characterised by high workloads and significant time constraints that often resulted in not giving due attention to quality EOLC that was ethical for the patient. Most participants reported being ‘caught in the middle’ of these ethical or moral dilemmas with the dying patients, and balancing the issues caused by the nature of the ED as a setting.

The participants’ experiences of ethical decision-making were not free of conflict, especially decisions about quality of life, the futility of treatment, and the initiation of EOLC conversations. Futility was expressed as a “balancing act” that required weighing the benefit of treatments against the potential risks and side-effects which would affect the quality of life. The relinquishing of the dying patient’s care by ED staff members was also revealed.

6.2.1 Treatment Decision

Decisions relating to the quality of life of the dying patient were viewed as a critical component of determining whether medical treatment should be given aggressively or ceased. Such dilemmas deepened when there were misunderstandings as to what a quality life and what a quality death entailed. The participants believed that Quality of Life (QOL) was often determined by what doctors and nurses defined as a quality life, rather than what the dying patient believed was quality of life:

> *I think we {ED doctors and nurses} assume quality of life as to what we would imagine it to be, as opposed to potentially what the patient would consider as quality of life, and that’s a very big ethical question in itself. As soon as we hear that the patient is independent or was able to walk, was able do diet three times a week, and they were 90, then you try a little bit harder, because you feel that they had a better life to go back to, even though you know that potentially it will be futile (Nurse Robert p. 6, L 29-37).*

> *We {ED doctors and nurses} are here to save people’s lives, and if we {ED doctor and nurses} think that this is salvageable, if they have a good quality of life, then we are more than happy to do whatever it takes to keep them alive (Nurse Abebs p. 5, L 15-25).*

> *The way I look at it is the quality of life of the patient before this event as happened. It all depends on how the quality of life of the patient. If the patient do not have a good quality of life … we {ED doctors and nurses} are just keeping the motor body alive just for the sake of keeping him alive. I think it is torture more than a blessing; however, if a patient has a good quality of life, {and a} 100 year old patient even then sometimes I feel like we should proceed with slightly more aggressive resuscitation if they are fully ambulant, if they are walking about, they are doing things on their own, or still driving, patient like that deserve a chance to be saved instead of straight away looking at them and classify them as futile (Nurse Chu pp. 2-3, L 58-60, 1-4).*

The participants believed that their own definition of what constituted quality of life counted when providing EOLC, although, it was unclear how much influence the ED doctors and nurses' own views impacted on treatment decisions based on quality of life. They believed that the differences and conflicts in views of what QOL was, raised ethical questions. The ethical question was through the process of how ED staff projected their own personal beliefs about what entailed a quality of life onto the dying patient when providing EOLC.

Most participants in the study reported that care provision and treatment were directed by their own beliefs, as opposed to what was best for the dying patient and their family. They believed that they would often "*try a little bit harder*" to save the dying patient, regardless of whether treatment was futile or not if this care was in accordance with their own beliefs.

The decision-making process on the futility of treatment was seen by the participants as contextual and heavily reliant on the circumstances of the dying patient. They believed that "futility with flexibility" was required, because futile treatment decisions were often not "black and white". According to the participants, there were contextual and flexible approaches to decision-making in relation to futility, as the following excerpt demonstrates:

> *Futility of treatment can be argued in lots of different ways and I think that it depends on the situation. If you have a 34 year old woman who wants to go to see her child's first birthday, and if you are 80, it is almost very futile treatment. But for that situation to give a woman another month of life – if she is prepared to accept the side-effects, that's not futile – so I think with futility, you have to be very careful with the context which you say something is futile or not … I think medical opinion as to count very highly about what is futile or not as well … from an ethical point of view, you should not be putting somebody and their family through something for very negligible positive outcome … a lot of the evidence showed that we {ED staff} know when what we are doing is futile, then what are we doing it for? ... we sort of feel legally obliged to do it (Dr Nnea pp. 5, L 3-7; Nnea p. 6, L 12-22).*

The contextual dependency of futile treatments was described by all the participants. Treatments that might be described as futile were provided in a context to keep the dying patient alive long enough for family members to have fitting goodbyes, as explained below:

> *It could be that we might have to leave the patient, for example, still intubated and attached to the ventilator just so that the patient is kept alive in a way for another family member to rush down and see them prior to them passing away. It could be things like that so, yes, those are all the things that we try to do to accommodate the patient's family members. I guess in a way, a lot of the care is also provided to the family members … Yes, so {futility} definitely is not black and white (Nurse Abigail p. 11, L 29-38).*

Futile treatment was often a balancing act with contextual considerations and the need for flexibility:

> *There may be other factors in the balance, for instance, presence and access to family to the dying person; family being able to see their relative alive before death. There may be a case for not stopping supportive care too quickly, for instance, not stopping the IV fluids and the antibiotics suddenly, and the patient being dead a couple of hours later when some care could have kept the patient alive for six to 12 hours to give the family an opportunity to get to the patient; for instance, interstate travel to see the dead patient. So certainly, with reference to avoiding or stopping futile care, there is a need for some flexibility (Dr Seamus pp. 25-26, L 40-45, 1-6).*

The participants stated that decisions about futility needed to be informed by a combination of factors such as medical opinion, what was in the best interest of the patient and their family, and the best available evidence. Many remarked that the dying patient and their family should not be offered aggressive treatment and heroic measures if there was a poor outcome that might not make any difference to the quality of life of the patient. Even though the participants were aware that treatments were futile in some cases, they still provided these futile treatments because they felt legally obliged to do so. The consequences of legal implications such as coroner’s cases and loss of registration, often led them to yield to requests for futile treatments from family members. This implied that the provision of futile treatments compromised the clinician’s moral obligations, despite being aware of the adverse outcomes.

The participants believed that futility was context dependent. The contextual dependency of futile treatment was clearly expressed by treating a young woman when death was imminent to be able to see the birth of her first child, compared to an 80 year old woman who had lived her life and may have multiple co-morbidities. As discussed, family reasons were major contextual factors that influenced futile treatment decisions.

Family reasons extended to keeping the patient alive regardless of the treatments considered to be futile, so that goodbyes could be said, and last respects paid. Overall, the contextual dependency and flexibility of futility was driven by family reasons.

In some circumstances, futility was reported by some participants to be medically driven. They reported that patients were given medical treatments that added no benefit to their care, but rather caused more harm. During family discussions about futility, some of the participants struggled with the choice of language used to discuss futile treatments. They voiced concerns about the lack of skills in how to discuss the topic of futility with dying patients and their families. Some participants who were senior staff stated that discussions on futility should not be undertaken by junior staff members, as explained in the following excerpt:

> *Actually, I don't look at it so much as the futility of treatment. I don't use the word futility with family; that treatment is futile … I put it all more in terms of the reserve and the capacity to recover from intensive care, but never never use that terminology of futility with the family because I think that just turns their family into a commodity. I hear medical registrars {junior doctors} going in and talking to a patient about what's going on, and their family and they are saying "so do you want me to do everything for your mum or just let her die?" Jesus like sorry, am really aggressive when am looking after a dying patient … so for me, that's our biggest problem is that – this horrible horrible language that people use around death, "do you want me to do everything I can to save her or just let her die?" Oh my god, of course they want you to do everything possible for their mum, you giant idiot! … so, we are super short-staffed. So, taking anyone off the floor to watch that conversation {when I have it as a senior} is a huge drag on resources … but their {junior doctors} comfort levels is definitely improved with exposure … (Dr Sam p. 7, L 22-58; p. 4, L 26-32).*

From this study, even though junior doctors did not often have appropriate language skills to discuss futility, there were also senior doctors who were not comfortable, as one doctor identified:

> *I guess the other really big barrier {is that} I have worked in more than one hospital where there have been particularly physician who are known to never have the 'you are dying' discussion with patients, and who actually treats every patient like they are going to be a win and never refers to palliative care (Dr Sam p. 8, L 24-33).*
>
> *Our research has shown that doctors are good at predicting those who have 12 months to live and know who to discuss end-of-life care discussion with, but they are still not doing it. Therefore, it's not a question of not knowing or recognising that death is imminent, it is rather a question of not wanting to talk about death may be due to been uncomfortable about initiating death conversation (Dr Turtle, pp. 4-5, L 44-60, 1-2).*

Participants believed that the choice of language surrounding death, dying, and futility was primarily associated with the inexperienced junior doctors in their use of phrases and inappropriate language when discussing futility with patients and their families. From the perspective of the senior doctors in this study, the language around the discussion of goals of care and futile treatments by junior doctors was a barrier to providing quality EOLC, because junior doctors would present treatment options as black and white decisions.

Data analysis showed that senior doctors often invested in research and educating junior doctors on futility treatments by allowing them to view how discussions were undertaken. Many of the participants emphasised that both junior and senior staff were uncomfortable with discussions around EOLC, futility, death, and dying, including advance care planning (ACP) discussions. In relation to education and training, senior staff often took it upon themselves to organise education by exposing junior doctors to the correct style and language when discussing EOLC. Education provided by senior doctors through role-modelling of how to undertake these discussions were shown to increase the comfort levels of junior staff. Although some junior staff might be inexperienced in using appropriate language, some senior staff were also shown to be uncomfortable about having discussions about EOLC, including the provision of futile treatment.

Most of the participants expressed that the responsibility for initiating EOLC discussions and decision-making should not be the responsibility of the ED but should be undertaken by the patient's long-term general practitioner (GP) or specialist. Some participants stated that the first conversation about EOLC should not be with an ED staff member and should not take place in an ED environment or setting characterised by a lack of privacy, noise, and time constraints. However, others believed that it has now increasingly become part of ED work, because no-one else was ready to undertake EOLC conversations. Some expressed that EOLC discussions were rewarding and satisfying. Many of the participants agreed that it should ideally be the GP's or the specialist's role to start EOLC conversations, but they still had EOLC conversations because they had no choice:

> *Often, we are the first people to have end-of-life care discussions, which I think is inappropriate, but am happy to ..., happy in the sense that yeah, we have to do it and we are often the first people to do it. I think obviously in unexpected illness and death, that's my role, but in people with chronic illness, it should be the family GP and/or the specialist involved in the care of the patient. In terms of those chronic illnesses, I get frustrated sometimes if none of those discussion*

> *have never happened with people that are clearly dying and have extremely poor quality of life, and who are brought in unwell and are in the dying process or have an illness that potentially is going to cause them to die … Sometimes, I have frustration that I am the one that has to do that, but that's always a positive experience (Dr Ahik p. 1, L 40-41; pp. 2-3 L 54-60, 1-3).*
>
> *As soon as the relatives get sick – you know, sometimes it's not necessarily the Emergency Department's job to initiate the {EOLC} conversation. Sometimes, it has to be the GP (Nurse Teresa p. 18, L 31-33).*

The decision to initiate EOLC conversations was accepted by ED staff with conflicting and mixed views. Some of the participants believed that ED staff had to make the decision to start EOL conversations, but that it should not be that way. Frustrations were expressed by some participants about being the first people to start the EOLC conversation when this should be the role of the specialist or the GP. According to the participants, the only time decisions about initiating EOLC discussions should be performed by ED staff was in an acute unexpected illness that could potentially end in death. Only then was it the ED role to have that discussion with the patient and the family about comfort care and EOLC measures. But when it was a patient with a long-term chronic illness from the nursing home/ community who was in the process of dying, or who would eventually die, and their GP or specialist had not told them that they were in the dying process or had not fully disclosed the extent of their prognosis, this was frustrating for the participants.

In chronic illnesses, the decision to initiate the EOLC conversation was believed to be the role of the GP or family specialist because they already had rapport and trust built with the dying patient and their family. The participants stated that the long-term GP/ specialist had a good knowledge of the disease(s) and its progress. According to the participants, in situations where EOLC conversations were had before presenting to the ED, follow-up and support were easier to facilitate, although, some remarked that in some situations, an external person, such as an ED staff member having these discussions may be needed, but should be used only as a second opinion referred to the ED by their primary GP or specialist, in place of not having a true and open discussion at all. According to the participants, ideally, for the best interests of the patient, an ED doctor should not have to decide to initiate an EOLC discussion in the ED setting.

The participants reported that ED might be an easy place to capture most family members for EOLC discussions because it was usually the first setting for people in crisis to access care. They agreed that ED staff had better access to patients' requiring EOLC discussions and their family members when they visit. But they suggested that if an ED clinician failed to use their opportunity to initiate an EOL conversation, the conversation might get missed for that admission and the patient might end up presenting back to ED with failed care plans. Suggestions on how to encourage GPs to make decisions to initiate EOLC as part of their role were made by the participants; for example, providing financial incentives for GPs. Most of the participants suggested that GPs should take charge of having EOLC and ACP discussions with either the patient or an enduring power of attorney (EPOA), and that they should be financially rewarded for having such discussions. They stated that even if a conclusive decision was not made with the GP, ED staff would still have some ideas of what the patient's wishes were and what their future prognosis might be.

Some participants expressed that they had come to accept that they had to initiate EOL discussions as part of ED work. They described that the normal expectation of care in the ED by the lay public and ED staff was to provide aggressive/heroic life-saving treatment to prevent death, but when EOLC was required in the ED setting/ environment, difficulty in decision-making was often reported by the participants. The majority of the participants who had accepted responsibility for decision-making on EOLC initiation reported more satisfaction on days when they had EOL discussions, and were able to facilitate a good EOLC in an ED setting, as opposed to the usual life-saving ED roles:

> *Patient who are actively dying in the emergency department, I am comfortable in having your very old and very sick and the – this might be what kills you – conversation, if this is what kills you, I can't pound on your chest and not let it kill you, because it isn't going to change anything … So, I have a lot of those discussions as well. At least once a week, I would be having that discussion … It feels very rewarding actually. And so, that's very satisfying as well … I feel it's just a bread and butter part of my job (Dr Sam p. 6, L 24-39).*
>
> *End-of-life treatment discussion; So, that's my core business at the moment, as I said, my Emergency Department looks after a well-connected bunch of affluent articulate elderly patient and I probably have an end-of-life treatment limitation and goals of care type discussion about three times a week in a clinical shift, and maybe once a month depends on the season, and in winter sometimes, I have it twice a day (Dr Turtle p. 3, L 23-26).*

A number of participants also believed that EOLC is a vital component of ED work, regardless of the nature of the ED. They expressed comfort with making decisions and having conversations about EOLC, and believed that making EOLC decisions was part of the “core business” of the ED. They reported having a significant amount of EOLC discussions and decisions in their ED setting.

According to the nurses, decisions about EOLC were not always collaborative, and they sometimes felt excluded from the decision-making process. When doctors failed to ask for nursing opinions about goals of care, nurses reported this as a disadvantage to the patient. The nurses commented that there were benefits for the patient when nurses voiced their opinions about care, although the specificity of how the patients benefited from those nurses who were able to voice their opinions when care was collaborative was not mentioned. They concluded that when care was collaborative, the best care was provided to patients. The participants described the importance of the nursing contributions to decisions about care. They stated that:

> *I think there's a lot of value in nurses being able to voice their opinions and suggestions, … senior doctors have learned in their years of working that there's quite a bit of value in asking nurses for their opinions, and I've seen that happen more and more lately. So, often in a resuscitation room, when doctors themselves might be out of ideas on what else to do for the patient, often they would actually go around the room and get the nurses to state what they think (Nurse Abigail p.16, L 15-45).*
>
> *ED doctors and nursing roles are very much aligned, the best care is where the doctor and the nurses are totally on the same page and they’re talking to each other about what’s happening (Dr Cat pp. 12-13, L 38-45, 1-4).*
>
> *It’s a collaborative sort of decision … and they make that decision with the other nurses present. In terms of – if you find a really good doctor, you find they discuss things with you (Nurse Abebs p. 4, L 9-25).*

The nurses expressed that years of working eventually allowed senior doctors to realise the importance of consulting nurses for their opinions on both complex and simple matters. The participants, particularly the nurses, believed the best care was provided when doctors and nurses were both on the same page and communicated effectively. They acknowledged that doctors were the decision-makers, but required team input from nurses, ICU specialists, pharmacists, and social workers. Team input was particularly important when decisions were to be made about life-saving measures, writing out medications for comfort, and confirmation of death. The nurses stated that collaboration as a team depends on having ‘a good doctor’. From the findings, a good doctor was indicated to be a senior doctor who had learnt over the years to value nursing opinions and to collaborate as a team.

The participants stated that collaborative care depended on the nurse's experience and whether the nurse showed interest in wanting to be included in the decision-making process. Some of the nurses maintained that the decision-making process was outside of their scope of practice. Other nurses noted a lack of inclusion in the decision making process when they were initially inexperienced in ED work, as presented in the following quotes:

> *So {as a nurse}, I can't really give advice or tell … when they should withdraw things, I would tell them that I'm not comfortable, because it is not my decision. It is none of my business. But that's just my opinion. I would get the doctor to come and have a chat with the family, because I don't feel like I'm educated enough to make a decision like that. But also, from a nursing point of view, it's out of my scope of practice. So, look, in terms of withdrawing treatment, … that's out of my scope of practice (Nurse Teresa p. 19, L 14-15; p. 20, L 9-15).*
>
> *Now it's a little bit easier, because I do have that experience, but back when I was a junior, absolutely I was scared to talk about that sort of thing {death and dying} … it's not my job to talk about prognosis, but it is my job to actually help support the patient and their family (Nurse Robert pp. 5-6, L 49-50, 1-12).*
>
> *I think inclusion in decision-making entirely depends on the doctors, but it can also depend on the nursing staff, sometime the nursing staff who make more of an effort to be included, and someone obviously who have done it more will have more of an input than those who might be newer to the resus roles (Nurse Callij p. 3, L 12-17).*

The nurses were well aware of their scope of practice. For example, decisions about treatment withdrawal were viewed as outside of the nursing scope of practice. Yet, as previously discussed, other nurses believed they should be included in the decision-making process, including decisions about treatment withdrawal. However, nurses who lacked experience reported intentional withdrawal from being involved in the decision-making process. For example, when patients asked questions about withdrawing treatment, the questions would then be referred to doctors because of the perceived lack of education of nurses to make such decisions. But with experience from working in an ED, there was no fear in answering any questions, and the nurses were able to provide support for patients and families.

Mostly, the nurses with experience stated they were also aware of the limitations of their scope of practice, but they knew that being involved in decisions about care, whether it be withdrawal or continued treatment, was crucial. The nurses reported that even though it was not within the scope of nursing practice to diagnose and deliver prognoses to patients and their families, they believed they were required to support them. Nevertheless, if the support needed by the patient required nurses to be part of the decision-making process, then they would. Overall, it was necessary for the nurses to know the limitations of their scope of practice to ensure that practices were safe, and care was not compromised.

Throughout the data, issues surrounding how the nature of ED and its setting worked to compromise the safe delivery of EOLC were reported by the participants. They reported that some of the disadvantages caused by the nature of the ED included the significant shortage of resources and staff, along with the high workloads. They believed that these disadvantages were why care of the dying patients was often relinquished by ED doctors to others (ED nurses, admitting doctors), even when the dying patient physically remained within the ED premises.

6.2.2 Relinquishing care

Many of the participants reported that when care was intentionally handed over to another clinician in an impromptu fashion, then care was said to be relinquished. According to the participants, the relinquishing of care was particular to the care of the dying patient and their family and could happen at any stage of the dying trajectory. The nurses reported that care was relinquished by doctors at the beginning of the care episode when the prognosis had only just been provided to the patient:

> *In terms of the patient coming in, thinking that they are just generally unwell, and then getting a bad diagnosis, generally in my experience what I've seen, the doctor sometimes talks to these people, talks to the patient if they're of sound mind, tells them what goes on, gives them a little bit of counselling – not very much, a little bit – and then, you know, generally goes away. They {doctors} go away. They don't come back – I hardly ever see doctors come back and check until the nursing staff have notified them of something, not necessarily time of death, but of observations decreasing or family members wanting to speak to them. But even then, because it's an ED, the doctors are busy, and by the time they've come back, it just doesn't feel right (Nurse Teresa p. 9, L 9-20).*
>
> *I had a lady who also arrested and passed away and her son, when he came in, I was with a junior doctor who broke the news to him and then left me to kind of just sit there and be with him for a couple moments (Nurse Abigail p. 21, L 21-23).*

The nurses reported that at the early stages of the dying journey, as soon as a prognosis was determined by the doctor, they would often leave them both physically and emotionally. The nurses stated that the doctors would often spend minimal time with the patient, providing no emotional support and never coming back to check on the patient on their own, unless nursing staff notified them to provide a review, or that support for the family was needed. Likewise, discussions around palliative care and resuscitation were always very brief with no attention to detail about EOLC. The nurses believed that the doctors just gave up once the patient was in their final hours of life after they had undertaken their initial diagnosis. The participants found that ED doctors would often just “leave” the rest {treatment and care} to the nursing staff:

> *They {ED doctors} just talk to the family and then leave the rest to the nursing staff. To me, I feel in general this is what they {ED doctors} did (Nurse Hu p. 2, L 58-60).*
>
> *The doctors will come in, they will have their discussion and they will write up what needs to happen and they would leave! (Nurse Robert p. 2, L 6-7).*

In contrast, the doctors did not believe they were relinquishing care; rather, they saw their role as one that was an extension of the nurses’ role. They expected the nurses to be informants who would bring their attention to anything that was required to provide care for the dying patient:

> *They {Nurses} actually do the palliative care stuff. They {Nurses} are the ones who come and get me when the families have questions that they can’t answer, or questions that need to come to the doctor. When they need more medication prescribed so that they can control nasal secretions, explaining what they are doing so it’s the nursing staffs that actually do the hard part of that job (Dr Sam p. 4, L 42-51).*

Not all the nurses believed that the doctors leaving the care encounter was a relinquishing of their roles once death was imminent, but they did state that the doctors at that stage frequently had nothing more to offer:

> *Obviously, nurses are the last stage of the dying process, the medical doctors have done their part, they have done the diagnosis … we are heading towards {death}. Obviously, everything comes back to us {Nurses} at the end, relies more on the nurses than on the doctors. I think from experience and what have seen so far, it’s more of a nurse playing that role {at the end of life}. Of course, the doctor comes in, they diagnose, they have a chat and explain to the family and the patient about where we are going and obviously they have played their part … because there are instances whereby in an Emergency Department, you have nurses sitting with patient, actually holding the patient’s hands till their last breath. It’s hardly for you to see a doctor doing that (Nurse Eve pp.1-2, L 8-12, 50-52, 4-8).*

The participants expressed that the relinquishing of care also occurred between the ED and the wards:

> *Yes. I think the culture of ED – I think that there is a very bad culture within ED where once they've referred for admission, you relinquish your care of that patient. I think that's a very dangerous culture and one that, I know myself and many interns are very uncomfortable with … maybe more senior doctors being a bit jaded. And as somebody working in the ED, you do everything you can for the dying patient, but there are limits in the sense that once you've referred them for admission, I find that it's tricky for you to continue to provide for that patient as best you can, because you're expected to kind of move on to the next patient … (Dr AC p. 4, L 18- 34; AC p.12, L 31-38).*

The doctors in the study recognised that the nurses had a caring role and that they would notify the doctors about any issues that might arise. The doctors relied on the nurses to seek them out if there were any issues for the patient. The doctor’s approach of waiting for the nurses to notify them of care needs was generally seen by some nurses as an act of relinquishing care to them. According to the participants, the relinquishing of care not only happened in the early stages of the dying process, but also when dying was imminent and the doctors perceived that they had done their part of the care which, was the acute phase of treatment to prevent death. According to the participants, when it was apparent that dying was imminent despite all the treatments, the relinquishing of care to the nurses often occurred.

The nurses expected the doctors to show support, care, and understanding towards the patient and their family. The participants believed that nurses had a clinical role to play initially, but that much of the role played by nurses occurred once EOLC had been confirmed and emotional support was required. Thus, the doctors provided diagnoses, and established goals of care and treatment options, but it was the nurses who cared for the dying patient.

Junior doctors revealed that they were expected by the senior doctors to relinquish the care of the dying patient once a referral for admission had been made. They were expected to move on from the dying patient once they were referred for admission due to staff shortages and high workloads. Regardless of the dying patient physically remaining situated in the ED, junior doctors felt pressured to be quick with patient care and were uncomfortable at not being able to go back to care for the dying patient.

The relinquishing of care for the dying was justified by the participants with a resignation that the dying patient was going to be made palliative. So, along with the relinquishing of care, there was also an inclination for care of the dying patient to be neglected and given a lower priority in the ED. The participants emphasised that staff and resources tended to be directed towards acute emergencies and life-saving procedures, while the dying patient may be left out:

> *Once the dying process begins, and heading towards the death trajectory, we often tend to neglect the patient in the cubicle, and yes, we put the monitoring on and we are watching and observing their deterioration, but we tend to forget that they could be scared and might just need someone to sit with them for that short period of time and touch them and reassure them, and overall, our presence is what counts more than anything else, making sure the patient don’t feel alone (Nurse Eve p. 2, L 26-36*).

> *Given the ED system, because you've got three other patients who are all going off their heads, and the one that is dying is quiet, so you can probably leave them for a bit. The focus becomes unintentionally shifted, and requires that {the dying patient} might get neglected slightly, which is tragic, … Because I remember, one patient particularly sits in my mind. She was put into a side room, but she was really distressed … and there wasn't anyone there suctioning her. The whole experience was noisy, the families were forgotten, the patient was in distress because, in some ways, they have been giving the label of "uh they are palliative, they are dying" – everyone's focus then shifts onto everyone else who still has a high chance of living, and people almost in their mind subconsciously kind of write {the dying patient} off, "okay they are fine, they are dying, I don't {need to do} anything there" (Dr Nnea p. 3, L 36-42; p. 4, L 28-35).*
>
> *Unfortunately, there was this one gentleman quite recently who unfortunately came in with abdominal pain as a resuscitation, and he crashed quite quickly. Turns out, his aorta was bleeding out. He had a AAA. It had burst. He had quite an extended abdomen, very grey and mottled. He was unfortunately passing away essentially, and he didn't have any family. And once they had established this diagnosis, they just put him in a general bed and shut the curtain and turned the lights out, and that was it. Nobody was sitting with him. Nobody – it was terrible (Nurse Teresa p. 15, L 22-30).*

Many of the participants observed that once the dying process had begun and the patient was dying, there was a tendency to neglect the patient in the cubicle, although, monitors were often left in place to observe and watch the patient as they died. According to the participants, they tended to forget that the dying patient could be scared and might just need someone to sit with them, give a therapeutic touch, and reassure them for that short period of time.

According to the participants, neglect of the dying patient in the ED was not intentional, because care for the dying was often very time intensive. They acknowledged that the intensive care involved in death and dying was not about doing procedures. Care was especially intensive in keeping the patient comfortable, administering pain relief, doing position changes, mouth care, and emotional support for patients and their families. However, difficulties in being available were expressed due to the ED system where there were other patients calling for attention. The dying patient was unintentionally neglected because they might be unconscious and had lost the ability to request attention when needed. The participants, particularly the new ED doctors, felt helpless and uncomfortable in these types of circumstances. Generally, the culture of the ED, such as staff shortages and the fast-paced setting, was believed as the reason for relinquishing care and neglecting the dying patient. The participants reported that although the ED was not set up for EOL/palliative care, this still occurred.

6.2.3 Experiencing dilemmas

Dilemmas experienced by the participants were largely due to the challenges reported in making decisions about treatment that were in the best interest of the dying patients and their families. Dilemmas were reported by the participants as ethical and/or moral. Most of the participants used the terms ethics and morals interchangeably, while others mentioned that their ethics were different to their morals. Resolving dilemmas was often challenging because dying patients, their loved ones, and ED staff had differing understandings of what was ethically and morally right. The participants expressed how they navigated their own morals and ethics:

> *In relation to dying, one moral issue which may come up is euthanasia. There's been a change or a development in Victoria. Euthanasia is already happening in some countries in Europe. If euthanasia becomes a legalised process, actually in the healthcare sector, there will be people {healthcare professionals} who can't take part or do euthanasia and others are okay to do it. It's a similar situation already in relation to abortion where some healthcare professionals won't do it, or take part, because of religious beliefs … it's important that on a moral basis – and without being sanctimonious, people who can't take part are not put under pressure and there is a back-up system for people who can't take part, they can move out of a room or not be linked or involved in a situation or process which is at odds with moral values (Dr Seamus pp. 23-24, L 16-45, L 1-12).*

The responses given by the participants revealed that everyone's moral code was different. Therefore, it was important to be aware of these differences because what an individual viewed as morally and ethically wrong would be different from what another person believed to be right or wrong. They spoke about moral issues related to euthanasia and abortion. Often, these moral issues were influenced by religious beliefs. Cultural differences were acknowledged, and the participants were still able to work with people and respect these differences in their professional roles. They described ethical dilemmas with legal implications as being in a 'tight spot' or 'caught in the middle', as the following quote explains:

> *And so, I was in a really tight spot because the patient clearly needed this pain relief that I had in my hand already drawn up, but I had no clear legal order. Yes, so to me, it was illegal and definitely an ethical issue, but at the same time, I could not withhold that pain relief from the patient … I could not in my own good conscience, stand there and withhold pain relief from this patient. I had to go give it to him, despite knowing that if anything happened, I didn't have the doctor's signature and I would be on my own in court. And so, the doctor refused to come from wherever he was to sign it, because he was clearly busy and I get that, but do I go ahead and illegally give the pain relief knowing the patient needs it so much? But should something happen, and the doctor's signature wasn't on that medication chart, it would all be me … No matter how*

> *good we get at getting doctor's signatures, no matter how good our doctors get at signing their orders, I think there will always be circumstances and situations where we are caught in the middle (Nurse Abigail p. 19, L 18-45; p. 20, L 1-9).*

The above excerpt reveals that the moral conscience of the nurse outweighed the legal implications. Morally, the nurse felt obliged to give the analgesia, despite knowing that her actions breached the standard of care that required a doctor to sign off on any medication, irrespective of the dose. It appeared that the participants were resigned to the issue that nurses will always be caught up in circumstances where they will be caught in the middle, irrespective of how good they are in their practice. Likewise, they described the ethical/moral lines as 'blurry' and often unclear, and this unclear distinction caused dilemmas in practice:

> *I guess when you say ethical is – sometimes the lines become a bit blurry when it comes to, like I mentioned, performing CPR, because clearly, you know CPR is not going to provide any benefit to this patient, they are arresting before your eyes. And I've had this before, a patient is arresting as I'm watching him and I'm standing there about to pounce on his chest, but there's someone on the phone just minutes away from getting that order as to whether we should or should not. So that's, you know, the ethical dilemma. Do I do CPR because legally, I should be doing it? (Nurse Abigail p. 18, L 10-30).*
>
> *Yes. I mean, I suppose going back to that negative experience, that was an ethical dilemma in the sense that … family were asking for different kinds of stuff {treatments}, and there were a lot of legalities being involved … well, I didn't know if we were doing the right thing by the patient … There's an ethical dilemma in the sense that you don't know – if that family member is making the right decisions. And then when you see that patient being so distressed because you're putting in more line you know, they're screaming, et cetera, and they're just really agitated, you just – there's a moment where you just feel you're not doing the right thing (Dr AC p. 6, L 26-36; p. 7, L 4-10; p. 8, L 30-38).*

According to the participants, ethical dilemmas were often reported due to the absence of information about whether to provide life-saving measures and cardiopulmonary resuscitation (CPR) at the time they were needed. Most reported performing CPR on patients who should not have had CPR, because the documents that confirmed their CPR status were not available. They also reported that family often requested life-saving treatments that breached ED staff members' own ethics/moral standards.

The participants believed they went against their ethical/moral standards when they felt they were not doing the right thing by the patient. Most of them reported that breaches in ethical/moral standards were compounded by ED staff members not knowing whether the decision-maker (often family members) was making decisions in the best interests of the dying patient. According to the participants when the interventions directed by the decision-maker (family member) started to cause more distress, they then began to sense that they may not be doing the right thing. Many provided examples of walking past a cubicle to find a patient who needed CPR, and it was provided because they were not aware of the patient's 'not for CPR' status at the time. As a result, they reported ethical and legal dilemmas because they felt legally obliged to grant family requests and to perform life-saving CPR when the documentation that would counter such a request was unavailable.

The participants suggested that when it was anticipated that the presentation of a patient to the ED would lead to CPR, decisions about their CPR status should be readily available to avoid such ethical dilemmas. They also suggested that family members should be encouraged to make decisions based upon what was best for the patient, rather than making decisions based on their own preferences. According to the participants, when CPR was not anticipated, but was still performed, it was reported to be an ethical dilemma.

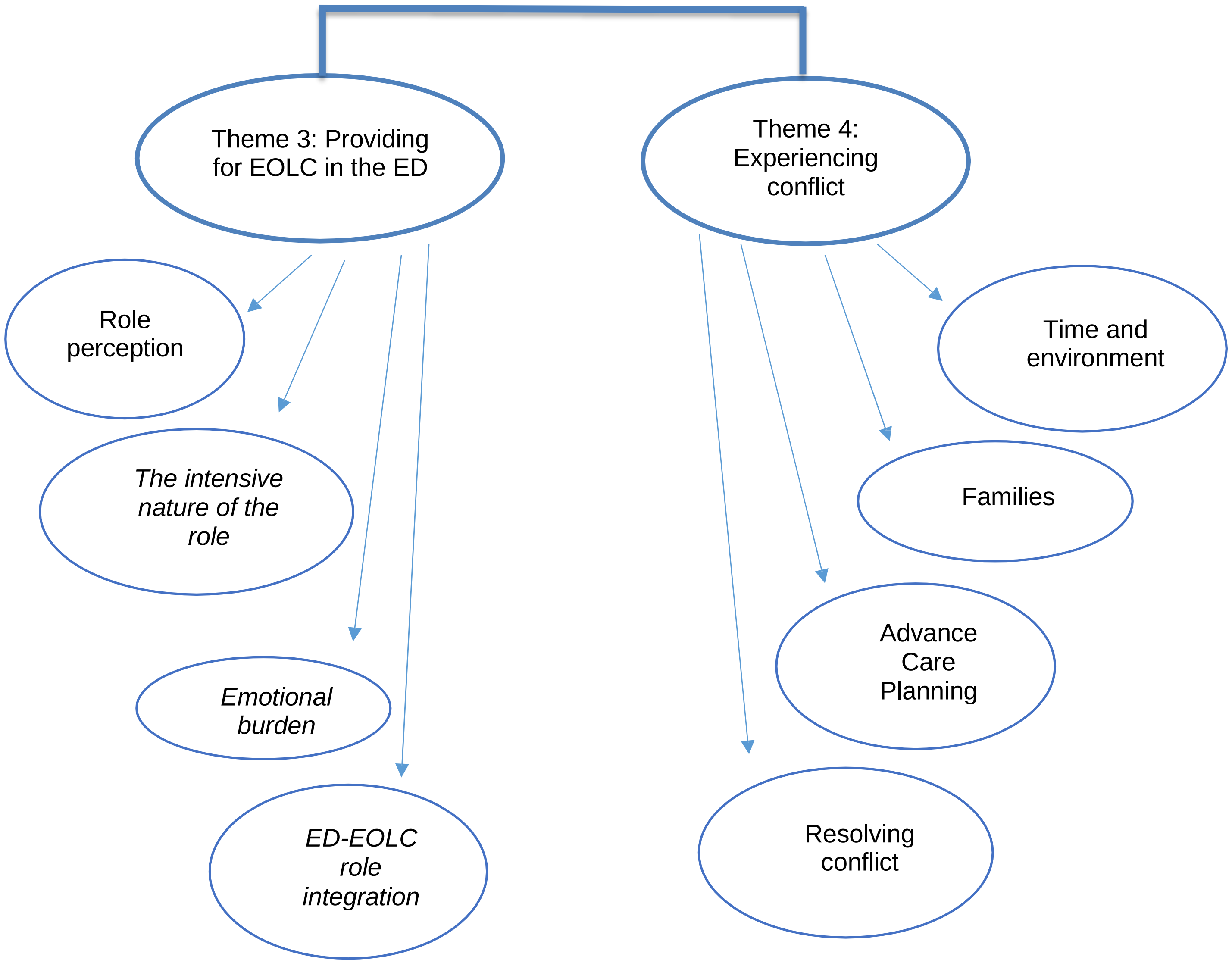
To summarise this chapter, two major themes were identified, illustrating that providing for respect and dignity, as well as addressing dilemmas, were key concepts in EOLC. The provision of respect and dignity in EOLC was important for the participants, regardless of the barriers reported. Some of the barriers described included lack of privacy, time constraints, and misunderstanding of patients' own definition of a respectful and dignified EOLC. Decision-making about care often involved difficulties, because the dying patients, their families, and other participants had various expectations about care which would often lead to ethical dilemmas. Decisions about the level of treatment, and whether to offer life-saving or comfort care, were often the major reason why the participants had these dilemmas. However, clinical practice principles and standards can be of guidance in directing treatment in such circumstances.

In the same vein, the contextual setting of the ED itself posed a number of dilemmas. The busy and chaotic nature of the ED took the attention away from the care needed for the dying patient in the ED setting. Dying patients were unintentionally neglected because the participants had to provide acute care to other ED patients. Overall, the ED setting provided a conflict against the provision of quality EOLC. One of the common findings within both themes ('providing for respect and dignity' and 'ethical dilemmas') was that the nature and setting of the ED, because of its high workload, time constraints, and staff shortages, often negatively affected the quality of EOLC provided to the dying patient and their families/loved ones. In the next chapter, the remaining two themes will be discussed in relation to how conflict caused by the nature of the ED as a setting impairs EOLC, and an exploration of the different forms of conflict that ensue as a result.

Chapter 7: Findings, Part B

Part B explores the two remaining themes of ‘providing for EOLC in the ED’ and ‘experiencing conflict’, together with their sub-themes. The findings were influenced by the context and setting of the ED. The ED is a busy and chaotic setting; time constraints and staff shortages were often reported by the participants. Providing EOLC in such a setting was a major source of conflict for the participants. They discussed how they navigated their roles considering the conflicts experienced due to the setting of the ED. The diagram below illustrates the two themes explored in this chapter and their sub-themes.

Figure 7.1: The two themes explored in this chapter:



7.1 Theme 3: Providing for EOLC in the ED; role of the participants: ‘But I think we are expected to fulfil those roles’.

The participants stated that EOLC was provided according to their expected roles and responsibilities. According to the participants, doctors and nurses had a set of distinct tasks, some of which overlapped. The accounts of the participants in relation to their understanding of each other’s roles highlighted differences in how nurses perceive the role of doctors, and vice versa. They had preconceived ideas about what they considered to be the important aspects of the doctors’ and the nurses’ roles.

The participants spoke about aspects that had an impact on their role of practicing EOLC in the ED setting. Most reported that time constraints, coupled with a high workload while attempting to provide quality EOLC was difficult. They struggled to establish a balance in their roles which frequently resulted in conflict. Conflict occurred because the participants understood that providing aggressive life-saving interventions for high acuity patients was only one aspect of their role, while at the same time, they were also trying to meet the demands of comfort and non-invasive EOLC. Due to the nature and setting of the ED, the participants felt conflicted by the requirements of their role for other ‘typical’ ED patients who needed urgent medical treatment, while also establishing quality EOLC for the dying patient.

The participants reported that it was just ‘really hard’ to facilitate good death, dying, and EOLC provision in the ED because it was often ‘busy’, and there were so many patients that required their attention. Most of the participants commented that EOLC needs are increasingly part of ED work, and the integration of palliative care into ED work had started to gain momentum. In this study, all the participants displayed concern for the dying patients. The delivery of quality EOLC was believed to be paramount and required ED staff to work together to achieve the best outcome for the dying patient and their families. Regardless of the similarities and differences that were perceived within their roles, the main objective of the participants was to ensure that comfort care was provided to dying patients.

In this theme, a description of how the roles were perceived by the participants is provided. The intensive nature of their EOLC roles is also explored. From their EOLC roles, the participants found themselves experiencing an emotional burden as they took on the grief and loss of the dying patient. They dealt with this emotional burden by maintaining professional boundaries as a response to the pain and loss of the dying patients, while at the same time, maintaining an awareness of how end-of-life comfort care fitted into their traditional life-saving ED roles.

7.1.1 Role perception

Differences in the perceptions of nurses about the role of doctors in EOLC, death, and dying were apparent throughout the data. The experiences of nurses highlighted that they understood the role of the doctors as fulfilling the need to be able to communicate effectively using ‘simple and clear’ terminology so that the patients and their family members could understand exactly what was currently happening (prognosis), including future plans for the dying patient. The nurses believed that these discussions were often difficult to have, especially when the prognosis was poor. The participants suggested that having these discussions allowed patients, family members, and staff to all be on the same page.

Many of the doctors themselves understood their communication role as being secondary to establishing the goals of care. According to the participants, the goals of EOLC were different for each patient. Some dying patients placed priority on the place of death, limitations in care (aggressive/comfort care), and religious rites and rituals. Many of the doctors believed that once the dying patient’s priority in terms of care were ascertained, the goals of care would then be established to match the patient’s priorities. However, according to the nurses, ‘simple and clear’ communication was perceived to be the major role of the doctors:

> *Doctors play a role in explaining very clearly in simple terms to the patient's family what exactly has happened and what is happening and what will happen. I think it's their role to really ensure that the family members understand and not just to, you know, kind of a give a – rattle on some clinical thing and then walk out. I think it’s really important doctors {explain prognosis very clearly} because that goes a long way in ensuring that the family members are at peace and find it easier to come to acceptance … So, I think doctors play a very big role in this. Again, they have to be clear and they have to make it clear to the patient's family members that this is something the patient is not going to come back from and, therefore, any extra treatment is not going to prove beneficial and, therefore, end of life care should then commence for the patient (Nurse Abigail p. 10, L11-18; p. 13, L 20-24).*

> *Doctors should be using plain English language to express what is going on to make sure that family members actually understand. Now, the doctor is the first to actually have that discussion. I think that it needs to be clear and concise … there’s some terminology that’s used that sometimes can be misconstrued to exactly what is going on with patients in their sense of “look we’ll make you comfortable” that becomes sometimes if everybody is not on the same page of knowing exactly what that means and that’s left up to interpretation; some*

> *people don't actually know that {comfort care} is what we are actually doing that we are at this point where this person will not survive, so I think that's where clear English, clear language comes into that (Nurse Robert p. 2, L 27-39).*

The nurses in this study believed that communication that was 'clear', 'simple', 'concise', and 'tactful' was crucial to do what was in the best interests of the dying patient and their family. The nurses reported that when communication about the goals of care were clear to the patient, it allowed for the acceptance of imminent death. But, when discussions were ambiguous, the dying patient, their family members, and ED staff were not on the same page and this ambiguity could potentially lead to conflict. The need for effective communication by using a clear and simple discussion style, as suggested by the nurses, was emphasised as a crucial aspect of the doctor's role.

Many of the doctors believed their primary role was to establish the direction and goals of care for the dying patient. The doctors remarked that their major role was to work out what is important (goals of care, limits of care, and outcomes) to the patient, because goals of care involve complex decisions. The ED doctors spoke about their role of establishing the goals of care:

> *I think the role of the doctor is ... to figure out what this person's priorities are, … What their goals of care are, what their limits of care are, and what they want to kind of achieve going forward (Dr AC p. 4, L 21-28).*
>
> *So, if they are actively sort of in the last few hours or days of their lives, I guess it's establishing their understanding of that facts and exploring all their goals, have they talked about how they want to die? Some patient will desperately want to die at home, or if they are from a nursing home, they might be able to provide syringe drivers with nursing care, they'd rather go back there because that's their own environment (Dr Nnea p. 3, L 46-49).*

The doctors in the study reported that their role was to establish the goals of care, especially when death was imminent. They expressed that their role was to determine the level of understanding a patient had about their prognosis. Subsequently, the patient's own understanding of their prognosis guided the goals of care. All the participants agreed that there were other sets of defined and unique roles that belonged to doctors and nurses.

Both the nurses and the doctors agreed that doctors have a role in prescribing the most suitable medication for either comfort or symptomatic relief. The majority of the participants stated that ED doctors should have the knowledge and skill required to chart medications that are needed at every stage of the dying process; for example, medications needed for supportive measures at the end of life when active treatments had been ceased. According to both sets of participants (nurses and doctors), the quotes below show that doctors need to be skilled in charting the right medications at all stages of the dying process:

> *It's also our role as doctors to make sure that dying patients are charted enough significant PRN {medication} as needed. So, that includes fentanyl, hyoscine, midazolam if they become agitated as well, and really just going through their medications and seeing does this benefit them in a symptomatic way? … another role in the sense of knowing when to cease active care as per the patient, and that includes, you know, maybe stopping their regular medications as well (Dr AC p. 5, L 22-28).*
>
> *Doctors are there to make sure the patient is comfortable, you know, write up the appropriate things {Medications} ... That's what they are there to do (Nurse Teresa p. 9, L 29-35).*

According to the participants, the provision of comfort was not just the main role of the nurses, but also of the doctors. Many of them emphasised that nurses provided comfort in a hands on/ practical fashion as opposed to doctors who appeared not to have a significant involvement in the provision of comfort. They argued that doctors still indirectly contributed to maintaining patient and family comfort when appropriate medications for symptomatic relief were charted. In the end, both groups of participants contributed to the comfort of the dying patient even though it was through different aspects of care.

The need for clear demarcation within the respective roles was further expressed by the participants. The role of doctors was distinct and described as the person who recognised and diagnosed the dying process. In addition, the intense emotional support described by both groups of participants was the major role of the nurse. Both groups described nurses as the major caregiver, and with that came the role of being an emotional support person for the dying patient and their families. The differences between the role of the doctors and the nurses is illustrated in the following quote:

> *The identification and the discussion to confirm the dying process belongs to medicine, but I think the nursing staff own all of the caring, all of the emotional support, all the actual caring, we doctors do the identification, then nurses do all the caring stuff (Dr Sam pp. 3-4, L 52-60, 1-2).*
>
> *I think my role {as a nurse} is just to be an emotional support, make sure that a person is quite comfortable (Nurse Abebs p. 4, L 36-37).*

The participants concluded that the nursing role was distinct from the doctors’ role. Both groups of participants stated that nurses owned all the physical and comfort care, including the emotional support, while doctors’ recognised deterioration and diagnosed a patient as dying. The doctors stated that it was the role of nurses to keep the patient comfortable by administering the prescribed medications and therapies that would assist the dying process. Administration of prescribed medication by nurses was one of many examples of hands on/ practical care that the participants often gave to the dying patient. The “hands on care” of the nursing role was described as “intensive” but was also the senior doctors’ role due to various reasons which will be discussed further below. This description of the nursing and senior doctor role as intensive was mentioned by most of the participants.

7.1.2 The intensive nature of the role

Working in the ED required the participants to undertake a complex set of tasks and roles which included the provision of traditional acute emergency treatments as well as providing care to an increasing number of people requiring EOLC. The doctors stated that EOLC was often more intense for nurses due to their numerous responsibilities. For example, the nurses managed and dealt with relatives, provided pressure area care (PAC) and mouth care, notified doctors of any issues, and managed aggressive patients. The intensity reported by the doctors was not often in relation to undertaking life-saving measures, but in providing comfort care. The quote below demonstrates why EOLC was so intensive for nurses, according to the doctors:

> *{End of life care}, it is often very intensive on the nursing staff. It is intensive in a different way, it is not in lots of machine, and there is not millions of drugs; the drugs used maybe half a dozen max probably 3 or 4. It is intensive on nursing staff for turning the patients, making sure their lips aren’t cracked, making sure they are comfortable in bed, so they often cannot do anything for themselves, so it is very intensive from a nursing point of view to keep the patient comfortable, intensive emotional relationship that is built up and that is required, the intensive kind of communication, so to do {end of life care} well, it is intensive sometimes even in doing nothing (Dr Nnea p. 3, L 10-13, L 32-37).*
>
> *From nursing perspective, it is a fairly intensive nursing. It often involves a lot of intensive nursing (Dr Ahik p. 2, L 18-21).*

According to the doctors, nurses did all the caring, practical actions, clarified the patients’ questions, provided extra information, advocated for the dying patient, provided comfort and palliative care, and supported patients and their families. The doctors emphasised that nurses have the ‘hard job’ because of the extra mindfulness, sensitivity, and care with words required in the care of the dying patient and their families. The doctors also said that EOLC involved lots of emotional expressions by the family, and the nurses often had to deal with these emotions. Overall, the ED doctors recognised that EOLC was ‘intensive’ and ‘demanding’ for nurses. The doctors also mentioned that EOLC was more demanding for nurses because of the lack of ED resources and the high workload. Regardless of the separate roles, teamwork and a collaborative care approach was observed by the participants as being optimal for quality EOLC in the ED setting.

The senior doctor's role was also described by the participants as intensive, even without doing anything practical like the nurses. The intensity of the senior doctor's role was due to the responsibility attributed to someone who was viewed as an experienced clinician. Senior doctors commented that the years spent working in ED had enabled them to acquire experience, knowledge, and skills in ED work, as well as in death, dying, and EOLC. The participants emphasised that there was a demand for the senior doctors' knowledge and skills in ED work and EOLC, all of which often made their role intense. The areas of care that contributed to the intensity of the senior doctor's role was expressed by many senior ED doctors:

> *Because I'm the senior doctor, I have to care for my staff that are also caring for that patient and family. So, because dying patients are very demanding – emotionally demanding patients, and so all the staff are affected, the nursing staff, the junior doctors, the social worker, and sometimes, you know, people who you're not even aware of being affected, so the ward person or the radiographer who came in to do the chest X-ray. So, it's quite a big role because … you're thinking of everything that needs to be done for the patient … So, it can be very, very intensive caring for someone who's dying (Dr Cat pp. 8-10, L 38-44-15-43, 1-29).*
>
> *It is an intensive emotional relationship that's built up and that is required. The intensive kind of communication. So, I think to do it well, its intensive sometimes even in doing nothing (Dr Nnea p. 3 L 32-37; p. 7 L 23-32).*

Like the nurses, the senior doctors reported EOLC as being intense, because they felt responsible for the general and emotional welfare of everyone on the team (nursing staff, junior doctors, social workers, and radiology staff). Regardless of whether death was unexpected or otherwise, patient and family care was prioritised. Every decision regarding care was carefully thought through and weighed up; for example, decisions about comfort care, assessment and planning for outcomes, as well as the need to give life-prolonging treatment so that patients had extra time to spend with their family. Overall, according to the senior doctors, EOLC was 'intensive' and 'demanding'.

The participants reported that the senior doctor's role was intensive in terms of communication, discussions with family, and establishing a good final memory of the dying patient for the family. Many of the participants described that a good experience of death still had to be created for the patients and their families, despite the ED context of time constraints and a high workload. So, although senior doctors were not performing any hands-on procedures, an intense sense of responsibility was reported. The intensity of the senior doctor's role was described as the need to be available and present, while at the same time attempting to run a department and look after approximately another ‘40-50’ patients with families who often ‘preferred’ to have senior doctors involved.

Many of the participants discussed the struggle involved in switching between the clinical and emotional roles. Initially, patients were viewed as a clinical case that needed to be solved objectively, but once the medical treatments had been provided to the best of their ability, then the participants moved to the emotional supportive role. Clinical roles began with the clinical aspect of life-saving measures and usually shifted to the emotional role, all dependent on the outcome of the care (death or deterioration). The role switch was described more often by nurses rather than doctors, who were assumed to be more objective about care from the beginning and carried that objectivity through to the outcomes of care. The nurses noted that the bulk of the emotional role belonged to them, while most of the clinical role appeared to be that of the doctors. The following quotes illustrates the switch in roles from clinical to emotional, often made by nurses:

> *But I think we are put in a fairly difficult position … for emergency nurses … during a resuscitation that’s going to have a poor outcome, I think emergency nurses we try and switch off when things are going bad that we are actually dealing with a person … but as soon as their family walks in, I find that at least everyone have worked with, and myself included, you kind of shift gear … you go from completely separating yourself from the situation to been there as an emotional support … I honestly think we fulfil two different roles; … one is we are very clinical; we separate ourselves to provide the best physical care we can, and then we also swap over and try to offer the best emotional care we can because it’s very difficult to offer both of those {clinical and emotional roles} at the same time I find … but I think we are expected and should be both of those roles (Nurse Callij p. 2, L 14-44).*

> *As ED nurses, we approach the issue in a more emotional way ... doctors are more clinical and the nurses are more emotional, that is the general impression of it, but of course its interchangeable, it can go both ways, but the doctor is more of a clinical approach and the nurse have got the bulk of the emotional approach (Nurse Chu p. 1, L 49-56).*

The nurses stated that they initially left their emotional support role behind, especially when an unwell patient with the potential for deterioration or death presented for care. The clinical aspect (life-saving measures) of care was initially focused on because it was the only way to ‘do the job’. The nurses did not initially view the ‘person’ as a person, but as an object they worked on. Even though, deterioration/ death was emotionally difficult every time, and never got easier, the nurses believed the initial lack of emotional investment in care was used as a way of coping. Otherwise, the participants believed it would be difficult to be an ED nurse.

The nurses also stated that as soon as they saw the patient as a ‘person’, which was often brought on by seeing a family member, then they switched roles and began to provide the emotional support needed. They believed it was impossible to be both clinically present and emotionally available at the same time. The clinical role came first, after which came the emotional role. The nurses agreed that both the clinical and emotional roles were their responsibility and they were expected to operate within both of these roles.

The participants also reported that the expectation to meet the ‘four-hour rule’ of assessing, diagnosing, and discharging or admitting all patients added to the pressure of their roles. One participant expressed the demand placed on their roles to meet the four-hour target:

> *So, when we feel like the only people culturally who are responsible for that four-hour rule … we have burnt ourselves to a crisp trying to meet the four-hour target. We have done everything we can, and so we have definitely reached that point where there is nothing more we could do, and if no-one else is going to be responsible for it, then we can’t win, I think … because otherwise, in that kind of environment, actually we will just burn out ... In our hospital, I do feel desperately for our Nurse Unit Managers (NUMS) because they go to bed meetings every day, and they have to defend every breach of the four-hour rule, and the ED aren’t the only people that are responsible for meeting that four-hour target … bed managers, admitting doctors … (Dr Sam p. 3, L 12-31).*

The participants expressed that the ED staff should not be the only ones who feel responsible for maintaining the four-hour rule, but that it should be included in the roles of bed managers, hospital co-ordinators, and admitting doctors. They reported that even when they had maintained the four-hour rule, a lack of bed availability, and referral and admission times often caused delays.

In summary, ED clinicians had different expectations of their roles. However, both groups of participants (ED nurses and ED doctors) contributed to patient care, but in different ways. The nurses performed intensive hands-on practical tasks, while the doctor’s role was more abstract. The senior doctor’s role in death and dying, was an intensive role. This role did not necessarily involve the practical aspects of care, but it was intensive in that the senior doctor would handle family discussions, oversee the general welfare of the team, and would also be involved in intensive communication. Overall, the roles of the doctors and the nurses were similar yet distinct, but both contributed to the comfort of the patient and their families. Due to the intensive nature of the roles, it was not uncommon for the participants to experience an emotional burden.

7.1.3 Emotional burden

Emotional burden refers to a state of taking on the emotional feelings (loss, pain, grief, sadness) of another person (Radwany et al., 2009). The emotional burden reported by the participants involved feelings of grief and sadness that were experienced in their role of providing EOLC. The emotional state was often induced by witnessing the patient and their family's own pain or loss. The participants were emotionally burdened with feelings of grief and sadness for various reasons, and these were usually associated with the circumstances surrounding the death of a patient. Often, when they believed that the circumstances surrounding death were tragic or traumatic, the emotional burden was felt to be far greater. For example, the unexpected death of a young person, and dying in distress/pain, caused a significant emotional burden:

> *Yes. I can say my personal feelings can vary according to the circumstances of the patient's approach to death, the circumstances of the dying patient. In terms of what I feel, I certainly feel sorry for anybody who's dying and also for the family and next of kin. The other sort of death that's particularly hard to deal with is the sudden unexpected death, and it's deeply distressing watching the family (Dr Seamus pp. 10-11, L 31-45, 1-12; p. 6, L 31-35).*
>
> *I always tell people this, it doesn't hit me in the initial stages that a patient comes in. Especially in a tragic circumstance, it's happened many, many times in the eight years I've been in ED … you've done your best, but the patient still ends up dying. And it still doesn't hit you completely … but then it comes out on TV … out on the news, and then you see the patient before the injuries with family and friends, and then it hits you. It hits me … and reinforces that this patient was a brother, a father, a son, and then it just makes the whole thing personal, and then it makes it hard because, you know, someone has just lost a son, a family member. And I've got brothers too, I've got a father, yes, you kind of personalise it for a bit; I don't just leave work and leave the whole episode at work, it usually goes along with me for a couple of days … and I think there will always be a part of you that will still be affected (Nurse Abigail pp. 6-7, L 44-45, 1-26).*

The participants reported feeling 'really' sad for the dying patient and their family who died in ED, especially if they were young and the death was unexpected. The sadness felt was greater when ED staff were part of the resuscitation team who had put in a great deal of effort to prevent the death. The failure and inability to prevent deterioration lead to the unexpected death, and this caused a significant emotional burden. Many of the participants generally accepted death with no emotional burden when death was expected and occurred in an elderly person. It was noted that the emotional burden and feelings of sadness were often not apparent until after the care episode had been completed. The participants emphasised that providing a debrief as soon as possible was an important event that needed to be facilitated by management and team leaders, but a debrief was not always provided. For example, like the other participants, one nurse recounted a traumatic death experience, the emotional burden that ensued, and with no de-brief facilitated:

> *Actually, these doctors were very senior. They should have known better. But little to everybody's knowledge – no-one knew that this patient had cancer, so they just thought this patient had an obstructed airway. So, they tried to tube the patient. That didn't happen because the airway was already closed. So, they attempted a surgical airway without any pain relief or any ketamine or anything. Without anything. And it was absolutely – I mean, it would have been traumatic for that patient, but it was traumatic for me to watch as a scribe nurse, I honestly didn't know what to write, because the minute they – you know, the scalpel – the minute they did that, you could tell the patient was in so much pain. ... This patient was awake. Their eyes were open. Their arms were moving. It was just – it was awful. I've never experienced anything like that. And they eventually got a surgical airway done and in. It was barbaric. I didn't think they did that kind of practice anymore. Do you know what I mean? It was cruel. It was so cruel. And then, a couple of days later, I find out the patient passed away in ICU. But you could say that was the start of the patient's dying journey, because eventually that surgical airway got infected. I was reading the coroner's case. Eventually, that surgical airway got infected and then obviously nature took its course, and yes, got worse. But to be a part of something like that was just horrific. I've never forgotten it and it's terrible. We're not allowed to talk about it with management, because you mention it and it's like nobody remembers it (Nurse Teresa p. 14, L 13-45).*

The participants who witnessed traumatic resuscitations where life-saving interventions were performed on a dying patient also reported that they carried the emotional burden of the trauma associated with the event. The life-saving measures provided in the quote above lead to the need for a gruesome surgical airway insertion with no consideration given for pain relief for the patient. Words such as ‘barbaric’, ‘cruel’, ‘terrible’, and horrific’ were used to describe the situation. In the end, the dying experience was not only traumatic for the patient, it was also traumatic for the nurse. Despite the need for a prompt debrief, it was not provided.

The participants recognised the need for a debrief, but they felt that support from management was not reliable, despite being emotionally burdened by the traumatic experiences. In this event, it was emphasised that the participants were not allowed to discuss the issue and the experience was treated as one that had never occurred. When a debrief was not provided by management, most of the participants ended up carrying the emotional burden of grief and pain with them into subsequent EOLC encounters.

The participants reported that the nurses often carried the emotional burden of grief and pain, while the doctors carried feelings of guilt, self-blame, and regret because they were the main decision-makers and gave directions for care. Therefore, the responsibility of the outcome, whether good or bad, was often carried by the doctors. The doctors spoke about their feelings of guilt, self-blame, and regret in terms of questioning whether things could have been done differently to prevent death, or maybe that aspects of care were missed:

> *So an unexpected person dying whilst you're caring for them is incredibly traumatic because you blame yourself. I think unexpected deaths are always incredibly challenging because – you can't help but go over and over in your mind, "Why did the patient die? Was there something that I missed?" and even when you realise at the time or afterwards, it wasn't something you did or didn't do for that patient, the disease process was so terrible that it was overwhelming and that patient died – I find the natural response I go to is, "What could I have done different to have changed the outcome to save that person? What have I missed? What have I done wrong?" (Dr Cat p. 8, L6-12; p. 14, L 28-38).*

For the doctors, the emotional burden of guilt and self-blame because of an unexpected/ traumatic death was widely reported. Doctors perceived that their inability to prevent an unexpected death was their fault because death prevention was a normal part of ED work. Consequently, the participants stated that the tendency to reflect on what could have been done to prevent death, even though death was the only outcome, was not uncommon. The concept of guilt and self-blame also highlighted the conflict regarding the focus of ED work to save lives, as opposed to the core values of comfort care. Although some doctors reported the self-blame as a reflective process for future practice, their feelings of guilt, regret, and self-blame remained. Overall, despite the feelings of sadness, grief, guilt, and self-blame felt by the participants, professional boundaries within the emotions expressed in EOLC provision were reported as being important.

Professional boundaries in the context of EOLC, death, and dying were related to the actions (hugging, crying) displayed by the participants in response to the emotional burdens that they felt. They felt that maintaining professional boundaries in EOLC, death, and dying could be difficult to balance. Death and dying was an emotionally fraught time and many of the participants believed they needed to offer emotional support to meet the needs of the patient and their family. In the same vein, they reported that they had to be cautious about taking on the patient's sadness/pain, so that they would not be over/under invested in EOLC provision with a dying patient, because this could lead to emotional fatigue and eventual burnout.

To maintain professional boundaries, the participants stated that they gave ‘compassionate EOLC care without true empathy’. They believed that caring with empathy required that they actively experience the feelings of another person. But they defined compassionate care as ED staff being present and available for the dying patient’s needs without empathising with the patient. This was a widely held opinion by doctors in comparison to nurses. The doctors generally used an objective approach towards EOLC, especially when it was not their own family or loved one. The doctors reported remaining professionally compassionate during care without being too empathetic. On the other hand, the nurses reported that they found it difficult not to empathise with the dying patient and their families. The following quotes provided below shows the doctors’ approach to maintaining professional boundaries:

> *And often the thing is that those patients and families need are not you doing things to them, they actually need you to show compassion and listen and be accessible ... especially if you don’t know the person very well, you can feel compassion towards the person dying and their family, but … don’t become overly empathised with them. You sort of have to develop a compassion rather than a true empathy (Dr Cat p. 5, L 39-44; p. 11, L 22-25).*

The ED doctors expressed that they had emotions and feelings that varied according to the circumstances of the dying patient, but those emotions were kept beneath the visible professional and objective approach of care. Similarly, it appeared that the art of compassion without true empathy was learned as a coping mechanism during and after EOLC completion to protect against the emotional burden.

In contrast, the nurses reported that maintaining professional boundaries without empathy was difficult. They spoke about the difficulty experienced in maintaining a strong professional nursing face when emotionally burdened:

> *You know how people say you have to put your nurse hat on when you walk into work and leave yourself behind? I don't know if you've heard people say that, but … look, when it comes to death and dying, for some nurses, it's really hard to make that split, I guess you could say. I remember we had a child – I was a part of resus and we had a child that unfortunately passed away and it sucked. It sucked so much. I burst into tears ... my nurse hat had completely gone. It was just raw, 100 per cent me. I burst into tears when the mother stopped hugging the child's body … she looked so miserable and I just latched onto her, and I couldn't help it. It was just – it was an instinct ... When it comes to death and dying. I feel like I don't have a strong nursing face. You know? If the relatives are crying, if the patient wants to hold my hand, I will cry with them. I will give them a hug. I will comfort them. You know, even though they don't know me (Nurse Teresa pp. 11-12, L 40-45, 1-30).*
>
> *Before we got to move {the dying patient} to a private area. But, in that moment, I felt like the family was so overwhelmed that I think I had to cross a bit of a professional boundary and just like, gave her a big hug and just comforted her in*

> *that moment. She came back to me later on, she thanked me and said, "Thank you for doing that for us, and thank for you for going above and beyond for this" (Nurse Abebs pp. 8-9, L 29-45,1-9).*

The nurses believed the expectation by ‘people’ to come into work with their ‘nurse’s hat on’ and leaving them self behind was a difficult split to make, especially in death and dying. In situations such as the tragic loss of a child, the presentation of a strong nursing face to hide emotions was almost impossible. The nurses reported that they cried with family members and hugged them if needed. Further to this, they felt they had to cross professional boundaries when they believed the death experience for the dying patient was a negative one. The nurses had a sense of responsibility for the poor death experience and, in turn, they felt the need to over-compensate (hugging in this case) to make up for the negative experience. Overall, the participants emphasised that exerting oneself emotionally and empathetically could eventually lead to compassion fatigue or emotional burnout.

One participant who attended a palliative care seminar spoke about the firm caution that a palliative care specialist gave to ED staff about professional boundaries. The palliative care specialist affirmed that empathy for the dying patient could be strong, but only within professional limits:

> *The palliative care person did affirm a firm caution – when I asked him about the feelings and empathy with family, a firm caution about not exteriorising oneself too much and he referred to the difficult balance … There may be situations where the empathy is strong within professional limits, but that may be a tragic situation and different people have got different styles in relation to expressing their feelings, and also there are differences in the type and range of feelings people have. So, there’s no simple answer, I would say, and certainly that contributes to the interest and value of awareness about feelings (Dr Seamus p. 13, L 6-26).*

The participants affirmed that they were cautioned not to exteriorise themselves because professionalism and empathy were difficult to balance. It was believed that empathy could still be expressed strongly, but within professional limits.

The participants’ emotional responses to patients’ death and dying were different and complex. They often responded with empathy and/or compassion and suggested that ED staff should be aware of their own emotional capabilities and expressions around death and dying. Awareness of each individual expression and how it fits into their roles allowed professionalism to be maintained, so that the needs of the dying patient and their family could be met.

7.1.4 ED-EOLC role integration

The study participants recognised that palliative care knowledge and skills were required in emergency work. Most reported an increase in seminars and conferences for ED staff concerning EOLC, and death and dying. Generally, they stated that EOL and palliative care work was now increasingly part of the ED staff role, and that this was a new aspect of their ED work.

Many of the participants reported that EOLC has a place within the ED, despite the conflict between the objectives of care in both fields of practice. The following quotes show the increased momentum for the integration of palliative medicine into emergency work, regardless of the differences in the goals of care. Many of the participants spoke about recent developments in education, with ED doctors now being qualified as palliative care physicians. They even expressed that EOLC was an important part of 'ED business':

> *Yes, death and dying, it is a very big part of emergency. Even if it might not be the first thing that comes to people's minds when they think of emergency, but it is, sadly. That's just reality (Nurse Abigail pp. 27 -28, L 39-45, 1).*
>
> *Palliative care should be integrated into emergency medicine. I know of one emergency physician that's actually gone into palliative care, and I think we as emergency physician on the whole will make good palliative care physician because I think we understand the physiological processes and understand our drug and things, so yeah, I think some form of palliative care kind of training will be good (Dr Ahik pp. 2-3, L 54-60, 1-3).*

Due to their experiences, the participants agreed that palliative care should be integrated into emergency work. Most of them acknowledged that death and dying were very much a part of ED work, even though the lay public might not perceive it to be so. Many of the participants believed there was increasingly more interest being shown by ED staff in palliative care as a speciality due to the increase in presentation of patients who needed palliative care in the ED setting. They emphasised that there were now more ED doctors undertaking diplomas in palliative care, and an increased number of ED doctors had dual qualifications in both ED and palliative care medicine. With dual qualifications and as role models, ED clinicians were able to share their knowledge and skills, and taught others in the ED how to have EOL discussions and care for dying patients within the ED.

In summary of this theme, the provision of EOLC in the ED by doctors and nurses has increased. Consequently, there are changes in role expectations as increasingly more people are presenting to ED requiring EOLC. The participants expressed an interest in further training and education in palliative care. Suggestions were made for resources to be directed towards education and training to better prepare ED staff for the role of EOLC. Despite the increased need for palliative care skills by ED staff, conflict still existed between the core business of the ED in its provision of life-saving measures and the provision of comfort care. Other aspects of conflict against EOLC provisions in the ED setting were discussed in-depth in the following theme.

7.2 Theme 4: Experiencing conflict: ‘I often feel conflicted’

The participants’ experiences of conflict referred to the discord between groups of people such as dying patients, their families, and ED staff regarding various aspects of EOLC. The major aspects of EOLC that often-caused conflict were disagreements about treatment, care plans, and unaligned goals of care. In addition, denial, and a lack of acceptance of the inevitability of death by the dying patient, family members, and ED staff often lead to conflict and disagreements. According to the participants, patients and family members who lacked a thorough understanding of the dying patient’s disease process often requested treatments that were of no benefit to the patient. Most of the participants reported that conflict affected the dying patient in a negative way because comfort measures were often delayed.

Conflict was not only limited to relational (patients, their families, and ED staff) sources, but the participants also experienced conflict in the way they delivered EOLC due to the nature of the ED itself. The nature of the ED was reported as being ‘chaotic’, ‘busy’, and ‘noisy’. Therefore, the participants described that these factors had a negative impact on the quality of EOLC they were able to provide. They often reported feeling conflicted because of the inability to facilitate what they believed to be a good EOLC. The conflict experienced was in the constant attempt to provide good EOL and comfort care measures against the ED environment, the lack of time, and the lack of information to guide appropriate treatment decisions.

7.2.1 Time and Environment: barriers to EOLC

Working in the ED involved significant time constraints due to the high workload and staff shortages. As a result, the environment was often busy and chaotic. The conflict caused by the lack of time in the ED was manifested as time pressures that inhibited the provision of quality EOLC. ED staff constantly worked against time and the environment to provide quality EOLC. The participants reported that one of the barriers to EOLC experienced was a result of lack of time to provide quality EOLC:

> *The barriers are obviously the time pressures, you know, it takes a lot of time to talk to patients and or talk to their relatives ... and I often feel conflicted in that sometimes I feel I am not spending enough time with the relatives in talking them through it and that sort of thing, just because there is time pressure of ED, so that to me, would be the greatest barrier to providing adequate palliative care (Dr Ahik p. 3, L 27-31).*

> *Because we have so many conflicting priorities depending on what your patient load is for the day ... So, I honestly believe time and just what the ED is, are the biggest barriers {to providing EOLC} … I think that one of the biggest barriers is time, the nursing staff and the medical staff, where I work I would probably say generally we try and actually prioritise these type of patients (dying patients), because we want to make sure that things are in place in that we are doing the right thing by them, but I would definitely say time is the general thing (Nurse Robert p. 7, L 7-31).*

Many of the participants reported the lack of enough time as a major barrier to the provision of EOLC. EOLC was time-intensive for the participants. Discussions around EOLC took a lot of time, and sometimes, time was not available to give the dying patient detailed information so they could make a well-informed decision. Many of the participants reported feeling conflicted within themselves about not spending enough time with the dying patient and their family because they were trying to care for the numerous other patients who needed their assistance.

The ED environment was also a cause of conflict because the participants stated that the ED was characterised as a busy and noisy environment and was not an ideal setting for where death and dying should occur. The ED setting and its environment was noted as one that did not facilitate EOLC, and the structure of most ED’s was reported to be one that did not promote privacy. According to the participants, most ED environments were open plan in which spaces for beds were demarcated only by cotton curtains. Hence, the structural setting did not facilitate the privacy required for the dying process. The participants expressed that the calibre of ED patients also contributed to the noisy and unrestful ED environment; for example, an agitated patient who screams and yells. Other patients with many acuities often brought chaos, a fast-paced approach, and disruption to EOLC:

> *And in terms of being in the ED, just that environment that it is, when you've got a lot of psyche patients screaming and yelling, or you've got lots of people coming in and out, I think that's a very undignified way to die if you are in that environment. ED as a setting is not suitable for end-of-life care … In another sense, I think that sometimes privacy is really important in end-of-life care in terms of having a single room, and obviously that's something that just can't be facilitated for ED, because all the doors are opened (Dr AC pp. 3-4, L44-45, 1-8; AC pp. 10-11, L 40-45, 1- 5).*

> *The ED in an extremely busy environment where they {dying patient} could get agitated, they could get uncomfortable. It can be scary, it can be confronting, not to*

> *mention how the family members feel, and so it would be – I often wished we could bring the patient to a quiet environment away from emergency, away from just the noise that constantly happens in emergency where patients can just have that peace, that comfort, you know, that quietness so that they can just, I guess, you know, spend their last hours in a noiseless environment, and at the same time, family members can just, yes, really have quality last few moments with their dying family member (Nurse Abigail p. 27, L 13-22).*

Throughout the experiences of all the participants, there was an over-riding issue of the unsuitability of the ED environment for EOLC provision. All the participants remarked that there was a sense that they were unable to provide what the dying patient needed in the ED setting. They believed an ED environment was not the right place to give comfort, and cultural and spiritual care. Consequently, attention to the needed aspects of care was difficult to facilitate. Many commented that due to the high workload of the ED environment, it was impossible to have staff who constantly watched to see when urgent help was needed for the dying patient.

The participants agreed that the dying process required privacy and a single room to spend private time with the dying patient. However, according to the participants, most EDs were not set up for privacy. Many reported that the physical environment of the dying patients were open plan spaces with no walls or doors and noisy and intrusive lighting, all of which were all ‘incredibly invasive’. Inconsistent information from different care workers, people coming in and out of the dying patient’s cubicle, multiple shift changeovers, and disjointed care were particular physical constraints in the ED environment that made it difficult to give the care that was needed for dying patients and their families. Most of the participants stated that, generally, most people would not want their lives to end in an ED environment, and that EOLC was better delivered in a palliative care ward.

In contrast, some of the participants believed that a good death could still occur in the ED, and that the environment could not be used as a reason not to strive for a good death experience. According to these participants, the natural ED environment will always be unrestful and chaotic; therefore, the ED environment should not be the focus. Instead, the focus should be on how to make sure quality care was given despite the chaotic environment. A good death experience was dependent on the ED staff members’ ability to be supportive, to plan, and to manage their time:

> *Unfortunately, we can't make it a quiet environment, but we can try and make it as comfortable as possible for the patient and the relatives. You know, just be there as a supportive arm. Do you know what I mean? Like, just be there for support (Nurse Teresa p. 21, L 13-18).*

> *I would say that there's definitely occasions when death can be good in ED … you just got to set yourself up with a plan and start executing them and depending on the needs of the patient, the patient's family {will depend on} how much time you would be allocating (Nurse Robert p. 3, L 28-47).*

These participants recognised that ED was not a quiet environment, but that this should not deter from the main goal which was the provision of comfort and support for the patient and their relatives. They stated that if the ED staff had a plan in place and managed their time according to the workload formula, the provision of EOLC could be good. The participants who worked in a private hospital ED environment, with access to resources and where consultants and senior registrars could be afforded, stated that the private hospital ED was not noisy and there was enough time for doctors and nurses to spend with the dying patient. In this setting, it was believed that both the environment and timeframes were not a source of conflict in providing EOLC. It was mentioned by the participants from private ED settings that the ED was in a high socio-economic status (SES) area with high levels of literacy. As a result, there was no relational conflict reported because often people in the area were reported to have reasonable expectations, as expressed in the quote below:

> *So, I work in a really privileged environment which is pretty much just consultant based, its private emergency department. We do have some registrars, but they are all very senior and we don't have much noise and whilst we have some queues and a lot of bed blocks, we have time to spend with patients that we need and it's a quiet and calm environment. I care for probably the wealthiest group in the country, but with that comes very good social connectedness and very high health literacy, and there is a few folks who have unreasonable expectations, but the vast majority have very reasonable expectations and are able to have discussions about end-of-life goals and so forth at a high level, so it makes it quite straightforward from a practice emergency medicine. Well, I don't have communication barrier and I can almost always find certain family member (Dr Turtle p. 1, L 43-46).*

In this ED environment, communication around EOLC goals were understood at a high level and was reported as being more effective with groups of privileged people. The patient's journey was smooth with no conflicts in relation to time, environment, and even between family members and ED staff.

7.2.2 Families

Families were reported as a major source of conflict at the end of life. Conflict was not only between family members, but also between ED staff and family members. ED staff members observed that some families were in a state of denial in not accepting the imminence of death, and would disagree with the goals of care between each other, or with the ED staff. The participants reported that the major causes of conflict between families and with ED staff were often about treatment options:

> *Conflict by the family members, and conflict within the family. From experience, it's just fight between family with differences to each side between family … one of the family members that already decided that the dying patient would be for palliative care, and another family member came in and said, "No, they should not be for palliative care", so there was a lot of fighting back and forth between the family, and there was a lot of threats made as well, like, we've got to get our lawyers involved, and, "Why won't you look after this patient?" … but they didn't realise the extent of the condition the patient had. So, it becomes a back and forth where no decision is made. It can be a bit selfish of the family, or might not put the patient's interest at heart (Nurse Abebs p. 5, L 3-36, L 37-40; p. 11, L 21-24).*

> *I understand that there may be some situation when someone has actively said they want very aggressive resuscitative measures for something you fear has a very, very bad or very low chance of a good outcome for that patients, and so that can be difficult when you kind of got conflicting ideas {between the ED clinician and the dying patient} (Dr Nnea p. 7, L 9-12).*

Many of the participants stated that families often disagreed with each other regarding the treatment that ED staff gave to the dying patient. Eventually, ED staff become part of the conflict because the family might see the care being provided as not being in the dying patient's best interests. Many of the participants recalled that families and loved ones who were in denial about the inevitability of death often caused obstructions to ensuring patient comfort and the provision of a peaceful environment*:*

> *But you do get families and the patient's loved ones who are very much in denial about what's happening, and whilst I understand it, it can be almost very obstructive to the process, so it can almost prevent us from making the patient comfortable, from making even just the environment around them peaceful whether or not it's due to lack of education, or it is just denial, that is a big one that can make the whole process almost unpleasant for everyone involved (Nurse Callij p. 3, L 42-47).*

The participants reported that due to denial and not accepting death, care would become counterproductive, as it omitted the much-needed comfort care for the patient. Many of the participants stated that family members' lack of medical knowledge was the crucial reason for conflict, and that if they had understood the medical condition, they would not disagree with treatments. They also reported conflict between ED staff (doctors and nurses) about the goals of treatment, despite having medical knowledge:

> *Yes, I have been in situation where a doctor has a different perspective and the nurse has a different perspective {regarding EOLC treatments}, but it's often with more junior doctors, and I generally just make it a point, not out if disrespect, just out of, I guess, concern for the patient. I generally, and also not to waste any time, I will go straight to, you know, the most senior doctor on that*

> *shift, or the consultant, generally … But, I would rather disagree at this point and be convinced that it's the right thing to do, than go ahead with the treatment and see that it obviously harms the patient and then wish that I could turn back the clock and disagree with the doctor at that point in time. Does that make sense? (Nurse Abigail pp. 17-18, L 37-41, 1-3).*
>
> *I and another {nursing} staff member basically ended up having not an argument with the clinician {doctor} that's driving the care of this patient, and when we didn't get the result {life-saving treatments} we wanted, we ended up chasing up the admitting doctors, arguing and fighting for several hours until eventually the patient is admitted to ICU. This lady was up in ICU for a little while and then inotropes were ceased, she recovered and she was discharged home from the ward (Nurse Callij p. 4, L 38-44).*

Conflict that occurred between doctors and nurses was commonly due to disagreement with the treatment being offered; or basically, disagreement about aggressive medical treatment versus comfort care. Often, conflicts occurred between nurses and the junior doctors. According to the nurses, some junior doctors did not realise that the treatment being provided added no value to the quality of life of the patient. Conflict caused by inexperience was often managed by nurses approaching the senior staff on duty, due to their clinical experience. According to the nurses, the goal of approaching a senior staff member was not to cause conflict, but to provide advocacy in the best interests of the patient. Scenarios such as the one outlined above were reported as a common occurrence within the ED setting and was often complicated because both doctors and nurses have the medical knowledge to support their stand. Generally, conflict and disagreements about the goals of treatment may potentially be avoided with an advance care plan (ACP) in place.

7.2.3 Advance Care Planning (ACP) – "not always helpful"

Advance care planning refers to legal documented wishes that are made when a patient is capable of deciding on treatment options believed to be in their best interests (Silvester et al., 2012). Many of the participants had conflicting ideas and opinions about ACP in the ED. ACP was reported to often cause conflict when families, patients, and ED staff members did not agree with the directions of the ACP. Some participants stated that ACP was not helpful when it was needed for an urgent decision at the end of life; however, others, believed it to be very helpful and that it proved to be beneficial for decision-making. The participants who commented that ACP was unhelpful often reported that it only served as a guide that enabled them to easily start conversations about EOLC. Overall, most of the participants felt that ACP did not contribute to how actual decisions around end of life choices were arrived at, but thorough discussions still needed to be performed with patients and their families before end of life decisions were made. The participants who reported ACP as being unhelpful, stated that:

> *ACP are not helpful, they don't help me decide what I am gonna do, and I don't just find them helpful … so it can help me to start a discussion, but it's extremely rare that it actually guides me as to what I should do … They are helpful inasmuch as they tell me that the patient is very unlikely to want invasive therapies and will probably welcome a discussion about therapy limitations and that's a nice door to open for me. The advance care planning is simply patient's preference and values sometimes even two decades ago…It's an awfully long way from so this person has now got a pneumonia, we think carefully about what we might do for them (Dr Turtle p. 5, L 40-56).*
>
> *ACP is unhelpful, because advanced care plan, gives us a bit of ideas, but when it comes to real life, what's to be done, it doesn't tell us what to do, the family often change everything (Nurse ZZ p. 14, L 37-40).*

The participants felt that ACP was only helpful to start conversations around EOLC because it took away the dilemma of 'how to start the conversation' but was rarely found to be helpful for patients' current situations. ACP only opened the door for a smooth entry into EOLC discussions, but it was extremely rare that it guided the participants as to current treatment plans (life-saving measures versus comfort care). Most of the participants still had to reassess their goals of care, because the ACP was not set in stone, and this aspect required continuous reassessment. According to the participants, family members might not agree with newly assessed goals of care, and conflict could still potentially occur.

Some of the participants believed ACP to be helpful because it allowed them to know for certain what the wishes of the dying patients are. The participants who found ACP helpful also commented that ACP helped to avoid family conflict, rather than create conflict, as previously believed by some of the participants. There was no family conflict because the families accepted the already stated wishes and did not have to carry the burden of decision-making. The participants who believed ACP to be useful stated that it was helpful for the following reasons:

> *Yes, ACP is definitely helpful. I think that if there's not an advanced care directive that's been made, it can be very tricky for family ... So, it is hard. It's a lot of pressure on a family to really know and decide as a collective, because there is often differing opinions between family members about what's best for the patient (Dr AC pp. 9-10, L 42-45, 1-4; pp. 6-7, L 43-45, 1-4).*
>
> *Absolutely, I love advance care planning, I think it's one of the greatest thing in the world, because it takes into account the patient and their thoughts and wishes and what they want at a time that {they} are actually able to tell you (Nurse Robert p. 8, L 31-33).*

Most of the participants who emphasised that ACP was helpful believed it removed the burden from family members to make the ‘right’ decision. Therefore, it was believed to be a good guide and gave direction, especially when the patient no longer had the competence to decide what they wanted. But they also commented that whether they believed ACP was helpful or not did not really count because the final decision still belonged to the family. Consequently, ACP was helpful only when family, including the participants, agreed with the documented goals of care.

Regardless of the ACP documents being helpful or otherwise, the participants stated that it was important to have the ACP information at the right time with all the right information. They also agreed that ACP documents should be with the patient at all times because ED staff had the natural tendency to provide curative interventions when there were no formal ACP documents provided. In some situations, the participants reported that patients had already been given care that was against their documented ACP wishes, due to the lack of availability of ACP documents. As a result, many stated that conflict about the goals of care could occur when ACP documents were not readily available:

> *Where the patient was obviously dying, but end of life care was not discussed appropriately, but there was no clear order as to not perform CPR, and we still did obviously on a patient who was dying, because often we have patients coming in from aged care homes unresponsive and there's no clear end of life care terms written out and the next of kin is unaware and they want everything done, and then that's when we start providing unnecessary care to a patient who obviously is dying and should not have had CPR performed (Nurse Abigail p. 12, L 39-45; p. 11, L 25-45).*

> *The next stage of barrier is incomplete information, so it’s rare that every bit of information you think you’d like about prognosis and current diagnosis and findings and patient preferences were available, you are never getting a complete picture … but you are trying to make these decisions with incomplete information and that’s very difficult indeed; it’s much easier if you can find an oncology letter that says this patient’s got stage 4 non-Hodgkin’s lymphoma and have tried six rounds of different chemo, and we have made a joint decision that there is no role for palliative chemo anymore. They have been referred to palliative care, and they have had the conversation with the family, and they’ve all adjusted, and they have all met the pall care physician and so forth. But it’s very rare to have that level of information (Dr Turtle p. 4, L 27-37).*

The majority of the participants reported that when resuscitation documentation was not available at the time of presentation to the ED, it often caused conflict in treatment because medical treatment was provided against the patient’s wishes. They suggested that ACP was to be done in a timely manner with all the right information provided. They remarked that on some occasions, ACP and referral letter information were incomplete, and they did not have a complete picture and history of the patient when trying to care for them. The participants suggested that the GP/specialist, send a detailed letter stating both ongoing and ceased treatments, including future plans. They stated that if this was done, they would know exactly what was happening and whether they had previously had any discussion about EOLC. The participants believed it was very rare to have such a level of information.

Many of the participants reported that some patients had no idea what an ACP entailed. Likewise, due to the family member's poor knowledge of ACP, they would often question why intervention and treatment were ongoing, despite the ACP orders. Consequently, they had to clarify and spend more time explaining the patient's treatment options, so that conflict could potentially be avoided. In cases of conflict, the participants suggested possible ways to resolve the conflict for the best interests of the dying patient and their family.

7.2.4 Resolving Conflict

Conflict occurs in all aspects of the healthcare environment, including the ED. In the ED, the participants believed that conflict was almost impossible to avoid. Conflict was caused by a lack of time, the ED environment itself, and treatment disagreements between family members and ED staff. Many of the participants believed that these conflicts were unavoidable, and that conflict resolution was a necessary skill. They believed that conflict should not be avoided when it occurred, but rather should be dealt with as soon as it was identified. Most of the participants found that when ED staff were honest about the prognosis from the outset, conflict tended to be avoided. They suggested that effective communication and working together as a team were important for resolving conflict, and should include other members of the team (junior doctors, nurses):

> *Well, it's not really avoiding the conflict because it's often there; it's how to deal with it, because, you know, people have very complicated family structures and relationships, and you can't avoid it because that's part of who that patient is and who the family are, but … I think I identify conflict early in those situations, and I try to negotiate how best to deal with conflict … I involve other staff members to help make them aware of what's going on so that they can help negotiate and care for the patient and their family, whilst dealing with conflict as best as possible. So, the other staff – when I say that I mean my junior doctors caring for the patient and family, my nursing staff caring for the patient and family, the social worker, at times security, if I think there might be a risk that the family might have a big fight or something. And I don't avoid it, and I do it early and I'm very inclusive (Dr Cat pp. 17-19, L 10-22, L 18-41, 1).*

> *We are lucky from an ED perspective that if you have this conflicts with patient and families, even within the family, they have different expectation or they have a different understanding to you, they don't want to die or they are going to survive this. We have got a really good relationship with the intensive care department where we don't have that conversations, saying to families "well tough, we are going to do it anyway" {withdraw life-saving treatments}. Well, you can, but the evidence also produces a lot of fallout in terms of their grief, and so our intensive care will often take these patient who maybe are having treatments that are futile or that are not going to end with good outcomes, but they can then take them to a better room; so one that is private and calm and quiet. It has support staff, it has one-on-one dedicated nursing staff and good access to drugs, and good access to social work and palliative care, and they can have this conversations sequentially, so I am very lucky that when there has been conflicts with different expectations, or different understandings of outcome, the reservation has often been intensive care kind of come in and take the patient to continue that process (Dr Nnea p. 7, L 17-29).*

The study participants all experienced conflict resolution very differently. One of the main techniques they used was effective communication by making sure the patient and their families were heard, with all questions being answered and clarified. According to the participants, communication was an important aspect of preventing conflict. They emphasised that communication between multidisciplinary teams was used to prevent and resolve conflict. Information obtained from every member of the team (doctors, nurses, social workers, security guards) were used to contribute to conflict resolution. Doctors regarded information from nurses as important because nurses spent more time at the bedside with the patient and their family. The knowledge and information nurses were privy to was used as an advantage to provide a good death, especially during times of conflict about care.

In some cases, the ICU team were also used as part of the multidisciplinary approach to resolve conflict. A team approach to conflict resolution was undertaken by the ICU team working with ED staff who had tentatively agreed with the demands of aggressive care by the family. Agreement for transfers to the ICU were made, but with a view to a slow removal of all aggressive interventions, rather than an abrupt stop to all treatments in ED. The slow removal of treatment by the ICU was achieved through the process of open and honest communication with the family so they could all agree and accept the inevitability of their loved ones' death. According to the participants, this slower process prevented conflicts and confrontation that could happen in the ED due to the family's current lack of acceptance of comfort care.

Open and honest discussions with the dying patient and their family, whether as a team (doctors, nurses, social workers, and security guards, including ICU), or individually, was a crucial way of resolving and preventing conflict. Several participants stated:

> *I think that if we had a medical doctor come along and actually be opened and honest from the get-go all of a sudden, it makes your job so much easier. Okay, cool, no worries, that's fine, everybody is on the same page and they know what's going on (Nurse Robert pp. 5-6 L 50, 1-4).*
>
> *Sometimes it's when the family or the patient feel like their concerns aren't being answered or listened to, I should say, that's when things can get very negative (Dr Cat p. 19, L 16-32; p. 17, L 24-31).*

Most of the participants remarked that conflict could be prevented when communication with the dying patient and their family members was transparent and all questions were clarified. They reported that open communication from the beginning of the care encounter made their provision of EOLC smoother because everyone (the dying patient, their family, and ED staff) was on the same page. According to the participants, when the dying patient and their family felt that their concerns were not addressed, conflict occurred.

In summary of this chapter and the two major themes, EOLC in the ED is no longer delivered in isolation; it is increasingly a significant part of ED work. Doctors and nurses are having to grapple with constant conflict due to the nature of ED work where the care delivered was often in opposition to EOLC. The ED is an environment characterised by chaos, noise, and a fast-paced approach to care aimed primarily at saving lives. The high workload and staff shortages were major contributors to the significant time constraints, which meant that the required attention needed to provide quality EOLC was not available. Other sources of conflict were often caused by disagreements between groups (patients, family members, and ED staff) of people in relation to providing the traditional ED life-saving care, as opposed to providing EOLC. Conflict and disagreements were perceived as unavoidable, but suggestions were made to resolve conflicts in a timely manner, so that quality EOLC could be provided to all patients and their families.

Chapter 8: Discussion

The previous chapters have presented the participants' experiences of death, dying, and the provision of EOLC within the ED. The experiences of the participants were in accordance with the principles of the Gadamerian phenomenological approach which aimed to understand the lived experiences of the participants in light of the contextual setting in which the experiences had occurred (Gadamer 1975). This chapter provides a discussion of the findings in the context of the available research studies on death, dying, and the provision of EOLC in the ED. Gadamer's philosophical concepts, thanatology, and the code of conduct for palliative/end-of-life care were incorporated into the discussion. Based on Gadamer's concepts, the researcher's experiences were embedded and applicable within the discussion. This established the principle of the fusion of horizons, as the researcher and the participants' understandings came together to create new meaning.

The integration of EOL/palliative care into the ED setting is gaining momentum (Stone 2001; Mills 2018; Levinson et al., 2019). However, significant gaps still exist within the literature about how ED staff specifically deliver EOLC in a context that is designed to cure and prevent death. Studies that have explored death and dying in the ED found that some ED staff were willing to provide EOLC and believed that the provision of EOLC was a privilege (Bailey et al., 2011; Marck et al., 2014). However, for most of these staff, the setting/nature of the ED was not conducive to the provision of EOLC.

Many of the available studies have focused on assessing, describing, and addressing palliative care needs within the ED, but few have included first-hand accounts of ED staff experiences. Importantly, there has been a lack of in-depth qualitative data generated on the issue. While not specifically focusing on ED staff experiences of death, dying, and EOLC, some authors have briefly described ED doctors' and nurses' experiences of EOLC. Many of these experiences of care in the ED setting were described as chaotic, busy, time-constrained, and characterised by a lack of privacy (Beckstrand et al., 2008; Smith et al., 2009; Bailey, Murphy & Porock 2011; Beckstrand et al., 2012a; Beckstrand et al., 2012b; Grudzen 2012). This finding is supported by the current study. In this study, many of the participants believed that the ED setting was not conducive for EOLC, and that the ED setting had a major impact on how EOLC was delivered.

The experiences described within the literature indicated that ED staff members found EOLC challenging and disadvantageous, primarily because of the setting/nature of the ED. Similarly, an investigation of ED doctors’ and nurses’ experiences of EOL/palliative care provision explained that the participants acknowledged that patients who needed EOLC were ‘moved out of the ED’ as a priority (Decker et al., 2015 p. 71). With the disadvantages of the ED setting, the participants in this study defined their experiences of EOLC provision as a source of conflict that revolved around the complexities of the EOLC decision-making process. The decision-making processes involved in treatment choices were often reported as challenging. In addition, the experiences of the participants were understood by, and meaningful to, the researcher, because the challenges were also experienced by the researcher, and this connection established Gadamer’s fusion of horizons.

The description of Gadamer’s fusion of horizons within the hermeneutic cycle was achieved in various instances within this discussion because the pre-understandings, prejudices, and prior hermeneutic involvement of the researcher as an ED nurse resonated with the challenges of providing EOLC, as described by the participants in this study (Nixon 2017). Waite (2003) stated that, according to Gadamer, rather than bracketing off the researchers’ prejudices, they become a hermeneutic inquiry tool that allows the researcher to open up to new understandings both in the ‘parts’ and the ‘whole’ of the data and the story. Understanding of the ‘whole’ meant that the researcher’s self-understanding of EOLC combined with the understanding of the participants was created (Grondin 2002; Gadamer 2004).

In this study, two main horizons were interpreted to generate discussion about the participants’ lived experiences of death, dying, and EOLC in the ED. The first horizon was that of the participants (the doctors and nurses), while the second horizon was that of the researcher. Both horizons often fused together when the experiences of the participants resonated with that of the researcher, but with the additional consideration of the socio-cultural factors that have shaped each horizon (Gadamer 1976; Zimmermann 2015). The fusion of horizons occurred through the process of hermeneutic constant dialogue through which the researcher’s own meanings were exposed to the potential for modification or a complete change (Gadamer 1975).

Fairfield (2012) likened Gadamer’s concept of constant dialogue with the structure of play, which was informal and fragile as opposed to an overly structured conversation can prevent a new understanding and meaning from coming into its own. Similarly, Pappas and Cowling (2003) explained Gadamer's construction of meaning as involving full participation, with both parties being accountable for their prejudices as part of the conceptual and perceptual process as it informs the conversation. Therefore, a deeper understanding of the participants' experiences in addition to that of the researcher can be gained. Self-reflection was used throughout the data interpretation process to ensure that an awareness of the researcher's own pre-understandings and prejudices was maintained while remaining open (epoche) to the participants' experiences (van Manen 2014). These reflections were documented as a fusion of horizons in relation to the discussed themes.

The hermeneutic analysis resulted in the emergence of a constitutive pattern (CP) that represented all of the identified themes. The challenges reported in decision-making by the participants emerged as a CP that cut across all the other themes. Diekelmann's hermeneutic analytic approach was conducted to identify categories, relational themes, and the constitutive pattern (CP). Early in the analysis (Stage 1), categories such as Quality of life, Futile treatment, and Conflicting roles were identified as potential CPs.

As the analysis proceeded, the two relational themes of 'Experiences of providing end-of-life care in the ED' and 'Death and dying in the ED context' were generated. From here, the overarching constitutive pattern that encompassed all the text emerged. At this stage, the constitutive pattern relating to 'The complexities of decision-making' about EOLC treatment as experienced by the participants was identified. This stage was known as the highest level of hermeneutical analysis i.e., an overall theme that pervades all the text and themes generated (Diekelmann et al., 1989).

Despite the challenges expressed in decision-making, the participants in this study were committed to providing quality EOLC. They described the provision of EOLC in the ED setting as a privilege, a satisfying experience, and that they wanted to achieve quality EOLC for the dying patients and their families. These findings extended beyond the available current knowledge of ED staff members' experiences of death and dying, especially in terms of the constant complexities in the decision-making process that were reported as they attempted to provide quality EOLC. The available research has not analysed the complexities of EOLC provision from a decision-making perspective in such depth. The identified constitutive pattern in relation to the complexities of decision-making in EOLC will now be explored.

8.1 Constitutive Pattern: ‘The complexities of decision-making’

‘The complexities of decision-making’ as an identified constitutive pattern was a constant presence in each of the major four themes explored in Chapters 6 and 7. This signified the difficulties in balancing treatment options as experienced by the participants when providing EOLC in the ED setting, specifically the treatment options between the provision of traditional ED life-saving treatments and comfort/EOL care. The complexities experienced in making decisions about care were influenced by factors such as the level of understanding of the prognosis by the patient and their family, the acceptance/denial of imminent death by the patient or their family, the experiences of the ED staff, and the uncertainty about who owned the responsibilities and roles of initiating EOLC conversations. ED staff constantly reported navigating these complexities to ensure that the decisions made were in the best interests of the patients and their families.

8.1.1 Lack of understanding of prognosis

The lack of understanding of the given prognosis caused complexities in the decision-making process when the patient and their family presented without knowledge of the extent of their prognosis, and were seeking life-saving measures despite the ongoing inevitable deterioration that was occurring. Requests for curative measures were also similar for patients who had not accepted the imminence of death. ED staff had to establish an understanding of their prognosis through in-depth discussions about treatment options. Despite these discussions, some patients and their families still requested aggressive treatments. White et al’s (2007) study on the decision-making process at the end of life reported that decisions about treatment choices were a challenging task, and that the physicians in their study had little or no guidance about how best to achieve a good decision (Caron & Sherbrooke 2005; White et al., 2007). In line with the previous research, the participants in this study often encountered difficulties in the decision-making process due to a lack of understanding of the prognosis by the patient and their family.

8.1.2 Professional experiences of ED staff

In this study, the complexity of the EOLC decision-making process was influenced by the professional experience of the ED staff. Inadequate professional experience and knowledge of EOLC provision often increased the complexity of decision-making. Decision-making was also complicated because of the uncertainties about who had the role and responsibility of initiating EOLC conversations. The available evidence shows that when patients and their families perceived that ED staff avoided initiating an open and honest EOLC conversation, decision-making about treatment options became challenging (Pattison et al., 2013; Visser 2014). The reasons for not initiating EOLC discussions were believed to be associated with ED staff members' inadequate knowledge about treatment options and a lack of confidence in having EOLC discussions (DeVader & Jeanmonod 2011; Beckstrand et al., 2012; Visser 2014). A similar conclusion was reached in this study as the majority of the participants reported inadequate EOLC knowledge and skills, especially in the area of having EOLC conversations. Due to the lack of knowledge and skills in EOLC conversations, some ED staff in this study were reported to avoid EOLC discussions.

The findings in this study showed that the complexities of EOLC decision-making tended to improve when the participants were able to establish a collaborative decision-making approach. The participants reported that in some cases, the patients often willingly granted the authority for the main decision-making to ED staff due to their prognostic knowledge and ability to anticipate imminent death. As the dying trajectory progressed, ED staff expected the families to take charge of the decision-making based on their perceived relational bonds. However, the literature has indicated that some family members were unsure of their roles and would often prefer not to be active within the decision-making process (Forbes et al; 2000; Meeker 2004; Caron & Sherbrooke 2005). However, families who were involved, despite the complexities of decision-making, reported a higher level of satisfaction with EOLC (White et al., 2007). Contrary to the findings of the previous research, in this study, ED staff stated that families were often willing to be part of the decision-making process which required the participants to be intentional about including family members in the decision-making process, but that conflict would occur when family members disagreed with decisions about EOLC.

Strategies to improve decision-making have been suggested in the previous research as the use of a collaborative decision-making model through which ED staff took the responsibility for EOLC conversations and recommended treatment plans (life-saving/curative or comfort care) that were consistent with the patients' and families' goals for care (Rosenfeld et al; 2000; Schaden et al., 2010; Baggs et al., 2012; Kolva et al., 2014). Similar to the available evidence, ED staff in this study recognised that effective communication as a collaborative team was important; for example, communication strategies in which conversations intentionally reminded family members to make decisions based on what the patient would have wanted, rather than what the family preferred (Charles et al, 1999; Hsiu-Fang 2006). Overall, the CP of " The complexity of decision-making" has revealed that inadequate knowledge and skills about EOLC made decision-making very demanding.

The remainder of this chapter will further discuss the findings in light of the literature, with consideration to the constitutive pattern of "The complexity of decision-making". This research study has aimed to investigate death, dying, and end-of-life care provision within the ED. The discussion has been guided by Gadamer's principle of constant dialogue, and moving from the whole of the data to parts of the data without bracketing the researcher's own being-in-the-world of practising as an ED nurse (Gadamer 1975; 2004). An act of open-ness to construct meaning and understanding were maintained using the researcher's own prior understandings as a tool of hermeneutic inquiry, as suggested by Gadamer (1976).

The first theme described the influences of the participants' own values and beliefs about EOLC decision-making. The ethical and professional conduct of the participants, as influenced by the context of EOLC decision-making in the ED setting were explored. Discussions about the views of the participants concerning the expectations placed on their roles in conjunction with the conflict experienced due to decision-making around the goals of care are discussed below. These themes include:

1) The influence of participants' beliefs and values on EOLC decision-making

2) Ethical and professional conduct in EOLC decision-making

3) Expectations of roles; the decision-making process

4) Decision-making pertaining to goals of care; conflicts

8.2 The influence of participants' beliefs and values on EOLC decision-making

The participants' personal beliefs and values referred to privately held views about death and dying. Some of the personal beliefs and values of the participants included the belief that death and dying must be respected and dignified; the belief in life after death; atheism; the belief that futile treatment must be avoided; and that death was inevitable. Even though these beliefs and values were personally held by the participants, they appeared to have a significant impact on their experiences of providing EOLC. This finding ties in well with the previous research that has examined how healthcare professionals' personal religious beliefs, cultures, and values influence their attitudes and decision-making about death, dying, and the provision of EOLC. Similar to this current study, the findings from these previous studies agreed that doctors' and nurses' personal religious beliefs, views, and culture concerning death and dying influenced their decision-making and the provision of EOLC (Kubler et al., 2011; Bulow et al., 2012; Peters et al., 2013; Ntantana et al., 2017; Frush et al., 2018).

The findings from studies that specifically examined the impact of religious beliefs on the provision of EOLC also explored the impact that the religion of doctors and nurses had on decisions to forgo life-sustaining treatments (Kubler et al., 2011; Bulow et al., 2012; Peters et al., 2013; Ntantana et al., 2017). The findings from these studies showed that healthcare professionals who have religious beliefs were unwilling to withdraw life-saving treatments, and often wanted more extensive treatments. Similar findings were obtained in the present study, as participants' religious beliefs influenced how they provided EOLC to patients and their families. For example, some participants in this study reported feelings of sadness for those patients who were dying with no religious beliefs, because they believed these patients had no hope of an after-life.

The influence of healthcare professionals' religious beliefs on death, dying, and the provision of EOLC has a historical foundation. Drawing from thanatological studies and the associated historical concepts of the Middle Ages, death and dying were significantly tied to religion. During the Black Death (plague) of the Middle Ages, healthcare professionals at the time believed the plague was the will of God and that it could neither be cured nor controlled (Coulton, 1929). In the present study, the participants also related their provision of EOLC back to their religious beliefs. For example, some Christian participants believed that the death of their patient was allowed by God because it was their time to die. Overall, the findings of this current study support the historical evidence of the significant influence that the healthcare professional's religious beliefs had on their provision of EOLC and their decision-making about care.

The available standards that guided healthcare professionals when delivering EOLC described that care of the dying should be based on the preferences of the patient rather than those of the healthcare professional. According to the 'Australian National Palliative Care Standard 4: the care of the dying' must be:

> *Based on current and comprehensive clinical assessment, delivered in accordance with the person's expressed values, goals of care, and preferences, as evidenced in their care plan, and informed by the best available evidence … The dignity of the person is prioritised at all times through a person-centred approach to their overall care (NPCS 2018, p. 17).*

Based on this standard, the values of the dying patient, combined with the best available evidence, were recommended as the major considerations for healthcare professionals to inform EOLC decision-making for the dying patient and their family (NPCS 2018). According to the standard, EOLC was believed to be dignified when care was provided based on the dying patient's preferences and needs (physical, psychosocial, or spiritual) (NPCS 2018). In this study, it appeared that the participants' experiences of providing EOLC and their decision-making were based loosely on their own values of what they believed was important about death and dying.

The participants who believed that death, dying, and EOLC needs to be respectful, ensured that patients' values were respected. According to those participants who believed that futile treatment must not be given, they reported ensuring that their patients never received futile treatments when they provided EOLC. Many of the participants believe that their personal views were of benefit to the patient. But in situations where the personal values of the participants were at odds with those of the dying patient, EOLC provision and decision-making were believed to be challenging. When values and beliefs were similar, EOLC was believed to be 'smooth and easy'. Overall, these findings are in accordance with those that explored the impact of similarities and differences in views and beliefs between healthcare professionals (HCP) and the dying patient in relation to the provision of EOLC. These previous studies described that differences in views about EOLC often caused moral distress for HCPs (Oberle & Hughes 2001; Shorideh et al., 2012; Forde & Aasland 2008).

According to Rundio (2019), moral distress was caused when an individual had their own convictions about what was right and which was often informed by their own values and beliefs, but they were not allowed to carry out what they believed to be right. Forde and Aasland (2008) stated that 51% of doctors in their study were morally distressed by having to provide EOLC that was against their own values and moral conscience. Other evidence reported that in comparison to doctors, nurses experienced more dissatisfaction when they believed that the care being provided went against their own values and beliefs (Shorideh et al., 2012; Kirby et al., 2014). Shorideh et al. (2012) claimed that nurses tended to experience higher moral distress due to their position at a lower level within the hierarchical structure of decision-making in relation to EOLC.

To explore the current findings about the influences of the participants' personal views, culture, and beliefs on the provision of EOLC and decision-making, Gadamer's philosophical underpinnings concerning traditions, cultures, practices, and historicity of individuals was used (Gadamer 1975). According to Gadamer, the social practices and traditions of a specific historical or cultural environment makes up the horizons of existence (Gadamer 1975; Dilthey 1986). The participants' own views and beliefs concerning death, dying, and EOLC, influenced by their specific social practices, traditions, and cultures, created a horizon. Dilthey's interpretation of Gadamer's hermeneutics explained that people's views and beliefs about life is developed based on their own experiences (historicity, traditions, truths), and for the participants in this study, on their provision of EOLC, while their decision-making processes appeared to be based on their own personal experiences of death and dying (Dilthey 1986).

Gadamer emphasised that there were no 'universal truths', but that the goal of hermeneutics was that, despite the differences in each other's views, there would be a form of consensus among cultures (Gadamer 1975). According to Gadamer, this was the actualisation of 'the fusion of horizons' (Gadamer 1975). The findings of the current study show that the differences in some of the views and beliefs between the participants and the dying patients showed a lack of consensus and an inability to create a fusion of horizons. For a consensus to be reached when there are differing views and beliefs, dialogue should be based on the willingness of people from different traditions, or different people with similar traditions, to work towards mutual understanding and to cooperate through continued dialogue (Gadamer 1975). Contrary to the concept of Gadamer's use of dialogue between patients, their families, and ED staff, the participants in this study often used the contributions of the ED team (nurses, doctors, and the ICU team) to resolve differences in views and beliefs.

Habermas interpreted Gadamer's continued dialogue as a conscious attempt by both parties involved to remain open to changing ingrained meanings so that a new understanding and interpretation of tradition could be forged (Habermas, 1986). In relation to this study, when EOLC and decision-making were challenging due to differences in views and beliefs between the dying patients, their families, and the participants, a continued dialogue based on the willingness of all the people involved could potentially create a consensus to achieve Gadamer's fusion of horizons.

In order to achieve a hermeneutic understanding of how the participants' beliefs and values influenced EOLC decision-making, an initial awareness of my own prejudices was undertaken, so that this could be used to assert the new conversation against my fore-meaning and to potentially arrive at a new understanding (Gadamer, 1975). As an ED nurse, Gadamer's fusion of horizons was achieved when my personal experiences of providing EOLC resonated with the accounts of the participants that care provision was challenging at times, in particular when I felt excluded from the decision-making process. For example, I believe that any form of care that causes a dying patient more distress should not be provided. But when I have been forced to provide care despite my belief that the intervention given was not in the patient's best interests, the moral distress reported by the participants was often experienced by myself. This was a bias that I held, which was used as a hermeneutic tool because it resonated with most of the participants.

In summary, the available Australian palliative care standards articulate that the values and beliefs of the healthcare professional should not determine whether the decision-making process and the delivery of EOLC to dying patients and their families should be 'smooth' or 'difficult'. The findings in this current study are supported by the available literature, in which the participants' views and beliefs influenced their provision of EOLC. The difference between the participants and the dying patients' beliefs, values, and culture made the decision-making process of EOLC challenging. The participants, particularly the nurses, were often 'caught in the middle', which resulted in moral distress. This study has highlighted the need to improve the decision-making process about EOLC between patients and ED staff. The participants reported that the process of making decisions about EOLC can result in ethical, moral, and legal issues that breached professional conduct guidelines, as discussed in the subsequent point.

8.3 Ethical and professional conduct in EOLC decision-making

Ethical and professional codes of conduct guide healthcare professionals when they are faced with ethical, moral, and legal issues relating to the provision of EOLC and decision-making (Berglund 1998). The findings of this study have revealed that breaches in ethical issues and professional conduct often occurred during the decision-making process about treatment at the end of life. The participants in this study reported that ethical decisions, whether to provide life-saving treatment, curative measures, or supportive/comfort care, were often challenging.

In this study, the participants' decisions on whether to give life-saving treatment, curative measures or comfort care were often guided by a combination of factors, such as the dying patient's quality of life, the patient's request to have life-prolonging measures for family reasons, and the participants' own moral understandings of what was ethical, moral, and legal. This finding ties in well with the previous research where the evidence has shown that the perceptions and the ethical and moral norms of the healthcare professional shape interventions provided at the end of life, while life-prolonging measures are provided based on factors such as quality of life and family requests, but often at the expense and dignity of the dying patient (Gielen et al., 2011; Dzeng et al., 2018; Grech et al., 2018).

In this study, as a result of the dilemmas faced in ethical decision-making, some of the participants referred to the ethical standards that were available to guide their EOLC practices. The participants indicated that they were aware of the code of ethics and the professional conduct that supported their EOLC practices. The participants had access to ethical standards such as The National Health and Medical Research Council (NHRMC 2011), The National Palliative Care Standards in collaboration with professional organisations such as the Australian Medical Association and the Royal College of Nursing Australia, and other professional practice guidelines such as the code of ethics for doctors and nurses. These standards and governing bodies collaboratively provided a position statement:

> *Respect for people requires helping them to engage with decision-making to the extent that they are able to, and wish to, be involved. Justice to all concerned requires the concerns of family and carers to be taken into account. Beneficence to the person will often require advance care planning, the use of end-of-life clinical pathways, and specific decisions to limit, withhold, or withdraw treatments that have become futile or overly burdensome. In striving to realise these values, good ethics and good clinical practice go hand-in-hand (NHRMC 2011, p. 20).*

This standard aims to facilitate best ethical practice for patients who are receiving EOL/palliative care for an advanced chronic or terminal condition in the last 12 months or so of their lives (NHRMC 2011). This standard support healthcare professional's clinical judgement and the engagement of the dying patient in the decision-making process while considering the concerns of family members. Some of the research has found that the recommendations of healthcare professionals did not always determine the acceptance or lack of acceptance of aggressive treatments by the dying patient (Tomlinson et al., 2011; Bulow et al., 2012; Oosterveld-Vlug et al., 2016; Frush et al., 2018). The factors that were considered as important determinants of the acceptance of aggressive interventions were different between the dying patient, their families, and the healthcare professionals (Tomlinson et al., 2011; Bulow et al., 2012; Oosterveld-Vlug et al., 2016).

The evidence has shown that for the dying patient and their family, decisions about accepting aggressive treatments or otherwise were based on hope, increased survival time, and quality of life, but healthcare professionals' decisions were often driven by the financial consideration and burden (Tomlinson et al., 2011; Wilson 2011). In this study, regardless of the views of the dying patient and their family members on quality of life, the participants believed their own views of what quality of life entailed, and that these were important factors to be considered in relation to whether aggressive treatments were given or otherwise. Rose and Welzs's (2018) study argued that quality of life (QOL) should not be considered as a trigger for resuscitation (life-saving care), because QOL was found to be an emotionally-induced term on which there were opposing views about its values, thus sometimes causing disagreement between families, staff, and patients. Other studies found that some dying patients were willing to have the decision-making about treatment plans shared with the healthcare professional and, in some cases, the dying patient simply wanted someone else to make the decisions on their behalf, because they were too stressed to make any decisions (Gielen et al., 2011; Frush et al., 2018).

According to Hayes (2012), ethical EOLC decisions must begin by establishing the goals of care of the dying patient. Once the goals of care are established, then the benefits and burdens of interventions are determined collaboratively with the dying patient, their family, and healthcare professionals (Haes & Koedoot 2003). However, providing EOL treatments without goals of care was reported to be a source of conflict (Hayes 2012). The findings of the current study have shown that the participants, especially the doctors, felt that the establishment of goals of care was an important aspect of EOLC, as consistent with previous studies.

The ethical principle of autonomy ethically and legally supported the idea that the established goals of care based on standards of practice, research, and experience must first be presented to the dying patient (Haes & Koedoot 2003). From there, the dying patient can autonomously establish their personal goals of care with the right to refuse treatment, including life-prolonging treatments (Hayes 2012). Correspondingly, if the healthcare professional determines that an intervention would be of more harm than benefit to the dying patient, then it is ethically justifiable to withhold (forgo) or withdraw (discontinue) treatment (Berglund 1998). Overall, the participants believed that ethical decision-making needed to be shared between the dying patient, their family, and healthcare professionals.

Historical evidence from thanatologists reveals that physicians have always been viewed as the main decision-makers in EOLC provision and have been placed in positions of control (DeSpelder & Strickland 1987). In the present day, this view has persisted in some cultures where doctors have been seen as the main decision-makers (Helman 2007; Glajchen et al., 2011; Coolen 2012). Recently, there has been a move towards a collaborative approach to decision-making between the patient, their family, and healthcare professionals. According to the current evidence, this approach has been referred to as the gold standard of care (Hayes 2012).

Gadamerian ethics also emphasises the dilemmas encountered in decision-making (Gadamer 1975). Gadamer argued that the concept of the ‘individual case’ should be employed, rather than the use of ‘universal principles’, as illustrated in the quote below:

> *The individual case on which judgement works is never simply a case: it is not exhausted by being a particular example of a general law or concept. Rather, it is always as an ‘individual case’, and it is significant that we call it a special case, because the rule does not comprehend it. Every judgement about something is intended to be understood in its concrete individuality, as the situations in which we have to act demand of us, is – strictly speaking – a judgement about a special case. That means simply that the evaluation of the case does not merely apply the measure of the universal principle according to which it is judged, but itself co-determines it, supplements and corrects it. From this, it follows ultimately that all moral decisions require taste … The man who finds that what is bad goes against his taste has the greatest assurance in the acceptance of the good and the rejection of the bad (Gadamer 1975, pp. 37-38).*

In the above quote, Gadamer explains that in coming to a decision, the case itself must be approached as an individualised concept that forms its own principles, rather than making attempts to fit the case into a principle or theory (Gadamer 1975). In relation to the current findings of this study, the participants’ ethical decision-making processes were often not influenced by a set of principles or theories, but by other external factors such as quality of life, family influence, and ED staff members’ own values. A Gadamerian ethical approach argues that every ethical case must be understood as an individual case (Gadamer 1975; Bruns 2002). Bruns’ analysis of Gadamer’s ethical decision-making recommended that randomness and contingency in coming to a common decision should be allowed because a set of principles cannot be wholly applied to the human lifeworld (Bruns 2002). In line with the findings of this study, Gadamer’s concept of ethical decision-making would require that each patient’s context be explored so that it develops its own theoretical guide, rather than the application of a universal principle.

Gadamer reported on the hermeneutic relevance of Aristotle’s ethics using the analogy that the heart of the hermeneutical problem is that even though traditions are the same, they must always be understood in different ways (Gadamer 1975). Ricoeur supported Gadamer’s view that ways of doing can be interpreted and narrated in many different ways (Ricoeur 2002). Gadamer believed that Aristotelian ethics was not concerned with the hermeneutic problem, nor with its historical/traditional dimensions, but with the right estimation of the role that reason must play in moral actions (Berglund 1998; Gadamer 1975). Gadamer proposed that Aristotle, the founder of ethics as a discipline independent of metaphysics where all other philosophies were developed from, restored the balance by showing that the basis of moral knowledge in humans is *orexis* (logic, power), or striving developed into a fixed attitude (Gadamer 1975; Vattino 2002), as described in the quote below:

> *Human civilisation differs essentially from nature in that it is not simply a place in which capacities and powers work themselves out, but man becomes what he is through what he does and how he behaves, i.e. he behaves in a certain way because of what he has become. Thus, Aristotles see Ethos as differing from physis in that it is a sphere in which the laws of nature do not operate, yet not a sphere of lawlessness, but of human institutions and human attitudes that can be changed and have the quality of rules only to a limited degree (Gadamer 1975, pp. 278-279).*

In the above quote, Gadamer argued that the discovered laws of nature did not apply to that of ethics. Other authors’ interpretations of Gadamer’s views on the laws of ethics was about human attitudes and institutions that change, as opposed to the laws of nature which remain the same (Habermas 1986; Vattino 2002). The findings of this study are in accordance with Gadamer’s perspective, as the participants reported their ethical practices as a flexible approach to care. Flexibility was reported in how each ethical decision was resolved based on the context of each dying patient. The ‘principle’ that guided ethical decision-making was established by the circumstances of the dying patient themselves, and these would change depending on the situation of the dying patient. Overall, Gadamer’s views on ethical decision-making were relevant for understanding the participants’ ethical decision-making processes.

The participants’ dialogue about relinquishing care and the neglect experienced by the dying patients was a common source of ethical concern when caring at the end of life. In medical ethics, the relinquishing of care without a formal handing over to another healthcare professional, and leaving the patient without care, was referred to as the act of abandonment. Abandonment is an unethical act with legal consequences (Han &

Arnold, 2005). The findings of this study show that doctors often relinquished care of the dying patient to nurses at the end of life because they believed they had nothing to offer at this stage of care. The findings are directly in line with the previous findings from a case study which explored the care of the dying in the ED, finding that care was often relinquished to nursing staff because care of the dying was predominantly attributed to nursing (Bailey et al., 2011). Other studies suggested that the reasons for delegating the task of EOLC to nurses were associated with doctors avoiding communication with the family and their lack of competence in EOLC (DeVader et al., 2011; Cipolletta & Oprandi 2014).

There is a gap within the literature on the facilitation of dying patients' continuity of care, and the abrupt relinquishing of care between healthcare professionals (doctors and nurses). Due to the significant lack of literature on the relinquishing of care at the end of life, the literature on neglectful care by healthcare professionals at the end of life was accessed. In this current study, the participants reported unintentionally neglecting patient care because of high workloads and time constraints. The participants also reported that care was often neglected once end-of-life care was ascertained to be necessary. Time and energy were redirected towards other patients who had a high chance of survival and acute emergencies. The literature on neglect provided sufficient evidence that helped clarify why EOLC might often be relinquished in an impromptu fashion by healthcare professionals.

Evidence that has examined neglect at the end of life was available from the perspectives of dying patients, their families, their loved ones, as well as doctors and nurses who provided EOLC. Dying patients and families had similar views about their experiences in the ED, reporting feeling 'neglected', 'segregated', 'forgotten about', and 'abandoned' (Bailey et al., 2011; Bailey et al., 2011; Beckstrand et.al, 2012). Like the reports of dying patients and their loved ones, evidence from the literature shows that ED staff were aware of the neglect experienced by dying patients and their families (Tse et al., 2016; Kongsuwan et al., 2016). However, they often reported that this neglect was unintentional, and was primarily due to the urgent care needed for other life-threatening emergencies in the time-constrained ED setting (Tse et al., 2016; Kongsuwan et al., 2016).

The current four-hour rule policy implemented by the National Emergency Access Target (NEAT) in 2011 aimed to reduce ED overcrowding by ensuring that all patients who present to an ED are assessed, diagnosed, and discharged or admitted to a ward within four hours (Sullivan et al., 2016). Generally, most Australian ED systems recorded approximately 50% daily block in ED access due to admitted patients not moving out of ED and the lack of availability of ward beds (Dobb 2010). The evidence shows that the four-hour rule has resulted in improvements in several areas, such as shortened ED length of stay, increased ward beds for admission, and reduced waiting times (Ngo et al., 2018; Nahidi et al., 2019; Forero et al., 2019). But stringent pursuit of the four-hour rule has been shown to increase pressure on ED staff, and may potentially jeopardise the quality of patient care, including EOLC (Stokes 2011; Sullivan et al., 2016).

Bailey et al. (2011) argued that neglect in EOLC was related to the ED doctors and nurses in their study who were not ready to acknowledge that death and dying was a significant part of emergency work, but who placed significant focus on life-saving interventions. Contrary to this finding, in the current study, most of the participants believed that death and dying was a significant part of ED work. The differences in this finding could be due to the increase in numbers of patients now presenting to ED for EOLC. Many of the participants in the current study expressed dissatisfaction about how dying patients were often classified as low priority. The current study reveals that there is a new dialogue about EOLC in the ED which emphasises that care of the dying should be prioritised in the same way as other normal acute emergencies. The recognition by ED governing bodies (ACEM, nursing management) for the need for palliative care skills training in ED showed that palliative care and emergency medicine/nursing as a speciality does not appear to be an implausible concept. This form of speciality is now gaining ground in Australia, as evidenced by the increased numbers of ED staff seeking additional qualifications in palliative care.

Historically, thanatological concepts of death and dying viewed EOLC as the responsibility of the family and the community (DeSpelder & Strickland 1987). Especially in ancient times, the care of the dying was performed with paramount consideration (Kerrigan 2007). EOLC, and the rites and rituals of passage were a necessity for the dying person, because if these were not performed, then it was considered to be a bad omen for the dying person in the after-life (Fonseca & Testoni 2011). Historically, the significant priorities placed on care at the EOL may not have been sustained to current times, as evidenced in the findings and within the current literature in relation to neglect and relinquished EOLC.

Gadamer’s ‘fusion of horizons’ was established because my experiences as an ED nurse resonated with the participants. Similar to the participants, I have experienced complexities in ethical decision-making. Making ethical decisions was often challenging for me when family members/substitute decision-makers made EOLC decisions that suited their own interests. I have experienced more difficulties when attempts have been made to advocate against decisions that did not benefit the patient. Based on my experience, doctors tended to relinquish the care of the dying to nurses with the underlying belief that they had performed their own part of the care (the life-saving aspect), and that EOLC belonged to the nurses. This can often be challenging because providing EOLC requires a different set of clinical skills for both doctors and nurses; for example, supportive end-of-life medications, repeated family discussions, care of the bereaved, and physical, emotional, and spiritual comfort. The absence of medical care often resulted in missed key aspects of EOLC, such as availability for repeated EOLC discussions as needed by the patients and their families.

Overall, the evidence from this discussion suggests that EOLC needs and ethical decision-making must be individualised and assessed based on what each dying patient would benefit from. Similarly, a collaborative approach to ethical decision-making has been recommended according to the code of ethics and professional conduct for Australian healthcare professionals. Gadamer's theoretical framework about ethics and decision-making makes it clear that ethical decision-making is not a 'one size fit all' principle. Gadamer argued that the laws of ethics, unlike the laws of physis, are bound to change according to human attitudes, beliefs, values, and norms. In this study, the participants believed that there was flexibility in ethical decision-making, but it was crucial that doctors and nurses understood their specific roles and responsibilities within the decision-making process. Uncertainty about how ED roles fitted into EOLC roles were often reported to be challenging. However, when good awareness of the roles was demonstrated, decisions that were ethical, legal, and moral were made when providing EOLC.

8.4 Expectations of roles; decision-making process

The expectations placed on specific roles was shown in the participants' views about what their roles were believed to be when providing EOLC. The participants who were doctors had an expectation of what the nursing role should be, while the nurses had their own understanding of what the doctors' role entailed. Some of the expectations of the roles aligned when the doctors and nurses had the same expectations of each other's roles, but there were also differences when there were mismatches with expectations of each other's role. Both groups of participants (doctors and nurses) agreed that they expected nurses to perform the hands-on clinical tasks (mouth care, pressure area care, pain management, emotional care, family care, facilitating spiritual care etc).

Similarly, studies on emergency nurses’ roles in ED EOLC have shown that nurses were significantly responsible for physical comfort as well as spiritual and emotional care, and support of dying patients and their families (Norton et al., 2011; Kirby et al., 2014; Decker et al., 2015; Yingting et al., 2018). A similar conclusion to the literature findings was reached in the current study, that the role of nurses was believed to be demanding because of the stressful, fast-paced environment, staff shortages, and time constraints, as well as the clinical and bureaucratic tasks (Couilliot et al., 2011; Kirby et al., 2014).

The cost of the emotional care and support carried out by nurses was reported in this study as an ‘emotional burden’. The literature on emotional burden revealed that there was a professional expectation that nurses should emotionally support the dying patient and their family (Morita et al., 2004; Cipolletta & Oprandi 2014; Wolf et al., 2015). In line with the previous research, the nurses in this study felt that they were professionally obliged to provide clinical care and, at the same time, to provide emotional support. For example, evidence from the primary literature showed that nurses were often burdened by the professional expectation to manage the emotions of the grief and loss of the dying patients and their families as well as their own (Morita et al., 2004; Karlson et al., 2017).

Inconsistencies in the participants’ expectations of each other’s roles were also found in the current study. In some cases, the views of doctors as to what their roles were differed to what the nurses perceived to be the role of the doctor. Contradictions were discovered when the participants who were nurses reported that the role of the doctors was to make EOLC decisions and to communicate EOL goals of care effectively. But doctors in the study perceived that their main role was to ‘figure out’ and ‘work out’ a dying patient’s goals of care so that the decision-making process could be facilitated.

Research studies that have explored how nurses perceive the role of doctors in EOLC, and how doctors perceive the role of nurses in EOLC was limited. There is a significant gap in the literature on research that has specifically explored how nurses perceive the role of doctors in EOLC and vice versa. This study appears to be the only one that has examined the differences in how these roles were perceived. The findings from this study have shown that common ground existed in the perceptions of the roles, but at the same time, differences were also present. Exploring this aspect was crucial because it highlighted the discord around the priorities of care that existed between ED staff (doctors and nurses). An awareness of these differences was important so that changes could be targeted at reconciling the differences, and improving the outcomes, for the dying patient and their family.

Much of the available research on EOLC in the ED has suggested that EOLC required a significant amount of collaboration between patients, their families, and ED staff (Norton 2011; Kirby et al., 2014; Tse et al., 2016). However, from the findings of this study, the misunderstanding in expectations of each other's roles could affect the care of the dying patient and their families. For example, as nurses in this study believed communication to be the crucial role of the doctors, many of the nurses reported that when communication was not effectively undertaken by the doctors from the beginning of EOLC, a lack of acceptance of death or ambiguity about the goals of care by the dying patient were often reported.

Due to the lack of evidence on the perspective of nurses in relation to the doctor's role, research that has explored the role of physicians in the ED from the perspective of bereaved families and loved ones was accessed. The findings from these studies showed that the communication style of the doctors was crucial in how EOLC experiences were defined (Redley et al., 2003; Marco et al., 2005; Bright et al., 2009). Families reported that doctors' communication styles were often harsh, with the use of overly technical language (Bright et al., 2009). The findings were consistent with those of the current study because the nurses agreed that doctors' use of language was often complex and unclear. Consequently, many of the nurses in the current study reported having to spend more time discussing treatment plans, despite the significant time constraints and high workloads.

In order to better understand the present perceptions of doctors' and nurses' roles in EOLC, death, and dying, historical expectations of the role of medicine, as explored in thanatology, were examined. Thanatologists' study of the Black Death in the Middle Ages highlighted the significant public expectations placed on medicine. At the time, the role of physicians carried significant authority and power (Coulton 1929; Lenz & Hybel 2016). Physicians at the time were expected to be able to cure the plaque (Black Death), but the remedies and portions provided were ineffective (Coulton 1929; Ziegler 1969). Consequently, physicians became objects of ridicule and were often scorned (Ziegler 1969; Aberth 2005). Similarly, in the present, high public, and professional expectations of health professionals still exist. Nurses are particularly expected to be emotionally supportive, as reported in the current study, while those who are unable to cope with the demands of the public and professional expectations of EOLC may become emotionally burdened.

As an ED nurse, I have also experienced the emotional burden of my EOLC provision. During the analysis of the participants' experiences of emotional burden in their role of EOLC provision, I was able to achieve a fusion of horizons because the accounts of the participants brought back my numerous memories of experiencing the emotional burden of the nursing role. I have experienced the emotional burden by often taking on the patients' and families' feelings of sadness, grief, and loss while providing EOLC. The emotional burden I felt was higher when dying patients were younger or if it involved tragic/ traumatic circumstances. My experiences were similar to the participants due to expectations both from the public and the profession to fulfil the emotional support role as a nurse.

Another fusion of horizons was established in the perception of the nursing participants of the doctors' role. Similar to the other nurses in this study, my historical pre-understanding was that the major role of the doctor was to know how to communicate effectively. The reason for this belief was that, from my own experiences, even when goals of care were adequately established, if the doctors' style of communication was ineffective, acceptance of the inevitability of death was often challenging. On the other hand, when doctors had good communication skills without a complete goal of care plan, EOLC still appeared to be less challenging and the dying patient with their families accepted the imminence of death more readily.

The contradictions in the perceptions of important aspects of EOLC roles between doctors and nurses is reflected in the philosophical work of Gadamer in *Truth and Method* (Gadamer 1975), in which his process of philosophical hermeneutics explained that individuals have different interpretations and understandings of concepts (Gadamer 1975), but that the process of hermeneutics could be applied to these differences so that they would come together to form a new understanding and a fusion (Gadamer 2004; Nixon 2017).

In relation to this current finding, the differences in the participants' interpretations of what was considered to be a crucial aspect of the EOLC role were different horizons, as defined by Gadamer. But a hermeneutic understanding would be reached when the doctors’ and nurses’ present understandings or horizon would move to a new understanding. According to Gadamer, the process of achieving a new understanding required that doctors and nurses look beyond their own interpretation with openness, not to look away from it, but to see it better. Consequently, a new understanding of each other’s roles would be agreed upon, resulting in changes through a fusion of horizons.

From the discussion of this theme, similarities and differences existed in what ED staff expected of each other’s roles. Most of the account of role expectations was corroborated by the provision of physical hands-on care, and emotional care for the role of the nurses. But differences were reported in the perceptions of what was believed to be the important role of the doctor. The foundations of the expectations of the roles were found in historical accounts of the expectations placed on the physicians’ role as the main decision-maker and communicator of care plans in ancient times. Unmet expectations in these roles in ancient times brought ridicule to physicians. In present times, healthcare professionals can also become emotionally burdened with public and professional expectations to behave in certain ways. It can be deduced that Gadamer’s philosophy emphasises the concept of collaboration (fusions) between healthcare professionals by achieving an understanding and preventing disagreements/conflicts to achieve effective EOLC.

8.5 Decision-making pertaining to goals of care; conflict

Conflict occurred as a result of disagreements due to the differences in understandings of the prognosis and the goals of care between the dying patient, their family, and ED staff. Like the findings in the current study, the recent research has shown that the causes of conflict between the dying patient, the family, and staff members were often because of mis-matched expectations in EOLC treatments and decisions, as well as poor communication (Towsley et al., 2015; Chiarchiaro et al., 2016**;** Heyland et al., 2017).

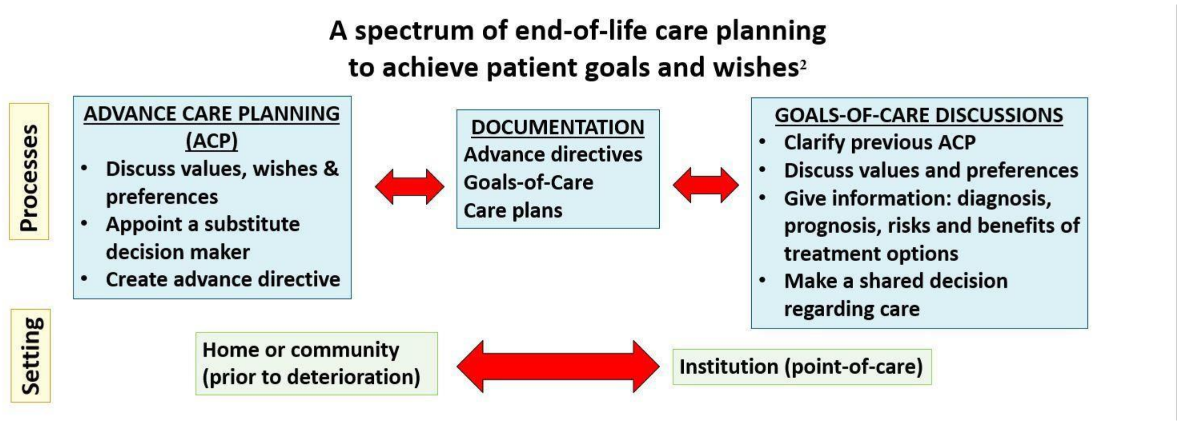
In line with the results of other studies, the participants in this study described that open, honest, and robust communication from the moment EOLC was determined were useful in avoiding conflict (Breen et al., 2002; Sharma & Dy 2011; Francois et al., 2017; Lamahewa et al., 2018). The participants in this study believed that when the dying patient, their family, and staff members felt that they were well informed about the prognosis, disagreements were avoided. Breen et al. (2002) found that the participants in their study reported that conflict between staff and family members were caused by feelings of dishonesty about the prognosis when ED staff had not been forthright about the goals of care (withdrawal of treatment) with the patient and their families.

Arendts et al. (2016) argued that a majority of the ED staff in their study believed that patients and caregivers should be told the truth about their diagnosis, but in practice, many withheld information or avoided discussion about the true extent of the prognosis. The reasons for this were the perceived lack of EOLC training for ED staff, and the lack of time to attend to the emotional needs that resulted from discussions about EOLC (Arendts et al., 2016).

In exploring the dying patients’ best interests during such conflicts, many of the participants in this study reported that advance care planning (ACP) was not instrumental in making decisions that were in the patients’ best interests at the time of presentation. Most of the participants believed that ACP often caused conflict between families, patients, and ED staff when one or more of the parties disagreed with the ACP decisions. They stated that ACP documentation was often performed when the patient had a non-significant disease burden but was often irrelevant to their current situation. The findings in this study were consistent with the previous research regarding the understanding that ACP was not beneficial for decision-making at the end of life, and recommendations to change ACP to the goals of patient care (GOPC) were emphasised (Thomas et al., 2014; Lewis et al., 2016; Levinson et al., 2019).

The aim of GOPC is to change the culture of medical/nursing decision-making (Levinson et al., 2014). GOPC identifies the patient who wishes to decline treatment and assigns them to one of four phases of care: 1) curative (life prolongation), 2) restorative, 3) palliative (no intervention designed to prolong life), and 4) terminal (care of the dying) (Mills et al., 2018; Hanning et al., 2019). Decisions about GOPC at the end of life were designed to be beneficial in making treatment decisions during a crisis, and especially in emergency team calls when difficult decisions were needed to be made at the point of care (Thomas et al., 2014; Staneks 2017). As opposed to ACP and Not for Resuscitation (NFR) documents which may already be in place, goals of care discussions were designed to explore the values and preferences for medical treatment at the time of presentation and at the point of care (Levinson et al., 2014; Levinson et al., 2019). The diagram below from Hanning et al. (2019) provides a visual illustration of the aims of GOPC discussions in comparison to those associated with ACP. Although there were links between the two (GOPC and ACP), the major difference was the time of institution (the point of care), as shown in Figure 8.1 below:

Figure 8.1: EOLC planning-GOPC



(Hanning et al., 2019).

As can be seen in this diagram, once GOPC were determined at the point of care, then ACP and treatment limitations were instituted. However, for patients who already had an ACP in place, GOPC was still discussed, but with consideration to their ACP wishes. Brimblecombe et al. (2014) argued that in patients who had GOPC summaries, calls for emergency medical review were lower compared to the overall cohort of their study.

The findings of studies that have examined the ED-lead goals of care regarding end of life discussions have shown that ED providers felt that goals of care discussions were part of their work (Mills et al., 2018; Hanning et al., 2019). However, in the present study, the participants felt conflicted in having to initiate end of life discussions because no-one else would undertake them. Despite the unwillingness to undertake discussions about EOLC, the findings of this study are consistent with the previous research, arguing that when ED staff had EOLC discussions, it improved outcomes and prevented treatments that were not beneficial at the end of life for patients and their families (Hanning et al., 2019).

Levinson et al. (2019) believed that most of the ED doctors in their study were capable of recognising end of life, although discrepancies and mixed understandings of EOL/palliative key concepts were reported. Similarly, Stone’s (2001) study, which explored how to determine the goals of care for patients approaching the end of life, reported on some of the negative language used by ED staff, such as, ‘Do you want us to do everything possible?’, rather than using affirming positive languages such as ‘I am going to give the best care possible until the day you die’. Stone’s (2001) study concluded that EOLC training on appropriate language during such conversations were needed for ED staff.

This finding on the impact of the language used in EOLC discussions is consistent with the findings of the present study, in which the participants described the use of negative language by ED staff. For example, the participants reported that staff often used language such as, ‘Do you want me to do everything for your mum or just let her die?’ Evidence is available to show that negative language used when discussing treatment can cause conflict and lead patients and their families to request futile treatments (Stone 2001; Weil et al., 2015). Similarly, in Gadamer’s interpretation of shared understanding (the hermeneutical experience), language was believed to be the pivotal medium. Gadamer stated that:

> *Language is the middle ground in which understanding and agreement concerning the object takes place between two people … language as the medium of understanding must be consciously created … for two people to be able to understand each other in a conversation, this mastery of language is a necessary pre-condition (Gadamer 1975, pp. 345-347).*

Gadamer’s quote also supports the evidence from the literature that choice of language in EOLC conversations is important (Gadamer 1975; Stone 2001). Gadamer believed that appropriate use of language in a conversation should be an intentional action that must be mastered, because it is the singular medium through which understanding can be created (Laverty 2003). This explains the misunderstandings reported due to the language choices used by staff, who had yet to master the conscious choice of language to create understandings in their conversations about EOLC with patients and their families.

In regard to my own perspective, a fusion of horizons was attained in agreement with the participants’ views of conflict caused by the lack of beneficial values of ACP**.** From my experiences of ED work, ACP rarely provided the much-needed guidance at the point of care when decisions needed to be made. On some occasions, conflict could potentially occur between families, dying patients, and ED staff, when ACP treatment plans were not agreed with. A fusion of horizons was also established between the participants and my understanding of techniques for conflict resolution. Similar to the participants’ views, I agree that conflict resolution is attained by adopting an open, honest communication style for all to come to an understanding.

In the same way, Gadamer’s concept of the hermeneutic circle addresses how a shared understanding can be reached, particularly in resolving conflict (Nixon 2017). In Gadamer’s view, understanding each other is central to resolving conflict. Hermeneutically, conversations are undertaken using an open dialogue in which each party opens them self to the other person, and a true acceptance that each other's point of view was worthy of consideration (Gadamer 1975). The concept of Gadamer's conflict resolution with an openness and willingness to enter into dialogue was often used by ED staff to get into the other's point of view to such an extent that an understanding of the individual and what they said was created.

Overall, the established goals of care appeared to be valuable in decision-making and conflict prevention in the ED. Goals of care assessments were not already available, but decisions were made collaboratively between the patient, their family members, and ED staff at the point of care. GOPC at the end of life is an area that has yet to be widely introduced to ED staff, as only a small number of participants in this study suggested the use of goals of care rather than ACP. The researcher only became aware of goals of care assessment during the data collection process. Therefore, it appears that there are still gaps and ambiguity that exist in its use. More research is needed in the area of GOPC to further establish its benefits.

This chapter has discussed the findings from the data exploring death, dying, and EOLC in relation to ED doctors and nurses. The discussion on the constitutive pattern (CP) of 'The complexities of decision-making' was pervasive throughout the findings and discussion chapter as an overarching pattern that all other themes were linked to. Four key points were discussed in this chapter using the literature, thanatological concepts, Gadamer's philosophical framework, and Gadamer's fusion of horizons, detailing my perspective on the findings.

The CP of 'The complexities of decision-making' was evident in the first theme that addressed the personal beliefs and values of the participants. The decision-making process for EOLC was complex because participants' personal values and beliefs often influenced the care provided. The available literature did not refute this finding, but recommended a collaborative approach to decision-making between patients, their families, and ED staff members. The CP was also evident in the theme of ethical and moral decision-making in relation to EOLC treatments, which were believed to be challenging, especially when decisions about the care provided went against the participants' own ethical and moral standing. Decision-making was also complicated by the differences reported in how nurses viewed the role of doctors. The differences in the views of these roles meant that the recommended collaborative approach to decision-making in EOLC might be difficult to achieve. Conflict resolution techniques were explored by the participants and supported by Gadamerian philosophical concepts of understanding. As described by Gadamer, the establishment of a hermeneutic understanding between the patients, their families, and ED staff will improve the decision-making process and ensure that quality EOLC can be provided to dying patients and their families.

Chapter 9: Conclusion

This thesis has identified the key areas of care and the challenges that ED doctors and nurses encounter when providing EOLC to patients and their families. The experiences of the participants were constructed around the challenges faced due to the environmental setting of the ED and the difficult balance in decisions between comfort care and life-saving treatments. The ED setting is an environment that is traditionally fast-paced, time-constrained, and short-staffed. In the ED, care provision is naturally aimed towards cure, and the prevention of death. For patients who require comfort in EOLC, decisions about what care is in the best interests of the patient can be difficult. Dying patients and their families can potentially be at a disadvantage when there are mismatches between the ED staff, the dying patient, and their family in relation to the aims of care.

EDs are generally the gateway to accessing healthcare facilities and, therefore, patients with various disease processes seek interventions, including those who require EOLC. In recent times, there has been a significant increase in the number of patients who present to the ED needing EOLC. According to the AIHW report (2017-18), more than 8 million patients present to Australian Emergency Departments per annum with 11 per cent of presentations accounting for patients over the age of 65. People aged 65 and over make up about 15 per cent of the general population but represent 22 per cent of all ED presentations (AIHW 2017-18). Often within this age bracket are patients at the end of life who present to an ED because they need access to hospital admissions for healthcare resources, are having a crisis, or require symptom management (AIHW 2017-18).

According to the participants in this study, patients who require EOLC in an ED were often prioritised at a lower level, with more time being given to acute emergency patients. Dying patients and their families often felt neglected and abandoned, with attention and care being directed towards patients who could be cured or who had a higher chance of survival. Dying patients and their families were transferred to areas that were often away from the critical areas. The moving of the dying patient from acute areas of care, combined with the time constraints and high workloads, contributed to the neglect and abandonment felt by patients and their families, a finding supported by previous studies (Bailey et al., 2011; Glajchen et al., 2013; Kongsuwan et al., 2016).

Bureaucratic and systemic issues of adhering to the curative model of care, in which ED staff are required to meet KPIs and undertake a number of tasks within a particular timeframe, affected the provision of EOLC. The ‘four-hour’ ED rule required that all patients were to be assessed, diagnosed, treated, and discharged or admitted within four hours. However, in EOLC, time was needed for family discussions, reassessing goals of care, physical comfort, mouth care, pressure area care, psychosocial care, and emotional and spiritual care. Palliative care bed shortages also meant that meeting the four-hour ED rule was almost impossible, and most patients died in ED while awaiting a bed on the ward. The responsibilities of the four-hour rule were shared in some EDs between the ED staff and the admitting and bed management teams because once patients were referred, it was up to the admitting doctor to ensure the four-hour limit by assessing the patient for admission on time and the bed manager providing a palliative care bed as soon as possible. The backlog of patients waiting for a bed, combined with the other acute emergencies needing care, increased pressure on ED staff, and often resulted in a lack of priority being given to the care of the dying patients and their families.

Regardless of the challenges faced in delivering EOLC in the ED, respect and dignity are major components of care provision. Respect and dignity were understood in terms of providing care that enhanced the comfort of the dying patient. Comfort was defined not just as the physical, but also in terms of the spiritual, emotional, and social. It was important that the dying patient had comfort in all these areas, because when one or more aspect of comfort was missing, a respected and dignified EOLC was not able to be maintained. All these aspects of care required making treatment decisions that were ethical, and the basis upon which treatment was determined to be futile or otherwise, often caused dilemmas.

The role of ED staff in the process of determining the treatments that would best benefit the patient and their family was described as challenging, and often resulted in emotional burden and moral distress. When the dying patients’ feelings of sadness and grief were taken on by ED staff, an emotional burden also occurred. ED staff who were forced to breach their own moral standards and values by providing care that was against their own beliefs were often morally distressed. Doctors were the main decision-makers, and when care outcomes resulted in unexpected/ preventable death, doctors felt guilty and blamed themselves. Nurses still carried much of the emotional care and burden but did not have feelings of guilt about the care provided.

Dilemmas were encountered when doctors relinquished EOLC to nurses without any formal handing over of care. Nurses believed that doctors often left the care of the dying patient to them once the clinical aspects of care were over, and end of life was diagnosed. Nurses themselves viewed their care roles as both clinical and emotional; however, the clinical aspect of their roles came first before the emotional roles. Doctors believed that although they were not physically present with the dying patient, they would still provide care if required, as they expected nurses to alert them of any care needs.

The role of ED staff in EOLC provision has increasingly been recognised as a key component of ED work. The aims of EOL/palliative care have been integrated into ED work, so that ED staff now have the knowledge and skills to care for patients who need EOLC in the ED. However, the lack of EOLC knowledge and skills held by ED staff caused dying patients to receive treatments that did not add any value to the outcomes of care. EOL/palliative care training programs to improve ED staff knowledge and decision-making about EOLC were often requested by the participants. Decision-making processes about treatment options were not free of conflict. Conflict often occurred between the family, the dying patient, and ED staff. But conflict resolution is a required skill that ED staff believed they must have, because conflict was often unavoidable.

9.1 Theoretical and philosophical underpinnings

The results of this thesis were consolidated using the theoretical framework of the Code of Palliative Care Standards, healthcare professionals’ Code of Ethics, thanatological concepts, and Gadamerian philosophical underpinnings in the discussion chapter. The Palliative Care Standards and the Code of Ethics are concerned with individualising care and allowing the dying patient to make decisions informed by best practice. The aims of the Palliative Care Standards and the Code of Ethics directly relate to the overarching constitutive pattern, which is based on the complexity of decision-making, with these complexities being present in all the identified themes. The thanatological framework directly related to the attitudes, beliefs, experiences, and values of the participants and how these influenced their decision-making in relation to EOLC, as discussed in Chapter 7.

To explore the lived experiences, understandings, and meanings of the participants, Gadamer’s hermeneutic phenomenological approach was used. Hermeneutics concerns itself with creating understanding and meaning (Gadamer 2004). The process of creating understanding between groups of people with various meanings and experiences was achieved using the hermeneutic circle (Gadamer 1965). Within the circle, understanding is initially created in parts before exposing those parts to the whole, so that a new construct of meaning can be created (Gadamer 1975; Dilthey 1986). Elements such as language, experience, truth, prejudices, and questioning were important to be able to come to an understanding to create new meaning (Gadamer 1975; 1989).

The use of language lends itself to a willingness to enter into dialogue with the intentional use of language that constructs understanding (Gadamer 1975). This construct comes from experiences informed by our historicity, prejudices, and biases (Grondin 2002; Gadamer 2004). However, truth emerges as a consensus formed by co-constructors (the participants and the researcher) through the phenomenological method of questioning, because it is important to obtain the participants' meanings and experiences of providing EOLC, rather than only examining EOLC itself (Gadamer 2004). When the described experiences re-awakened the lived meanings of the researcher, a fusion of horizons within the hermeneutic circle was created (Gadamer 1965).

The hermeneutic interpretive approach used in-depth interviews with doctors and nurses who had experienced EOLC provision in an ED. The interviews generated rich data, which is evidenced by the depth of the data analysis. Qualitative studies have no pre-determined sample size; however, the initial low response rate might be considered as a limitation. Although phenomenological qualitative research also does not have a set criterion for sample size, the depth of data obtained guided the decision as to whether more participants were required (Polit & Beck 2008). The generalisability of the findings is applicable to other EDs in Australia because the participants were from across Australia. The findings were significantly fused with the views of the researcher, which established Gadamer's concepts of truth and the transferability of these findings to other EDs (Gadamer 1989).

Critics of Gadamer's phenomenology believe that all fore-knowing, bias, and prejudice must be suspended to prevent distortion within research findings (Polit & Beck, 2008). However, Gadamer believed that the researcher's fore-knowing was a critical hermeneutic inquiry tool (Gadamer 1975). The researcher's experiences of providing EOLC in the ED were openly brought into the discussion through the act of self-reflection. The critical act of awareness of one's own pre-conceived ideas ensured that the participants were not guided to communicate the researcher's expectations, but instead, it assisted the participants to describe their own individual experiences. The use of Gadamer's interpretive phenomenology allowed an approach of openness to interpret the experiences of EOLC provision by ED doctors and nurses (Gadamer 1975).

9.2 Research questions

This study has aimed to explore the experiences of ED doctors and nurses concerning death, dying, and the provision of EOLC. Four questions were addressed that were formulated to focus on the participants' perspectives. Answers to these questions have identified the components that can potentially lead to change in the EOLC practices of ED staff. According to Gadamer, through a constant willingness to engage in dialogue, new meanings and understandings can be achieved (Gadamer 1976; 2004). The findings of this study can open channels of dialogue to better effect change and create new meaning in the EOLC practices of doctors and nurses within the ED. This research has aimed to understand the experiences of ED doctors and nurses in relation to death, dying, and EOLC. With consideration to the constitutive pattern of 'The complexities of decision-making', four broad research questions were identified and answered using information obtained from this study. The questions and their answers are provided below.

9.2.1. What are the barriers and facilitators to providing quality end-of-life care within the Emergency Department according to doctors and nurses?

One of the barriers to providing quality EOLC was caused by the misconceptions held by the lay public and some ED staff that people who seek medical intervention in an ED are primarily seeking curative life-saving treatment. The mismatched expectations about treatment between dying patients and ED staff were barriers that often inhibited the decision-making process, and the provision of quality EOLC. Further barriers were apparent in the lack of prioritisation of EOLC for dying patients and their families in the ED. Patients who presented to the ED seeking EOLC were considered a low care priority. Emergency care and ED staff were directed towards more acute and critical situations. Once a patient's do not resuscitate order (DNR) had been agreed upon, both medical and nursing attention declined rapidly and, as a result, caused barriers to quality EOLC provision.

Barriers were also a result of high workloads, the fast-paced setting, and ED design, all of which inhibited the time and attention needed to provide EOLC and to make decisions that would benefit the patient and their family. Time constraints often lead to an inability to facilitate holistic EOLC for the dying patient and their family. ED staff did not have enough time to spend with both the patient and their family to develop a rapport, establish a relationship, and promote comfort (physical, emotional, mental, spiritual, and psychological comfort). The setting and design of most EDs did not allow for the privacy needs of the dying patient and their family, with most EDs having cubicles demarcated only with cotton curtains, resulting in information being able to be heard by people within close proximity. Another barrier to quality EOLC was the lack of ACP documentation and goals of care information at the point of EOLC, when and as required. It was rare for ED staff to have a complete care plan when the dying patient arrived in the ED. Incomplete information on the direction of care often lead to decisions and the provision of care that opposed the wishes of the patient.

Facilitators of quality EOLC were based around undertaking care for the dying patient in a timely manner, with the timely recognition that an individual was dying, so that decisions about the care plan according to the patient’s wishes were put in place as soon as possible. Timely referral to, and quick response time by the palliative care team were believed to facilitate quality EOLC. The participants believed that ED staff who did not recognise that a patient was dying might not develop care needs and decisions that would benefit the patient. ED staff reported that dying patients whose referral and admission processes were delayed, often spent more time in the unsuitable ED setting. However, once death and dying were recognised, and palliative care measures were started by ED staff without waiting for the palliative care personnel, this facilitated quality EOLC.

EOLC was facilitated when mentoring and guidance were provided to junior staff by the senior staff. Junior staff reported increased confidence levels and felt they were able to provide quality EOLC after watching a senior staff member provide care a number of times. Junior staff took note of the right behaviours, the right ways to have an EOLC conversation, and the questions they needed to ask, including how and when to refer patients to the palliative care team. Quality EOLC was facilitated by appointing a person who had an interest in death and dying, who acted as a champion in the department for any issues relating to dying patients and their families. As a result, ED staff were aware of who they needed to seek out for information if any education was needed. Overall, good communication by ED staff was noted as a facilitator of quality EOLC. ED staff who had effective communication skills were able to facilitate EOLC by discussing goals of care in such a way that the dying patient and their family were able to make an informed decision that enhanced EOLC.

9.2.2. What are emergency doctors' and nurses' educational and formal training needs for end-of-life care/palliative care skills?

Most of the ED staff stated that they did not have any formal training in EOL/ palliative care, and recognised that they were under-skilled in this area, but would want to learn both through coursework or by observing others with experience in EOLC provision. In particular, educational needs were identified in areas of how and when to have EOLC conversations. ED staff did not know what the content of an EOLC discussion should be and how it should be approached. Education was needed for the ability to recognise the right time to initiate an EOLC discussion with the patients and their families. ED staff believed the general population also needed education on EOLC conversations, because if the lay public were not included in education about having an early conversation pertaining to EOL/ palliative care, it would still be a challenging process. Normalising EOLC conversations within the lay public meant that when the patient and their family presented to the ED, they would already be aware, and so it would be less challenging to guide them through, as opposed to when there were no expectations, groundwork, or pre-thoughts about EOLC expectations.

For ED staff, education needs were requested for understanding and facilitating the specific palliative care needs of each patient. For example, nurses requested education on practical skills such as setting up syringe drivers and Grasby pumps, while doctors requested education on EOL/palliative medications and preparation for palliative care community transfers. Education was requested on knowing the available EOL/palliative care services and how to correctly make decisions to guide patients and their families who were seeking support and information to meet their specific care needs. Education was also requested on the essential end of life rites and rituals specific to particular cultural groups.

9.2.3 What is the role of palliative care in the Emergency Department and is it clearly defined?

The role of palliative care within the ED community is evolving, with a growing interest in creating palliative care as a specialty within ED. The increase in the number of patients seeking EOL/palliative care in ED has risen, and ED staff are expected to provide care needs. Over the past decade, ED staff are increasingly becoming dual qualified in both emergency and EOL/palliative care. More training is being provided by governing bodies for ED staff to access palliative care diplomas and training. Much interest has been expressed in having government bodies fund postgraduate training in palliative care.

Most EDs now see palliative care as an important part of their work with the awareness that there is a lack of EOL/palliative care skills and knowledge. In most EDs, palliative care teams have a presence in facilitating education needs and training for junior doctors. Some ED staff believe that palliative care in the ED is not ideal, as most people would not want to end their lives in such a setting. Nevertheless, as long as death, dying, and EOLC occur in the ED, the role of palliative care remains important. Due to the increasing role of palliative care in the ED, the future design of EDs has been suggested to include designated palliative ED beds along with dedicated specialty palliative ED staff to be allocated.

9.2.4. What are the attitudes, experiences, and beliefs among emergency care doctors and nurses regarding the provision of end-of-life care in the Emergency Department?

The attitudes, beliefs, and experiences of ED staff in relation to the provision of EOLC in the ED were informed by their own personal opinions or through their general belief system. Personal opinions were those that individual ED staff valued as an important aspect of EOLC. For example, some ED staff valued respect and dignity as being important for EOLC, while others valued various elements such as quality of life, avoidance of futile treatment, and the non-medicalisation of death and dying by facilitating the natural process of dying, rather than preventing death. Other general beliefs about death and dying were centred on atheistic views, a belief in an after-life, and a belief that death is inevitable. These views and beliefs often served as a coping mechanism when the role of EOLC provision caused feelings of emotional burden for nursing and medical staff. Generally, ED staff experiences of death, dying, and EOLC were believed to be challenging because of the difficulties in facilitating EOLC and the associated decision-making in the ED setting. The ED is characterised by a high workload and a fast-paced setting that inhibits the time and attention needed to provide high quality EOLC. Experiences of EOLC were difficult because ED staff were not trained to provide EOLC, and ED medical treatments were aimed at the prolongation of life and avoidance of death. However, death and the dying process still occur in the ED, so the traditional life-saving role often contradicts the goals of EOLC.

9.3 New knowledge and its impact

In this study, the findings showed a difference in the perception of doctors and nurses in the definition of what they believed to be the important aspects of their roles. The nurses believed that the effective communication of the prognosis and plans was the crucial role of the doctors. However, the doctors believed that working out the goals of care for the patient was more important. Differences in perceptions of the important aspects of the roles can have an impact on the focus of a collaborative team approach to care. The differences must be reconciled, so that a collaborative approach that benefits the patients and their families can be fostered.

The findings also showed differences in the understandings of what the relinquishing of care was believed to be. Nurses reported that doctors often relinquished the care of the dying as soon as the patients DNR/ comfort care orders were established. However, most of the doctors believed they were not relinquishing the care of the dying patient, but expected the nurses to approach them for any concerns that required a doctor, despite many of the doctors believing that nurses were needed more in end-of-life care.

In this study, many of the participants believed that ACP was not useful in determining care that would benefit the patient at the end of life. Suggestions were provided to utilise the GOPC documents, as these were made at the point of care when it was needed. The GOPC documents were reported as being relevant for the patient’s current situation. ACP were believed to be useful in starting conversations around EOLC but did not provide information for a current prognosis.

The findings revealed that EOLC provision was easier for doctors and nurses when caring for patients and their families who had similar beliefs and values to them. On the other hand, the provision of EOLC was believed to be difficult when providing care that went against the doctors’ and nurses’ own beliefs, values, and ethical and moral standing. The participants reported that their own beliefs and values also weighed into the decision-making process at the end of life. The participants would advocate if they believed that the decisions made were not in the best interests of the patient, but they would also consider their own ethical and moral beliefs in relation to the issue.

From the findings, there are significant advances in the area of the integration of EOL/ palliative care into ED work. The participants reported that EOL/palliative care in the ED is now increasingly part of ED work. Over the past decade, there has been a surge in the number of ED doctors with dual qualifications in palliative care. Conferences on EOLC which are specifically tailored for ED staff are increasingly being organised, and ED governing bodies are now including EOLC scenarios within their exams. Overall, EOL/palliative care is now believed to be part of ‘ED business’.

9.4 Implications for medical practice

The Australasian College for Emergency Medicine (ACEM) is the governing body that provides training for emergency physicians. ACEM has recently recognised EOLC as an important aspect of ED work by including components of EOLC in their examinations. However, an EOL/ palliative care training program is needed for ED doctors. The training program may assist ED doctors to be more confident in the areas of discussions about EOLC, decision-making, management of symptoms, medication prescriptions, and community discharge planning. EOL/ palliative care education programs have been shown to improve EOL knowledge and skills (Bradley et al., 2002).

The findings in this study showed that the working conditions of ED doctors are poor and include expectations to be quick with patient assessment, diagnosis, and discharge plans, but having discrete protected times for ED physicians to provide EOLC would motivate them to be more thorough with their EOLC. Similarly, the provision of incentives for GPs to have EOLC discussions is needed. Rewarding GPs financially for EOLC discussions before presentation to an ED would increase the number of patients who had some introduction to EOLC discussions. This would benefit ED physicians in terms of reducing the workload of the ED physician, and enabling them to focus on other aspects of EOLC.

The need to increase collaboration between ED physicians and admitting palliative care teams would be beneficial. There is the potential for better collaboration, especially in referral waiting times by having quicker response times once referred. The definition of urgent referral for ED doctors are very different from that of the palliative care specialist where patients would often stay in the ED for longer periods of times waiting for admissions (Smith et al., 2010). Most of the doctors in this study recognised that palliative care teams are often under-resourced and lack funding. The lack of resources in palliative care means that a specialist may not be available to review a patient when urgently needed. It is important that ED doctors are trained in EOLC and palliative care. ED doctors who are palliative care-trained can potentially admit patients on behalf of palliative care, and then move them to the wards once the beds are ready. Improved communication, a stream-lined referral process, and collaboration through an interdisciplinary approach to care will help to facilitate patient care for quicker transfers out of the ED to a suitable environment and reduce the workload of ED physicians.

9.5 Implications for nursing practice

In-depth incorporation of EOLC into nursing education is critically needed, as many of the nurses in this study described having inadequate formal education within the nursing curricula. ED nurses should be encouraged to undertake diplomas and courses in EOL/ palliative care as a minimum due to the increased demand for EOL/palliative care skills in the ED. Currently, many of the junior nurses have learnt appropriate ways of providing EOLC by watching senior nurse's role model the right behaviours. Hence, it is important that senior nurses provide a supportive and nurturing environment for EOLC learning, whether death is expected or unexpected, to manage the experience of emotional burden.

Nurses carry most of the emotional role in EOLC and would therefore benefit from having an environment in which they have the emotional support they need, access to regular debriefing, and positive departmental morale. These can significantly lessen the emotional burden carried by nurses. Bereavement support for nurses has been shown to increase ED staff members' ability to cope with death and dying, and prevent emotional fatigue and burnout (Keene et al., 2010; Cooper et al., 2019). Having a designated ED palliative care nurse specialist with marked ability to ensure that nurses know where they can find EOLC information would allow improved access to palliative care education and resources.

Nurses play a critical role in EOLC provision because they spend more time with the patients (Keene et al., 2010). It is important that nurses are part of the decision-making process. The inclusion of nurses in decision-making would be beneficial, because they may be privy to information that other members of the healthcare team are not, although junior nurses may not feel confident to seek participation in the process, but it is crucial that a culture of inclusion is created so that nurses can contribute to the care of the patient. The evidence has shown that patient outcomes were better when a collaborative approach to EOLC was employed (Hayes 2012). Strategies to improve collaboration should include joint EOLC education training and programs for both doctors and nurses to improve collaboration and communication.

9.6 Implications for the ED system and governing bodies

The NEAT target to ensure that 85 per cent of patients have a less than four-hour ED stay is a tight target and seemed to be unrealistic (Dobb 2010; Sullivan et al., 2016). It has been well established that EOLC is time-intensive, and meeting the four-hour target is not always feasible (Stokes 2011). Admitting beds are not always readily available for patients needing EOLC. A need for review of the four-hour rule policy is warranted to accommodate EOL/palliative patients who need more time outside of the four hours. Currently, ED staff feel culturally responsible for meeting the four-hour target as KPIs for funding are prioritised over patient care. The policy must take into consideration the roles that need to be played by bed managers, ward staff, and the medical and surgical admitting doctors to ensure that all parties carry out their roles within the four-hour limit to improve care outcomes.

EOL/palliative care patients are still spending longer periods of time in the ED due to bed shortages and ward staff who are often not ready for the patients. Having an ‘in-between’ short stay ward or dedicated bed spaces within ED for EOL/palliative care patients while they are waiting for a bed space on the ward would benefit the patient and alleviate the pressure to move them out of the ED. The current systems and policies were also barriers to quality EOLC. Bureaucratic and systemic expectations that focus on tasks that are measurable and meet KPIs often have an impact on EOLC (Sullivan et al., 2016). Often, EOLC tasks are not measurable; for example, having an EOLC conversation cannot be measured, and spending quality time with the patients and their families cannot be quantified. However, all these tasks are crucial and not necessarily recorded within the KPIs. Recognition is needed for these tasks as part of the expectation of ED work, so that ED staff can spend the time needed to provide quality care for the patients and their families. Providing systems that can measure the quality of care provided in terms of emotional support, decision-making support, and quality time with patients and their families’ needs to be built into the system of care.

9.7 Implications for future research

This research has raised questions that need further investigation. Research is needed to explore the decision-making processes of ED staff when providing EOLC. This research would provide knowledge on the tools that can assist ED staff on how best to come to a decision that benefits the patient and their family. In addition, further research is required to establish the benefits of the goals of care made at the point of care, as opposed to long-term advance care directives. The research on the benefits of the goals of care made at the point of care should be carried out to address the challenges associated with EOLC decisions that do not add value to the care of the patient.

Future research should focus on determining the experiences of ED staff in regard to their roles in EOLC. Similarities and differences were evident between ED doctors and nurses in the expectations placed on each other's roles. It is important that a qualitative methodology be used to examine these differences, so that ED staff can become more aware of their own underlying assumptions. The knowledge of these assumptions will allow the roles to be redefined and will ensure that ED staff are aware of expectations, and work to create a stronger collaborative approach to EOLC for patients and their families.

9.8 Study limitations

The findings of this study should be interpreted in light of a number of possible limitations. The first lies within the characteristics of the sample. There was an over-representation of senior ED doctors, and from the findings it was clear that the experiences of senior doctors were different from those of junior doctors. Although many of the senior doctors did discuss the experiences of the junior doctors, the findings would have been more representative of the junior doctors if they had been equally able to provide their own first-hand accounts. Therefore, the differences in experiences might not allow the results to be generalised to other junior doctors. More research focusing specifically on the experiences of junior ED staff is warranted.

Another limitation concerns the use of Gadamer's methodology. The quality of data obtained in qualitative research is highly subjective. In particular, Gadamer (2004) recommended the interpretation of data through an awareness of one's own previous fore-knowing. This component may be considered as a limitation in other research paradigms. In addition, the small sample size of qualitative research may inhibit generalisability, but the findings of this study are applicable and transferable to other ED settings and the field of study.

A potential limitation lies within the recruitment method. The self-selection of participants could have meant that participants who have previous interest in the field of EOLC might be part of the study. Therefore, findings could be influenced because participants might provide answers that they believe would benefit the research study. But the interpretation process of the data using Gadamer's creation of understanding and meaning along with Gadamer's hermeneutic circle eliminates the potential for bias that self-selection of participants could have caused (Gadamer 1975). Both of these Gadamer's concepts emphasises that when the experiences shared by an individual resonates with the other, then a new construction of meaning based on truth is generated. In this study, the constructs of the participants resonated with each other and with that of the researcher.

9.9 Study strengths

The strengths of the study include the use of a hermeneutic design of data analysis steps that fit with Gadamer's hermeneutic approach. The in-depth seven step analysis (Diekelmann et al., 1989) ensured that the goal of Gadamer's hermeneutics was achieved as the understanding of meanings that were embedded within the participants' responses. Diekelmann et al's (1989) seven step analysis provided continuous examination of the whole and the parts of the text, with constant referral back to the text (Gadamer 1975). This provided rich interpretations that were grounded and focused on the experiences of EOLC provision by ED staff.

A key strength of this present study was that the sample was nationally representative of ED staff across Australia, including staff in rural, private, and public ED settings. Therefore, the findings can be transferred and generalised across Australian ED settings. Another of the strengths of the study was the validation of the interpretations of the participants' experiences by the research supervisors. This allowed inconsistencies to be exposed so that the final themes were accurate interpretations of the participants' experiences.

9.10 Constitutive Pattern discussion – 'The complexities of decision-making'

This study has offered significant insight into understanding the experiences of ED doctors and nurses who provided EOLC in an ED. The findings established the constitutive pattern (CP) of 'The complexities of decision-making' in the ED. The identified CP was an overarching pattern that cut across and related back to all the findings. From the findings, the first theme of 'providing for respect and dignity' showed that ED staff were prepared to navigate the complexities involved in providing a respectful death experience by coming to a collaborative decision to provide the best outcome for the patients and their families. The second theme also tied in well to the complexities of decision-making when ethical dilemmas were experienced due to the difficulties in balancing treatment options. The participants' ethical decision-making was influenced by their personal values and beliefs. EOLC and decisions about treatment were believed to be challenging due to the differences in beliefs between the participants and the patients.

The two major remaining themes about EOLC roles in the ED, as well as experience of conflict, both demonstrated that decision-making was complex. In regard to the roles of the participants, the differences reported in the perceptions of roles and the relinquishing of care often lead to significant complexities in decision-making. There was often a lack of understanding of the prognosis, and this resulted in a lack of acceptance or denial of the imminence of death by patients and their family members. Consequently, this would cause conflict and disagreements that deepened the complexities in making decisions that benefited the patient and their families. Goals of patient care (GOPC) assessments lead by ED staff can prevent conflict caused by long-term ACP decisions, because GOPC decisions are made at the point of care and are often relevant to the patient's current prognosis.

Finally, the integration of EOLC and palliative care into ED work is gaining momentum, especially in Australia. In particular, this study has demonstrated that doctors and nurses are increasingly required to provide EOLC, palliative care, and to make decisions despite the complexities reported. The environmental barriers, time constraints, the relinquishing of care, and the segregation of the dying in the ED all contribute to the complexities reported in making decisions at the end of life. Also, the differences in the perceptions of roles between doctors and nurses needs to be reconciled. A reconciliation of these differences will lessen the complexities encountered within the decision-making process regarding EOLC provision and improving collaborative decision-making. Once, decision-making concerning care is more collaborative, quality EOLC will be provided to patients and their families.

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Appendix 1: Summary table of studies included in literature review

Author, Date, and Location	Aim/Objective	Sample and Setting	Methods and Methodology/ Design	Instruments	Major Findings	Limitations and Rigour/Validity
Beckstrand et al., 2012 USA	To explore rural emergency nurses' perceptions of end-of-life care obstacles	N=236 nurses 52 rural hospitals	A cross-sectional survey research design	A 57-item palliative care questionnaire	Rural emergency nurses live and work on the frontier. Top obstacles in providing EOLC reported were issues with family, ED environment, and concerns about patient's wishes	A convenience sample. Other health professionals might have completed surveys. However, good response rate
Grudzen et al., 2012 USA	To explore attitudes and beliefs among emergency care providers regarding the provision of palliative care services in the ED	N=20 emergency physicians	Thematic analysis using grounded theory	Three semi-structured focus groups	Physicians acknowledged the benefits of palliative care in the ED. Culture of emergency medicine was sometimes at odds with the culture of palliative care	Results are not generalisable. Findings were not triangulated
Le Conte et al., 2010 France	To describe the characteristics of patients who die in emergency department and the decision to withhold life support	N=2,420 patients 174 EDs	A 4-month prospective cross-sectional survey	Standardized case report form	Death in ED mainly occurred in elderly patients with multiple chronic diseases. Palliative care training is needed for ED clinicians	No report of how reliability and validity of the tool used for data collection was obtained
DeVader et al., 2012 USA	To discuss important concepts in PC and ED physicians using an illustrative case	N=1 case study	Case study	Four questions to guide the case study	Patient desires differ from reality of care. Palliative care is underutilised. Significant cost to the healthcare system	Results of study cannot be generalised
Shearer et al., 2014 Australia	To investigate Australian ED staff perspectives and needs regarding palliative care provision	N=22 doctors N=44 nurses	Descriptive statistics and content analysis	Qualitative interviews and quantitative survey	Lower levels of palliative care confidence were found in nurses compared to doctors	Limited generalisability

Author, Date, and Location	Aim/Objective	Sample and Setting	Methods and Methodology/Design	Instruments	Major Findings	Limitations and Rigour/Validity
Lamba et al., 2012 USA	To characterise emergency physicians' perceived educational and formal training needs for palliative care-related skills	N=42	Descriptive statistics	Survey rating their formal training and knowledge of palliative care	Most respondents agreed that palliative care skills are important for emergency physicians. More training needed on pain management, management of hospice patient, and withdrawal of treatment	Findings not generalisable. The reliability and validity of tool used is unknown
Bradley et al., 2013 Australia	To determine current knowledge and attitudes to the provision of palliative care in Australasian EDs	N=35	Simple statistics	Survey	Poor access to palliative specialist teams on site. Inadequate training in palliative care. Need for integration of palliative care into EDs	Small sample size. Low response rate. Validity of survey was not reported
DeVader & Jeanmonod 2012 USA	To determine effects of education in hospice and palliative care on emergency medicine residents' knowledge and referral patterns	N=21	Prospective cohort study Descriptive statistics Grounded theory	A survey (quantitative and qualitative questions)	Education improved knowledge of hospice qualifying diagnoses. Education improved their comfort level in discussing end-of-life care with patients and families	Validity and reliability of survey was not reported. Small sample size
Smith et al., 2010 USA	To better understand the experiences of acutely symptomatic patients seen in ED	N=14 patients N=7 family members	Grounded theory to code responses	Semi-structured interviews	Patients and families felt unprepared to manage symptoms at home, uncertainty and anxiety, communication is essential, conflicting perspectives about purpose of palliative care	Small sample size. Sample selection bias. Ungeneralisable results
Jelinek et al., 2013 Australia	To identify what was important to PC and oncology staff in the management of patients with advanced cancer who present to ED	N=11	Exploratory qualitative study	Focus groups	ED staff found themselves 'caught in the middle' and significantly experienced difficulty due to environmental and resources disadvantages	Results non-generalisable to other settings
Glajchen et al., 2011 USA	To improve referral for palliative care needs among frail elderly in the ED	N=1,587 participants	Descriptive statistics	A newly developed triage tool	Elderly ED patients had unmet needs and the project expedited the referral rate to palliative ad hospice care	No discussion of the validity of the tool used in screening

Author, Date, and Location	Aim/Objective	Sample and Setting	Methods and Methodology/Design	Instruments	Major Findings	Limitations and Rigour/Validity
Bailey et al., 2011 UK	To explore how emergency nurses manage the emotional impact of death and dying in emergency work and presents a model for developing expertise in end-of-life care delivery	N=28 emergency staff, patients with terminal illness and their relatives	Ethnography	Unstructured observation of practice and semi-structured interviews	Investment of the therapeutic self in the nurse-patient relationship, management of emotional labour, development of emotional intelligence	
Strote et al 2011 USA	To explore both the effects of patient death on academic emergency physician (EP) and the coping mechanisms they use to deal with these events	N=145 EPs	Descriptive analysis	Survey	No training or coping mechanism, personal coping techniques	Low response rate
Heaston et al., 2006 USA	To determine the perceived obstacles and supportive behaviours in providing EOL care to dying patients in ED	N=169 emergency nurses	Descriptive statistics	A 73-item questionnaire	Emergency nurses have a great workload to care for dying patients. Emergency nurses have to deal with angry family members, the poor design of EDs that do not allow for privacy. Supportive behaviours were good communication, private place to grieve, ED physician meeting families after patient's death	Limited generalisability
Detering et al., 2010 Australia	To investigate the impact of advance care planning on end-of-life care in elderly patients	N=309 legally competent medical in-patients	Randomised control trial	Participants randomised to receive usual care or usual care plus ACP	Advance care planning improves end-of-life care and patient and family satisfaction. It reduces stress, anxiety, and depression in surviving relatives	A single centre study. Exclusion of non-English speaking background patients
Detering et al., 2014 Australia	To develop and evaluate an interactive ACP educational programme for GPs and doctors in training	N=148 doctors in a rural setting	Pre/post-test design	Training and intervention materials	The change in self-reported confidence to undertake ACP conversations	Biased sample

Author, Date and Location	Aim/Objective	Sample and Setting	Methods and Methodology/Design	Instruments	Major Findings	Limitations and Rigour/Validity
Seal 2007 Australia	To explain the role of patient advocacy in the Advance Care Planning process	N=81 nurses in an acute care public hospital	Non-randomised controlled trial	Likert Scale survey administered pre- and six months post-intervention to pilot, control, and focus group	Nurses experienced encouragement to ensure patients could make informed choices about their end-of-life treatment, the ability to uphold these wishes in practice and job satisfaction from delivering appropriate end-of-life care	Non-generalisable findings
Fulbrook et al., 2005 Europe	What are the experiences and attitudes of European critical care nurses to the presence of family members during CPR of an adult relative? What are the differences in nurses' attitudes to family presence with respect to: (a) decisions about resuscitation, (b) processes of resuscitation, and (c) outcomes of resuscitation?	N=130 emergency UK & European nurses	Descriptive statistics, parametric and non-parametric tests analysis using SPSS	Survey questionnaire	Generally, nurses supported the presence of family members, although UK nurses held significantly more positive attitudes than their non-UK counterparts in the areas of decision-making, processes, and outcomes of resuscitation	Unrepresentative sample Sample bias Questionnaire validity
Seow et al., 2014 Canada	To determine the pooled effect of exposure to one of 11 specialist palliative care teams providing services in patients' homes	N=3,109 patients	Retrospective cohort study	3,109 patients with care from specialist palliative care teams 3,109 patients who received usual care	Community-based specialist palliative care teams, despite variation in team composition and geographies, were effective at reducing acute care use and hospital deaths at the end of life	Majority of patients had cancer, therefore limited generalisability to patients with other diagnoses
Marck et al., 2014 Australia	To assess the barriers and enablers regarding end-of-life care for cancer patients, as perceived by Australian ED clinicians	N=4,501 ED clinicians	Descriptive analysis	Survey	Most clinicians felt comfortable providing care to the dying and found it rewarding	Low response rate

Appendix 2: Summary of Diekelmann’s seven stage analysis

Stage 1: An overall understanding of all the interviews

Doctors		Nurses
1. Respect patient wishes *(AC)*	**Patient and Family - centred end of life care.**	1. Dignity & Respect (*Abebs)*
2. Death is not to be prolonged *(Ahik)*		2. Christian Beliefs, Respect *(Abigail)*
3. Emotional and Clinical care *(CCL)*		3.Dignity & Respect, Celebrate life *(Callj)*
4. ACP conversations *(Nnea)*		4. Black and White, Natural, Respect *(Chu)*
5. End of life care conversations *(Samantha)*		5.Inevitable, Natural, Christian Beliefs *(Eve)*
6. Respecting patient wishes *(Turtle)*		6.Respect patient and family wishes *(Hu)*
7. Emotional and clinical support *(Samantha)*		7.Respect for patient and family *(ZZ)*
		8.Patient advocacy *(Robert)*
		9. Compassion and care *(Teresa)*

Stage 2: Section and Categories

Examples of Categories

Truth-Telling, End of life discussions, Comfort Care, Cultural Awareness

All-Important Final hour, Goals of Care, Inevitable, Confronting, Experiences

Advocacy, Go the Respect, Dignity, Family, Good Death, Bad Death,

Family Care, Available, Dying Phases, Acceptance, Faith, Christian Beliefs,

Mentorship and Guidance, Normal, Euthanasia, Impact of beliefs & views,

Quality of Life, Emotional Burden, Boundaries, Time Pressures,

Relinquishing of care, communication, Conflicting Roles,

Coping Mechanism, Taboo Topic, Conflict, Traumatic Deaths, Self-Blame

Stage 2 Extended: Excerpts from the text to support each category

Written interpretation of a Category	***Excerpt supporting the category***
1. A guideline but still need to assess each patient (Nurse)	*And the advance care directive itself is a useful guideline to help us when we are doubt or we do not know which direction to look to that's why I think it's a good tool but always I feel that assess the patient on a case to case basis and that's is where we should always fall back to before we proceed (Nurse Chu p. 3, L 33-36)*
2. Its extremely rare that it actually guides me as to what I should do (Doctor)	*so it can help me to start a discussion its extremely rare that it actually guides me as to what I should do so if the patient is moribund and I can't get in touch with family I have left voice mails and no one is picking up then it can help me a little bit to guide my decision about treatment limitations whilst am waiting for the family to get back to me (Dr Turtle p. 5, L 40-43.*

Stage 3 and 4: An example of what occurred in stage 3

Initial interpretation of excerpt below was categorised as Bad ***Death***

> *"And, for me personally, I guess the sadness you feel for a family who's not a Christian is a lot deeper because you know that their separation is forever, as compared to a family who is a Christian" (Abigail P 5-6 L 35-45, 1-6)*

Interpretation now changed to ***Feelings of Sadness*** after further analysis with the team (Research Supervisors)

Stage 4: Similar themes were grouped together so that a link between multiple themes can be generated

Similar themes grouped together	***Excerpt supporting the themes***
ACP still has its place, Still needs reassessment of ACP on each admission, Tricky for Family Pressure on Family Different opinions between family When there is no ACP Ensure ACP done for patient in GERRI & GEN MED ACP are important and useful **(Doctors)**	*Yes, definitely. I think that if there's not an advanced care directive that's been made, it can be very tricky for family. And I mean, I sympathise with them in the sense that, you know, sometimes you panic at that situation and you're, like (indistinct) et cetera. So it is hard. It's a lot of pressure on a family to really know and decide as a collective, because there is often differing opinions between family members about what's best for the patient (Dr AC PP 6-7 L 43-45, 1-4).*
	people who have got terminal diseases that are well established metastatic cancer end stage pulmonary lung disease, end stage heart disease ***who either have never had a conversation*** *about it or there is documented discussion of what people want and or the family have no idea what that means or they are having chemotherapy,* ***"they are not dying" or "he was fine yesterday I spoke to her on the phone"*** *and lack of understanding which makes preparing people for the fact that you are not goanna intubate this person bigger than they are never goanna wake up they are goanna be dying soon and what that means Dr Nnea p 4 L 15-22*
2. ACP HELPFUL ACP done timely Have something set in place FIRST THING WE LOOK FOR USEFUL ATIMES ACP often unavailable Takes time Time consuming **(Nurses)**	**I think everyone should have a right to decide what to do if they have ever find themselves position**. So, I think it's a really good way to know the level of treatment that someone wants (indistinct) someone wants, and that decision is up to them. **I don't think we should be making that decision for them.** I think the patient should be able to make that decision by themselves, and I think that most people are quite sensible (Nurse Abebs p. 13, L 18-33)
	so I think there's a very big place for advance care planning, and not just advance care planning but **for it to be done in a timely manner** (Nurse Abigail p. 25, L41-42).

At the end of this stage, an overarching relational theme of 'Experiences of providing EOLC in ED' was generated.

Stage 5: Common meanings and shared practices were identified (nurses).

The initial Constitutive Pattern of **'Conflicted Roles'** was identified

1.) Respect and Dignity
- Adhering to patient's wishes
- ED death can still be dignified
- Respectful and dignified for families

2.) Emotional Burden
- D & D is confronting
- Emotions in unexpected death
- Unexpectedly –expected
- Death on arrival

3.) Experiences & inexperience
- Effects of inexperience
- Lack of knowledge and education
- Incorporation of palliative care into ED medicine
- Access to resources

4.) Personal Beliefs, culture and values
- Christian Beliefs
- Scientific view, Biological view
- Natural view
- Black and white
- Others
- Effects on caring

5.) Grief
- Personal grief experiences
- Grieving experience by HCP
- Grieving with gratitude
- Coping strategies

6.) Role of nurses
- Clinical-emotional
- Patient and family care
- UG is no suffering
- Empathy, compassion
- Available present
- General
- Professional boundaries

7.) Role of doctors
- Collaborative role
- Inadequate knowledge and skills
- General
- Treating relinquished care

8.) Peculiar ED issues
- High workload
- Lack of privacy
- Environmental factors
- ED; a bad place for death
- Time constraints
- Relinquishing care-communication

9.) Ethical, legal and moral obligations
- Euthanasia
- Futility with flexibility
- Quality of life
- Neglect and priority
- Nurses caught in the middle
- Moral dilemmas

10.) Conflicts & Disagreement
- Reasons
- Resolution
- Mistrust
- Unacceptance/acceptance

11.) ACP
- Helpful/unhelpful
- Preparedness for death
- Treating R.C

12.) Management systemic issues
- Types of ED patient-Intro
- All death is positive
- Things you can't control
- Improvements/recommendation

13.) Fears
- Associated with death and dying? influence
- Attitude
- Positive and negative frequency

The initial Constitutive Pattern of Conflicted roles

Nurses

Stage 5: Common meanings and shared practices were identified (doctors)

1.) Respect and dignity
- Adhering to patient's wishes
- Dignified deterioration
- Systemic, cultural, spiritual care

2.) Emotional burden
- Emotionally challenging
- Achieving Quality, good/bad death
- Personal experiences
- Grief
- Feelings (guilt, regret, sad, blame)

3.) Education needs
- Experience, exposure, inexperience, education
- Access to pall care resources
- D/C planning
- Referral process

4.) Beliefs, values, biases
- Religion
- Dying is a process
- Rites and rituals

5.) Role of nurses
- General
- Comfort
- Final hour, family
- Knowledge of prognosis by family

6.) Role of doctors
- Family and patient care
- Relinquishing of care
- High workload as a senior
- EOLC is intensive
- Collaborative approach and opposite
- How to make a good decision

7.) ED setting
- Despite setting, still can provide good death
- Not the right place
- Disjointed care
- Time constraints
- How dying patient are treated in ED
- How to treat dying
- Staffing issues
- ICU/ED
- Lucky/unlucky

8.) Peculiar ED issues
- High workload
- Lack of privacy
- Environmental factors
- ED; a bad place for death
- Time constraints
- Relinquishing care-communication

8.) Ethical/moral issues
- Good quality of life
- Futility is context dependent
- Euthanasia
- ACP
- Traumatic deaths
- Management/systemic issues

9.) Conflicts
- Reasons
- Consequences
- Resolving
- Role conflict
- Forced to provide treatment
- Acceptance/unacceptance
- Family power

10.) Good communication
- Early, open, honest
- Avoiding EOLC discussions
- Initiating role
- Integration
- Integration, where are we?

11.) Miscellaneous
- Types of ED patient
- Site specific culture
- Frequency of positive and negative
- Recommendation

The initial Constitutive Pattern of Conflicted roles

Doctors

Stage 6: Relationships among themes emerge (Doctors and nurses themes combined together for similarities and differences). An initial overarching theme of conflicted roles was generated.

1.) Respect & dignity

- Adhering to patient’s wishes
- Dignified deterioration
- Respectful and dignified for families
- Respect culture, traditions, religion, values

2.) Emotional burden

- Emotions associated with unexpected/expected death
- Grief
- Emotions associated with personal experiences

3.) Experiences, in-experiences, education

- Experiences, exposure, education
- Lack of knowledge and education
- Access to palliative care services

4.) Beliefs, culture, values

- Christian beliefs
- Scientific view, biological view
- Natural
- Others
- Effects on caring

5.) Role of nurses

- Clinical-emotional
- Comfort
- Patient and family care
- Available and present
- Professional boundary

6.) Role of doctors

- Family and patient care
- Collaborative approach
- General

7.) ED setting

- Not the right place-environment, time, disjointed care, privacy, high workload
- Relinquishing care
- Lucky/unlucky

8.) Ethical, legal, moral obligation

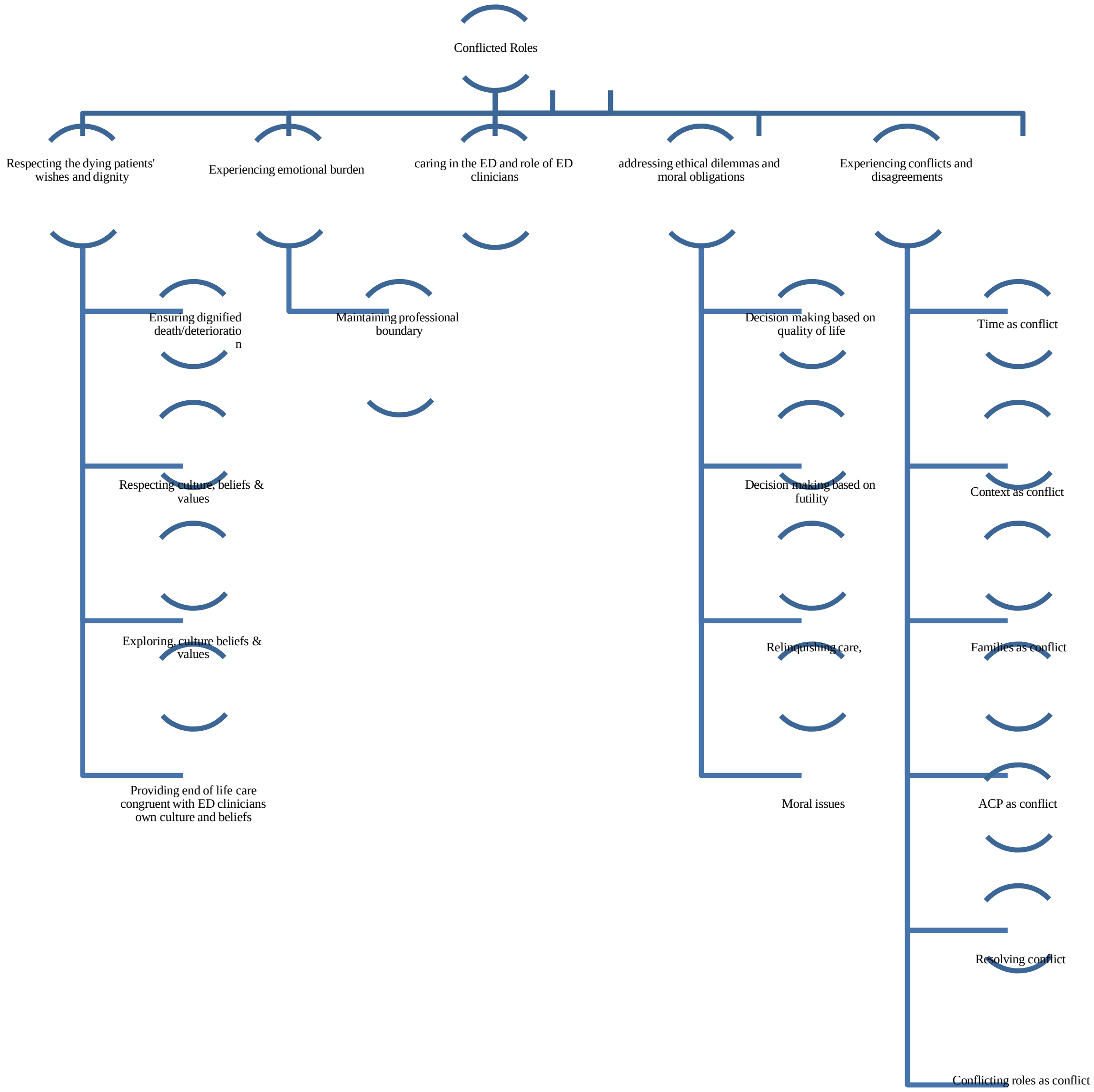
- QOL
- Futility
- Euthanasia
- ACP
- Management
- Neglect and priority
- Relinquishing care

9.) Conflicts and disagreements

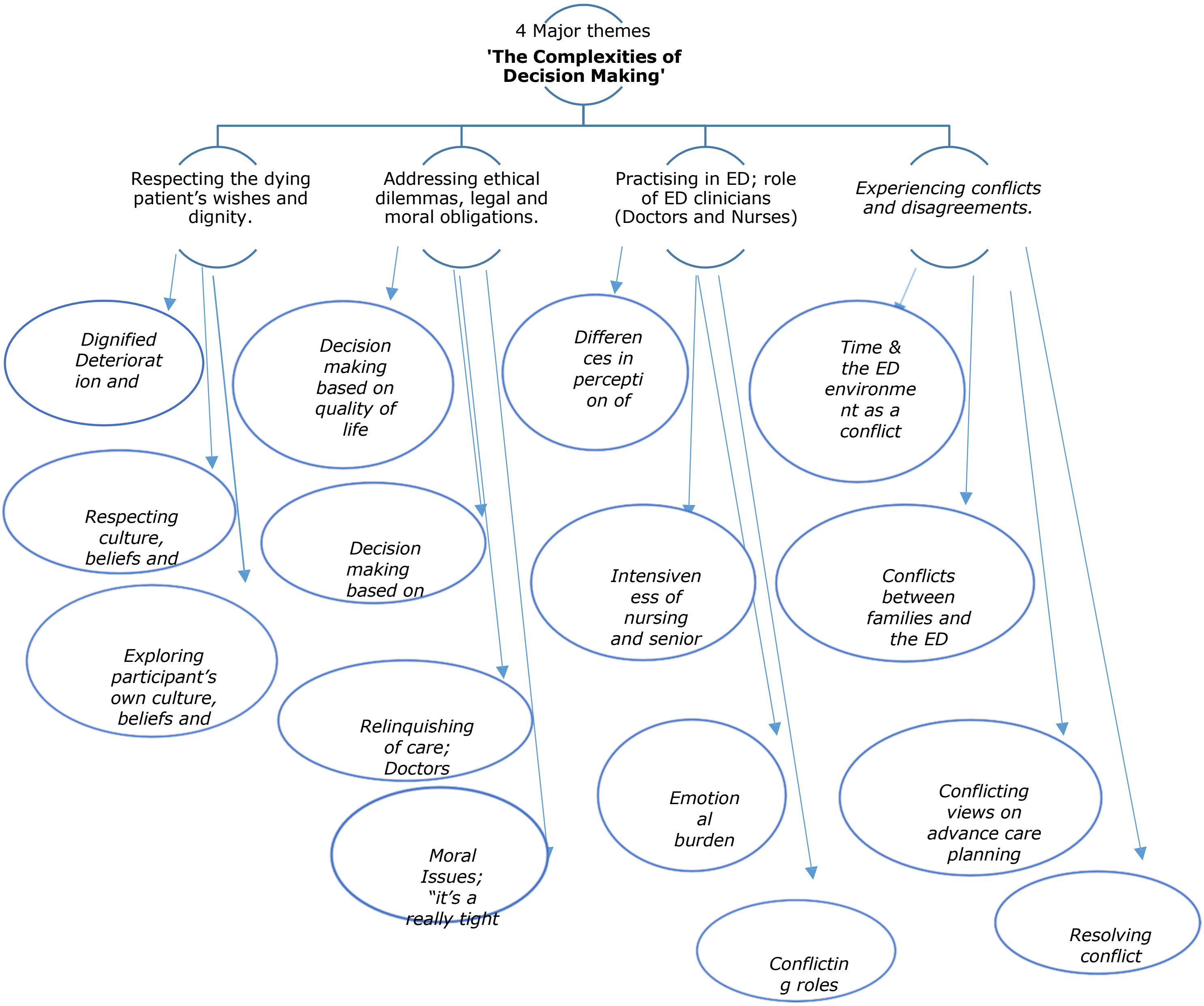
- Reasons
- Resolution
- Consequences
- Role of conflict
- Forced to provide treatment
- Acceptance/unacceptance

Doctors and nurses themes combined together for similarities and differences

Stage 7a: Draft of themes and sub-themes



Stage 7b: A final overarching constitutive pattern of 'The Complexities of Decision Making' that cuts across all the identified major themes and its subthemes was identified.



Appendix 3: 7909 SBREC Final Approval Notice

Dear Oluwatomilayo,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.:	**7909**
Project Title:	Death, dying and end-of-life care provision by doctors and nurses in the emergency department - a phenomenological study
Principal Researcher:	Miss Oluwatomilayo Adesina
Email:	ades0009@flinders.edu.au

Approval Date:	5 April 2018	Ethics Approval Expiry Date:	**31 December 2021**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment(s):

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number:7909'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

Kind regards

Andrea

Ms Andrea Mather (formerly Fiegert) **and Ms Rae Tyler**
Ethics Officers and Executive Officers, Social and Behavioural
Research Ethics Committee

Ms Andrea Mather | Monday - Friday	T: +61 8201-3116 | E: human.researchethics@flinders.edu.au

Ms Rae Tyler | Monday, Wednesday and Friday mornings	T: +61 8201-7938 | E: human.researchethics@flinders.edu.au
A/Prof David Hunter | SBREC Chairperson	T: +61 7221-8477 | E: david.hunter@flinders.edu.au
Dr Deb Agnew | SBREC Deputy Chairperson	T: +61 8201-3456 E: deb.agnew@flinders.edu.au
SBREC Website	Social and Behavioural Research Ethics Committee (SBREC)

Research Development and Support |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

CRICOS Registered Provider: The Flinders University of South Australia | CRICOS Provider Number 00114A

Appendix 4: ACEM Ethics Approval

AUSTRALASIAN COLLEGE FOR EMERGENCY MEDICINE

34 Jeffcott Street, West Melbourne Victoria 3003, Australia
ABN 76 009 090 715
Tel 61 3 9320 0444
Fax 61 3 9320 0400
Web www.acem.org.au
Email admin@acem.org.au

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02 May 2018

Oluwatomilayo Adesina
College of Nursing and
Health Sciences Flinders
University

By email: ades0009@flinders.edu.au

Dear Oluwatomilayo ('Tomi')

Re: Application for research access to the ACEM membership

I am writing in response to your application to advertise – to the ACEM membership – participation in a study entitled *Death, dying and end-of-life care provision by doctors and nurses in the emergency department - a phenomenological study*

Thank you for supplying the documentation required by ACEM to assess your request against our Standard Operating Procedure. I am pleased to report that, following review by the ACEM Scientific Committee, the request has been **approved**.

In these circumstances 'access to membership' is defined as placing an advertisement and link in the ACEM Bulletin, which is emailed to the membership on a weekly basis.

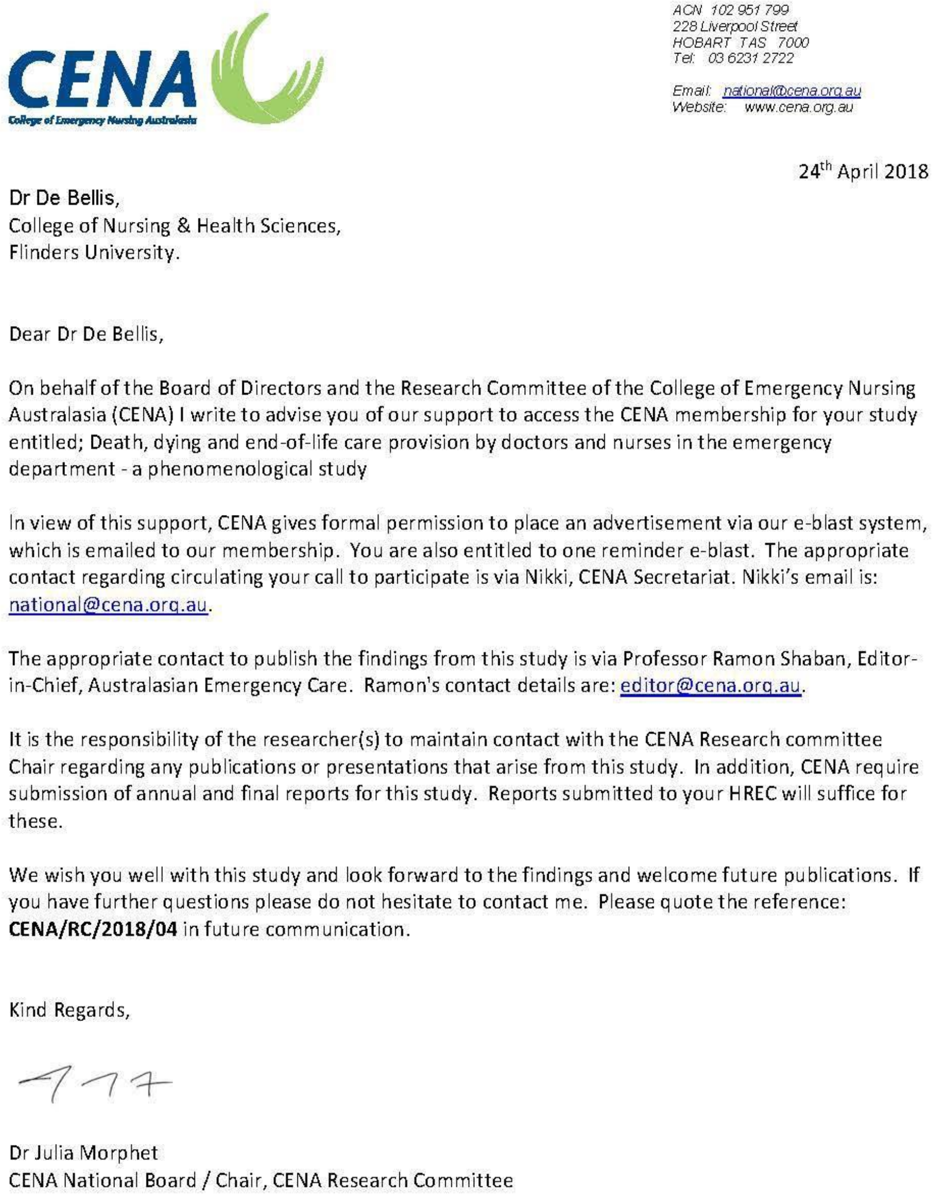
If you require any further information, please do not hesitate to contact ACEM Policy and Research Administrator Richard Whittome on (03) 8679 8810 or richard.whittome@acem.org.au.

Yours sincerely

Dr Yusuf Nagree

Chair, Scientific Committee
Australasian College for Emergency Medicine

Appendix 5: CENA Ethics Approval



CENA
College of Emergency Nursing Australasia

ACN 102 951 799
228 Liverpool Street
HOBART TAS 7000
Tel: 03 6231 2722

Email: national@cena.org.au
Website: www.cena.org.au

24th April 2018

Dr De Bellis,
College of Nursing & Health Sciences,
Flinders University.

Dear Dr De Bellis,

On behalf of the Board of Directors and the Research Committee of the College of Emergency Nursing Australasia (CENA) I write to advise you of our support to access the CENA membership for your study entitled; Death, dying and end-of-life care provision by doctors and nurses in the emergency department - a phenomenological study

In view of this support, CENA gives formal permission to place an advertisement via our e-blast system, which is emailed to our membership. You are also entitled to one reminder e-blast. The appropriate contact regarding circulating your call to participate is via Nikki, CENA Secretariat. Nikki's email is: national@cena.org.au.

The appropriate contact to publish the findings from this study is via Professor Ramon Shaban, Editor-in-Chief, Australasian Emergency Care. Ramon's contact details are: editor@cena.org.au.

It is the responsibility of the researcher(s) to maintain contact with the CENA Research committee Chair regarding any publications or presentations that arise from this study. In addition, CENA require submission of annual and final reports for this study. Reports submitted to your HREC will suffice for these.

We wish you well with this study and look forward to the findings and welcome future publications. If you have further questions please do not hesitate to contact me. Please quote the reference: **CENA/RC/2018/04** in future communication.

Kind Regards,

Dr Julia Morphet
CENA National Board / Chair, CENA Research Committee

Appendix 6: Open ended Interview questions

Interview Questions

Death, dying and end of life care provision by doctors and nurses in the emergency department – a phenomenological study.

Section 1: Demographic Questions

1.1 What is your age? _______________

1.2 Are you male or female?
☐ Male ☐ Female

1.3 Are you a doctor or nurse?
☐ Doctor ☐ Nurse ☐ Please specify level e.g. Intern, Registered/ Enrolled nurse_________

1.4 What is your highest education level?
☐ University graduate ☐ Graduate diploma ☐ Master's degree ☐ Doctoral degree
☐ Professional degree (MD, JD, etc.
☐ Other_________________________

1.5 How many years have you worked in the emergency department? ________________

1.6 Do you undertake any other roles within the emergency department?
☐ Team leader ☐ Shift Co-ordinator ☐ Triage Nurse ☐ Resuscitation Roles ☐ None
☐ All the above ☐ Other; please specify_____________

1.7 Have you undertaken any specific additional study/ educational programs on palliative care, end of life care or death and dying? ☐ No ☐ Yes

If Yes, please describe the additional educational program you have undertaken, the level, content, and length:

Section 2

Interview Questions

Can you please describe your own values and beliefs about death and dying – your personal perspective?

Can you please begin by describing what it is like to care for someone who is dying within the ED?

What in your opinion is the role of doctors and nurses in ED concerning death and dying?

Can you describe what care you are able to provide to people who are dying, and their relatives?

Can you describe any negative experiences of caring for a dying patient or their relatives in an emergency department?

Can you describe any positive experiences of caring for a dying patient in an emergency department?

What ethical issues have arisen for you when caring for a person who is dying and relatives in ED?

What are the barriers to providing end of life care for people who are dying and their relatives in ED?

What facilitates good end of life care for people who are dying as well as their relatives in ED?

What do you believe can be improved concerning the care of dying patients and their relatives?

Can you give me your views on the futility of treatment and decisions about withdrawing treatment or active treatment when a person is dying or elderly?

Additional prompting questions as appropriate.

Appendix 7: 4 major themes and 14 subthemes