

Registered Nurses' Experiences of End-Of life Care in the Acute Care Setting in Singapore

by

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List of Abbreviations

ACP Advance care planning

AMD Advance medical directive

EOL End-of-life

ICA Immigration & Checkpoints Authority

MOH Ministry of Health

PQOL Professional quality of life

RN Registered nurse

SBREC Social and Behavioural Research Ethics Committee

UK United Kingdom

WHO World Health Organization

Glossary of Terms

MediSave

A national medical savings scheme that helps individuals set aside part of their income to pay for their personal or approved dependents' hospitalisation, day surgery and certain outpatient expenses as well as their healthcare needs in old age.

MediFund

An endowment fund established by the government that provides a safety net for patients who face financial difficulties in settling remaining bills after receiving government subsidies and drawing on other means of payment, including MediShield Life, MediSave and cash.

MediShield

A basic medical insurance plan that helps cover large hospital bills and selected outpatient treatments.

ElderShield

A severe disability insurance scheme that provides basic financial protection to those who need long-term care, especially in old age. In the event of severe disability, ElderShield policyholders will receive a monthly cash payout for a period of time, depending on the plan.

Filial piety

Filial piety (in Confucianism) is the important virtue and primary duty of respect, obedience and care for one's parents and elderly family members.

Taboo

Anything that is prohibited, disallowed or forbidden. The word 'taboo' is used in the context of death and dying.

Abstract

Background: With its rapidly ageing population, Singapore's approach to end-of-life (EOL) care is evolving. However, the provision of high-quality EOL care must be explored in the context of a multicultural society. With changes taking place in the health sector, it is an opportune time to explore the perceptions and experiences of nurses regarding EOL care and what it entails. Identification of the characteristics of effective nursing care for dying patients, especially in the acute care setting, is essential. Nurses working in acute care settings are responsible for caring for both acutely ill medical patients receiving curative treatments as well as patients who need EOL care. Little data are available on this increasing trend in the Singapore healthcare system. Therefore, it is essential to investigate the lived experiences of acute care nurses caring for dying patients.

Aim: The primary aim of this study is to explore the everyday care practices and experiences of Registered Nurses when caring for dying patients in an acute care setting in Singapore.

Methodology: This research study took a hermeneutic phenomenology approach guided by the philosophy of Hans-Georg Gadamer, whose concepts include belonging to tradition, situation, text, true questions, dialogue and fusion of horizons. A purposive sample of 16 Registered Nurses from acute medical, surgical, oncology, haematology and intensive care units participated in this study. Data were collected over a period of six months using 45-minute semi-structured interviews. A data analysis method developed by Fleming, Gaidys and Robb was applied to gain an understanding of the data through the lens of Gadamer's philosophy.

Findings: Analysis of the 16 interviews resulted in the emergence of four overarching themes: (1) experiencing emotional labour, with supporting subthemes of helplessness, dealing with unanticipated or sudden deaths, feeling sad, feeling guilty and inadequate support at work; (2) barriers to providing optimal EOL care, with supporting subthemes of knowledge of symptom control, misconceptions of palliative care, conflicts of interest among healthcare professionals, switching roles and staffing constraints; (3) transforming and understanding EOL care, with supporting subthemes of building connections, providing support to patient and families and fulfilling wishes; and (4) ways of managing care

effectively, with supporting subthemes of open communication, working as a team, palliative team support, addressing training needs and personal coping.

Conclusion: This study provided an in-depth understanding of the everyday care practices and experiences of nurse participants caring for dying patients in the context of the multicultural Singaporean society. This study also highlights the tenets of Gadamer, who promoted the exploration of knowledge from a range of vantage points. Adversities associated with caring for dying patients meant that nurse participants developed resilience, which contributed to their professional and personal growth. The findings have significant implications for EOL nursing education, nursing practice, health policy and future research on EOL care in acute care settings in Singapore. These recommendations provide a strategic focus for how to improve EOL care practices along the care continuum.

Declaration

I certify that this thesis:

- 1. does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and
- 2. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

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| Signed: | | | |

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Preface

I developed an interest in caring for the dying after practising in an oncology/haematology ward for three years. I have personally cared for dying patients and acknowledge that 'being in the world' of nursing practice has led to my experiential connections with my fellow nursing colleagues and dying patients. In Singapore, death is not acknowledged as openly as it is in Western cultures, and disclosures of diagnosis and prognosis may be regarded as detrimental to patients. My personal encounters with the deaths of my father and, more recently, my sister, who died in an acute care setting, propelled me to further investigate and understand the phenomenon of caring for dying patients. The less than optimal care of my sister caused me great anguish. I witnessed the bluntness of the attending doctor when disclosing my sister's prognosis to her—she passed away the following night. In some way I blamed the entire team and the system, dwelling on it for many years. Engulfed by my unprocessed grief, I wished to find some closure.

I have entered the 'life world' in which there are relationships with nurses and patients of different languages, genders, social classes, races and ethnicities. I understand that my perceptions of caring for the dying may be different from those of other nurses working within the same framework. As I drafted this thesis, I began to see the phenomenon from different vantage points, completely transforming my vision. I am aware that an absolute understanding can never be realised. However, I hope that this study will show nurses who care for dying patients that their horizons can be widened. In this way, I hope to contribute to nursing knowledge. My reading of Gadamer's texts was often from his English-translated texts, which was challenging for me; therefore, I do not know how much was lost in translation. However, other philosophical texts, including those from Koch (1996), Geanellos (2000) and V. Fleming, Gaidys and Robb (2003) have enhanced my understanding, and I will represent Gadamer's thoughts as clearly as possible. In this thesis, several key concepts, including belonging to tradition, situation, true questions, dialogue, fusion of horizons and application, have been intertwined.

Chapter 1: Introduction

1.1 Overview of the Study

The first chapter of this thesis introduces the study and provides an overview of the thesis. This thesis presents a study on the Registered Nurses (RNs') experiences of End- of- life care (EOL) care underpinned by the work of the German philosopher, Hans-Georg Gadamer (1976, 2004). Gadamer (2006) asserted that human understanding is possible, and that all events must be interpreted in light of their own unique cultural and historical backgrounds. He was interested in how understanding was made possible. He believed that humans are connected through language and culture that influenced the understanding. Gadamer (2006) emphasised the importance of language, promoting the use of the hermeneutic method for interpretation and it is unique to each individual processing. Gadamer's hermeneutic method was used to underpin this study because it helped to broaden my lens of understanding. I also recognise that readers may have different interpretations of the experiences of Registered Nurses (RNs) in end-of-life (EOL) care in acute care settings. Chapter 1 introduces the context of this study and provides a short synopsis of each chapter.

1.2 Context of the Study: Health Structure in Singapore

Singapore is a multicultural society with a resident population of 5.6 million people, comprising 3.99 million citizens and permanent residents and 1.64 million non-residents. The majority (74.1%) of the population is Chinese, while Malaysians and Indians make up 13.4% and 9.2%, respectively (Department of Statistics Singapore, 2018). Singapore has an ageing population—CNA (2018) has reported that, by 2019, Singapore would be an aged society, defined as 14% or more of the population aged 65 years or above. By 2030, one in four Singaporeans will be over the age of 65 (Department of Statistics Singapore, 2018). The general state of health in Singapore is excellent and comparable with international standards. High education levels, excellent housing, safe water and sanitation, high-quality medical services and the active promotion of preventive medicine have significantly boosted the health of Singaporeans. The leading causes of morbidity and mortality are cancer, coronary heart disease, stroke, pneumonia, diabetes, hypertension and injury. In 2017, cancer,

ischaemic heart disease and pneumonia accounted for approximately 78.3% of all causes of mortality. Of the total deaths, 31% were related to cancer (Ministry of Health [MOH], 2017).

Reports by E. Davies and Higginson (2004) and the House of Commons Health Committee (2004) have shown that the number of deaths at home is decreasing, while the number of deaths in hospitals is increasing. Despite many patients preferring to die at home, death frequently takes place in acute hospital settings (Beng et al., 2009). The total number of deaths in 2017 was 20,904, with 63.1% occurring in hospitals (60.2% in public hospitals and 2.9% in private hospitals), 24.1% in private residences, 6.2% in nursing homes and charitable institutions, 4.3% in sick receiving houses and 2.3% in other locations (Immigration and Checkpoints Authority Singapore, 2017). CNA (2016) estimates that 65% of patients at the end stages of life need palliative care, and 70% of patients wish to receive EOL care at home. The number of patients needing palliative care annually, either at hospitals or in the home, is predicted to double from 5,000 to 6,000 in 2013 to more than 10,000 in 2020 (MOH, 2017).

In its 2000 analysis of the world's health systems, the World Health Organization (WHO) (2000) ranked Singapore sixth globally. Since 2004, the Joint Commission International has accredited 13 hospitals and medical facilities in Singapore. Singapore's healthcare infrastructure consists of both public and private healthcare facilities that offer high-quality medical care. Citizens and permanent residents are entitled to subsidised government healthcare services through a compulsory national savings scheme known as the Central Provident Fund to which employees, depending on age and income, contribute a proportion of their monthly salary. Central to this healthcare financing plan is the '3M' system, a medical insurance scheme that pays for the majority of the population's healthcare needs. 3M comprises MediSave (a compulsory savings scheme initiated in 1984), MediShield (a lowcost basic medical insurance scheme initiated in 1990) and MediFund (an endowment fund to help needy Singaporeans initiated in 1993). In addition, ElderShield is a severe disability insurance scheme that provides basic financial protection for those who need long-term care. Singapore's healthcare philosophy advocates personal responsibility for health expenses. Foreigners are exempt from making Central Provident Fund contributions but may buy private insurance (Sullings, 2019).

Ten public hospitals, six community hospitals and 20 polyclinics are located throughout the island. Primary healthcare services such as outpatient medical care, health screening, dental

care and pharmacy services are subsidised by the government. Polyclinics provide only 20% of the primary healthcare services, while private medical practitioners provide 80% (MOH, 2018a). The government heavily subsidises 75% of public hospitals providing acute care services. Community hospitals, day rehabilitation centres and home services provide intermediate care, while nursing homes, shelter homes, hospices, day care services and home services provide long-term care. The ageing population, compounded by low fertility rates, the changing notion of filial piety and debilitating chronic conditions, has led to an increase in the number of frail seniors in nursing homes. Thirteen private hospitals, the majority of which have been accredited by the Joint Commission International, provide an excellent level of medical and nursing services. Public and private healthcare services differ in cost. The majority of non-Singaporeans prefer to access private healthcare services because the waiting times for consultations are shorter. There are numerous private clinics located across the island offering outpatient services (MOH, 2018b). The following section discusses End of Life (EOL) care provisions in Singapore.

1.3 End-of-Life Care in Singapore

EOL care refers to the support provided for people who are approaching death (National Health Service, 2015). Most Singaporeans live in tight-knit families, which tend to avoid conversations about EOL care. Typically, major decisions related to the medical aspects of care are made by families, but conversations relating to death and dying are less forthcoming (Lien Foundation, 2014). EOL care practices in Singapore are relatively new—even physicians grapple with this evolving concept and are attempting to improve their conversations with patients and families. EOL care conversations are stressful for both caregivers and physicians, and it can be challenging to meet the cultural expectations of patients and families (Ang, Zhang, & Lim, 2016).

The 2010 Quality of Death Index placed Singapore to attention, leading to a serious reexamination of the quality of EOL care at the national level. The Quality of Death Index, produced by The Economist Intelligence Unit (2015) and commissioned by the Lien Foundation, ranked Singapore eighteenth out of more than 40 countries. Since the 2010 Quality of Death Index, the Singapore government has placed more focus on and allocated more resources to palliative care, and the coordination of care has improved. The MOH commissioned the development of the National Strategy for Palliative Care, which was implemented in 2012. Given that it takes time to optimise systems through continual improvements, EOL care is an evolving phenomenon. Awareness about palliative care and palliative care services has slowly grown to meet the demands of the ageing population. Although the transition to and transformation of EOL care services has been initiated, EOL care in Singapore continued to be inadequate. Singapore has started to adopt some key strategies from countries that have established national policies to promote improvements in EOL care. Despite the changes, a national framework on EOL care in Singapore is absent and continued to pose considerable challenges for health care professionals to cope with death and dying.

Subsequently, in the 2015 Quality of Death Index, among the eight Asian countries, Singapore emerged second after Taiwan, which was in the top place for the region (The Economist Intelligence Unit, 2015). The index, which measures current EOL care services across 40 countries, draws from four broad categories—the basic healthcare environment and the availability, cost and quality of EOL care. Singapore was ranked sixth and eighth, respectively, in affordability of care and quality of care. Britain was ranked the highest worldwide, followed by Australia and New Zealand. These countries fared well because they all have national strategic plans for EOL care in healthcare and medical education policies. India was ranked the lowest of all countries.

A report by the Lien Foundation (2015) highlighted that since the implementation of the National Strategy for Palliative Care, financial constraints have been alleviated and patients have unlimited access to MediSave. In the area of human resources, training and education in palliative care have been introduced for healthcare professionals. The report also highlighted the need for doctors and nurses to be better equipped with basic palliative care knowledge. To date, there are 57 registered palliative care specialists (Singapore Medical Council, 2017), 34 of whom are practising full-time. Fifteen doctors are currently receiving training in the sub speciality of palliative care medicine (Singapore Medical Council, 2017). There are seven advanced practice nurses specialising in palliative care and 784 RNs trained in palliative care (Singapore Nursing Board, 2017). At the end of 2017, there were 41,440 nurses in Singapore (Singapore Nursing Board, 2017), 26% of whom were foreigners, mostly from Philippines, India, Myanmar and China (Singapore Nursing Board, 2017). Foreign nurses may face cultural challenges when caring for the dying. The review of the literature

will highlight some of these challenges. The following section discusses the development of palliative care in Singapore.

1.4 Development of Palliative Care in Singapore

For rapidly ageing populations such as that found in Singapore, there are many challenges, obstacles and issues with respect to palliative care. One such challenge is the cultural taboo associated with death and dying. Conversations related to death and dying can be difficult. The hospice movement gained momentum in the United Kingdom (UK) during the 1960s. Older people in the UK are aware of hospice care and the types of services offered to them (Catt et al., 2005). Forty-five per cent of people between the ages of 55 and 75 have visited a hospice and understand that a hospice is for the care of the dying. In contrast, hospice care in Singapore began in 1985 when St Joseph's Home opened 16 beds for terminally ill patients (Goh & Shaw, 1994). The Singapore Hospice Council was registered in 1995 and has since grown from five to eight members serving patients in different zones. Despite its evolution, hospice awareness in Singapore is still lacking. A telephone survey of 2,880 Singaporeans between the ages of 15 and 65 years revealed that only 35% had heard of hospice or palliative care (Hum, Tan, Goh, & Ju, 2005). A 2014 survey conducted by the Lien Foundation reported that only 44% of doctors and 59% of nurses who had frequent contact with terminally ill patients in Singapore were familiar with hospice palliative care. Although there was an increase in awareness, approximately 50% of doctors and nurses were unfamiliar with hospices. The report on Lien Foundation survey 2014, also highlighted the need for doctors and nurses to be better equipped with basic palliative care knowledge (Ramchandani, 2015). However, both surveys have provided an impetus to channel more efforts towards education in creating awareness and receptivity among Singaporeans and healthcare professionals with regard to hospice and palliative care.

The Singapore Hospice Council supports the engagement of more doctors in the field of hospice and palliative care. In 2006, palliative medicine was approved as a medical sub speciality. Palliative medicine is included in the educational curriculum for all family physicians. The Singapore government is also expanding the pool of nurses trained in palliative care through the Health Manpower Development Programme, a pioneer program implemented in 2006 that funds nurses to obtain an advanced diploma in palliative care. The

National Cancer Centre Singapore also collaborates with Flinders University in Australia, which offers certificates in palliative care to south-east Asian healthcare professionals.

To meet the demands for expertise in palliative care for Singapore's ageing population, the Singapore government aims to increase inpatient beds to 360 by 2020 (Today Online, 2017). The number of inpatient hospice beds grew from 137 beds in 2011 to just 147 in 2014, implying that by 2020, twice the current workforce and expertise will be needed (Lien Foundation, 2015). It has been estimated that the number of patients needing palliative care in hospitals and homes will double from 5,000–6,000 per year in 2013 to more than 10,000 per year in 2020. Currently, there are four inpatient hospices, eight home care services, two-day care services and four hospitals with palliative care teams (MOH, 2018a, b). While growth has been significant, it has been slow to dispel the discomfort of nurses dealing with death and dying.

The increased focus on palliative care has, to a certain extent, addressed these concerns. For the past two years, the development of advance care planning (ACP) has been the subject of debate in Singapore (Ng, 2009). ACP has gained maturity in countries such as the United States, the UK, Canada and Australia. In the UK, ACP has been identified as an essential element in the EOL care strategy of the National Health Service England's (2015) gold standard framework. The *End of Life Care Strategy* (Department of Health, 2008) and the Liverpool Care Pathway (Ellershaw & Wilkinson, 2003) have been put in place to address patient needs. However, in Singapore, ACP is not widely practised. Currently, EOL care is managed using an advance medical directive (AMD), a legally binding document signed by two people in advance that indicates whether one wishes to have extraordinary life-sustaining treatment in the event of terminal illness or mental incapacitation (Law Society of Singapore, 2017). Since the introduction of legislation in 1996, approximately 15,000 Singaporeans have signed AMDs.

There are many barriers and boundaries to understanding death and dying in south-east Asian cultures, and conversations about death are still taboo in Singapore. The next section presents the aims of study, which have guided the research questions and methodology.

1.5 Aims of the Study

The primary aim of this study is to understand the EOL care practices and experiences of general practice RNs working in acute care hospitals in Singapore and how they are affected by caring for the dying. The following section presents the research question used to gain an understanding of the experiences of general practice nurses in acute hospitals in Singapore.

1.6 Research Question

The research question aims to obtain an understanding of the EOL care practices and experiences of general practice nurses in acute care hospitals. This study was designed to answer the following research question:

What are the everyday experiences of general practice RNs caring for the dying in an acute care hospital in Singapore?

1.7 Significance of the Study

EOL care is a complex, individual and highly demanding practice in which clinical attention must be paid not only to the physical needs of patients but also to their psychosocial and spiritual needs. General practice nurses must primarily assess the vulnerabilities and discomfort of dying patients. There is a dearth of qualitative studies on nurses' EOL care practices and experiences in the context of Singapore acute care. Studies on the experiences of acute care nurses have mostly been published in journals from Western and many southeast Asian countries. Some studies have been conducted on nurses trained in palliative care and oncology in Singapore, but few have been conducted in the acute hospital setting. More studies are needed to understand the experiences of general practice nurses in caring for the dying.

Since 2010, the development of and training in palliative care has increased. However, given the paucity of studies in the local and acute care context, there is an increased need to understand the EOL care practices and experiences of general practice RNs in acute care hospitals. Moreover, most nurses will be involved in EOL care at some point in their careers, regardless of their speciality, level of exposure or training. Physicians often manage EOL issues, but nurses are the important team players. Challenges faced by nurses when providing

EOL care such as time and communication constraints are commonly recognised. To understand these challenges, general practice nurses at acute hospitals are the primary target of investigation.

Given that it affects all healthcare professionals who deal with death and dying, it is essential to shed more light on EOL care. Most nurses do not feel adequately prepared by their training to care for dying patients. To effectively prepare nurses to care for dying patients, education should be incorporated into undergraduate and postgraduate courses and professional development at healthcare institutions. Caring for the dying patient may elicit emotions such as stress, anxiety, sadness and fear. Nurses' attitudes towards death and dying may affect the nursing care they provide. Nurses are present at both the beginning and the end of life and play a key role in caring for dying patients. Compared with other healthcare professionals, nurses spend more time with the dying. RNs play a pivotal role because they are the first focal point of contact with the dying.

With a rapidly ageing population, designing an optimal healthcare system that balances quality, accessibility and cost is challenging. The demands of the ageing population keep evolving and it is time that the Singapore government looks beyond the roles of doctors and nurses to the needs of families and communities. The lessons that can be learned are best evaluated by exploring the experiences and practices of RNs in EOL care. The sociocultural rituals practised by dying patients and their families often involve RNs; thus, it is appropriate to understand and evaluate the challenges and barriers to EOL care from the perspectives of nurses. This caring for the dying will provide succinct insights and may motivate healthcare administrators and professionals to review current EOL practices in acute care settings. RNs may be the drivers of future healthcare and nursing policies, nursing practices and nursing education of EOL care practices. Nurses can reveal what is needed to improve EOL care practices in Singapore. How RNs can provide a meaningful dignified EOL journey for patients and their families is pivotal. This research will aid in the understanding of how EOL care practices can be improved in an evolving demographic landscape such as in Singapore. This study will contribute to the current body of nursing knowledge on EOL care practices and resources in acute care hospitals.

1.8 Organisation of the Thesis

This thesis comprises nine chapters. Chapter 1 introduces the research, which is underpinned by the work of the German philosopher Hans-Georg Gadamer (1976, 2004). It introduces the topic by describing the healthcare structure, challenges presented by the ageing population, EOL care provisions and the growth of palliative care in Singapore. It also presents the aim, research question and significance of the study.

Chapter 2 reviews and critically appraises the literature related to nurses' experiences of EOL care in acute care hospitals using critical appraisal checklists from the Joanna Briggs Institute. The review of studies on nurses' experiences on EOL care are evaluated, synthesised, summarised, and categorised under various themes. The review found different challenges nurses experienced when caring for dying patients. The important themes that emerged from the reviews were lack of education and knowledge; disclosure and truth telling; lack of time; cultural and physical barriers in the health care setting; communication barriers; symptom management; and nurses' personal challenges in the care of dying.

Chapter 3 discusses the theoretical framework of Hans-Georg Gadamer (1976, 2004, 2006), whose philosophical underpinnings guided this study. It also provides an overview of the differences between phenomenology and hermeneutic phenomenology, the various philosophies of other hermeneutic philosophers and the rationale for adopting Hans-Georg Gadamer's hermeneutic philosophy to address the research question. The methodological approach was also based on the gaps identified in the review of the literature.

Chapter 4 details the research methods. It describes the method of data collection and recruitment of the target population. Because Gadamer did not provide a method of data analysis, V. Fleming, Gaidys and Robb's (2003) method, which upholds the tenets of Gadamer's philosophy, was employed to analyse the data. Chapter 4 also discusses the researcher's reflexivity, ethical considerations and how rigour and quality were maintained throughout this study.

Chapter 5 (Part 1) reports on the findings of Themes 1 and 2 in which the complex and diverse challenges of nurses are elaborated. Theme 1, 'experiencing emotional labour', is supported by five subthemes: helplessness, dealing with unanticipated or sudden deaths, feeling sad, feeling guilty and inadequate support at work. Theme 2, 'barriers to providing optimum

palliative care', also has five subthemes: knowledge of symptom control, misconceptions about palliative care, conflicts of interest among healthcare professionals, switching between multiple roles and staffing constraints. These findings are supported by examples of participant testimonies.

Chapter 6 (Part 2) provides the findings on Themes 3 and 4, 'understanding EOL care', which is supported by three subthemes—building connections, providing support to patients and families (which include spiritual support, alleviating physical sufferings & symptoms, and offering meaningful support) and fulfilling wishes. It highlights the participants' deeper care approaches to patients and their families. Theme 4, 'ways of managing care effectively'. Supporting subthemes include open communication (enhancers & barriers), working as a team, palliative care team support (providing comfort care & providing emotional support for families and patients), addressing training needs and personal coping. These findings contribute to the understanding and development of the nurses' intentions in caring for the dying in acute care hospitals.

Chapter 7 discusses the key findings of the study in the cultural context of Singapore. They are (1) the moral distress of nurses and its impact on caring for dying patients, include managing disclosures, communication challenges and cultural differences on death and dying; (2) the culture of acute care, includes the role of nurses and their challenges; (3) organisational barriers, (4) transforming care, include development of personal and professional growth, providing spiritual care and personal coping; and (5) the fusion of horizons. It also addresses how the researcher's understanding fused with that of the study participants to demonstrate the development of a new understanding—transforming care through resilience that led to personal and professional growth. The findings are discussed with reference to the literature and theory on nurses' experiences in caring for the dying.

Chapter 8 addresses the conclusion of this study. The key implications for education, practice policy, and recommendations for future research is addressed. The study limitations, strengths and researcher's personal reflections included.

In summary, this chapter presented the thesis underpinned by the philosophical tenets of Hans-Georg Gadamer. This chapter has provided an overview on the context of study, EOL care, and development of palliative care in Singapore, aims of the study, research question, significance of the study, and the organisation of this thesis. Chapter 2 focuses on the literature related to nurses caring for dying patients from both Western and Eastern studies and its significance in the Singaporean context.

Chapter 2: Literature Review

2.1 Introduction

This chapter provides a coherent review of RNs' experiences of providing EOL care in the acute hospital setting. This study adopted Gadamer's hermeneutic philosophy. Gadamer (2006) asserted that understanding cannot take place without reference to a person's historical, cultural, ethnic and socio-political background. According to Burns & Grove (2009), it is necessary to review, evaluate what is known, and unknown in the area of research interest. The literature on EOL care is vast, and studies originating from both the West and the East are included in this review. However, the literature on EOL care in Singapore is scarce, and is limited because of the country's specific cultural and healthcare context. The quality and rigour of the literature were assessed using quantitative and qualitative critical appraisal checklists from the Joanna Briggs Institute (2011). The research question underpinning this review was: What are the everyday experiences of general practice RNs caring for the dying in an acute care hospital in Singapore? The next section elaborates on the search strategy and specific inclusion and exclusion criteria.

2.2 Search Strategy

The following databases and search engines were used to access published and grey literature: Cumulative Index to Nursing and Allied Health Literature, MEDLINE, Science Direct, Blackwell Synergy, British Nursing Index, Web of Knowledge and Google Scholar. This was augmented by a hand search of current journals and books. Additionally, colleagues and librarians were notified, and past conference papers and theses were obtained.

Despite the dearth of literature pertaining to EOL care in Singapore, themes pertinent to the region were found in related papers. The review included published reports and literature reviews from the previous 11 years. To enhance the precision of the search and to focus on the topic of interest, inclusion and exclusion criteria were established to retrieve primary research data. The inclusion criteria for studies were as follows:

Primary studies on EOL care for adults aged 18 years and over

- Studies focusing on the experiences of EOL care of general nurses with no qualifications in oncology or palliative care (although studies on nurses working in palliative care and oncology wards were included)
- Studies in the context of the acute care setting
- Studies in the context of east-Asia
- Qualitative, quantitative or mixed-method designs
- Published in English

Studies excluded from the review were those that were not:

- Primary research
- Peer reviewed
- Ethically approved

The following key words and phrases were used: 'nurses' attitudes on death and dying', 'nurses' experiences of death and dying', 'perceptions of nurses on the care of the dying', 'end-of-life care', 'death and dying', 'dying well', 'comfort care', 'palliative care', 'attitudes towards death', 'terminal care', 'location of death', 'advance care planning and hospital nurses' experiences on EOL care' and 'good death and bad death'. The period was limited to 2009–2018 to ensure that included studies were relevant and up to date. Papers from 2003–2008 were also considered to evaluate the evolution of the literature and how EOL care has evolved. Cross-referencing and searching for other relevant articles pertaining to nurses' experiences of EOL care in acute care hospitals were also conducted. Some review articles included older studies to comprehend the chronology of events, development of concepts and the social processes that have taken place to understand the concept of death and dying.

Using the key words and phrases only, the database search retrieved a total of 6,598 articles. This number was narrowed down by applying the following filters: 'date', 'research article', 'peer reviewed', 'references available', 'subject major', 'academic journal' and 'English language'. For example, when searching for relevant articles on nurses' experiences caring for the dying in acute care hospitals, the filters 'subject major' (i.e. terminal care, nurses attitudes, caring for dying), 'full text', 'English language' and 'academic journals' were applied, reducing the number of articles from 1,534 to 85. These were further screened according to their titles, abstracts and inclusion and exclusion criteria. Following removal of

duplicates, a total of 41 papers remained, eight of which were quantitative studies, 32 qualitative studies and one a mixed-method study (see Figure 2.1). The studies originated from Australia (4), Canada (3), China (2), Hong Kong (1), Iran (2), Ireland (2), Italy (1), Japan (1), Nigeria (1), New Zealand (1), Spain (2), Sweden (4), Thailand (1), UK (5), United States (9) and Singapore (2). The literature review articles are summarised in table form (see Appendices 1 and 2).

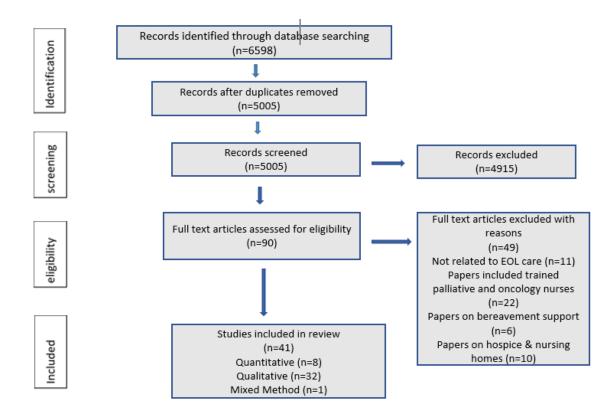


Figure 2.1: Database search for relevant articles (PRISMA-adapted from Robertson-Malt, 2014)

2.3 Quality Appraisal of Relevant Articles

The literature was systematically evaluated using critical appraisal checklists from the Joanna Briggs Institute. To ensure methodological validity prior to inclusion in the review, the Meta-Analysis of Statistics Assessment and Review Instrument was used to appraise quantitative cohort, case control and observational studies, while the Qualitative Assessment and Review Instrument was used for qualitative studies (Joanna Briggs Institute, 2011) (see Appendices 3 and 4). Quantitative studies were evaluated for their research methodologies, including sampling, design, measurement tools and appropriateness of statistical analysis. The research

design used in the quantitative studies were; cross -sectional survey (n=5), descriptive survey (n=2) and mixed method (n=1). Qualitative studies were evaluated for congruency between paradigm, methodology and method, the influence of the researcher on the research, data collection and data analysis. In total, qualitative papers that adopted descriptive exploratory designs were; (n=14), phenomenology (n=10), Gadamerian philosophy (n=1), Heideggerian philosophy (n=1), ethnography (n=2), grounded theory (n=5). Using the relevant appraisal checklist, each paper was assessed in terms of its focus, whether it had used a qualitative or quantitative paradigm, its data collection methods, its location and its sample size (see Appendix 2). In general, all included literature were of good methodological quality and had similar aims and objectives. The reviewed studies were all conducted in acute hospitals from different care settings. The majority of the reviewed studies were from the western perspective. Although there were some studies from the east Asian perspective, there were limited studies from the Singaporean multi-cultural context. This gap highlighted that there was a further need to understand the care practices of RNs' in the Singaporean context of acute hospital on EOL care. Following this appraisal, papers were synthesised and categorised under the common descriptive themes that surfaced from the findings of each study. Examples of the appraised papers can be found in Appendices 3 and 4. The analytical themes generated from the review of the various studies are discussed under the following headings: lack of education and knowledge, disclosure/truth telling, lack of time, cultural and physical barriers in healthcare settings, communication issues, symptom management and nurses' personal challenges in the care of the dying.

2.3.1 Lack of education and knowledge

Eight qualitative studies (Casey et al., 2011; Hopkinson, Hallet, & Luker, 2003; Jack, Gambles, Murphy, & Ellershaw, 2003; Johansson & Lindahl, 2012; Mahtani-Chugani, González-Castro, de Ormijana-Hernández, Martín-Fernández, & de la Vega, 2010; Terry & Carroll, 2008; G. N. Thompson, McClement, & Daeninck, 2006a; Wallerstedt & Andershed, 2007) and three quantitative studies (Powazki, et al., 2014; Sasahara, Miyashita, Kawa, & Kazuma, 2003; Toscani, Di Giulio, Brunelli, Miccinesi, & Laquintana, 2005) have investigated nurses' experiences caring for dying patients in the acute care setting. These studies have highlighted that general practice nurses lack of education and knowledge on EOL care negatively affected the quality of care. Inadequate preparation to deal with patient

and family demands caused situational tension among nurses, who felt ill-equipped to deal with the unknown. Moreover, the diverse and complex needs of families, which created conflicts, pose great challenges for nurses. Building the caring relationship with the patient was one aspect but having to deal with family preferences added to the complexity of care.

As found by G. N. Thompson et al. (2006b) and Casey et al. (2011), who both utilised a Grounded Theory approach, ongoing regular assessments and reviews of individual patients in healthcare settings posed great challenges for nurses. A study by G. N. Thompson et al. (2006a) revealed the social issues of nurses striving to provide high-quality EOL care but being pulled in many different directions. Psychological issues experienced by nurses included facilitating and maintaining 'lane changes' (where RNs on the one hand care for acute patients where there is an emphasis on cure, on the other hand, patients who need palliative care support), accessing resources, being present and manipulating the care environment. Two studies revealed that physicians were A study by Casey et al. (2011) revealed that to 'die well' meant incorporating holistic palliative care for the comfort of patients. To realise holistic care, organisations must pay attention to the emotional labour of staff and staffing constraints.

Two studies revealed that physicians were reluctant to initiate strong analgesia for patients in severe pain because of their fear that it might hasten death (G. N. Thompson et al., 2006a; Casey et al., 2011). This decision creates a moral distress for nurses providing active palliative care and impedes their ability to honestly communicate with patients' families. G. N. Thompson et al. (2006a) used the constant comparative method of analysis to compare incident with incident and category with category, adding rigour to the data analysis and findings. The authors reported that participant observation occurred in the context of the care environment, but no direct observations of nurse—patient interactions were made. Observations of care practices would have provided detailed data on the care component. In both studies, the methodology was well explained, but G. N. Thompson et al. (2006a) only collected data from two teaching university hospitals in Canada, while Casey et al. (2011) conducted interviews at six different settings.

The medicalisation of care was also echoed in a Spanish study by Mahtani-Chugani et al. (2010), which highlighted that the curative aspects of care took precedence over palliative care. The lack of understanding and knowledge of palliative care caused a misalignment of

understanding in relation to the goals of care for terminally ill patients. Nurses' lack of confidence and knowledge in palliative care prevented them from advocating for their patients. This lack of confidence and knowledge on palliative care was further compounded by the nurses inability to reveal the truth about prognosis or to handle such a tense situation (Mahtani-Chugani et al., 2010). Although a qualitative approach was used, the authors did not specify the number of focus groups or participants in the focus group discussion. The process of data collection was not well elaborated in this study.

The lack of education and knowledge among nurses with respect to identifying and managing symptoms was shown in a cross-sectional study conducted by Sasahara et al. (2003). A questionnaire survey, which included 80 items related to the difficulties encountered when caring for terminally ill patients, attracted responses from 375 nurses working in three general hospitals, representing an adequate response rate of 70.2%. At least 90% of the nurses participating in the study had insufficient knowledge regarding medications for symptom control. These results cannot be generalised because the nurses were recruited from only three hospitals located near Tokyo. Given that there are 8,000 general hospitals in Japan, the sample may not represent the entire population of Japanese nurses.

An Italian study conducted by Toscani et al. (2005) had similar findings to those of Sasahara et al. (2003). Toscani et al. (2005) used a mixed-method approach, enhancing the depth and breadth of the topic under study. Toscani et al. (2005) conducted interviews with nurses and doctors and reviewed the notes of patients who had died. The majority of the health professionals lacked the knowledge to recognise imminent death, even when it was apparent. The nursing attention was more directed to physical care than to alleviate symptoms. The lack of recognition of imminent death by nurses may have been the reason for 11% of the patients dying alone in the acute care setting. It could therefore be argued that this study revealed the emphasis was on technical care than on quality care of the patients.

In contrast, Wallerstedt and Andershed (2007) interviewed nine nurses who had worked more than 3 years in primary home care, community care (home care and nursing home) and acute care settings in Sweden. Using a phenomenological approach, one-to-one interviews were conducted. Data were analysed using Gorgi's (2000) framework of analysis. Three main broad themes surfaced: ambition and dedication, everyday encounters and satisfaction and dissatisfaction of 'actual' and 'ideal' EOL care in the acute care setting. Their findings

strongly suggest that nurses' encounters with dying patients gave them invaluable experience, increased their professional awareness and developed their professional knowledge in dealing with dying patients and their families.

Similar findings were echoed in a cross-sectional, mixed-method prospective study by Powazki et al. (2014). A modified validated questionnaire adopted from the Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project for Quality Palliative Care, 2018) was distributed to 209 nurses, resulting in 123 (59%) completed responses. The questionnaire comprised two parts: Part I captured demographic characteristics and provided a single open-ended question, while Part II comprised 20 questions on domains recommended by the National Consensus Project for Quality Palliative Care. The nine domains were knowledge of care needs, physical care, psychosocial care, communication, ethics, religion, culture and spiritual and bereavement issues. The findings were analysed using descriptive statistics. Older nurses experienced greater levels of capability and comfort when caring for the dying, particularly in the domains of knowledge, physical care and psychosocial care. Similarly, Agustinus, Chan and Ang (2014) found that older nurses were more comfortable dealing with death and dying. A limitation of the Powazki et al. (2014) study was its low response rate of 59%. Because this survey was conducted in an academic medical centre, its generalisability beyond the centre is debatable. They used only one openended question in Part I and a Likert scale in Part II of the questionnaire that may have limited the richness of data. More than 40% of participants had negative responses to the areas of bioethics, communication, cultural, spiritual and bereavement issues. However, these statistically negative responses may not have revealed the true essence of discomfort experienced by the nurses participating in this study because the nurses were not interviewed to capture the intricate details of their discomfort.

Jack et al. (2003) conducted a descriptive qualitative study in the UK that explored nurses' perceptions of the Liverpool Care Pathway, which was introduced by the National Health Service in 2000. Fifteen nurses with more than one-year experience were recruited from various acute care hospital settings. Two one-hour focus group interviews were conducted, followed by a supplementary interview. Data were analysed using Colaizzi's (1978) framework of analysis. After using the Liverpool Care Pathway, nurses' knowledge and confidence improved, and they were more prepared to handle new challenges.

In contrast, undergraduate nurses had different views on their lack of education, knowledge and preparation. A phenomenological study conducted in the UK by Terry and Carroll (2008) on first-year nursing students' encounters with death revealed that every death in clinical practice was both a learning experience and a source of potential emotional distress. Some students experienced avoidance behaviours, while others felt unsupported by their mentors and that the dying patients and their families were not adequately cared for. The theme of abandonment was evident in the findings. Three cohorts of first-year nursing students who had completed at least one clinical placement (307 in total) were recruited in the study. Students were asked to complete a questionnaire and participate in a tape-recorded focus group interview that aimed to explore their experiences. In total, 184 questionnaires were completed. Approximately 100 students had encountered their first death in clinical practice as a student nurse. Fourteen nursing students participated in one of three focus groups. The findings highlighted some interesting salient points—feelings of abandonment among student nurses, patients and families; a lack of effective mentorship; lack of an ideology focusing on holistic psychosocial care and the unconscious mirroring of ward staff avoidance behaviours, resulting in participants' failure to provide optimum care with respect and dignity. Participants' distress increased when inexperienced staff meant that last offices were not performed until two hours post-mortem or after rigor mortis had set in.

The focus group participants indicated that relatives often felt abandoned. Ward nurses were more consumed by urgent life matters, which took precedence over the care of relatives. Inappropriate directions and actions of ward staff after the death of a patient caused distress to relatives and student nurses. Student nurses revealed that they struggled with their own emotions and felt incompetent to deal with relatives' emotions, which challenged their communication and professional skills. They experienced being left alone, a lack of follow-up and difficulty coping and often avoided dying patients. Students in this study believed the culture of 'busyness' led to the failure to provide holistic care to the dying. These factors and the transference of professional behaviours had a significant negative impact on the nursing students' first-year clinical practice, meaning that newly qualified nurses may lack preparation in caring for dying patients. This lack of clinical support and supervision implied a lack of role modelling and proper training in EOL care, which concurs with a study by Parkes (1998). The ability to anticipate death early should be taught by educational institutes, mentors, lecturers and ward staff, thus allowing time for nurses to adopt effective coping

mechanisms in distressing situations. A pertinent point illustrated in this study was that clinical practice is an important part of professional development, echoing the findings of Mok, Lee and Wong (2002). Although this study was conducted on student nurses, it indirectly revealed the negative behaviours of ward staff when faced with a dying patient.

In summary, the above reviews revealed nurses lack of knowledge in EOL care and palliative care; the inadequacy of the nurses to deal with complex demands of the patient and family; experienced nurses who gained professional knowledge through their encounters as opposed to an undergraduate nurses who experienced the lack of guidance and clinical support; and the culture of acute care impeded the quality of care to the dying patients. The next section of the literature review discusses disclosure and truth telling.

2.3.2 Disclosure and truth telling

The extent of disclosure remains unclear because of the legal, ethical and cultural issues found in developing countries compared with Western societies (Chaturvedi, Loiselle, & Chandra, 2009; Clarke & Ross, 2006; Costello, 2006; Wu & Volker, 2009). Distress may be reduced if healthcare professionals are honest about patient diagnoses and prognoses (Fallowfield, 1997; Wilkinson, 2002). The idea of simply telling the truth raises many provocative questions. The disclosure of information by nurses may not be ethical or provide comfort to relatives, and truth telling may go beyond of the professional scope of nurses (Costello, 2000, 2006). Traditionally, the duty to impart diagnoses and prognoses to patients lies primarily with doctors, but this area is not readily addressed by all institutions or cultures (Beyraghi, Mottaghipour, Mehraban, Eslamian, & Esfahani, 2011; Heidari & Norouzadeh, 2014; Katz & Sidell, 1994; Parsons et al., 2007; Valiee, Negarandeh, & Dehghan Nayeri, 2012). 'Skilled companionship' is any area that should be developed so that the truth may be spoken freely, allowing patients to adapt to and gradually accept their journeys (Salander, 2002). An enormous diversity of views exists among nurses in approaching death and dying patients (Komaromy, 2006). Despite many nurses receiving basic professional training on EOL care, the question remains as to whether this is sufficient. Basic nursing needs are addressed universally, but spiritual needs may be neglected. Nurses may bring their unique cultural and spiritual perspectives to the provision of EOL care, which may be a source of tension between nurses.

In a Singaporean study, data collected from the 1990s revealed that up to 40% of patients had not been told their diagnosis and up to 84% of healthcare professionals colluded with family members in not telling the patient the truth (Lee & Wu, 2002). From family members' perspectives, the non-disclosure of information was beneficial rather than harmful. Nurses, who are the key players in providing care, struggle both internally and professionally in maintaining this collusion (Chaturvedi et al., 2009). This 'conspiracy of silence' affects communication when addressing the topic of death and dying (Chaturvedi et al., 2009). Nondisclosure makes the task of nursing more onerous when nurses have to balance being consistent with various health professionals, being open to questions and discussions, providing specific information for patient care and having separate discussions with patients and caregivers (Clayton, Butow, & Tattersall, 2005; Parker et al., 2007). Research has shown that talking about death and dying with loved ones is perceived as disrespectful and insensitive, particularly in Asian cultures (Kwak & Salmon, 2007; Wu & Volker, 2009). Concealing the truth and delaying the acceptance of death act as a 'security blanket'. Studies have also shown that the method of communication about prognosis, EOL care and death may be determined by other factors, including the patient's age, gender and family role, the family's openness to talking about illness, disability and death and individual emotional coping abilities (Elkin, Kim, Casper, Kissane, & Schrag, 2007).

An experimental study (Panagopoulou, Minziori, Montgomery, Kapoukranidou, & Benos, 2008) of medical students, who were asked to either discuss or conceal a diagnosis of terminal illness, found that concealing a diagnosis was significantly less stressful than disclosing it. This demonstrates that doctors are more comfortable with concealing diagnoses because it reduces their own stress. The study also highlighted that nurses and doctors found that managing collusion was one of the most difficult issues in clinical practice. Despite the need to tell the truth, they were not prepared to face the consequences of disclosure, which may have decreased a patient's hope of living. Other studies have focused on the mental preparation of family caregivers for death (Hebert, Prigerson, Schulz, & Arnold, 2006). The EOL care experiences of RNs in Singapore with respect to their levels of preparedness, knowing what to say to terminal patients (medical), their ability to discuss grief and loss, how to maintain relationships with friends and family (psychosocial), talking about the meaning of death (religion/spirituality), talking about funeral arrangements and professional patient—caregiver communication is yet to be explored.

An American study by Peterson et al. (2010a) utilising the Grounded Theory approach explored the experiences 15 RNs who were involved in nursing the dying. Using a questionnaire survey, fear of death was measured using the Multidimensional Fear of Death Scale (Neimeyer & Moore, 1994) and the Frommelt (1991) scale, which examined attitudes about caring for a dying patient. In addition, interviews were conducted that focused on the skills and deficits of nurses when caring for the dying as well as their personal experiences, coping capacity and educational preparation. Participants had all experienced caring for a dying patient. Audio tapes were transcribed and coded to generate themes. The nurses in this study expressed several concerns about caring for dying patients, including personal concerns, patient concerns and family concerns.

Personal concerns included the inability to allocate sufficient time for dying patients and their families, which was a barrier to nurses' performance. Nurses also feared not having enough experience to care for the dying. Separating their personal emotions from their caring duties and maintaining a professional distance was challenging. With respect to patients, nurses were primarily concerned about their informational needs. Nurses often had to act as mediators between doctors and families. At times, they felt stressed and frustrated having to fill in the gaps when doctors failed to provide sufficient information to patients. While they were unprepared to share information, they also wanted to ensure that pertinent information was not omitted. Nurses were also concerned about meeting patients' physical and emotional needs. With respect to families, effective communication such as finding the right words, disclosure of patient prognoses and mediating between patients and family was difficult. Notably, the nurses' primary concern was their lack of education and training on communication skills when nursing the dying. Despite feeling comfortable caring for dying patients, nurses expressed their concerns about disclosing information and their lack of communication skills. The scope of disclosure had its boundaries and does requires further analysis.

The discussion of death and its preparation is a dynamic process and should occur in stages so that families can be responsive and assimilate information at their own pace (Emanuel, Fairclough, Wolfe, & Emanuel, 2004). However, disclosure or truth telling appears to be an uncomfortable path for many RNs. The next section discusses the lack of time as a barrier to the optimal care of dying patients.

2.3.3 Lack of time

Fourteen qualitative studies included in the review have demonstrated that one of the major barriers to providing EOL care is the busyness of acute care wards. Studies found that most of the nurses' time was taken up by organisational demands, dealing with anxious relatives and managing care priorities, and that the lack of time for EOL care impedes the ability of nurses to communicate with patients and families. The lack of time and the busyness of wards has been found to be detrimental to the provision of comfort and palliative care (Agustinus et al., 2014; E. Anderson, Salickiene, & Rosengren, 2016; Casey et al., 2011; L. S. Chan, Macdonald, Carnevale, & Cohen, 2018; Costello, 2006; Decker, Lee, & Morphet, 2015; Hopkinson et al., 2003; Johansson & Lindahl, 2012; King & Thomas, 2013; Mak, Chiang, & Chui, 2013; Peterson et al., 2010a; Roche-Fahy & Dowling, 2009; G. N. Thompson et al., 2006a,b; Wallerstedt & Andershed, 2007) and two quantitative studies (Ingwu, Nwaiku, & Ohaeri, 2016; Sasahara et al., 2003). Vig and Pearlman (2003) and Murray (2012) have highlighted that spending time with terminal patients and their families to offer reassurance and alleviate fear and anxiety was an important goal in EOL care. With more time, nurses may be able to enhance the quality of life of dying patients.

In an ethnographic study aimed at capturing a wide range of nurses' experiences of death and dying (Costello, 2006), 29 RNs from two hospitals specifically caring for the elderly were recruited. In-depth interviews were carried out for 40–50 minutes in non-clinical areas to capture content with no interruptions. Data were interpreted using semiotic analysis informed by the work of de Saussure (1974), who argued that the elements of speech derive meaning from their relationships with other elements. This technique of analysis was useful for the researcher, who was able to isolate and distinguish concepts by focusing on the cultural features surrounding the text rather than on the text itself. The findings suggest that the experiences of nurses depended on their sense of control over the dying process. There was less emphasis on the EOL care of patients and more on the nurses' ability to manage organisational demands. Interestingly, less emphasis was placed on patients' autonomy or empowerment in decision-making. Nurses described EOL care experiences as 'good' when they had some control over the dying process such as being involved in disposal of the body, when they were could predict an imminent death and make patients, relatives and other staff aware of it and when death occurred at a time that minimised disruptions to the ward routine

(i.e. during the night). The nurses' experiences of 'good' and 'bad' deaths derived from whether it negatively affected the ward environment—a seamless flow of events during and after the dying process was considered 'good' by the nurses. In contrast, a death was considered 'bad' if it was sudden and unexpected, causing disruption to the ward routine, if time constraints meant that nurses were unable to prepare for death, or, more significantly, if patients and relatives were unprepared. Challenges encountered by nurses included the inability to relieve patients' pain, insufficient time to establish relationships with families and the lack of communication about diagnosis with patients and families, causing a climate of uncertainty.

Busyness has serious implications for nursing practice. There is a need to improve communication around diagnosis and to avoid 'blocking behaviours' with patients and families. This challenges practitioners to focus on the death process and prioritise patients' needs over organisational demands. There is also the need for patients to have some autonomy in shaping events at the end of their lives.

Some studies (Bradbury, 2000; Seymour, 2000) of 'medicalised deaths' imply that nurses were unprepared to deal with the unpredictability and prolongation of life. Nurses may be more concerned about routine ward practices and unknowingly attempt to conceal the social fact of death from other patients. It has also been pointed out that 'good deaths' must incorporate a degree of social control in which the patient is 'ready to die' (Payne, Langley, & Hillier, 1996). Facilitating a 'good death' requires a high level of communication skills between nurses, patients and other health care professionals. Costello (2006) study revealed the cultural challenges faced by nurses when death is denied from the social perspective. Comprehensive, effective and sensitive communication skills are needed throughout the process of dying. The next section discusses the cultural and physical barriers related to caring for dying patients.

2.3.4 Cultural and physical barriers in the healthcare setting

A review of 17 studies on the care of the dying demonstrates the negative aspects of care. Nurses who attempt to provide both active and palliative care for different patients in acute care settings feel overwhelmed by the reality of dying patients' needs. Nurses encounter difficulties juggling the needs of acute care patients and those of dying patients in the same

environment (E. Anderson et al., 2016; N. E. Anderson, Kent, & Owens, 2015; L. S, Chan et al., 2018; Espinosa, Young, Symes, Haile, & Walsh, 2010; King & Thomas, 2013; Kongsuwan, Keller, Touhy, & Schoenhofer, 2010; Lai, Wong, & Ching, 2018; McCallum & McConigley, 2013; Zheng, Guo, Dong, & Owens, 2015). The lack of privacy for dying patients and the inability to control the physical environment causes distress and frustration for nurses. The lack of privacy was consistent with the findings of other studies (Bloomer, Endacott, O'Connor, & Cross, 2013; Costello, 2006; Sasahara et al., 2003). Forty-two per cent of nurses working in Japanese hospitals (Sasahara et al., 2003) agreed that there was a lack of private rooms for the families of dying patients. The lack of privacy is congruent with the findings of Tan et al. (2006) in which 67% of nurses believed that the appropriate place for care of the dying was in a single room.

In one Spanish study, nurses expressed that the focus of care was on diseased organs rather than on patients (Mahtani-Chugani et al., 2010). The findings of the focus group interviews were based on a consensus of opinions rather than individual lived experiences, but they revealed the unpleasant reality occurring in acute care settings. Nurses also highlighted that if the relatives were well informed about prognosis and treatment options, they could deliver more comprehensive care that met families' expectations.

The reviewed literature demonstrates the culture of acute care and how nurses struggle to provide and prioritise care. A study on the experiences of Taiwanese nurses in caring for dying patients in hospices revealed that nurses often encountered many challenges within a multicultural context (Wu & Volker, 2009). Despite the hospice setting, it was difficult for nurses to provide quality care for dying patients with respect to managing patient preferences, cultural taboos and negative beliefs about palliative care. Taiwanese nurses were educated in palliative care, but the adequate provision of care failed because of cultural barriers and patient resistance to accepting palliative care. However, nurses perceived death and dying to be a sociocultural process and were able to integrate their care with their patients' beliefs. Overall, the Taiwanese hospice nurses experienced satisfaction and had an increased understanding of EOL issues. Their work motivated them to re-evaluate their personal philosophies of death and dying and the cultural meanings attached to a 'good' death. Although culture was a barrier, the nurses expressed the need to respect and incorporate clients' cultural belief systems.

The interaction between culture and emotions is supported by other studies (Mok & Chiu, 2004). It is also reflected in a study by Wong, Liu, Szeto, Sham and Chan (2004), which found that abandonment may occur when nurses are unprepared for dying and death and cannot answer questions, provide comfort or simply tell patients what will happen. This avoidance is reinforced by McCormack (1997), who has observed that nurses may inappropriately limit their contact with a patient or their family before the patient dies. Emotional scars from previous negative experiences can lead to these avoidance behaviours (Quill & Cassell, 1995). This lack of confidence in communication with relatives highlighted the importance of enhancing communication skills for nurses in EOL care. Nurses will often procrastinate when advocating for patients, and their discomfort may prevent them from being confident in managing EOL care. Finding a balance between organisational expectations and meeting the psychosocial needs of dying patients, which goes beyond just listening and talking, creates demands for nurses on a daily basis (Mok & Chiu, 2004).

When dealing with the sociocultural process of dying, until the illness trajectory reaches a plateau, the sharing of information must be adapted for different levels of care. Studies have also shown that the culture of care is different for general practice nurses than it is for palliative care nurses (Casey et al., 2011; Clarke & Ross, 2006). These studies have found that general practice nurses prioritise task-oriented routine care and organisational and environmental demands, while palliative care nurses feel empowered to communicate, which is the core element of their care. This emphasises the marked difference in the culture of care between general practice and palliative care nurses. In contrast, G. N. Thompson et al. (2006a) found that nurses who were able to facilitate a 'lane change' (meeting the acute care needs and palliative care needs) could meaningfully fulfil the needs of patients. This 'lane change' may be facilitated by patients and relatives understanding the illness trajectory and care outcomes.

An Iranian study (Boroujeni, Oskouie, Mohammadi, & Sanberg, 2008) revealed a somewhat a different perspective from the Islamic point of view. Using a Grounded Theory approach and purposeful theoretical sampling, 18 nurses were recruited to explore their interactions with dying patients and their families and to examine how they dealt with EOL care situations. Semi-structured interviews were used to collect data. Results showed that striking a balance in EOL care was a major challenge in four core areas: restorative and palliative

care, information and hope, expectations and abilities, and intimacy and distance. The nurses had to provide two extremes of care—restorative and palliative. They were ambivalent about disclosing the truth of imminent death because they were instilled with the Islamic belief that God alone directed life and death and, further, that it would erode the patient's hope for living. These findings are in complete contrast with those of Heyland et al. (2006), who found that more than 90% of respondents wanted to be told about their disease. However, the cultural context in Iran is different, and nurses were hesitant to disclose the truth.

On the contrary, Periyakoil et al. (2005) argued that rather than having the belief that hope is lost, nurses should transfer it the hope of dying well. This study also revealed the differences in personal coping strategies employed by younger and more experienced nurses. Experienced nurses knew how to detach and find a balance in their professional involvement with dying patients. However, in the Boroujeni et al. (2008) study, Iranian nurses felt overwhelmed with organisational and personal pressures when providing EOL care and needed constant support to meet the needs of the terminally ill. The authors recommended improving nurses' communication skills in this area of care. Although the study highlighted key pertinent areas experienced by Iranian nurses when providing EOL care, it had some methodological weaknesses. The duration of each interview was not clearly stated, and the interviews were only partially translated into English, meaning that the translated data may not have been fully captured. Although the authors reported that content analysis was conducted and data were categorised, they did not specify the framework of analysis used.

A study conducted by Tan et al. (2006) explored the emotional attitudes and practical experiences of nurses caring for dying patients in a 400-bed acute care district hospital in Singapore. A structured questionnaire was distributed to 246 participating staff and assistant nurses working in medical, surgical and intensive care units. There was a 73% response rate, resulting in 180 completed questionnaires. The questionnaire, which was both quantitative and qualitative in nature, explored the attitudinal, ethical and communication issues involved in the care of dying patients. The findings revealed that 60% of the nurses felt uncomfortable nursing dying patients in an open ward, while 45% believed that physicians rather than nurses should tell patients the truth about dying. Most of the nurses agreed that relatives should be allowed at the bedside of dying patients. Among the various ethnic groups, Filipino nurses felt uncomfortable, frightened and exhausted when nursing the dying, although the numerical

scores utilised failed to reveal the specific negative aspects. Although the authors reported that there was a qualitative aspect to data collection, they did not mention the method of data analysis or discuss any qualitative findings.

In summary, the reviews portrayed that the nurses encountered numerous challenges in the acute care setting. They struggled to balance the needs of the acute care patients, and those that needed palliative care and EOL care support, and were confronted with their personal fears and discomfort caring for the dying patients. Nurses also faced challenges with family who resisted palliative care due to cultural taboos. It also revealed from the reviews that palliative care trained nurses felt more empowered and comfortable to communicate as compared to general practice nurses who were more task oriented and lacked communication skills. The emphasis on private room to facilitate EOL care seemed to be congruent in most studies. The nest section discusses the communication barriers related to caring for dying patients.

2.3.5 Communication barriers

Various studies have portrayed findings strongly related to the barriers to effective communication in acute care hospital settings, reflecting inadequacies in communicating with dying patients and relatives regarding options of care (see Appendices 1 & 2). Bloomer et al. (2013) employed a qualitative approach and non-participant observation to elicit rich data, followed by focus groups and individual semi-structured interviews for clarification. The study was conducted in two acute medical wards. Twenty-five nurses participated, and 20 episodes of observation were conducted. The care of dying patients was reduced to a focus on tasks when nurses minimised their communication with and attention to dying patients. Nurses in this study were reluctant to interact with dying patients' relatives and completely shifted their priorities to routine tasks. When patients' relatives asked questions about prognosis, nurses avoided answering and referred them to physicians. Nurses chose not to communicate with dying patients and relatives implied that they felt uncomfortable, anxious and distressed when interacting with dying patients' relatives and coped by disengaging. The method of data collection, which included one focus group interview for each ward with six nurses, was rigorous. Using the Grounded Theory approach and observations in different acute care settings may provide more in-depth discovery of experiences of nurses' encounters. Grounded Theory allows for the ability to study nurses from different care settings and may provide deeper meaning including interactions with their patients (Birks & Mills, 2015).

A study conducted by Aslakson et al. (2012) using four focus groups at three surgical intensive care units revealed that communication barriers occurred when physicians reviewed patients in the absence of relatives and treatment progress was not explicitly revealed to family members. Communication barriers were further compounded when family members were unavailable to discuss prognoses or, vice versa, when doctors were unavailable for family members when they needed information. Family members frequently failed to attend meetings to avoid receiving bad news. When there were multiple decision-makers in the family, the process of communication became too complex. There were different opinions among healthcare professionals regarding the transparent communication of patient prognoses, causing confusion and raising obstacles for providing effective EOL care.

In an earlier study conducted by Lin et al. (2000), communication related to EOL issues was often complicated by the reluctance of family members to discuss diagnoses and prognoses. Reasons for not discussing EOL issues (Lin, Tsai, Chiou, Kao, & Tsou, 2003) included the following: discussions about dying were likened to wishing death for patients and may hasten death; talking about dying may lead to hopelessness; terminal illness is not socially acceptable; a person's final days should be characterised by calm rather than anxiety; and patients do not need to be involved in decision-making. This 'conspiracy of silence' directly or indirectly led to nurses limiting their communication with patients and relatives. These studies showed that the ability of nurses to communicate therapeutically was a critical element and a cornerstone of EOL care (Curtis et al., 2005; Ferrell & Coyle, 2010; Funnell, Koutoukidis, & Lawrence, 2008; Latour, Fulbrook, & Albarran, 2009).

In summary, the reviewed studies highlighted nurses faced communication barriers related to their lack of confidence to disclose diagnosis, prognosis, information sharing, and options of care. Nurses avoided communicating with patients and family and shifted their attention to routine care. Nurses colluded with family not to tarnish the hope of living. The next section discusses the importance of symptom management.

2.3.6 Symptom management

Most of the studies reviewed highlighted the importance of symptom management, ineffective pain management in dying patients and the lack of individualised treatment (E. Anderson et al., 2016; Boroujeni et al., 2008; Hopkinson et al., 2003; Jack et al., 2003; O'Hara, 2011; Peterson et al., 2010; Roche-Fahy & Dowling, 2009; G. N. Thompson et al., 2006b; Toscani et al., 2005; White & Coyne, 2011). Pain management is seen as an important aspect of care for dying patients. Unalleviated pain is a concern for terminally ill patients worldwide (Smeltzer, Bare, Janice, & Kerry, 2008). This is supported by an earlier study in which hospital nurses expressed that pain and symptom control among end-stage heart failure patients was critical, and referral to a palliative care team was crucial in improving quality of life (Borbasi, Wotton, & Redden, 2005). Nurses experienced distress when physicians failed to manage pain effectively. Another study conducted by Steinhauser et al. (2000) found that over 70% of participants (patients, families and care providers) considered pain and symptom management one of the most important aspects of EOL care.

Efstathiou and Clifford (2011) reviewed some of the challenges encountered by critical care nurses in symptom management. Pain management in critically ill and dying patients poses challenges. Critical care nurses expressed concern about the timely delivery of medication because of prescribing limitations, despite the wide range of pharmacological interventions available. Cosgrove, Nesbitt and Bartley (2006) found that the use of a common pain assessment tool provided little value in assessing semi-conscious patients, and that effective pain assessment tools were essential for helping critical care nurses to assess pain objectively.

However, Toscani et al. (2005) cautioned that the individual and cultural perceptions of pain may profoundly affect patients' suffering, thus the approach must be individualised. Toscani et al. (2005) found that severely ill patients who died in Italian hospitals were inadequately managed for symptoms and, even at the terminal stage, patients continued to receive life-sustaining treatments, taking precedence over their quality of life. However, nurses interviewed in the O'Hara (2011) study felt that they could control symptoms effectively when they applied the Liverpool Care Pathway framework. Nevertheless, the vast majority of studies have found that symptom management is inadequately addressed. Besides the issue of symptom management, an emergent theme of the literature review was that related to nurses' personal challenges when caring for dying patients.

2.3.7 Nurses' personal challenges

Of the 41 studies reviewed, 39 studies consistently highlighted the personal challenges and feelings experienced by nurses involved in EOL care (see Appendices 1 & 2). The reviewed papers clearly highlighted that the provision of EOL care by nurses in acute care settings was difficult and stressful. There were multiple barriers discussed in (section 2.3.1-2.3.6). Apart from those barriers mentioned earlier, the review of literature also highlighted nurses were confronted with personal challenges (see Appendices 1 & 2) that impeded the care for dying patients. Many studies reported that ongoing psychological pressure, anxiety, moral distress, emotional exhaustion and fatigue experienced by nurses when dealing intensively with dying patients and their relatives (N. E. Anderson et al., 2015; Becker et al., 2017; Funk et al., 2017; Lai et al., 2018; Odachi et al., 2017; Zheng et al., 2015).

These studies highlighted that the Chinese nurses in the oncology ward and nurses from the ICU, suffered moral distress because of self-limitation, lack of knowledge and confidence and inexperience in psychological care (Valiee et al., 2012; Zheng et al., 2015). This was similar to those nurses who were personally affected, and felt unprepared to face dying patients due to a lack of knowledge in the field of palliative care, not knowing enough about dying process and the ability to engage and explain to relatives and conflicts which they experienced between health care professionals (E. Anderson et al., 2016; Chuah et al., 2017; Croxon & Deravin, 2017; Mak et al., 2013). Other studies also highlighted nurses experienced negative outcomes which disrupted their thoughts, affected their sleep, felt abandoned and were concerned about inadequacies for future care practices (N.E. Anderson et al., 2015; Mak et al. 2013; Terry & Carroll 2008). This caused feelings of frustration, incompetence, stress and dissatisfaction among general practice nurses.

Other personal challenges included when nurses witnessed futility of care, the inability to advocate for patient's and family's needs, involved in collusion, and when care was not delivered to the level of patient's interest, was compounded with heavy workload (Aslakson et al., 2012; Broom, Kirby, Good, & Lwin, 2016; Chan et al., 2018; Espinosa et al. 2010; Mahtani-Chugani et al., 2010; Rice et al., 2008). It was also reported that nurses struggled to manage their own grief and felt unsupported, having the sense of being alone and being unable to seek emotional support from others, including management (Casey et al., 2011; Croxon & Deravin, 2017; Funk et al., 2017; Wallerstedt & Andershed, 2007). Apart from

above, moving between different situations and prioritising complex care needs, including striking a balance between terminal and acute care was found to be onerous as reported in these studies (Chan et al., 2018; G. N. Thompson et al., 2006a; Roche-Fahy & Dowling, 2009). Reflecting the meaning of death and personal experiences of death of their own family members brought unpleasant memories to these nurses who worked in acute hospitals (Iranmanesh et al. 2009; Mak et al., 2013). Some of the challenges nurses faced from the review of literature indicated the lack of personal communication skills and knowledge in palliative care (E. Anderson et al., 2016; Banerjee et al., 2016; Croxon & Deravin, 2017; Decker et al., 2015).

It is evident in the findings of various studies that dealing with death and dying requires a certain level of comfort and preparation of nurses to provide high-quality care to avoid burnout and minimise stress. Physical symptoms such as tension, headache, fatigue, stomach pain, back pain and high levels of apprehension were experienced by nurses who encountered stress and burnout (Mojoyinola, 2008).

The reviewed papers clearly highlighted that the provision of EOL care by nurses in acute care settings is difficult and stressful. There are multiple issues to deal with when caring for dying patients. Dealing with the emotional concerns of patients and relatives caused frustration, feelings of incompetence, stress and dissatisfaction among general practice nurses. Communication barriers (e.g. sharing information, disclosure and speaking in a language that relatives could understand) and juggling organisational and patient demands impeded the ability of acute care nurses to perform their work efficiently and effectively. Challenges were further compounded by the lack of knowledge and education in EOL care, the lack of experience in dealing with EOL care situations and poor management of symptom control. Nurses frequently encountered difficulties in applying the philosophy of palliative care in acute hospital settings. The emphasis of care in acute settings was on curative approaches and was guided by technical and scientific evidence. The role of the acute care nurse is multifaceted and dealing with complex EOL care issues reflected their incompetence and unpreparedness in skills and knowledge. Managing cultural norms and practices and striving to provide individualised care added to the burden of care delivery for acute care nurses.

The majority of studies have been conducted in Western countries, and the literature pertaining to the Singaporean context is scarce. The changing health landscape in Singapore, especially in the provision of EOL care, warrants further attention. There is a dire need to conduct studies exploring the experiences of acute care nurses when providing EOL care in acute care hospitals in Singapore, specifically with respect to how care is provided and managed in the multicultural context. Questions such as, 'What are we doing right? What is lacking when providing EOL care? and 'Are there similarities or differences to Western settings? must be answered.

The conduct of this research will identify the care concerns of the RNs' on EOL care and recommendations can be made to address them. Nurses play a key role in providing EOL care, and those working in acute care settings are faced with the responsibility of caring for both acutely ill medical patients receiving curative treatment and patients who require EOL care. With this increasing trend in the Singaporean healthcare system, it is evident that little research is available on the subject. Therefore, it is essential to explore the lived experiences of acute care nurses caring for dying patients.

Many previous studies adopted a qualitative research methodology that have embraced the phenomenological or ethnographical approach, but few have used the interpretive Gadamerian approach. Most of the qualitative studies utilised individual and focus group interviews to capture the phenomenon from the perspectives of patients, relatives and nurses. Some studies have explored the topic using quantitative methodologies such as questionnaires, which may fail to provide rich in-depth data and insights about nurses' experiences.

Therefore, the present study was guided by an interpretive phenomenological approach. As researchers, we interpret phenomena in which we exist and, therefore, have no detached standpoint (Koch, 1995). The philosophy of Gadamerian hermeneutics offers a potential framework to guide nurses through the process of research, thus helping them to develop knowledge associated with the 'how' and 'art' of nursing. As a researcher, my knowledge, understanding and prejudices form part of the research data. This will be discussed in detail in the subsequent chapter on methodology.

In summary, this literature review chapter highlighted the nurses experience various challenges when providing EOL care. Beyond these challenges, little is known about the specific concerns of nurses caring for dying patients in the Singaporean context. To provide, support and equip nurses to deliver care for their dying patients, research is needed to explore nurses' everyday experiences when caring for dying patients.

Singapore is ethnically and culturally diverse. In a multicultural environment such as Singapore, nurses must be culturally competent when providing care to those from various backgrounds to decrease the likelihood of misunderstandings in the delivery of care. Nurses must not only manage culturally diverse patients but also show sensitivity to colleagues and patients from different ethnic backgrounds. Nursing patients in their final days can be upsetting. How nurses perceive their roles with those at the end of their lives, their comfort in providing EOL care and the challenges they face is an interesting area of research. Many studies have addressed 'good deaths' from the perspective of patients in Western cultures. However, there has been a lack of research conducted from the Eastern perspectives, especially on nurses' experiences of EOL care in acute hospitals in Singapore. This is the gap that need to be investigated.

The delivery of care, especially EOL care, poses challenges to nurses and is compounded by the cultural expectations of patients and the medicalisation of death. Hospital nurses' experiences of EOL care can provide further insights into the way they deliver care for the dying. This study aims to investigate acute hospital nurses' experiences of EOL care. It is appropriate to understand and evaluate the challenges and barriers to EOL care from the standpoint of nurses. RNs may drive future policies in improving EOL care in Singapore. Therefore, it is necessary to understand the available resources in Singapore and those that can be improved.

Chapter 3: Methodology

3.1 Introduction

The literature review has revealed a number of aspects of nurses' experiences when caring for dying patients from the perspective of studies conducted in Western countries (e.g. Australia, Canada, England, Iran, Ireland, Spain and New Zealand). Given the lack of available data for Singapore, understanding nurses' experiences in the Singaporean context may make an important contribution to how nurses can manage the care of dying patients. Thus, the aim of this study is to understand the everyday experiences of nurses caring for dying patients in acute care settings in Singapore.

This chapter provides a discussion of the theoretical framework that underpinned this study, which aims to understand the experiences of RNs caring for dying patients in the context of an acute care setting in Singapore. This chapter explains the study design and rationale for selecting a qualitative hermeneutic interpretive approach rather than a quantitative approach. It also discusses the differences between phenomenology and hermeneutic phenomenology, the philosophies of other hermeneutic philosophers and why Hans-Georg Gadamer's (1976, 2004, 2006) philosophical approach was selected to address the research question. A sound methodological design and theoretical framework is critical because it adds value and rigour without compromising the research (Balls, 2009; Polit & Beck, 2008).

The application of Gadamer's hermeneutic philosophy, with its emphasis on historicity, language and culture, provided an understanding of nurses' experiences caring for dying patients and generated rich meaningful data (Gadamer, 2006). It facilitated a deeper understanding of nurses' experiences when caring for dying patients. The research design served as a blueprint for the conduct of the study and directed the methodological decisions used for data collection and analysis (Burns & Grove, 2009). The selection of an appropriate methodology determines the quality of research in terms of validity and the insights it provides (Polit & Beck, 2008). The philosophical hermeneutic approach of Gadamer (1976, 2004, 2006) was adopted to uncover the meaning of nurses' experiences in Singapore as a multicultural society, where language plays a powerful role in the interconnections between the interpreter and nurses' experiences (Gadamer, 1976, 2004, 2006; Mantzavinos, 2005).

Gadamer's philosophical framework was deemed suitable to explore nurses' experiences, and the responsibility of the researcher was to understand nurses' clinical experiences and to reach a fusion of the horizon as described by Gadamer (2006). This fusion was achieved by recognising and acknowledging the meaning of language and culture for RNs in Singapore.

3.2 Qualitative Research Approach

Qualitative and quantitative research methods are two types of approaches used in nursing research (Creswell, 2009; Polit & Beck, 2008). The quantitative approach emerges from a branch of philosophy known as logical positivism, which assumes that knowledge is generated through the application of logical principles and reasoning (Carter, 2000). Quantitative research methods deriving from the natural sciences emphasise objectivity, measurement, reliability and validity (Carter, 2000; Creswell, 2007; Sekaran, 2003). In this approach, researchers adopt a distinct non-interactive approach with their subjects, believing that boundaries must exist to ensure objectivity. Evidence derived from randomised clinical trials remains the gold standard. This methodology uses statistical measures to express the relationships between variables (Burns, Grove, & Gray, 2011) and is based on ontological and epistemological assumptions that follow the hypothetico-deductive or positivist school of thought in shaping the research inquiry (Morgan, 1983). The positivist philosophy argues that generated knowledge cannot be perfect but should be viewed from a probabilistic stance and can be generalised (Carter, 2000).

In contrast, qualitative research, which has emerged as a valid alternative approach to research, is more holistic and does not reduce participants to their functioning parts (Parahoo, 2006). Qualitative research produces statements, which aligns with the aim of this study to explore the subjective feelings and experiences of nurses from their perspectives rather than from the perspective of the researcher (Polit & Beck, 2008). Six significant characteristic features have been highlighted by qualitative researchers: a belief in multiple realities; the commitment to identifying an approach; understanding a phenomenon from a participant's point of view; conducting an inquiry that does not alter the natural environment; acknowledging the researcher's participation in the research; and reporting the findings while maintaining the richness of the data (Polit & Beck, 2008; Streubert & Carpenter, 2011). This study utilised the qualitative perspective to get the subjective meanings of the Registered

Nurses experiences caring for dying patients. Table 3.1 succinctly highlights the differences between quantitative and qualitative approaches to research.

Table 3.1: Differences in Quantitative and Qualitative Approaches

| | Quantitative | Qualitative |
|------------------------------------|--------------|----------------------------|
| Ontological assumption | Objective | Subjective |
| Epistemological assumption | Positivism | Phenomenology |
| Aim of inquiry | Universality | Particularity |
| Role of researcher | Outsider | Insider |
| Researcher-respondent relationship | Detached | Involved |
| Research methods | Statistics | Description/interpretation |

Source: Adapted from Streubert and Carpenter (2011).

The qualitative approach adopted in this study allowed participants to be open with their opinions about the positive and negative aspects and challenges faced when caring for dying patients. Qualitative research exposes the weakness of the quantitative approach in which researchers may strip the subject matter of context to maintain objectivity (Sandelowski, 2001). Qualitative research is committed to investigating the perspectives of participants in the social world (Mason, 2002). Although there are several approaches to social inquiry, a qualitative approach was chosen for this study because it was the most suitable method for exploring the everyday experiences of RNs caring for dying patients in the Singaporean context (Berger & Luckmann, 1967). This study utilised interpretive methodology in which one's preconceptions and prejudices facilitate the understanding of meanings generated from participants (Gadamer, 1976, 2004, 2006; van Manen, 1997, 2007). Although there is no one theory or approach used by all phenomenologists, common features exist. The methodology utilised by each philosopher differs. The two broad fields of phenomenology are hermeneutic (interpretive) phenomenology and transcendental (descriptive) phenomenology (Parahoo, 2006; Polit & Beck, 2008; Streubert & Carpenter, 2011). Phenomenology and the major differences between the philosophers will now be discussed.

3.3 Phenomenology and Hermeneutic Phenomenology

According to Parahoo (2006), methodology relates to the thoughts, beliefs and strategies employed by the researcher during the enquiry. Phenomenology is being increasingly used as a methodology in social science and nursing research (Kaufer & Chemero, 2015; Parahoo,

2006). It is an inductive descriptive research approach with a focus on human phenomena and is suitable for studying humanistic disciplines such as that found this study—the everyday experiences of nurses caring for dying patients (van Manen, 1997, 2006). The word 'phenomenology' originates from the Greek word *phainein*, meaning 'to appear' (Crotty, 1998). In the field of psychosocial science research, it has been used as an integral field of inquiry and is recognised as a reputable qualitative research method (Streubert & Carpenter, 2011). The focus of a phenomenological study is to explore the different ways in which people experience and understand their world and their relations with others and the environment (van Manen, 1997, 2006). Phenomenology was appropriate for this study for two reasons. Firstly, it was anticipated that the nurse participants in this study would share their caring experiences because caring appears in their conscious minds (Moran, 2005). Secondly, it enabled the researcher to understand their world without prejudice or presupposition. This design involved questions relating to human experiences and realities, the answers to which were elicited by asking nurses about their natural environments. Phenomenology generated rich, descriptive data to help the researcher to understand nurses' experiences when caring for dying patients (Dingwall, Murphy, Watson, Greatbatch, & Parker, 1998).

Although there is no one theory or approach taken by all phenomenologists, there are some common features, albeit with some distinctive differences, utilised by phenomenologists. The various approaches to phenomenology include positivist (Husserl), transcendental, descriptive, post-positivist (Merleau-Ponty), existentialist (Satre), interpretivist hermeneutic (Heidegger) and constructivist (Gadamer) approaches. van Manen (1997) embraced both descriptive and interpretive phenomenology as a more contemporary approach (Dowling, 2007). The methodology utilised in each field differs. Early phenomenological researchers were influential German philosophers (Parahoo, 2006; Polit & Beck, 2008; Streubert & Carpenter, 2011). A common feature of phenomenology is that evidence of the world is shown through experience, not as it is thought but as it is lived (Richards & Morse, 2007). Phenomenology is appropriate for studying experience because, similar to peeling back the layers of an onion, an understanding of internal meaning can be obtained (van Manen, 1997). It connects participants in their shared experiences (Creswell, 2009). I was able to explore participants' views through conversational interviews, verbatim transcriptions and thematic analysis of the emerging issues, subsequently interpreting the accounts of participants'

experiences caring for dying patients. Essentially, the aim was to understand the nature of the collective participant experience to broaden the understanding of meaning from different viewpoints. Below is Table 3.2 that illustrates the genesis of descriptive versus interpretive phenomenology.

Table 3.2: Descriptive versus Interpretive Approach

| Husserlian Phenomenology | Philosophical Assumptions |
|--|--|
| Edmund Husserl (1859-1938) Positivist | Uses reduction "epoche" (refrain from pre- |
| Damana Hussell (1007-1700) I Ushtivist | conceived judgement) |
| Tradition: German Philosophy | concerved judgement) |
| Belief: Cartesian Dualism (mind body split) | Attempting to set aside presuppositions and |
| Phenomenology as quest for certainty | to see phenomena in its purest form |
| Mechanistic view of the person | to see phenomena in its purest form |
| Ahistorical | Bracketing defends the validity or |
| Descriptive or eidetic | objectivity of the interpretation against self |
| Descriptive of cidetic | interest |
| Strongly epistemological (experience the fundamental | interest |
| source of knowledge) What is the nature of the relationship | |
| between the knower and what can be known | |
| Heideggerian Phenomenology | There are a number of concepts in |
| Martin Heidegger (1889-1976) Interpretivist | interpretive phenomenology |
| Wartin Heidegger (1005-1570) Interpretivist | "being in the world" (dasien) "fore |
| Tradition: German Philosophy | structures |
| Belief: Cartesian Dualism | "life world existential themes" – originated |
| Non Foundationalist as it focusses on meaning that arises | from Merleau-Ponty's work |
| from the interpretive interaction between historically | ("lived space", "lived time", "live body" & |
| produced texts and the reader | "live human relation") |
| produced texts and the reader | the hermeneutics"- the manner in which |
| Ontological- question the nature of reality and "Being" in | interpretation through understanding is |
| the world. It is to emphasise that human cannot abstract | achieved by the circular process of |
| themselves from the world | continuous re-examination of propositions |
| themserves from the world | Involves back and forth questioning which |
| Person exists as a "being" in and of the world | leads to expanding circle of ideas |
| Historical | Heidegger's Challenge: can "bracketing" |
| What is shared in culture, history, practice, language & | occur as envisaged by Husserl? |
| society is vital for interpretations | Can anyone put aside all that has influenced |
| society is vital for interpretations | and fashioned their beliefs and |
| | understanding? |
| Gadamerian Phenomenology | Uses reduction "epoche" (refrain from pre- |
| Hans-George Gadamer (1900-1996) Constructivist | conceived judgement) |
| Tradition: German Philosophy | Attempting to set aside presuppositions and |
| Two central positions: | to see phenomena in its purest form |
| Prejudgement | Bracketing defends the validity or |
| Phenomenology as quest for certainty | objectivity of the interpretation against self |
| Mechanistic view of the person | interest |
| Ahistorical | |
| Descriptive or eidetic | Experience is obtained through the mind of |
| Strongly epistemological (experience the fundamental | consciousness as it appears |
| source of knowledge) What is the nature of the relationship | tonorious as it appears |
| between the knower and what can be known | |
| The state of the s | |
| | l . |

Source: Adapted from Tuohy et al. (2013).

There are two main schools of thought rooted in phenomenology philosophical traditions, namely descriptive phenomenology and interpretive phenomenology (hermeneutics). Descriptive phenomenology was first developed by Husserl (1962), who emphasised the description of the meaning of human experience from an epistemological standpoint. Heidegger, a student of Husserl, departed from Husserl's philosophy and moved towards interpretive phenomenology, which emphasises the importance of interpreting and understanding human experience from an ontological stance rather than merely describing (Polit & Beck, 2008). According to Streubert and Carpenter (2011), the lived experience of the everyday world is the central focus of phenomenology. It is the interpretation of meaning, as seen in this study on the various everyday experiences of RNs caring for dying patients.

The term 'hermeneutics' has its origin in the Greek verb *hermeneueuein*, meaning 'to interpret', and the noun *hermeneia*, meaning 'interpretation'. The term derives from Hermes, the wing-footed messenger-god associated with the Delphic oracle, who was responsible for changing the unknowable to a form that humans could understand via language and writing (J. L. Thompson, 1990). Therefore, the aim of interpretive phenomenology is to describe, understand and interpret participants' experiences in context. Geanellos (1998a) pointed out that understanding and interpretation are the primary concerns of hermeneutics. C. Taylor (1985) defines interpretation as follows:

Interpretation in the sense relevant to hermeneutics is an attempt to make clear, to make sense of an object of study. This object must, therefore, be a text or a text analogue, which in some way is confused, incomplete, cloudy, seemingly contradictory—in one way or another, unclear. The interpretation aims to bring to light an underlying coherence or sense. (p. 15)

Rapport (2005) defines hermeneutic phenomenology as 'the science of interpretation of texts, whereby language, in its written or spoken form, is scrutinised to reveal meaning in phenomena' (p. 125). Gadamer (1976, 2004) argued that each researcher's interpretation is influenced by his or her unique personal experiences. Therefore, Gadamer (2004) claimed that there is no one single interpretation, emphasising that

there cannot . . . be any single interpretation that is correct in itself . . . the historical life of tradition depends on being constantly assimilated and interpreted. An interpretation that was correct in itself would be foolish ideal. (p. 415)

Thus, interpretation and hermeneutic understanding promotes textual reflection and increases one's thoughtfulness (van Manen, 1990). Phenomenology and hermeneutics are rooted in

philosophy and, according to van Manen (1990), these terms are used interchangeably in the literature. They play a complementary role in research because they have been modified by subsequent scholars over time.

The following sections discuss the major differences between the philosophies of Husserl, Heidegger and Gadamer. Subsequently, the paper argues how the research aligns with the philosophical intent of Gadamer and the application of the five stages of interpretive data analysis to complement the philosophical tenets of Gadamer as the best fit to answer the research query. In this study, this approach illuminated minute details, created meaning, encouraged awareness and produced an understanding of the everyday experiences of nurses caring for dying patients in Singapore (van Manen, 1990).

3.4 Husserlian Phenomenology (1859-1938)

Husserl is described as both a phenomenologist and a transcendental philosopher (Moran, 2005). He was a mathematician who is credited for introducing the study of the 'lifeworld' (Koch, 1995, 1996, 1999). Husserl (translated in 1970) argued that phenomena must be understood in terms of what individuals experience pre-reflectively, free from cultural context and without resorting to interpretation (Dilthey, 1985; Moran, 2000). Phenomenology is an attempt to present a phenomenon freely and without prejudice in such a way that it can be described precisely and understood in the best possible way (Dowling, 2007). Husserl's philosophy emphasises the description of a person's lived experience and the ways in which he or she expresses it. Husserl's transcendental phenomenology is essentially based on intentionality, eidetic reduction and constitution of meaning (C. Adams & van Manen, 2008). The term 'intentionality' relates to being conscious of something, some object, meaning that all forms of consciousness are characterised by intending objects (Zahavi, 2003). In other words, to understand the world is to research, question, theorise and become fully part of it (van Manen, 1997). 'Eidetic reduction' or descriptive phenomenology, which has a strong psychological orientation, aims to obtain fundamental knowledge about phenomena (Maggs-Rapport, 2001). Eidetic reduction is often referred to as an objective phenomenology, which adopts the positivist paradigm and bracketing as a strategy to achieve objectivity. Eidetic reduction involves suspending personal prejudices to reach the essence of an experience through pure consciousness (Kafle, 2011). Husserl believed in phenomenological reduction with a reflection on existing beliefs, allowing one to obtain unadulterated phenomena that would otherwise be unobtainable. 'Constitution of meaning' refers to identifying the essence or structures that constitute consciousness and perception of the human lifeworld (Koch, 1995).

Descriptive phenomenology involves four steps: intuiting, analysing, describing and bracketing (Streubert & Carpenter, 2011). Intuiting involves immersing oneself in the phenomenon under investigation. Analysing involves exploring the relationships within the phenomenon. Husserl's focus is strongly grounded in an epistemology that regards experience as the source of fundamental knowledge (Dowling, 2007). The describing phase takes place when verbal descriptions are grouped together to analyse the critical elements in participants' lived experiences (Burns & Grove, 2009; I. Holloway & Wheeler, 2002; Streubert & Carpenter, 2011).

A distinctive feature of Husserlian phenomenology is the use of bracketing. Bracketing is a process of suspending personal beliefs so that the researcher can 'enter the world' of the research participant (Clarke, 1999). This enables the researcher to analyse the data without conforming to their own presuppositions (Ahern, 1999; Ashworth, 1997; Clarke, 1999). According to two proponents of Husserlian phenomenology, Colaizzi (1978) and van Kaam (1966), the given phenomenon must be separated from one's own beliefs and experiences by bracketing or holding back preconceived and pre-learnt feelings, traditions, beliefs and ideas that do not allow the true essence of the experience to be revealed (Cohen & Omery, 1994; Gearing, 2004). The use of bracketing ensures that the researcher's own experience does not influence the research process, reducing bias (Paley, 2005; Parahoo, 2006). However, this creates subjectivity because one cannot be completely disconnected or totally eliminate objectivity (Gearing, 2004). Bracketing is the fundamental component of studies using the Husserlian phenomenological approach (Gearing, 2004).

In contrast, hermeneutic phenomenology Gadamer (2006) acknowledges that biases cannot be set aside because they are integral and essential to the interpretive process (cited in van Manen, 1997). While the present study used intuiting, analysing and describing, I also acknowledged my previous experiences caring for the dying from different cultural perspectives, which may have influenced the research process. I reflected on and interpreted the emerging data from a wider perspective (Koch, 1996), concurring with Heidegger as an interpretive phenomenologist. Martin Heidegger is a philosopher who built upon the

foundation laid by Husserl by transforming the idea of intentional consciousness of the world into the concept of 'being in the world' (Heidegger, 2007).

3.5 Heideggerian Phenomenology (1889-1976)

Heidegger (1889–1976) was an existential phenomenologist whose beliefs were deeply phenomenological and whose philosophy focused on ontology (the nature and relationships of being). Heidegger's work led to a major shift in phenomenology. Heidegger considered phenomenology as destructive because the researcher fails to see the larger meaning behind every day experiences. The researcher must discover hidden concealed truths and go beyond the description of the lived experience of the person to interpretation and hermeneutics (Burns & Grove, 2009; Polit & Beck, 2008; Streubert & Carpenter, 2011). Husserl and Heidegger also influenced the work of Gadamer.

The word hermeneutics is derived from the Greek word *hermeneia*. This suggests that understanding can emerge in various forms, including language, text, interpersonal communication, personal experiences with oneself and society and reflections involving language, religion and art (Gadamer, 1976). Thus, hermeneutic phenomenology investigates and describes through reflection and writing. The description of a phenomenon leads to an understanding of the meaning of the experience (Osborne, 1994).

Interpretive phenomenology includes a number of concepts; 'being in the world', 'forestructure', 'lifeworld existential themes' and the 'hermeneutic circle' (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). Heidegger's radical movement took place when he published his text *Being and Time*. He strongly dismissed the notion of intentionality and favoured existentialism, which he termed *dasein*, meaning 'being in the world' (Heidegger, 1958, 1962; Moran, 2000). Heidegger advocated that the past, present and future can help make sense of being in the world and create better contextual understanding (Annells, 1996; Heidegger, 1958, 1962; Moran, 2000).

Heidegger rejected Husserl's notion of bracketing thoughts or presuppositions. He argued that one can never bracket one's thoughts and that one's pre-understanding cannot be avoided in the development of understanding (Keller, 1999). As his work evolved, Heidegger (1958) replaced the concept of knowing with that of understanding, asserting that understanding is only possible when there is knowing. Heidegger also believed that the researcher is part of

the research. Therefore, the researcher's previous understanding and knowledge ('forestructure') helps in interpreting the phenomena under investigation (i.e. the world of the participant) and must be acknowledged and integrated into the research findings (McCance & Mcilfatrick, 2008). This aspect is termed 'co-constitutionality' (Flood, 2010). Finlay (2008) argued that to understand, we must recognise what has influenced our understandings and views of the world. Rather than setting aside these understandings, they must be brought to the fore so they can be recognised as influences and biases. Through this acknowledgement, the researcher can be open to other people's meanings and the understanding that experiences are linked to social, cultural and political contexts (Flood, 2010).

This focus on interpretation and hermeneutics is radically different to the philosophy of Husserl, who emphasised the pure description of lived experience. Heidegger further asserted that the researcher's responsibility is to unveil the experiences and hidden meanings of participants (H. Wilson & Hutchinson, 1991). Heidegger (2005) believed that being in the world is understood through language and speech. He also introduced the concept of 'facticity' to describe the lived experience of being in the world as a temporal mode of *dasein* (Heidegger, 1962). Heidegger expressed the nature of 'being' as Dasein in this manner:

Dasein, on the basis of its metaphysical constitution, on the basis of being-in-the-world, is always in its very possibility already beyond all being. And in this being-beyond it does not come up against absolute nothingness. Rather, on the contrary, in this very being-beyond Dasein holds before itself the binding commitment as world (cited in H.Rapport, 1991, p. 90)

He developed this thought to highlight what is hidden in meaning. Heidegger asserted that researchers' previous understandings and knowledge, known as 'forestructure', stems from their experiences and helps in interpretation. Standing (2009) refers to forestructure as prior awareness, fore-conception, pre-awareness or pre-understanding before interpretation can be understood. When investigating a phenomenon, the researcher is inseparable from his or her assumptions and preconceptions, which must be acknowledged and integrated into the research (Flood, 2010; McCance & Mcilfatrick, 2008). Therefore, in the present study, my prior extensive knowledge in and clinical exposure to caring for the dying was acknowledged as valid and grounded in reality. There was continuous self-reflection, one of the core characteristics of phenomenology (Rapport & Wainwright, 2006). My previous experience facilitated the interpretation and contextualisation of data analysis.

Heidegger (1927) displayed his radical thinking by introducing the concept of the 'hermeneutic circle'. The hermeneutic circle is the manner in which interpretation through understanding is achieved by a circular process of continuous re-examination of propositions (Rapport & Wainwright, 2006). Hermeneutic circle is a reciprocal process involving backand-forth questioning that leads to an expanding circle of ideas known as the 'hermeneutic circle'. Using this circle, the researcher attempts to discover the true meaning of the experience (McConnell-Henry, Chapman, & Francis, 2009). Understanding occurs when the researcher and participants meet through dialogue and openness. In the present study, I encouraged participants to freely share and describe their interactions, workloads and experiences in the context of their daily care of dying patients. My background knowledge and understanding led to the specific research inquiry. Hermeneutic scholars claim that personal knowledge is both useful and necessary to phenomenological research (Geanellos, 2000). Questioning, verbatim transcription and examining and re-examining the text back and forth helps create the hermeneutic circle. The researcher moves in and out of an imaginary circle, connecting with the parts, then the whole, then the parts once more, taking time to understand the text with each iteration. The hermeneutic circle refers to the idea that the understanding of a phenomenon as a whole can only be in reference to its individual parts, and the understanding of each individual part can only be in reference to the whole (van Manen, 1997). Interpretation must be found within the context and continually changes throughout the research process.

Gadamer (1976, 2004, 2006) adopted much of Heidegger's work. The next section explores Gadamer's philosophical notions of hermeneutics and explicitly demonstrates how they helped me understand the experiences of RNs caring for dying patients in acute care settings.

3.6 Hans-Georg Gadamer (1900-2002)

Gadamer was a student of philosophy and was influenced by the work of Husserl and Heidegger. Gadamer's philosophy derives from Heidegger's ontological structure of understanding, fore-meanings and prejudices. Gadamer's (1975) main ideas, which are closely aligned with those of Heidegger, were described in his text *Truth and Method* (Gadamer, 1960, 2003), which laid the foundations for demonstrating how universal interpretations of phenomena can be unveiled through art, play and language. Gadamer

(2004) revealed the limitations held by positivists, who dominated the scientific field of study:

The question arises as to how we can legitimate . . . hermeneutical conditionedness of our being in the face of modern science, which stands or falls with the principle of being unbiased and prejudiceless. . . The genuine researcher is motivated by a desire for knowledge and by nothing else. And yet, over against the whole of our civilisation that is founded on modern science, we must ask repeatedly if something has been omitted. (p. 10)

Gadamer (1960) exposed the rigidity and limitations of the scientific world and argued that revealing the truth about subjective experiences of life, death and history is only possible through interpretation. In *Truth and Method*, Gadamer (1960, 2003) argued that only hermeneutic phenomenology could provide the basis of understanding and interpretation of phenomena. He went further by extending and developing Heidegger's work. Two key positions advocated by Gadamer (1976) were 'prejudgement', or one's preconceptions, prejudices or horizons of meaning that are part of one's linguistic experience and make understanding possible, and 'universality', or the notion that the person who expresses themselves and the person who understands are connected by a common human consciousness, making understanding possible (Converse, 2012; Dowling, 2007). Other central concepts in Gadamer's philosophy include belonging to tradition and language, dialogue and true question, fusion of horizons, prejudice and the hermeneutic circle (Gadamer, 1998), all of which are mutually intertwined. These concepts are discussed in the following sections.

3.6.1 Belonging to tradition and language

Gadamer (2006) believed that one must have a pre-understanding, foreknowledge or prejudgement of a phenomenon before one can understand its meaning. He purported that, as human beings, we have common prejudices arising from our histories, which may prevent understanding. Awareness of one's prejudices can isolate the meaning of text. Therefore, one of the core tenets of his philosophy is bringing one's fore-understanding to the subject of concern. The 'history of effect' implies that understanding is possible when there is already a relationship between the phenomenon under study and the culture to which the researcher belongs. Understanding is more readily obtained when the researcher and participants are connected by a common language (Palmer, 1969; Lawn, 2006b). Gadamer (2006) viewed words as the expression of language. In this study, participants were able to express

themselves in their own words during interviews, and, as the researcher, I could gain an understanding from their perspective. This task was not easy because questions must elicit a meaningful reciprocal dialogue. My ability to understand participants' points of view required me to be able to understand expressions used by ethnically diverse nurses. Understanding was made possible because of my shared history of 'being in the world' with participants.

Gadamer (2006, as cited in Annells, 1996) placed much emphasis on language and its understanding as being fundamental in immersing oneself in dialogue. It is through language that one can connect and 'be in the world' of participants (Annells, 1996; Converse, 2012; Moran, 2000; Sherratt, 2006). My 17 years of clinical experience caring for dying patients facilitated my understanding of participants' conversations and analysis of the texts. However, my previous experiences may or may not have been similar to those of participants. Prejudices formed through experience create the platform from which one views the world (Koch, 1996). The text must be understood in its original context, and nothing should be added to invoke further understanding of the phenomenon (Gadamer, 2006). Gadamer (2004) highlighted that having the 'right horizon of inquiry' helps in the interpretation of reality. The Gadamerian hermeneutic approach takes the position that the writer is embedded in the social, cultural and historical world (Gadamer, 2004), which must be taken into consideration when understanding the experiences of nurses caring for dying patients. Gadamer uses the analogy of learning an ancient language in which one must interpret each sentence before attempting to understand the linguistic meaning of parts of the whole sentence. V. Fleming et al. (2003) also place an emphasis on language, arguing that historical awareness is positively associated with the development of understanding. Therefore, my horizon of understanding and prejudices ultimately influenced the development of my understanding in the present study.

3.6.2 Dialogue and true questions

Understanding occurs when the researcher and participants meet through dialogue and openness (McConnell-Henry et al., 2009). The emphasis is on conversation whereby the possibility of understanding can occur through listening to one another (Gadamer, 2001). Gadamer (2006) asserted that the researcher and participants must be like-minded. Dialogue was a crucial feature of this study. Participants were allowed to take the lead, and I was open

to a range of possibilities by actively listening to participants and interpreting the words in the transcript. This dialectic movement applies not only to the text but also to the relationships between the interpreter's fore-understanding, participants and text. Gadamer (2006) asserts that knowledge occurs when there is a dialectic movement in the conversation between the researcher and participants. He refers to this notion as a logical 'Socratic-Platonic movement' between the questions and answers. The researcher's fore-understanding guides the inquiry. This study involved conversations with nurses in the form of questioning, engaging in dialogue and examining the text. Dialogue was the crucial feature, and, importantly, my background was similar to those of participants. As the researcher, my preunderstanding of what it means to care for a dying patient from my years of nursing melded with the experiences of participant nurses. As such, approaching a study from the perspective of one's own tradition and listening and allowing oneself to understand all possibilities of what the transcript has to convey is unique. The dialectic movement involves a back-and-forth interpretation of the text, known as the hermeneutic circle, a movement from the entirety of the text to its parts and back to again.

Gadamer (2004) expressed hermeneutics as follows:

We must understand the whole in terms of the detail and the detail in terms of the whole . . The anticipation of meaning in which the whole is envisaged becomes actual understanding when the parts that are determined by the whole themselves also determine this whole. (p. 291)

Gadamer (2004) agreed with Heidegger's notion of being in the world, which occurs in the dialogical process of the hermeneutic circle but took this a step further by constructing a fusion of horizon between the interpreter and the phenomenon under study (Dowling, 2007). In the present study, I listened to the audio recordings and read the transcripts repeatedly, staying open to what they had to reveal. Gadamer (2004) metaphorically equated this to play (*spiel*), in which there is constant back-and-forth movement, an oscillatory effect in which there is engagement between the researcher and text to open up the understanding of possibilities.

At times, I struggled to understand the text. According to Gadamer (1998), only a person who has questions may acquire knowledge. He argued that there is no one method of asking questions and that learning takes place when something deserves to be investigated. Questions need to be open and are an essential aspect of the interpretive process to help form

a new horizon and make understanding possible (Lopez & Willis, 2004). Questioning opens up possibilities of meaning; thus, what is meaningful passes into one's own thinking on the subject. To ask a question means to bring into the open that which is unknown. Thus, the essence of the question must have some direction. The openness of the question is boundless, but questions also have their limitations. I listened to the audio and read the text several times to provide different dimensions to understanding. Reading the text and hearing the language directly developed understanding of the RNs' perspectives or meanings (Palmer, 1969). According to Gadamer (2006), the ability to go beyond what is stated and ask questions enables the development of one's horizon. It helps to revisit the horizon of preunderstandings. Questioning led to entering into dialogue and being able to understand possibilities. This metaphor of 'play' meant looking at the phenomenon in its entirety, leading to a fusion of horizons.

3.6.3 Fusion of horizons

Gadamer (2004) defines the concept of horizon as 'the range of vision that includes everything that can be seen from a particular vantage point' (p. 3001). Turner (2003) asserted that an individual's horizon or viewpoint is constantly in the process of formation and is shaped by both the past and awareness of the present. My horizon in relation to caring for the dying had been influenced by my personal encounters with family deaths, caring for dying patients and my reading of the literature. Likewise, the study participants had their own horizons shaped by their individual histories and cultures. How these horizons come together is an important consideration in the hermeneutic approach.

Understanding is derived from the personal involvement of the researcher in a reciprocal process with participants. Application is an integral part of the hermeneutical process with respect to understanding and interpretation. Merging of the text based on the questions is central and is a mixture of the past and present (Palmer, 1969). Engaging in bilateral communication allows one to see one's own horizon and move beyond it to see the present. Taking a broader perspective can aid the researcher to better understand the present. To have a horizon means being able to see beyond to what is 'close at hand' (Annells, 1996). Gadamer (2006) also highlighted that an individual's horizon is not static but is constantly evolving. In Gadamer's view, if a person cannot see far enough and overvalues that which is nearest to hand means that he or she has no horizon.

Geanellos (1998a) believed that the only way to reach an interpretive understanding is by engaging with the text inside the hermeneutic circle. Hekman (1986) asserted that 'In this interpretive dialogue, between the text and the interpreter, resides the fusion of horizons, which is a fusion of the text's horizon with that of the interpreter' (p. 111). Understanding does not merely involve recreating someone else's meaning. According to Hertz (1997) and Freeman (2007), ongoing critical self-reflexivity and conversations about the experience while simultaneously living in the moment and actively constructing interpretations of the experience are important components of hermeneutic phenomenology. Past experiences enhance understanding, which was achieved through the researcher's openness to fusing the horizon of the phenomenon of interest (Koch, 2006). However, Gadamer (1987) argued that a definitive interpretation is not possible—the components of the hermeneutic circle of understanding, which include prejudice, linguistic understanding, historicity, fusion of horizons and lived experiences, are important to interpretation (Annells, 1996). Gadamer (2006) indicated that horizons are not static but are continuously being formed and acknowledged the possibility that a fusion of horizons may never be reached. My understanding of caring for the dying prior to the interviews was different to that following the interviews. The hermeneutic task of reconstruction occurred when the participants and I reached a common understanding, which was based on conversations with the many participants in this study (see section 3.6.2).

To reach a point of fusion is just one phase of understanding (Gadamer, 2006). When applied to this study, the understandings gained from the fusion of horizons emerged from my preunderstandings of caring for dying patients. An appreciation of the greater complexity of what it means to care for dying patients was reached. The fusion of horizon is not an end in itself but merely the emergence of a new understanding. However, the researcher must know when to stop rather than continuing indefinitely. V. Fleming et al. (2003) highlighted the difficulty of making a decision based on resources and/or time. In this case, it was not possible to return the findings to the study participants to ask them to comment on the development of understanding. However, it was possible to share the evolving understanding with participants and ask whether there was anything they might add. In this manner, the rigour of Gadamerian philosophy was applied.

3.6.4 Prejudice

The word 'prejudice' often connotes something negative. Gadamer worked towards changing this negative connotation to something positive. According to Gadamer (1976), prejudices, traditions or authority may hinder true understanding. However, he claimed that from the ontological perspective, understanding is not possible without prejudice and that prejudice and tradition do not necessarily distort understanding. Indeed, the failure to acknowledge tradition, history and prejudice can block the understanding of being. Prejudices are formed by the nature of one's experiences and through the lens of one's culture and tradition. To enable all possibility of understanding meant that as a researcher, I had to put aside my prejudices and be open to the views of participants to gain an understanding of the phenomenon under study. The researcher must continually self-reflect to achieve deeper understanding and meaning (Binding & Tapp, 2008). Given that my clinical experience working in the acute care setting and caring for dying patients was from a traditional nursing background, it was impossible to disassociate from my prior beliefs and prejudices. Therefore, my pre-understanding of caring for dying patients allowed me to enter into the hermeneutic circle to understand the present (Geanellos, 1998b). Further, understanding takes place when a fusion of past and present horizons occurs (Gadamer, 2004; Grondin, 2003). The formation of common opinion through dialogue leads to discussion. Thus, the implicit prejudices over which one has no conscious control appear to influence interpretation without one being aware of it. Gadamer (1977) highlighted that interpretation required us to thematise our prejudices to arrive at a proper understanding of an issue. Gadamer (2004) stated that 'a person who is not ready to put his or her own prejudices in question is someone to whom there is no point in talking' (p. 44).

Therefore, throughout the investigation of the phenomenon, I engaged in continual self-reflection to attain meaning or understanding. This ongoing self-reflexivity, supported by Geanellos (1998a), V. Fleming et al. (2003) and Robb (2006), is seen as a positive opportunity to gain new understanding and knowledge. The role of prejudice is a central feature in Gadamerian hermeneutics, which is in contrast to the philosophy of Edmund Husserl, who advocated detachment from presuppositions and all external influences (highlighted in section 3.4).

3.6.5 The hermeneutic circle

Gadamer (as cited in Koch, 1996) describes the circular process of hermeneutics as a fusion of horizons. The emphasis on language strongly affirms the position of the researcher in the hermeneutic circle. The circle is used as a metaphor to explain the dynamic movement between parts of a text and the whole text (Annells, 1996). To understand the meaning of the nurses' experiences, I was aware of my fore-understanding and remained open to and aware of my biases to enable the text to convey a unique understanding against this fore-understanding (Gadamer, 1989). The hermeneutic process is a dialogical process in which the researcher's horizon and the topic of study is combined. This rigorous forward and backward interaction assists in the completion of the hermeneutic circle (Allen & Jenson, 1990).

The hermeneutic circle consists of three main steps: first, a naive reading by the researcher to become familiar with the text and begin formulating thoughts about its meaning for further analysis; second, a structural analysis in which meaningful patterns and connections are identified; and third, interpretation of the whole text, which involves an initial interpretation and reflection (Flood, 2010). Gadamer (2001) dismissed the bracketing and phenomenological reduction advocated by Husserl, arguing that it is impossible to eliminate one's own concepts in interpretation. However, Gadamer's contribution to hermeneutics is merely philosophical, and he provided no set rules or methods for the researcher to follow (Gadamer, 1998, 2006, 2008). The hermeneutic circle is a process by which understanding may be achieved rather than a set of rules for gaining understanding. The circle must be reentered on more than one occasion to enable understanding to emerge and the identification of a horizon. The researcher moves back and forth to gain a complete understanding of the entire context of the text. The hermeneutic circle, in which attention is placed on the text, awareness of life, interest in human meaning and how we make sense of it, can be applied to gain a deeper appreciation of the experience.

3.7 Rationale of the Theoretical Framework

Gadamer's (1976, 2004, 2006) interpretive framework was used to guide this study. Moving away from the scientific method, which places much emphasis on objectivity, I brought my personal experiences to the study, aiding in the interpretive process. My personal horizon of

caring for the dying is disclosed in the analysis of data and presentation of the findings in Chapter 5. Disclosure of one's personal thoughts of the phenomenon under investigation involves disclosing one's preconceptions and biasness in the interpretive process. The essence of qualitative interpretive research is to acknowledge the researcher as a 'voice' in the research itself (Guba & Lincoln, 2005). In other words, this type of research involves an engagement of the researcher's own horizon in the interpretive process. This study was driven from my perspective as a nurse who had practised in the acute care setting for 17 years. Having worked in various acute care settings, I clearly understood the context of the nurses' experiences caring for dying patients in an acute care setting. Therefore, I was able to bring a personal perspective to the phenomenon under investigation. My personal encounters with death and dying influenced the interpretive process throughout the data analysis. However, I do not claim that my interpretations are definitive because they may differ from those of other interpreters. I agree with Gadamer (1976, 2004, 2006) that each interpreter brings a unique horizon and will interpret the data in different ways, even if the interpretations are similar. Gadamer (2006) emphasised,

There cannot . . . be any single interpretation that is correct in itself . . . The historical life or tradition depends on being constantly assimilated and interpreted. An interpretation that was correct in itself would be a foolish ideal. (p. 398)

A hermeneutic Gadamerian phenomenological approach was selected to guide the research project. The basic elements of phenomenology (descriptive) and hermeneutic phenomenology (interpretive) from various philosophers were applied. A key difference between hermeneutic and descriptive phenomenology is that hermeneutic phenomenology does not require researchers to bracket their preconceptions during the research process but to use their foreknowledge as part of the analysis (Lowes & Prowse, 2001). Descriptive phenomenology embraces the philosophical underpinnings from an epistemological stance, while interpretive phenomenology is based on an ontological stance. The interpretive approach was useful in examining the contextual features of experiences that were directly relevant to practice obtaining an understanding of the everyday experiences of RNs caring for dying patients in acute care settings in Singapore. The constructivist hermeneutic approach enabled me to bring to light to the hidden features of experiences that may have been overlooked in a purely descriptive approach (Rather, 1994). Part of choosing Gadamerian phenomenology was the consideration of personal experiences and reflections related to the issues under investigation.

The aims of this study and the approach offered by Gadamer provided a context, logic and criteria for the conduct of this research. The study was situated within a hermeneutic theoretical framework, and Gadamer's framework was chosen to understand the possibilities of nurses' experiences when caring for the dying. Gadamer's hermeneutic framework offered a way in which the research aims could be realised. After reading Gadamer's translated text as well as the reviews and works of others who have used his philosophy to develop a theoretical framework (V. Fleming et al., 2003; Geanellos, 1998a; Koch, 1996; Robb, 2006), a detailed insight and understanding into his philosophical stance was gained and applied, confirming his philosophy as appropriate in underpinning the theoretical framework of this study into. Although Gadamer did not specify a method, it is important to discuss the qualitative methods used for this study to show how systematically the topic was investigated. These methods such as a critique of different interpretive approaches, rationale used in Gadamerian -based approach, establishing trustworthiness, ethical considerations, sampling strategy and data storage are discussed in Chapter 4.

Chapter 4: Methods

4.1 Introduction

Chapter three discussed the Gadamerian philosophic hermeneutic framework for how understanding can be made possible. However, Gadamer (2006) did not offer a method or set of rules for research processes; rather, he focused on how understanding can be developed or made possible when engaging with participants in context. Indeed, none of the German philosophers discussed—Husserl, Heidegger nor Gadamer—developed research methods. They were more concerned with philosophy, which is used by many nursing researchers to underpin qualitative studies. van Manen (1997) acknowledged that there is no prescribed recipe or set of techniques for interpreting and understanding human experience. The absence of a prescribed method presented the opportunity for me to adopt approach V. Fleming et al.'s (2003) approach to data analysis.

This chapter presents a brief critique of the existing interpretive approaches in relation to Gadamer's hermeneutic phenomenology. Given that there is no definitive method for investigating the concept of understanding using a Gadamerian framework, the analysis and interpretation of the data were conducted using the five-step approach devised by V. Fleming et al. (2003). This chapter includes a discussion on the appropriateness of the method used to gather, analyse and interpret the study data. I attempted to analyse all subtleties in the data, utilise relevant texts and apply sensitivity to guide the process of analysis. The modified method provided by V. Fleming et al. (2003) is based on the tenets of Gadamer's philosophy, and the discussion provides an interpretation of how it helped retain the concepts highlighted by Gadamer.

4.2 Critique of Different Interpretive Approaches

Gadamer (1976) was primarily concerned with the philosophical means of obtaining a deep understanding of text. However, he neither offered a method nor dismissed the concept of method but acknowledged that to reach understanding, a systematic methodical direction is required. Gadamer (1975) also argued that it is not simple to recommend a method. van Manen (1997) emphasised the necessity of finding an approach that can guide the research

inquiry and that reflects interpretation. Authors have suggested various methods to undertake phenomenological and hermeneutic studies (Colaizzi, 1978; Diekelmann, 1992; Giorgi, 1989; Koch, 1995, 1996; van Manen, 1984). However, a clear distinction between phenomenological and hermeneutic methods must be acknowledged. V. Fleming et al. (2003) highlighted the existence of several approaches, philosophies and philosophers. Among a 'pot of ideas', V. Fleming et al. (2003) were aware of the limitations of the various approaches.

Colaizzi (1978)offered seven-step approach to conducting Heideggerian phenomenological research in the field of psychology. Colaizzi (1978) highlighted that the researcher can modify his steps but reinforced that significant modifications are only required if the study is underpinned by the work of Gadamer. Colaizzi (1978) recommended validating findings by returning to study participants (Reiners, 2012). However, although researchers who utilise Gadamerian philosophy wish to ensure rigour, their aim is to develop their own understanding of the experiences of study participants (V. Fleming et al., 2003). According to Colaizzi (1978), pre-understanding may only be used to generate research questions, not to inform understanding. Therefore, Colaizzi's (1978) method would have been unsuitable because it does not recognise pre-understanding, which is in direct contrast to Gadamerian philosophy.

van Manen (1984) developed a phenomenological method comprising the following steps: turning to the nature of lived experience, existential investigation, phenomenological reflection and phenomenological writing. Although, these steps are consistent with Gadamer's philosophy, inconsistencies are evident under the element of pre-understanding. According to van Manen (1984), knowledge gained from pre-understanding conceals understanding of the phenomenon. However, Gadamer (1990) takes a strong stance on pre-understanding, arguing that it must be revisited many times through the process of reflection to gain understanding. Therefore, van Manen (1984) method was not chosen for data analysis.

Giorgi (1989) is a psychologist whose approach is firmly grounded in Husserlian phenomenology, which anchors on phenomenological reduction and bracketing. However, this approach is not suitable for a study grounded in Gadamerian philosophy (Cohen & Omery, 1994; V. Fleming et al., 2003; Paley, 1997) because Gadamer (1988) argues that

understanding cannot be separated from one's preconceptions. Understanding does not occur in parts but as a whole. One cannot be separated from one's historicity, prejudices and preconceptions. It is in the harmony of all parts that lies 'the criterion of correct understanding' (Gadamer, 1988, p. 68).

Diekelmann's (1992) research approach is based on Heideggerian hermeneutic phenomenology. This method also poses difficulties for researchers who use Gadamerian philosophy. Diekelmann uses a team approach to data analysis. Transcripts are distributed to the various members of the team prior to group discussion. Disagreements on analysis are resolved by returning the transcripts to participants for verification. According to Diekelmann (1992), this approach serves to resolve biases and eliminate inconsistencies between team members. Diekelmann's attempts to control bias, however, contradict Gadamerian philosophy, the emphasis of which is on developing a deeper understanding through language, culture and history. The explicit dialogical engagement of the researcher with participants deepens and broadens his or her understanding of the world. The active dialogical partnership between the researcher and participants is important because it is through dialogue—an active toing and froing or back-and-forth movement—that meaning emerges (Gadamer, 1975). Through the dialogical relationship, researchers consciously risk their ideas, deepening their understanding and expanding their horizons. Alternatively, Diekelmann's team approach to deepening understanding may be considered a useful Gadamerian approach.

Koch (1996) grounded her research in Gadamer's hermeneutic philosophy, utilising three Gadamerian concepts: pre-understanding, the hermeneutic circle and openness in interviews. However, these concepts or their relationships were not adequately articulated. Therefore, I utilised the method advocated by V. Fleming et al. (2003), enabling the retention of Gadamer's tenets. This approach is discussed in the subsequent sections of this chapter. Table 4.1 illustrates the critical differences in approaches used in relation to Gadamer's hermeneutic philosophy.

Table 4.1: Interpretive Approaches to Gadamer's Hermeneutic Philosophy

| Author | Methodological Approach | Application to Gadamer's Philosophy |
|--------------------------|---|---|
| Colaizzi (1978) | Must have pre-understanding of the topic to generate research question but does not suggest that all understanding is dependent on pre-understanding Uses a seven-step approach Flexible and can be modified Data returned to participants for verification to ensure rigour | Unsuitable Gadamer believed that understanding is dependent on pre-understanding Does not offer a method Data do not have to be returned to participants for verification because it is about developing understanding |
| van Manen (1984) | Steps include: Turning to the nature of the lived experience Existential investigation Phenomenological reflection Phenomenological writing Pre-understanding is regarded as concealing and narrowing analysis | Unsuitable Gadamer's notion on pre- understandings have a positive view Pre-understandings are revisited repeatedly |
| Giorgi (1989) | Grounded in Husserl's phenomenology Associated with reduction and bracketing | UnsuitableGadamer believes all understanding is dependent on pre-understanding |
| Diekelmann (1992) | Grounded in Heideggerian hermeneutic phenomenology Utilises a team approach to control bias in analysis Data are returned to participants for verification and to resolve team disagreements | Unsuitable Team approach must be used to develop a deeper and fuller understanding |
| Koch (1995) | Utilises three Gadamerian concepts: Pre-understanding Hermeneutic circle Openness in interview | UnsuitableUnable to reveal a clear relationship with Gadamer's concepts |
| V. Fleming et al. (2003) | Utilises all Gadamerian concepts: Pre-understanding Dialogue & true question Fusion of horizon Prejudice Hermeneutic circle | Suitable Able to reveal clear relationship with Gadamer's concepts |

Source: Adapted from V. Fleming et al. (2003)

4.3 Rationale for the Approach Used in Gadamerian-Based Research Methods

Gadamer (2001) viewed hermeneutics as an approach rather than a method providing specific guidelines on the acquisition of new knowledge (Debesay, Naden, & Slettebo, 2008). Gadamer's primary intention was to reveal the conditions that facilitated the understanding of being in the world. Therefore, his hermeneutic approach may be viewed as an ontological philosophy, and his process of understanding is not limited to any particular qualitative or quantitative method (Gadamer, 2004). However, in an interview conducted with Heidelberg philosopher Carsten Dutt, he stated that a method is only useful if it is effectively used for benefit (Gadamer, 2001). This understanding suggests that if a method effectively incorporates hermeneutic philosophy, then it may be productively applied to research.

The research method developed by V. Fleming et al. (2003) offers a possible option to adopt Gadamerian philosophical concepts in practice. After reviewing many hermeneutic research papers that had used this method, I was drawn to it because it was based on Gadamer's original work *Wahrheit und Methode* (*Truth and Method*), which was written in his native German. V. Fleming et al. (2003) were all fluent in German, with one being a native speaker. The authors developed the method using the language underpinning Gadamer's philosophy; thus, it was assumed they could detect subtle nuances in their interpretation. I felt confident that the authors would have reached a consensus in the translation of the text to English. Thus, V. Fleming et al.'s (2003) method provides an accurate interpretation of Gadamer's philosophical concepts.

Prior to developing their data analysis method, V. Fleming et al. (2003) undertook a critique of other researchers who had used Gadamerian philosophy to inform their studies. The authors engaged in rigorous academic evaluation, taking the limitations of other studies into consideration and minimising any shortcomings as they developed their method underpinned by Gadamer's philosophy. This was another clear signpost that their method was appropriate for this study. V. Fleming et al. (2003) also identified the existence of other approaches to phenomenological and hermeneutic research in which Gadamer's philosophy was used.

From Dowling's (2007) review of different phenomenological approaches and V. Fleming et al.'s (2003) article, I developed an adequate understanding of Gadamer's hermeneutics.

According to Dowling (2007), Gadamer was a constructivist who adopted a phenomenological stance but did not eliminate the distinction between phenomenology and hermeneutics. The method developed by V. Fleming et al. (2003) offered a more structured and valid technique for this study.

A review of studies conducted from 2004 to 2015 that had utilised V. Fleming et al.'s (2003) method guided this study's approach to Gadamerian hermeneutic philosophical concepts. Initially, it appeared that Howlin's (2008) study on understanding advocacy in children's nursing had adopted Gadamerian hermeneutic philosophy. Howlin (2008) used V. Fleming et al.'s (2003) method to identify, transcribe and record her pre-understandings in a reflexive journal. She discussed the hermeneutic circle and fusion of horizons, but there was no clear reference to V. Fleming et al.'s (2003) method or Gadamer's philosophy of understanding. Instead, Howlin used Benner's (1984) method of data analysis, which is based on Heidegger's philosophy of being in the world, to produce paradigm cases, exemplars and themes. Methodological inconsistencies were apparent—Howlin (2008) reinterviewed study participants to verify their accounts but did not reflect on the development of her own understanding. The purpose of a qualitative study is to show richness in the data, but Howlin simply mentioned in the limitations that the findings could not be generalised. Overall, it appears that Howlin (2008) confused Gadamer's and Heidegger's philosophy rather than adhering to Gadamer's philosophy. Although the application of V. Fleming et al.'s (2003) method was limited, the study did provide an insight into the method.

A study by Grassley and Nelms (2008), *Understanding Maternal Breastfeeding Confidence:* A Gadamerian Hermeneutic Analysis of Women's Stories, used V. Fleming et al.'s (2003) method to guide analysis, particularly the use of open dialogue with participants and the application of the hermeneutic circle. The authors did not report on the identification of preunderstandings, which is essential in Gadamer's hermeneutic circle for understanding to take place. V. Fleming et al. (2003) have also affirmed that identifying one's pre-understanding is necessary in the hermeneutic circle approach. The absence of pre-understanding showed a methodological weakness in the Grassley and Nelms (2008) study. The authors did not mention whether they had reached a fusion of horizons. Although Gadamer (1987) highlighted that a definitive interpretation is not possible, the components of the hermeneutic circle, including prejudice, linguistic understanding, historicity, fusion of horizons and lived

experiences, are significant for interpretation (Annells, 1996). Despite the divergences from Gadamer's tenets, the application of V. Fleming et al.'s (2003) method was useful.

A hermeneutic study by SmithBattle (2009) explored the effectiveness of home visit programs for young mothers in the United States by seeking to understand the mothers using Gadamer's hermeneutic philosophy rather than benchmarking them against objective clinical parameters related to health, parenting and development. The author discussed the preunderstandings, dialogue with participants, the hermeneutic circle and the fusion of horizons in detail but failed to present a clear method of analysis. However, the study reflected V. Fleming et al.'s (2003) method in the discussion.

A hermeneutic qualitative study conducted by Skår (2010) on the meaning of autonomy in nursing practice was inspired by Gadamer's philosophy, which guided the research process and the analysis of the interview transcripts. The study found that the meaning of autonomy in nursing practice was to be knowledgeable and confident. In-depth and focus group interviews were analysed using V. Fleming et al.'s (2003) method based on Gadamer's hermeneutic philosophy to derive emerging themes from the transcribed interviews. The researcher reported that her pre-understandings as both a nurse and nursing teacher assisted in and expanded on the interpretation and that her reflections throughout the research process possibly influenced her findings. However, she did not detail her pre-understandings or reflections. Nonetheless, V. Fleming et al.'s (2003) analytical steps were displayed in a table showing the interpretation of the transcripts. Although it was not reported whether a fusion of horizons was achieved, it appears that V. Fleming et al.'s (2003) method systematically guided the research analysis.

A Norwegian study based on Gadamerian hermeneutic philosophy explored the meaning of the actualisation of self-care resources among a group of older home-dwelling people (Söderhamn, Dale, & Söderhamn, 2013). The narratives used in this study were derived from informants who had participated in a randomised survey conducted by the same authors in 2010 (Dale, Söderhamn, & Söderhamn, 2012). The V. Fleming et al. (2003) method guided the reanalysis of narratives. Although the reanalysis was done systematically, the interpretations may have differed from those of the first study in which the researchers had the advantage of interpreting the narratives first-hand. However, in Gadamer-based research, the text is the starting point of interpretation and may be re-examined several times. Gadamer

(2006) argued that definitive interpretations can never be achieved. However, by examining the text a number of times, different understandings may be gained. In the case of Söderhamn et al. (2013), the researchers brought their pre-understandings during the interpretation process and achieved a fusion of horizons. The researchers acknowledged their self-reflection and that they understood the text beyond their pre-understandings. Notably, the reanalysis was conducted systematically using V. Fleming et al.'s (2003) method, which supported the tenets of Gadamer.

A paper by Rykkje and Råholm (2014) on understanding older peoples' experiences of dignity and its significance in caring was guided by Gadamer's (2004) hermeneutic approach. The findings showed that dignity is always present and involved the whole human being. The hermeneutic research process facilitated this understanding through dialogue with participants, exploration of texts and the hermeneutic circle. However, the authors did not discuss their pre-understandings and how their shared understandings were obtained. The study adopted V. Fleming et al.'s (2003) method of analysis in which text excerpts of interviews revealed emerging themes. Passages representing the whole and the parts were offered to demonstrate new understandings.

The abovementioned studies all supported my decision to use V. Fleming et al.'s (2003) method of data analysis to support the tenets of Gadamer's philosophy. The method has not been fully applied by many authors. However, reviewing the studies based on the hermeneutic approach and V. Fleming et al.'s (2003) method confirmed my decision to apply this approach to understanding the experiences of RNs in caring for dying people in an acute care setting in Singapore. V. Fleming et al.'s (2003) method was utilised to support Gadamer's philosophical ideas. The following five interdependent stages in Figure 4.1offer a clear process:

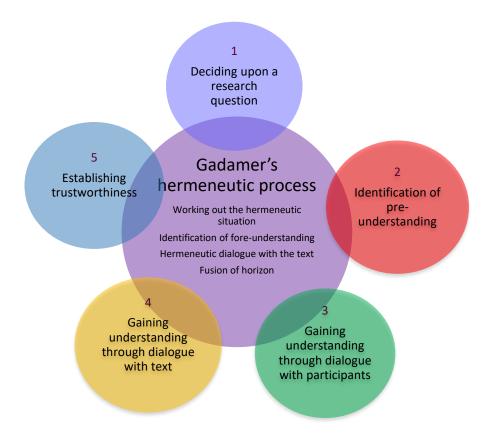


Figure 4.1: Adapted from V. Fleming, Gaidys and Robb's (2003) method to support Gadamer's tenets

The following section discusses these steps and how they were applied to this study.

4.3.1 Step 1: Deciding upon a research question

To conduct research and gain a better understanding of reality, the fundamental element that first needs to be considered is the research question (Burns & Grove, 2009). The research question in qualitative studies informs the theoretical and methodological preferences (Green & Thorogood, 2009). V. Fleming et al. (2003) caution that the research question must be suited to Gadamerian philosophy. The researcher must consider what they wish to study and why, as well as take into account any philosophical considerations, implying that the research question must be well articulated before the design and other methodological processes are chosen (Steward, 2006). In this case, the area of interest must be congruent with the aims of hermeneutics so that the findings and conclusions will be useful. V.E. Fleming and Moloney (1996) have argued that it is essential to ensure internal consistency, thereby contributing to the expansion of knowledge in nursing practice.

Gadamer (2006) emphasised the importance of the research question, which influences the entire research process. The desire to achieve a deep understanding aligns with Gadamer's philosophical tradition. Therefore, the essence of the question opens up possibilities for understanding. The research question informing the present study was influenced by my long-standing interest in caring for the dying. Chapter 2 revealed the lack of research on understanding the experiences of nurses caring for dying people in acute care hospitals in Singapore. However, I appreciated the Western studies and was intrigued to discover more from the local perspective. After much reading and reflection, the quest for more understanding in this area of practice opened the pathway for more questioning. Therefore, throughout the research process, asking the relevant questions kept me and the participants oriented to the subject under study. Through a process of iteration, the research question was developed as follows:

What are the everyday experiences of general practice RNs caring for the dying in an acute care hospital in Singapore?

The essence of this question provides a sense of direction to reveal possibilities (Gadamer, 2006). Understanding is not possible without questioning, and Gadamer (2006) repeatedly highlighted this close relationship in hermeneutics. As a researcher, I wished to develop my understanding alongside that of participants by asking open questions.

4.3.2 Step 2: Identification of pre-understandings

The identification of pre-understandings was pivotal in allowing understanding to develop. Without pre-understanding, one cannot confront the various beliefs and opinions of other researchers and traditional texts (V. Fleming et al., 2003). Researchers who wish to underpin their work with Gadamerian philosophy must identify their pre-understandings and prejudices. Failure to do so will lead to challenges when attempting to confront, confirm and abandon pre-understandings, preventing researchers from achieving a fusion of horizons. The development of deeper understanding may be enhanced through reflexivity and confrontation with various beliefs such as the opinions of colleagues, researchers or those found in traditional texts (V. Fleming et al., 2003; Gaidys, 2007; Robb, 2006).

Geanellos (1998b) argued that pre-understandings may be deepened in two ways. First, statements may be generated by reflecting on pre-understandings to represent their meaning

more clearly. However, because statements may be interpreted superficially, the second means is to write stories, which can deepen self-awareness and better represent pre-understandings. In contrast, Robb (2006) and Gaidys (2007) addressed their pre-understandings using mind mapping. Both authors conducted interviews with their colleagues and subsequently analysed the text. In this manner, the pre-understandings became more visible, transparent and understandable. V. Fleming et al. (2003) have all used the hermeneutic process to develop the method detailed in Step 4 (see 4.2.4). By exploring the different ways of addressing pre-understandings, I was able to decide how to identify my own pre-understandings of what it is like to care for the dying. Through self-reflection, I recalled my past experiences and the challenges that influenced my pre-understandings especially caring for dying patients. As such, the following pre-understandings emerged:

- 1. Communication about dying with patients and family members
- 2. Personal encounters and challenges concerning death
- 3. Managing the care of the dying
- 4. Coping with stress related to death and dying

Identification of the above pre-understandings helped to clarify the issues pertaining to caring for the dying. To gain a deeper understanding, I approached a colleague who had worked in acute care and had experienced caring for dying patients. With the colleague's permission, the conversation was audiotaped, and the dialogue was transcribed. I listened to the audiotape dialogue and read the text several times to gain a full and in-depth understanding of the dialogue. I employed Step 4 of V. Fleming et al.'s (2003) research method to gain understanding through dialogue with text. This dialogue led to an expanded understanding of caring for the dying. Altogether, there were four main themes and 18 subthemes, which are discussed in Chapters 5, 6 and 7 on the findings.

My discussions with colleagues who had shared my experiences of caring for dying patients led to a greater awareness of my pre-understandings and biases and helped to form a shared understanding. The sharing of experiences uncovered my own understandings and viewpoints, enabling me to focus on the evolving horizon and effectively orient the study. Examining the text and listening to the audiotapes repeatedly, as purported by Geanellos (2000), Robb, (2006) and Gaidys (2007), helped to clarify my understanding. Likewise, conversing with the 16 participants helped me to appreciate the question and enter and re-

enter the hermeneutic circle from an open stance. I kept a reflective diary in which to capture verbal and non-verbal cues, emotions, impressions, expressions and personal feelings. This approach aided in further developing an understanding of the phenomenon in the analysis of data from the participants.

4.3.3 Step 3: Gaining understanding through dialogue with participants

V. Fleming et al. (2003), Robb (2006) and Gaidys (2007) have claimed that by using oneself as the research instrument, the researcher can develop a deeper understanding of the phenomenon under study. The in-depth interview is the primary method of data collection in phenomenology to understand what an experience is really like for participants (Parahoo, 2006; Silverman, 2005;). Therefore, this research, which was content specific, endeavoured to gain an understanding of the meaning of caring for dying people. According to I. Holloway and Wheeler (2002) and Parahoo (2006), semi-structured interviews are more specific to the research focus. In the present study, I used a focused interview guide (see Appendix 10) with each participant to cover all areas pertaining to caring for the dying in acute care settings. This was used to encourage participants to talk freely and express their experiences in their own words (Burns, et al., 2011; Polit & Beck, 2008; Streubert & Carpenter, 2011). There was only one central research question that guided the study, 'What are the everyday experiences of general practice RNs caring for the dying in an acute care hospital in Singapore?' Qualitative approach adopts an inductive way of questioning from the participants specific experiences to wider understanding of the phenomenon (Burns, et al., 2011). Hence the interview proforma was a guide. With an inductive approach to questioning, the 'driver' of questions remains with participants. As they responded to question, second and third questions were posed and depended on their earlier responses.

The review of literature on EOL care helped in the development of the guided interview questions to capture the wider perspective on EOL care. In addition, advice was sought from supervisors for further comments and revised accordingly. I also tested the guided interview questions on one of my colleagues who was willing to be interviewed to share her experiences on EOL care. This interview further helped me to develop the questions to capture the nuances of participants experiences.

From the Gadamerian perspective, it is during this stage that the researcher would interact with participants to gain an understanding of the phenomenon of interest. Understanding is only possible through dialogue, and I was open to the opinion of others. I was careful to ask the questions in a logical sequence from the general to the specific. I wished to ensure that all potential areas related to caring for the dying patient were covered. This way of questioning also allowed me to exercise flexibility in progressing the interview from the general to the specific. A face-to-face conversational interview was conducted for 45 minutes in a quiet environment. Data were collected from November 2015 to June 2016. Participants were interviewed in a quiet seminar room in the polytechnic library, which was convenient for them. The quiet environment away from their workplace enabled the RNs to express their feelings without inhibition. An interview guide (see Appendix 10) was used during the conversation. A sample portion of a participant's transcript is attached (see Appendix 11).

I began with a general broad question such as 'Can you tell me about yourself and your nursing background?' The dialogue was followed by a specific open-ended question such as 'In your experience, what does care for the dying involve in your setting?' I adopted an open stance that followed V. Fleming et al.'s (2003) directions to capture historical moments. The course of the conversation was determined by using probes to maintain the focus of the interview, seek clarification of meanings and provide deeper understandings (A. Jones, 2007). The interviews were digitally recorded and transcribed. The audiotaped records enabled me to listen as often as possible to capture their original form (Silverman, 2005) in the first level of analysis.

Interactions took place not only with participants but also with the transcribed text. Gadamer (2006) highlighted that the major aim of the conversation is to allow the researcher to become immersed in the subject matter. He argued that language was the medium through which understanding can be achieved (Gadamer, 2006). By using empathic responses and congruent body language (B. Wright, 1992), I established a rapport with participants, encouraging them to narrate their experiences in caring for the dying. From their gestures, it was evident that participants were comfortable and relaxed. Two participants became emotional as they recalled working with dying patients. However, they were comfortable sharing their experiences and were able to complete the interview. At times, more direct probing questions were asked when I required clarification of information (Polit & Beck, 2008). Complete

concentration and rigorous participation in the interview process improved the accuracy, trustworthiness and authenticity of the data. The conversation was related to the subject matter and did not cross over into other topics. The dialogue was solely conducted by me and was not delegated to research assistants (Gadamer, 2006; van Manen, 1984). My personal involvement enabled me to develop an understanding of what it is like to care for the dying in an acute care setting. Speaking to nurses from different acute care settings helped establish a common ground upon which to proceed with the conversation. In this way, I was able to achieve genuineness, which Gadamer (2006) established as a prerequisite to developing understanding between participants using spoken language. According to Binding & Tapp (2008), it requires the researcher to be open to the meanings of the participants while continuously reviewing my own pre-understandings and to be open to arrive at a new meaning (see Appendix 12).

Although the interviews may have appeared formal, they were conducted as conversations to allay fears and anxieties, lending genuineness to the sharing process. Throughout the conversations, no participants mentioned feeling uncomfortable. I used my communication skills appropriately in developing a shared understanding. Dialogue with the participants broadened the field of horizon, and I gained an understanding through a fusion of horizons with participants. Descriptive notes were taken during each interview to extensively capture the interaction, providing rich material for analysis (Polit & Beck, 2008). These descriptive notes were kept along with the tape recorder in a locked drawer for protection and retrieval of information. Participants were instructed to ignore the device during the interviews. Prior to the conclusion of interviews, I offered each participant the opportunity to ask questions or add comments that were not addressed during the interview. No other issues were raised. Notes were written following the interviews.

As the researcher, I was aware of how the understandings of participants merged with my personal feelings and experiences and how these were integrated in the study. I was mindful that my understanding of participants could never be fully achieved because it constantly evolved, and I was also aware that one's horizons are temporal in nature (Gadamer, 2006). Throughout the dialogue with participants, I was aware that each participant brought their own unique culture and traditions and that seeing the phenomenon from the perspectives of others would pose challenges in reaching a shared understanding (V. Fleming et al., 2003).

As highlighted by V. Fleming et al. (2003), the researcher must truly be receptive to his or her similarities and differences to participants. This facilitates a fusion of horizons between the researcher and participants within the hermeneutic circle.

According to M. F. Johnson (2000), it is difficult to put oneself in the same situation because each individual brings a different pre-understanding with respect to their historical awareness. I had to make conscious effort to see through the eyes of the participants to understand the phenomenon of caring for the dying. V. Fleming et al. (2003) recommend speaking to participants two or three times to gain a better level of understanding. However, in this research, I only had one conversation with each participant. According to Gadamer (2006), shared understandings and encounters will vary because of how they are passed down historically and culturally. Therefore, having two or three conversations would defeat the purpose of the Gadamerian approach because conversations could continue indefinitely. In my opinion, effective communication skills and the ability to analyse the conversation through the hermeneutic circle are important considerations for the development of understanding. While understanding was sought, I was aware that total understanding may not be achieved because of the temporal nature of one's horizon (Gadamer, 2006). Throughout the scheduled interviews, I was able to gain better understanding through effective open-ended questioning skills. According to Streubert & Carpenter (2011), openended questioning skills provides the participants to move freely with greater latitude with their responses and this helped me to use V. Fleming et al.'s (2003) method effectively.

4.3.4 Step 4: Gaining understanding through dialogue with text

Gadamer (2006) repeatedly emphasised the superiority of the spoken word over written text. He regarded writing as 'self-alienation' and overcoming it as 'the highest task of understanding' (Gadamer, 2006, p. 392). The meaning of 'text' not only refers to transcripts. Not only did I read the transcripts, but I listened to the audio recordings and observed nonverbal expressions during the conversational interviews. This meant constantly engaging with the text back and forth within the hermeneutic circle (Gadamer, 2006), which was also guided by V. Fleming et al.'s (2003) method. I chose to transcribe all interviews rather than engaging an experienced transcriber because I wanted to fully immerse with the text, upholding Gadamer's tradition. Hard copies of the transcripts enabled me to make comparisons of the development of understanding.

By reading the text several times and simultaneously listening to the audio recordings, I became more familiar with the words, which helped with the integration of subtle nuances such as the tone of voice, choice of words and pauses. My research diary helped to capture non-verbal expressions such as silence, pauses and tears that I observed during the conversations. Gadamer (2006) highlighted that analysis of the text must move back and forth and then return to the whole text. In this way, the researcher can question and move within the hermeneutic circle. V. Fleming et al. (2003) identified the following four steps that may be done either sequentially or simultaneously to enrich understanding:

- Each text was examined to find an expression that reflected the fundamental meaning
 of the conversation as a whole. This was essential because the meaning of the whole
 influences the understanding of every other part of the text (V. Fleming et al., 2003;
 Gadamer, 2006). Pre-understandings previously identified using self-refection were
 brought to the text to elicit an initial understanding. Some expressions held more than
 one meaning, and I identified as many meanings as possible in the expressions.
- 2. In the second step, a sentence-by-sentence analysis elicited meanings and contributed to the understanding of what it was like to care for the dying. Through transcription, the meaning of each sentence was identified, and each sentence in the text was coded, analysed and grouped into themes. I revisited and listened to the audio recordings several times to build a stronger understanding of the phenomena. I rechecked my transcripts, relooked at specific sentences and phrases that identified the participants care practices and experiences at EOL care. I highlighted the statements with coloured ink and placed my comments at the end of each significant statement. The themes were then challenged and reflected upon through my pre-understandings and historicity of my experiences of caring for the dying in the acute care setting. I repeated the coding process several times and checked with my supervisors so as not to omit any details of the participants expressions. I grouped similar meanings and expressions in the overall question of experience caring for the dying.
- 3. In the third step, the meaning of each sentence or section of the transcript was related back to the text as a whole so that a new understanding that expanded on my pre-understandings of caring for dying patients could be achieved. While identifying themes, I was aware that the back-and-forth movements between the parts and the whole overlapped with the previous step. V. Fleming et al. (2003) acknowledged that

- such interdependence can happen. In hermeneutic philosophy, the movement back to the whole is essential as it allows fulfilment of the hermeneutic circle. This occurred when I began to identify the emergent themes from the various participants. I looked for the commonalities among the participants and validated the emergent themes.
- 4. The fourth step involved identification of the passages that represented our shared understandings, resulting in a number of themes and subthemes (V. Fleming et al., 2003). This process could continue indefinitely. Because each understanding can change with time, a decision was made when both my understanding and that of the participants merged into a horizon (V. Fleming et al., 2003). The availability of time and resources can also dictate the frequency of cycle repetition, and analysis ceased when the shared understandings elicited no further meanings.

4.3.5 Step 5: Establishing Rigour

Trustworthiness

Trustworthiness is an essential component of qualitative research and is the final step of V. Fleming et al.'s (2003) method. The findings should reflect the meaning of the nurses' experiences, and trustworthiness relates to the methodological integrity of the research process and the truthfulness of the findings. In Gadamer's (2006) view, integrity refers to the meaning of the experiences, not only the content. This is supported by L. A. Watson and Girard (2004), who suggest that meaning relates to the whole in which the researcher and participants dynamically bring their histories, language and culture back and forth in the hermeneutic circle. To demonstrate rigour, plausibility and robustness in qualitative research, Guba and Lincoln (1994) use the terms credibility, dependability, confirmability and transferability, which are applicable to the Gadamerian research process, as the criteria by which to judge the trustworthiness of a study. In addition, the researcher's continual reflexivity added to the rigour of the study.

4.3.5.1 Credibility

The term 'credibility' is often preferred to internal validity in the qualitative paradigm (Silverman, 2005; Streubert & Carpenter, 2011). Credibility is similar to verification and is achieved through prolonged engagement and maintaining an audit trail of the data (Tobin & Begley, 2004), which was done by checking back with supervisors and colleagues (Creswell,

2003, 2007, 2013), also known as member checking (Streubert & Carpenter, 2011). Creswell (2003, 2007, 2013) supported the view that member checking helps to validate the accuracy of emerging themes. The analysis of data reveals the intended focus of the research and the perspectives of participants, which must be represented as clearly as possible (V. Fleming et al., 2003). The description, interpretation and verbatim passages are included in the chapters on findings to demonstrate the fusion of horizons and meanings. I closely adhered to Gadamer's tradition of language by quoting passages to convey and support my understanding. During the process of coding, transcripts were read repeatedly to elicit themes and subthemes. Notes were written immediately following each interview to capture small nuances of expression.

This research was supervised by two supervisors who both had vast experience in EOL and palliative care and were experts in qualitative research. My prolonged engagement with the data along with constant verification, supervision and regular cross-checking from supervisors provided credibility and rigour to the interpretations and possibilities of meanings. Transcripts were also given to a colleague who had completed doctorate to compare the coding and the consistency of the data interpretations.

4.3.5.2 Dependability

Dependability refers to the stability of the data over time and the conditions of the study (Polit & Beck, 2014). While the experiences of participants may be similar, the conditions and context of studies may vary. Dependability is demonstrated by using an audit trail in which the researcher provides detailed descriptions of how the research was undertaken (I. Holloway & Wheeler, 2002). Dependability is achieved when other researchers can follow the trail and potentially arrive at the same or similar conclusions (Koch, 2006). According to Koch (2006), the researcher should explain why particular methodological decisions were made. Arguably, there are some researchers who do not agree with such an audit trail (Cutcliffe & McKenna, 2004). However, if a researcher is not subjected to scrutiny, he or she cannot receive a 'wise judgement' of the study (Koch, 2006; Polit & Beck, 2014; Rolfe, 2006). I kept a record of all process logs, notes and debriefings with colleagues and supervisors to enable an evaluation of the accuracy of the findings, interpretations and conclusions supported by the data (Lincoln & Guba, 1985). In this study, the application of

V. Fleming et al.'s (2003) method made tracking possible so that others can follow the same processes and come to similar understandings.

4.3.5.3 Confirmability

Confirmability is a process criterion (Streubert & Carpenter, 2011), meaning that the findings have emerged from the research rather than the researcher's point of view. Researchers must expose their decision trails to scrutiny (I. Holloway & Wheeler, 2002) to demonstrate how they have interpreted the findings and reached conclusions (Tobin & Begley, 2004). Arguably, other researchers may not agree with the findings because they were not immersed in the data (Sandelowski, 1998). V. Fleming et al. (2003) suggest returning the transcribed interviews to participants. However, Gadamer (2006) emphasised three important considerations in relation to genuine conversation: openness to the position of others, the essence of questioning and the concept of possibilities. The interviews were transcribed verbatim and therefore did not require confirmation by the participants as a true and accurate record.

Confirmability was established when credibility, transferability and dependability were addressed and applied (Ryan, Coughlan, & Cronin, 2007). During the interview phase, nonverbal expressions were observed, and I recorded in a diary, and a reflexive journal was kept throughout the research process. The need for rigour in the research process involves more than just a post-hoc reflection, and reflective notes were undertaken throughout and following the interviews and throughout the analysis (Koch, 2006). Referring to the notes and texts helped me to eliminate prejudices and engage in critical reflexivity to be more open to scrutiny and develop a fusion of horizons on the subject matter. Constant reflection and an awareness that objective understanding can never be fully achieved was underpinned by ethical considerations.

4.3.5.4 Transferability

Transferability refers to the extent to which findings can be applied to other situations and contexts (Polit & Beck, 2014). A detailed description of the context, location, participants and analysis was articulated. In this way, readers are kept informed and can resonate with the study (Amankwaa, 2016). The findings from this study, although not generalisable, have shown some salient similarities and have overlapped with other studies from different parts

of the world. However, by using V. Fleming et al.'s (2003) method, the focus was on the trustworthiness of the research process and the findings may be similar or transferrable to other acute settings, especially in the Asian region.

4.3.5.5 Reflexivity

According to Fontana (2004), reflexivity is considered a critical factor influencing the researcher's interpretation of findings. Through constant immersion in the data, either consciously or subconsciously, reflexivity recognises that researchers are part of the social world under study. Through constant reflection, investigators' pre-understandings are challenged and expanded (Parahoo, 2006). Primeau (2003) stated that 'Reflexivity enhances the quality of research findings through its ability to extend our understanding of how our positions and interest as researchers affect all stages of the research process' (p. 10). Shaw (2010) highlighted that reflexivity enables researchers to evaluate and develop an explicit awareness of themselves. Reflexivity related to my position as a novice nurse, my experiences caring for dying patients in acute care settings and my pre-understandings, which were some of the motivational factors that influenced the specifics of this research (Clancy, 2013; Cousin, 2009; Jootun, McGhee, & Marland, 2009). My interviews with participants prevented me from fixating on my personal experience and enhanced the context of the study through my rapport with the participants.

My pre-understandings and prejudices may have been different to those of the participants in this study. Reflection can help to broaden the interpretation of the data findings to reach a fusion of horizons. Thus, reflexivity allows the researcher to be introspective and to identify any external forces, such as culture, history, politics and social interactions between the researcher and participants, that may shape the study (Sandelowski & Barroso, 2002). Following each interview, I kept a record of my thoughts, and feelings, and recorded my observations and interpretations. Reflecting on my feelings, thoughts, and observations was done consistently after each of the 16 interviews. These records show a concerted effort to reflect and allow an expansion of the possibilities of understanding of caring for dying patients. Reflexivity helped to reduce my own biases and enable a realistic interpretation of participants' accounts (G. Frank, 1997; Kleinsasser, 2000; Underwood, Satterthwait, & Bartlett, 2010). Continually discussing my interpretations with my supervisors provided

assurance that no important factors had been missed during the analysis, increasing the rigour and trustworthiness of the findings.

In summary, the rigour of this study was ensured by applying the established criteria of credibility, dependability, confirmability, transferability and reflexivity. In Gadamerian research, interpretation can be complex because of the influence of culture and language. Using V. Fleming et al.'s (2003) method, I was able to detail the processes employed so that readers can understand how the findings were derived from the statements. The following section describes how the study was conducted in relation to ethical considerations and data collection and storage.

4.4 Ethical Considerations

In conducting this study, I was bound by my professional code of ethics as well as the guidelines on research conduct provided by Flinders University and the Nanyang Polytechnic Institutional Review Board. I was fully aware of my responsibility to protect the respondents from physical, emotional or social harm (McHaffie, 2000). Sensitive topics are often explored in qualitative research, increasing the risk of unintentional harm (Streubert & Carpenter, 2011). With the above in mind, I adhered to all ethical requirements stipulated by the National Health and Medical Research Council, Australian Research Council and Universities Australia (2007), Australia (NHMRC, ARC & Universities Australia) and Institutional Review Board and Nanyang Polytechnic Singapore before engaging with the participants.

4.4.1 Ethical approval

Approval from the Social and Behavioural Research Ethics Committee at Flinders University (Project No. 6950) was obtained prior to data collection (NHMRC, ARC, & Universities Australia,2007). A copy of the approval is provided in Appendix 5. Permission to access RNs enrolled in the advanced diploma program was obtained from the Nanyang Polytechnic Institutional Review Board. A copy of the approval is provided in Appendix 6. The nature of the research study was explained to all RNs specialising in the chosen field of interest and enrolled in the advanced diploma program at the School of Health Sciences (Nursing) by their respective course coordinators, who read out a script in class and provided an information sheet, acceptance form and a self-sealed envelope (see Appendices 7, 8 and 9).

Participants who were willing to participate could respond by email or phone or by placing the completed acceptance form with their contact details in the self-sealed envelope in a box provided at the school. I then contacted all potential participants to arrange an interview. Participants who voluntarily agreed to be interviewed were assured that they could withdraw at any time or refuse to answer questions without consequence. A contact number specifically for the research and university email address were provided if participants had any queries. I had no direct involvement in recruitment and participants were free to contact me for an interview. There were no identified conflicts of interest.

4.4.2 Maintaining confidentiality, anonymity and privacy

For ethical reasons, the identity of all participants has been concealed. The consent form (see Appendix 9) is the only document containing the names of research participants. Pseudonyms were used in all other records and transcripts to preserve confidentiality. To adhere to the ethical principle of beneficence and justice (Burns et al., 2011), only my supervisors and I had access to transcripts. Consent was obtained prior to recording interviews. Munhall (1988) asserted that obtaining ongoing consent during conversation encouraged reciprocal participation and allowed participants to withdraw should they feel uncomfortable. Participants were informed that they could terminate the interview at any time or refuse to answer questions without consequence. All raw data were de-identified and were retained in a secure place for five years. Assurance was given to all RNs that there would be no negative consequences should they decide not to participate in the study. Participants were assured that the findings of the study would be portrayed in a manner that preserved their identities (NHMRC, ARC, & Universities Australia, 2007).

The nature of this study meant that it had the potential to cause emotional distress, and participants were assured that counselling support services were available on the campus should they require assistance. The proper conduct of this study was done to ensure that the strict ethical standards were maintained as part of the consent process (Creswell, 2013; NHMRC, ARC, & Universities Australia,2007). During the conversations, none of the participants expressed distress. All 16 participants remarked on how much they enjoyed the conversation and appreciated the opportunity to participate.

4.5 Recruitment of participants

The decision was made to recruit RNs with more than a years' experience working with dying patients. The decision to recruit acute care nurses was partly because of the dearth of literature in the Singaporean context. A purposive sampling strategy, which is considered the most appropriate for phenomenological studies (Burns et al., 2011; Streubert & Carpenter, 2011), was used to select RNs who met the criteria. Purposive sampling also allows for 'discovery' rather than for the testing of hypotheses and is a strategy described by Lincoln and Guba (1985) as 'emergent and sequential'. It may be likened to trailing for clues in a particular direction until the questions have been answered and the phenomenon can be explained (Koch, 2006; Silverman, 2005). I organized a study information session, explained, briefed and provided information of the study to all course coordinators of different specialties in the school. The course coordinators, then provided the information to all potential participants in their respective classes. A script was read by the course coordinators to the potential participants. The participants who indicated their interest to participate in the study were given an acceptance form to write their contact details in a self-sealed envelope. Participants were instructed to drop the self-sealed acceptance form in the box provided at the School of Health Sciences, Nursing reception counter, at level 3. I collected the responses from the drop box on a weekly basis, contacted the participants and arranged a face to face meeting with the participant and provided the information sheet (see Appendix 7) to allay any doubts he/she may have about the study. Afterwards, I obtained the participant's written consent prior to the interview. Audiotaped conversations were undertaken with 16 RNs who met the established inclusion criteria (see Table 4.2).

Table 4.2: Inclusion Criteria

| Inclusion Criteria |
|--|
| Registered nurses who had worked in acute care units for at least one year |
| Had direct involvement in caring for the dying |
| Were able to speak in fluent English |
| Were able to give informed consent |

These participants were post-graduate students at NYP. The recruitment was assisted by the course coordinators from different specialties. Participants who fitted the criteria responded

and were contacted (See Appendices 7 & 8). Participants were assured that their identity deidentified and pseudonyms used in this thesis or in the resultant dissemination of findings.

4.6 Storage of Data

All collected data were stored securely in a password-protected computer as well as a back-up hard drive. According to Benton and Cormack (2000), data storage serves three purposes: to ensure that data are not lost, to enable accessibility to information and to enable only the researcher to analyse the data. My academic supervisors and I were the only personnel to have access to the electronic sources of data. A password-protected personal laptop was used for data analysis. All verbatim transcripts were de-identified and kept confidential and were accessible only to me, my supervisors and the research committee. According to the Social and Behavioural Research Ethics Committee, all data must be kept for five years in accordance with the Australian Code for Responsible Conduct of Research (NHMRC, ARC, & Universities Australia, 2007).

In summary, this chapter provided a brief critique of existing interpretive approaches and the rationale for adopting V. Fleming et al.'s (2003) method for data analysis. Gadamer (2006) did not offer a method, just the philosophical concepts underpinning how understanding might be possible. V. Fleming et al. (2003) used these concepts to develop a research method for researchers wishing to utilise hermeneutics in research. After evaluating other research methods, V. Fleming et al.'s (2003) method including (deciding on a question, identification of pre-understanding, gaining understanding through dialogue with participants, gaining understanding through dialogue with text, and establishing trustworthiness), which clearly reflected Gadamer's philosophy, was deemed the most suitable for this research. The chapter concluded with a discussion of the ethical considerations including (ethical approval, maintaining confidentiality, anonymity & privacy, recruitment of participants, and storage of data) for this study and how rigour was established throughout the research process through credibility, dependability, confirmability, transferability and reflexivity. The following chapter provides the findings on the emerging themes and fusion of horizons pertaining to the experiences of RNs in caring for dying patients in the acute care environment in Singapore.

Chapter 5: Findings: Part 1

5.1 Introduction

Chapters five and six present the findings related to four themes with respect to nurses' experiences caring for dying patients. Participants' experiences were unique and varied. Chapter five presents an overview of the four themes illustrated in Table 5.1. Theme 1, 'experiencing emotional labour' and theme 2 'barriers to providing optimum palliative care' discussed in this chapter. Theme 3, 'transforming and understanding EOL care', and theme 4, 'ways of managing care effectively', are presented in Chapter 6 respectively. Themes 1 and 2 and their various subthemes are illustrated in Figures 5.1 and 5.2. Chapter six discusses the third and fourth themes, 'transforming and understanding end-of-life care' and 'ways of managing care effectively'. Overviews of themes 3 and 4 are illustrated in Figures 6.1 and 6.2, respectively.

Table 5.1 Overview of themes and sub-themes

| Chapter 5 | Chapter 6 | | | | |
|--|--|--|--|--|--|
| Theme 1: Experiencing emotional labour Sub-themes: Helplessness Dealing with unanticipated or sudden deaths Feeling sad Feeling guilty Inadequate support at work | Theme 3: Transforming and understanding end-of-life care Sub-themes: Building connections Providing support to patients and families (spiritual support, alleviating physical suffering and symptoms & offering meaningful support Fulfilling wishes | | | | |
| Theme 2: Barriers to providing optimum palliative care Sub-themes: Knowledge of symptom control Misconceptions about palliative care Conflicts of interest among health care professionals Switching between multiple roles Staffing constraints | Theme 4: Ways of managing care effectively Sub-themes: Open communication -enhancers -barriers Working as a team Palliative care team support -providing comfort care -providing emotional support for families and patients Addressing training needs Personal coping | | | | |

To make sense of themes and correctly interpret the transcriptions, each theme and subtheme was analysed along with the associated narratives from the transcripts. Details of themes and the verbatim words of participant ts are shared in subsequent sections. Gadamer (2006) purported that interpreted descriptions are subject to the history, prejudices and finitude of the researcher. The first question asked of participants was, 'What is it like caring for dying patients in an acute care setting in Singapore?' Participants' experiences provided the foundation for a possible understanding of EOL caring practices in Singapore.

5.2 Overview of Participants

Sixteen nurses from five different hospital acute care wards participated in this study. All RNs who participated in this study were female. The ages of participants ranged between 25 and 49 years, while years of working experience ranged from five to 18 years. There were nine younger nurses who had five to six years of working experience in medical units and seven senior nurses who had seven, 14 and 18 years of working experience in geriatric, cardiology medical, surgical, and oncology units. Their ethnicities were Chinese (n = 8), Malay (n = 3), Indian (n = 4) and Filipino (n = 1), and religions included Christian (n = 4), Muslim (n = 3), Hindu (n = 4) and Buddhist (n = 2). Three nurses were free thinkers (n = 3). Twelve nurses worked in the acute medical wards of various disciplines, including cardiology, geriatric, general medicine and surgical wards. One nurse worked in an intensive care unit, and three nurses worked in the oncology and haematology units. The range of wards demonstrates that EOL care is provided across various disciplines in the acute care setting. A summary of participants' demographics (age, gender, ethnicity, religion and nationality), years of working experience and highest qualifications obtained is presented in Table 5.1.

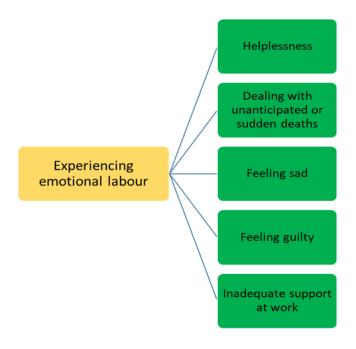
Table 5.2: Participant Demographics

| Particip ant | Age Range | Gender | Ethnicity | Religion | Highest Qualificatio n in Nursing | No. Years in Acute Care | Area of Clinical Practice |
|-----------------|--------------|--------|-----------|-----------|---|-------------------------------|---------------------------------|
| P1 | 26–49 | F | Filipino | Christian | Bachelor's degree | 18 | Geriatric, cardiology |
| P2 | 50-55 | F | Indian | Christian | Diploma | 7 | Haematology |
| P3 | 26–49 | F | Chinese | Christian | Diploma | 5 | Medical |
| P4 | 26–49 | F | Chinese | Christian | Bachelor's degree | 7 | Medical |
| P5 | 18-25 | F | Indian | Hindu | Diploma | 5 | Medical |

| P6 | 18–25 | F | Chinese | Free thinker | Diploma | 5 | Surgical |
|-----|-------|---|---------|--------------|-------------------|----|-----------------------------------|
| P7 | 26–49 | F | Malay | Muslim | Bachelor's degree | 7 | Renal, intensive care |
| P8 | 26–49 | F | Chinese | Free thinker | Diploma | 7 | Geriatric |
| P9 | 26–49 | F | Chinese | Hindu | Diploma | 14 | Medical, surgical, oncology |
| P10 | 26–49 | F | Malay | Malay | Diploma | 6 | Medical |
| P11 | 18–25 | F | Chinese | Free thinker | Bachelor's degree | 5 | Geriatric |
| P12 | 18-25 | F | Malay | Muslim | Diploma | 5 | Medical |
| P13 | 26–49 | F | Indian | Hindu | Bachelor's degree | 7 | Medical |
| P14 | 18–25 | F | Indian | Hindu | Bachelor's degree | 5 | Medical, surgical |
| P15 | 26–49 | F | Chinese | Buddhist | Diploma | 5 | Geriatric |
| P16 | 26–49 | F | Chinese | Buddhist | Diploma | 5 | Haematology |

The next section presents the findings pertaining to Theme 1, 'experiencing emotional labour'. Subthemes included helplessness, dealing with unanticipated or sudden deaths, feeling sad, feeling guilty and inadequate support at work. The theme and its associated subthemes are illustrated in Figure 5.1.

Figure 5.1: Theme 1: Experiencing emotional labour



5.3 Theme 1: Experiencing Emotional Labour

All participants referred to experiencing emotional labour as they narrated their experiences in the various acute care settings. The nurses confronted a range of diverse and complex interpersonal challenges, some of which led to emotional labour as well as personal and professional struggles. Participants reported on the intensity of their emotions, which consumed their energy at work. Some mentioned that at times they found it difficult to cope with these negative feelings. They also indicated that they felt unsure about how to engage in therapeutic conversations with patients and families. Participants also reported that they needed to prioritise their work while simultaneously adopting different roles to meet the needs of patients and families. The five subthemes associated with for Theme 1 were (1) helplessness, (2) dealing with unanticipated or sudden deaths, (3) feeling sad, (4) feeling guilty and (5) inadequate support at work (see Figure 5.1).

The narratives shown below highlight the emotional labour experienced by participants. Participants expressed a diverse range of emotions associated with the challenges encountered in daily care activities, which evoked feelings of helplessness, sadness and guilt. Frustration and inadequacy were experienced when dealing with unanticipated or sudden deaths. Participants also described occasions when they felt they did not receive support or understanding from ward managers. Participants also experienced staff shortages when they were responsible for many dying patients, adding to their emotional labour. Therefore, emotions such as feelings of helplessness, sadness and guilt and dealing with unanticipated or sudden deaths are examples of the inner turmoil experienced by all nurses in this study. The following sections present the findings for each subtheme and concludes with a summary.

5.3.1 Helplessness

All nurses in this study used the word 'helpless' to describe their powerlessness in what to do or how to help dying patients. They witnessed the struggles of patients and felt unable to render assistance to help their patients feel better. Participants felt helpless when they witnessed the physical deterioration of patients and were unsure of what other means they could offer to alleviate suffering. When they witnessed care that was conflicting, participants were unsure how to provide assistance to patients and families. For example, patients may

have been unwilling to receive further treatment, but their families may have insisted on aggressive treatment, even when it was futile. They described helplessness in their struggle to withdraw or share information and provide sound advice. The following narratives provide some examples of helplessness.

One participant who had 18 years of clinical experience in the acute geriatric medicine and cardiology units. She was forthcoming about her personal experiences and was able to identify with the concerns of her patients and their relatives. At one point, she became emotional (silently crying) when she talked about being unable to fulfil the wishes of her patients:

As a nurse, I want to respect what the family wants. But when I look at the patient, his eyes [are] speaking to me with different message. I also can feel what the patient wants. He wants to die peacefully, but the family wants a different outcome (P1, Lines 66–69).

She expressed her views on caring for the dying in different ways. She was highly expressive and brought her own historicity to the discussion. She faced a helpless situation when she found herself in a dilemma trying to fulfil a patient's wish while adhering to the family's request. There appeared to be a strong emotional connection between her and the patient, yet she felt helpless. She further expressed her struggle with truth telling when a young patient had minimal hope of recovery. She felt she could not tell the truth, even when she knew there was no hope. She commented that 'some young patients, even when prognosis is poor, don't want to let go and die. When they verbalise to you, my heart is broken, but I feel helpless on how to help them' (P1, Lines 71–72).

Similarly, another participant spoke about her feelings of helplessness when caring for a patient who had undergone a bone marrow transplant. Her distress at witnessing the patient's physical decline was expressed as follows:

As I a nurse, I want to nurse him to have quality life. I want to nurse him to be a happier person tomorrow. I want to have the belief that the family comes in and see him happier than yesterday, you see. I believe I want to hear the doctors say everything is resolved and you can go back soon. But I feel so helpless and don't know how to help him feel better (P2, Lines 51–54).

She further stated:

At one point of time, I refused to go to his room. I feel like I am losing him, losing him in my care [crying silently]...I am losing him as a nurse. I just felt helpless. The management and intervention, which I hoped, did not help. I find that I am losing him, I don't know how

to express. I can't do more and I start to backtrack myself. I refused to go to the room (P2, Lines 92–97).

This participant struggled when faced with the physical deterioration of her patient as she witnessed the futility of his medical care. She could not bring herself to face the reality of the situation or accept the impending death of her patient. It appeared that the relationship she had built with this patient was ending. Another two participants recalled their helpless situation and narrated the downward trajectory of their patients' decline. They both commented:

He's not able to tell us what he wants, one thing, and the second thing is that he was always groaning and moaning. He became so confused. Just looking at him was quite hard, but you don't know what to do for him also (P3, Lines 57–59).

I nursed this patient, she is also a case of colon cancer, I think she is like 40–50 years old. Her CA [Cancer] already spread a lot already. There is really no cure for her anymore, so what the doctor did was to give her a PT/OT [physiotherapist/occupational therapist] to see her. When she came to us, she was very plump, she lost a lot of weight. She insisted on doing things by herself, but she can't do it. And the fact that for her to get up from the bed to the commode, to pass motion, is very difficult already, and she refused to pass in the diapers, so she will force herself, all her strength, using all her strength to get up already, and after that, she will be sitting in the toilet, on the commode for like 30 minutes, and she will cry, she said "I can do it'. It's like seeing her going down [deteriorating] (P6, Lines 43–49).

The above two narratives revealed the functional decline of patients. For one participant, it was overwhelming, and she was helpless on how to address the physical pain. Whereas, another participant could not directly advise the patient to accept physical assistance. Despite her feelings of helplessness, she was able to sustain the patient's dignity and indirectly reluctantly supported the patient to perform her activities of daily living, even though she was caught in a helpless situation.

Another participant who had six years of working experience in an oncology ward expressed similar sentiments, stating 'I find it very challenging and at the same time the patient's condition is deteriorating and . . . I wish that I know how to handle the family members by providing some comfort words' (P10, Lines 82–83). This quote illustrates that the participant was unable to provide equal attention to the needs of both the patient and the family.

Similarly, another participant shared her experience in this manner:

The doctor told him frankly that he can't recover because the tumour was too big. It gotten worse. If I'm not mistaken, it has spread to his brain already. So, it was too big. They

[doctors] can't start chemo. I think the family didn't want chemo or anything else. He just asked me, 'Why did it happen to me?' I just told him, 'I don't know how to reply you'. I just felt helpless and could not reply him. I just said I'm sorry (P12, Lines 47–53).

Every participant had experienced the physical deterioration of patients under their care. They felt anguished, anxious, distressed and helpless when being unable to alleviate patients' pain and suffering. Participants also revealed that they were affected by the physical changes in their patients' conditions and the conflicts that EOL care could raise between the persons involved. In addition to dealing with physical decline, many participants also witnessed conflicts in care directions between family members, patients and the medical team. One participant highlighted a helpless situation in which there were three different instructions to follow, affecting her role as a nurse. The inability to decipher patients' needs along with the conflicting demands of relatives is expressed in the following quotes:

Doctors give one instruction, relatives another, patient insist on doing other measures and looking at us. We are torn apart and helpless who to listen. We don't say anything, we just let the team, the family or the patient . . . make the decision. We just stand aside, not knowing what to do (P3, Lines 174–177).

The above quotation implies that the patient and family members placed the participant in a helpless situation. Because of the conflicting care demands, the participant felt unable to exercise professional discretion and was forced to take a neutral stance. Similarly, another participant who had seven years of working experience in a medical ward echoed similar sentiments regarding her attempts to alleviate her patient's symptoms when the family had different expectations:

Sometimes the patient is already in pain and breathless, sometimes they may not be able to express their need. When you asked them, where is the pain, they will just [say], 'Pain', but they couldn't explain to you where the pain is, how is the pain like and all that. It's like how to help him when I don't know what he is trying to say. I want to help but . . . family is saying a different thing (P4, Lines 101–104).

In the above situation, the patient and the family perceived the pain differently. Moreover, the above participant strived to obtain clarity from both the patient and the family but gained little insight and was helpless to render assistance.

Three participants shared their diverse conflicts they witnessed. Similar to the above participant, they shared the conflict they felt. The first when the wife of a dying patient had insisted on feeding him, even after the grave impending situation had been explained:

She just could not accept the prognosis and just wanted me to feed the patient. I am just lost and don't know how to respond to her. I'm very sure that the doctors would have updated the wife about his condition and prognosis, but I think she really couldn't accept it (P5, Lines 26–28).

This illustrates the dilemma faced by the above participant regarding the ethical and legal implications in having to continue feeding a patient when it was no longer appropriate. Her narrative demonstrates how morally and ethically distressed she felt in this helpless situation. Another participant highlighted the conflicts of interest between nurses and physicians. She expressed that she felt caught between the family and did not know how to express to them that care was futile for a bone marrow transplant patient:

Even my ICU [Intensive Care Unit] colleagues, my friend actually tells me like, haematology doctors are too hopeful. They do not present the real picture to the patients, so they even tell them perhaps, like you know, after extubating, there's still chances, but actually the ICU team don't feel so. I try to give subtle hints to the family. I know the doctors are aggressive (P16, Lines 98–101).

Having to witness the futility of care reveals the struggle faced by the above participants, who felt helpless when witnessing the false hope given by the medical team. The culture of acute care is like raising the hope of relatives by continuing with aggressive treatment. It also reveals that families may be more focused on finding a cure than providing comfort. In this case, the family was not willing to take chances, but this participant felt distressed when the truth was concealed.

Another conflict narrated by one participant who had worked as a care coordinator in a renal unit for nine years but caring for the dying was still a challenge for her. She stated that although information sharing with patients was vital, she was unsure how much she should reveal to avoid misleading them:

I am not a person who is comfortable to open the Pandora box of something that is sensitive because once they start expressing out to me, I don't know how to close it back. During that period of time, I am not well exposed how to counsel, how to withdraw and sometimes I try to avoid. I really don't know what to say to him. I cannot say everything is going to be okay because that is really lying. When I am distancing from him because I don't want him to ask me more questions and I can't provide him with the answers (P7, Lines 9–11, 30–31).

The majority of participants had similar concerns. One participant stated that, 'Patient kept on asking what is going on with me. As a nurse it was a struggle to me whether to tell or not to tell. On the other hand, relatives kept reminding me not to reveal [the] diagnosis' (P1,

Lines 49–50). Similarly, another participant commented that 'Sometimes we [nurses] are very scared . . . We don't want to offend the family members by saying anything which is not supposed to say . . . We are also helpless what to say' (P13, Lines 97–98). Another participant encounter expressed in this way:

I feel that as much as I, I wanted to let him know that his wife is suffering, but it's still hard, it's still hard for me to ask him to just let his wife go. So, I was actually quite helpless at that point in time (P11, Lines 39–40).

The above quotations illustrate that Registered Nurses experienced helplessness in situations related to information sharing, prognosis and the fear of revealing a diagnosis. Two participants adopted blocking behaviours and distanced themselves when patients wanted to connect with them. They struggled internally and created boundaries for themselves. Another two participants felt the inner turmoil, which they expressed as feelings of helplessness.

In summary, the nurses expressed the helplessness they experienced in some situations when caring for dying patients. They felt a sense of inadequacy in providing effective, high-quality EOL care in the acute care hospital setting. Participants were aware of the consequences of futile care when conflicts arose between physicians, patients and nurses. Witnessing the physical decline of patients, feeling unable to fulfil patients' wishes and being unable to include emotional aspects of care were all examples of the helpless situations participants faced. The next section describes the participants' distress in managing care expectations from patients and families when faced with unanticipated or sudden deaths.

5.3.2 Dealing with unanticipated or sudden deaths

The majority of participants described that they were inadequately prepared to handle unanticipated or sudden deaths, which caused them distress in their everyday encounters. This is illustrated by the following quotations:

The old elderly are fragile—one moment they are okay, one moment they are not okay, you know. On that day it was during morning medication round. He asked my colleague for a cup of Milo. My colleague just went off to pantry to get Milo. When she came back, the patient is gone. For both of us it was shocking. I tried calling the relatives—the son sounded so angry over the phone (P1, Lines 27–33).

He was only 40 years old. Went for 2D echo and was told that he has clot. He was on telemetry monitoring. The next day I was on morning shift. Before I could start my duty there was a code blue. I remembered I spoke to him yesterday before I left. He collapsed in the toilet and we all tried to revive him, but we could not. The wife [was] screaming and

shouting in the ward, saying that 'My husband was just fine yesterday, how could this happen?' and things like that. I am shaken by this. It's really so, life is so precious, like so easy for person you can see smiling happily the day before and the next moment, they are just gone like that. It was very disturbing for the rest of the day (P5, Lines 50–58).

These narratives imply that the families were unable to accept the sudden death of their loved one and had transferred their anger to the nurses. This situation caused added emotional distress for both participants when attempting to disclose the news. Both participants were emotionally shaken by the incident, which lingered in their minds until the end of their shifts. A young nurse participant narrated her difficulty in accepting her first unanticipated death after having established rapport with a patient:

There's a patient who was, I was caring for him and he was okay, everything was fine, I was still educating him on not having to burst the blisters on the mouth. I came back the next shift, he was gone. It was shocking for me and I was emotionally distressed by it. I did not anticipate this to happen. I build the rapport with him. Because he was the first death I encountered in the bone marrow transplant unit (P15, Lines 13–18).

A young nurse participant expressed how she was caught in a dilemma when faced with a sudden death:

I was on night shift that night. When I went there, only his second wife was there. So, everything went very fast, his heart rate went down. He actually was very aggressive before his death. It was active resus, his condition just deteriorated. He died and I was the charge nurse. About the 30 to 40 people who came up to see him. All they asked were what happened, what did you do to him, why he was on this state, why did he throw the cup to the opposite patient. All they were trying to do was to blame the nurse, but no one knew why he was even hospitalised in the first place (P14, Lines 197–205).

The young nurse not only had to deal with the sudden death but distressed by having to manage the family's aggressive demands. This quote implies that the family was unable to accept the futility of care. These quotations demonstrate that participants felt inadequately prepared to handle unanticipated deaths. Many expressed feelings of frustrations when families displayed intense negative responses to patients' deaths. Managing the lack of acceptance of sudden death by families was challenging for all nurses. Three young participants reported that sudden deaths were tragic and traumatic when families projected their anger and challenged their practice. Participants felt that they were blamed for the deaths. One young participant reflected on the fragility of life when patients' conditions constantly changed in a volatile environment and that it was difficult to bear such a 'huge responsibility'. Another young participant suggested that managing families' expectations and continuous queries made her less effective when faced with demanding unpredictable

situations. In addition, another young participant commented that she felt shocked when her patient died suddenly. She had built a deep connection with the patient and found it difficult to cope with the bereavement process. The next aspect of emotional labour described by all participants was that of feeling sad.

5.3.3 Feeling sad

All nurses experienced sadness as they witnessed the suffering of the patients and the turmoil faced by families. Sadness was associated with the relationships established with the deceased and the family, especially when the patients were of similar age or younger than the participants. A young nurse participant with five years of working experience in a geriatric ward commented:

I nursed this patient for two months and we build a relationship. He is very open to me. But his prognosis was poor. He does not want chemo and he does not want to go into unconsciousness and refused all painkillers. He requested to go home but his condition was so, so bad. I felt so bad as his wish was not fulfil. He is just two years younger than me. It kept playing in me (P15, Lines 70–76).

Some participants indicated that the impact of the dying process was similar to what they had felt with their own family members. The suffering witnessed by nurses resulted in feelings of sadness, which were magnified by the nurses' inability to speak for the patient or control situations beyond their means. Watching patients deteriorate caused much distress and sadness. The following excerpts illustrate the depth of sadness felt by some participants:

As a nurse I felt very emotional because this elderly man resembled my father, the closeness of a family. My dad died two years ago. If I see such situation, my memories of my dad comes. I just feel so sad and I can't help feeling that way (P1, Lines 37–40).

The above participant reflected that the dying patient had resembled her father. Although this elicited pleasant memories, she was still sad. On the other hand, another three participants expressed that their feelings of sadness were often related to their personal experiences (like reminding of their loved ones who suffered, having to witness unnecessary repeated invasive procedures and blood tests, and felt a sense of incompleteness and dissatisfaction when outcomes were unsatisfactory when treatment ceased for a dialysis patient). The following quotes elaborates how it affected them personally:

My brother died of cancer. He suffered so much. I cannot bear seeing him going for treatment and receiving the chemotherapy. He deteriorated, and he died a year later. When

I see the patients in my ward, it reminded me of him [brother]. It really impacted me as I don't like to see people suffering (P9, Lines 110–115).

Nursing-wise, when the PICC [Peripherally inserted central catheter] line was blocked, and he had to go for operation to take it out and to fix it, you know that moment, it was very sad for me. You know, we tried to keep it as patent as much as possible, but sometimes when the chemo drugs are too strong for him, it will block. Why must this happen to him? He is such a nice guy (P2, Lines 67–69).

I knew since the time he was diagnosed and his dialysis programme, I was with him. I knew everything about him. You know, I was the one who ended his dialysis when he was sent to ICU. It is something I cannot forget. This is even worse for me. He was in ICU. He was unaware of his surroundings. When I wanted to end the dialysis, his wife requested for a minute. She did that to me three times. It affected me a lot. Once . . . the wife is full-term pregnant and is going to deliver anytime. She was telling him, 'I will be okay, don't worry'. Second time, she was professing her love for her husband. Here, me waiting, listening to her words, made me feel uncomfortable. I was thinking aloud, 'Just let me off the machine and let me walk out of the room'. I don't want to face in this tense atmosphere where I am emotionally drained. The more she stops me, it is agonising me as if his life is in my hands, but actually it is in the hand of God. It was like a torture to me. I was caught in between the sympathy and to execute my duty professionally. I felt I was torturing my patient. Once I stopped the machine, I could feel the sadness engulfing me (P7, Lines 114–134).

Witnessing the suffering of the patient and his wife was unbearable for Participant 7. Her words convey the stress and fatigue she felt in dealing intensively with this dying patient. The emotional farewell between the patient's wife and her husband was overwhelming for her.

Another participant found that truth telling was a difficult task. She expressed the sadness she felt as she witnessed her patient's physical deteriorating condition:

When I was nursing her, her entire chest area was actually already invaded by cancer cells. So, according to the doctor, there is really no way, in a way, of curing her because it was in an advanced stage. Every time when I was changing her, I could see the facial expression, she was really in a lot of pain. I feel so sad for the patient and her husband (P11, Lines 36–39).

Managing the unrealistic expectations of families and dispelling the hope of living was difficult for her to manage. She struggled to understand how she could provide support when the family was distressed.

The participants in this study felt sad caring for dying patients. The sadness was prominently displayed when they had built a strong connection with their patients. Their everyday encounters evoked feelings of sadness, inadequacy, incompleteness, frustration and stress.

They felt deeply moved, which also evoked feelings of guilt when faced with challenging situations.

5.3.4 Feeling guilty

Nurses experienced feelings of guilt when they were unable to help patients and families cope with the realities presented to them or facilitate closure. Participants reported feeling guilty when they were preoccupied with acute care management and were unable to balance their tasks caring for dying patients. Participant 11 commented, 'I think when nurses are overwhelmed, including me sometimes; we tend to neglect the patient who is dying because he/she can't voice their discomfort. So we are, we are always busy with those who are actively seeking treatment' (P11, Line 146).

Some nurses in this study struggled to provide appropriate advice to patients and family members. They experienced personal and professional conflicts over care directions for their patients. One participant narrated her experience of guilt when a patient consulted her about his treatment plan and whether he should get married with his condition. She felt that her advice did not result in a positive outcome. The patient died shortly after his marriage and was unable to witness the birth of his child. She carried intense guilt, which she expressed as follows:

I really don't know what to say to him. I cannot say everything is going to be okay because that is really lying. I can't also say that you should also strive because he has always been until to the point . . . partly I felt that, what if I have told him not to get married but just concentrate on dialysis? Maybe he might live longer, and his finances will be focus on health conditions (P7, Lines 35–38).

The impact of guilt persisted for another participant who had established a close relationship with the patient. As she witnessed the patient's decline, she adopted blocking behaviours by not entering his room for three days, but simultaneously felt guilty for not seeking closure with him:

The feeling is I am watching the room, watching room number 5. The feeling I have inside me and something is stopping me from entering his room the last three days. But then on the third day, I just wanted to walk in to see how he is, and then he looked so miserable. I went to his room the day before he passed away, which was isolated, and then he held my hand and told me, 'I may not see you tomorrow' (P2, Lines 159–162).

In contrast, a young participant felt guilty about spending less time with her patient. The demands of acute care prevented her from being able to provide care for the dying. She expressed her guilt as follows:

So, one staff nurse to 18 patients in the acute setting, so you know, it's like a touch and go, like five minutes, I see them, then I have to attend to other patients, it's like, I don't have that personal touch with them at all. I just feel guilty (P12, Lines 74-75).

These narratives convey that participants were dissatisfied with the care they were able to provide. The constant lack of time, missing small nuances of patients' needs and trying to balance acute care with caring for dying patients all affected their emotions. This burden of care added to the emotional labour through feelings of guilt. This guilt was enhanced when they described the absence of adequate support at work, which is discussed in the following section.

5.3.5 Inadequate support at work

In addition to mental distress, the nurses in this study expressed their dissatisfaction when ward managers failed to pay attention to or understand their mental wellbeing. Caring for the dying causes emotional distress and fatigue when the care is intensive. The following quotations describe the inadequate support participants experienced when caring for dying patients. One participant who worked in a Bone Marrow Transplant Unit commented:

So far, in the ward I worked, the nursing officers, they have their own tasks to do and complete. To ask whether the nurses are doing fine or how you feel today nursing this patient, they don't ask. Most patients who come to my ward are actually at the dying process. The sisters [nursing officers] should know this, but they never ask the nurses how we feel nursing the patient today or at least at the end of the week. They [nursing officers] never ask whether we [nurses] are ready to nurse this patient. Emotionally, we are drained. I only took three days out from nursing this patient. Some of my colleagues have been drained for months, even though they are not nursing the same patient but emotionally very burdened. They carry their emotions to their family, causing a kind of isolation at their homes. They worry and fear (P2, Lines 147–156).

The above participant expected informal support for herself and her colleagues but was disappointed. The lack of support highlighted that ward managers tend to concentrate on their own routine tasks. Nurses' emotional wellbeing was overlooked and their mental readiness to care for the dying was not valued or supported by ward managers. Participants felt that the ward managers did not care. It was also evident that despite the emotional distress experienced by nurses, they continued to care. It appears the participants carried this burden

with them, affecting their interactions with their own families. They felt isolated from their families, causing tension and anxiety.

Another participant who worked in a geriatric discipline was deeply concerned about the inadequate support or resources provided by ward managers to new general practice nurses. She expressed her concerns in this manner:

The staff just passed out from school and they have to face with this kind of situations, patients passing on quite frequently. Sometimes they may not be able to take it emotionally. I think it will be better . . . if the ward managers can talk to them or link them to, er, like resources for them to go to (P8, Line 108).

Support or resources to assist newly trained nurses to cope with the demanding environment were often overlooked. Participants believed that newly trained nurses are not provided with adequate emotional support from management when caring for dying patients. The delegation of duties to newly trained nurses would also be uneven, adding to the impact of emotional labour.

Similarly, another participant from a medical ward expressed that added to the emotional burden of inadequate support, the quality of nursing care is compromised because of inadequate staffing. She believed that patients would receive better care with more staff: 'I feel that maybe can have a little bit more to improve the quality of care, like to have one or two more nurses' (P4, Line 86). Likewise, another participant worked in a surgical oncology unit, added that appropriate support from the palliative care team would help her and her team to better manage dying patients: 'If we have more APN [Advanced Practice Nurse] or palliative-trained doctors in the ward, that will be good. As for now, we don't have so many' (P9, Lines 74–75).

Another participant commented that when nurses were faced with contradictions in care management and ward managers failed to assist or provided support, it added to the emotional labour: 'If there is a conflict or contradictory management issues, if the supervisor chooses not to help resolve, then it becomes your problem' (P1, Line 104).

All participants in this study strongly expressed the emotional labour they felt from the lack of support when providing care for dying patients and their families in the acute care setting. Feelings of helplessness, sadness and guilt, facing unanticipated or sudden deaths, grieving for the loss of their patients and receiving inadequate support at work were all strong

emotional consequences for the nurses. Besides the emotional labour of caring for the dying, participants faced other multiple challenges. One such challenge was the barriers they faced when providing palliative care in the acute care setting. The findings of Theme 2 on barriers to providing optimum palliative care are elaborated in the next section. Theme 2 and its associated themes are illustrated in Figure 5.2 below.

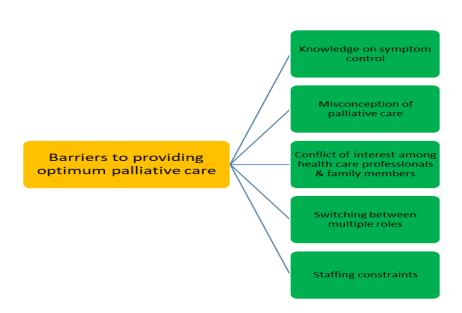


Figure 5.2: Theme 2: Barriers to providing optimum palliative care

5.4 Theme 2: Barriers to Providing Optimum Palliative Care

Theme 2 pertains to the barriers in providing EOL palliative care. All nurses in this study expressed their difficulty in meeting the palliative care needs of patients, which was attributable to their general lack of knowledge of symptom control. The nurses indicated that misconceptions held by patients, relatives and doctors about palliative care added to their challenges. In addition, conflicts of interest within the multidisciplinary team delayed early referral to palliative care. Another challenge expressed by nurses was that they had to juggle their priorities in the acute care setting because of staffing constraints. Five subthemes were identified: (1) knowledge of symptom control, (2) misconceptions about palliative care, (3) conflicts of interest among healthcare professionals and family members, (4) switching between multiple roles and (5) staffing constraints are demonstrated through the narratives of the participants. All participants in the study acknowledged the importance of addressing

symptom control and the need for more training in palliative care. The following section highlights some of the barriers encountered by the nurses in providing EOL care.

5.4.1 Knowledge of symptom control

Dealing with human suffering led to emotional turmoil for the nurses in this study. In addition to human suffering, the narratives portray that distress was increased when nurses believe they lacked the knowledge and skills to address symptoms such as pain. The majority of participants in this study reported that their lack of understanding and knowledge of palliative care create feelings of incompetence and uncertainty. All nurses spoke about conflicts between patients and family members regarding preferences for alleviating symptoms. The conflict is further heightened by tensions between nurses, patients, family members and physicians when care plans are not effectively communicated to all parties. Examples of this lack of knowledge are provided in the following quotations:

Because of his condition, he's not able to tell us what he wants, one thing, and the second thing is that, he was always groaning and moaning. Just looking at him was quite hard, but you don't know what to do for him also. I was feeling uncomfortable not knowing how to manage him. The management is up to the doctors. We just make sure that he's positioned comfortably, but as for the pain in the leg or wherever the pain is, we are not sure . . . what he is going through. We just tried our best; we give him whatever he needs (P3, Lines 57–63).

The above participant narrated her feelings of helplessness and her inability to address the needs of a patient who was deteriorating rapidly and suffering from pain. There may have been other existential issues that she felt unable to address. Despite being able to assist in the physical aspects of care and gaining the trust of her patient, she admitted feeling unable to provide care effectively. Similarly, another participant shared the following:

I think in the acute care setting, if you know that the patient is not going to make it, comfort measures are important. But the physicians kept taking blood, blood. The patient is already dying. It is like traumatising the patient and they are helpless to refuse blood taking. I don't see the purpose here. I told the doctor, 'Why you are taking?' (P5, Lines 170–175).

If I see my patient cry or upset, I will also cry. They still have the hope and I do not want to minimise their hope. So, I will do it indirectly. I cannot bring myself to tell them openly to discontinue further investigation or treatment (P5, Lines 225–228).

The narratives above conveyed about the physician continuing aggressive treatment even when it was no longer beneficial for the patient. Rather than shifting the care to focus on comfort, the aggressive treatment continued, which she believed was unnecessary. She felt

conflicted and uncomfortable about the fact that palliative care was not initiated but also lacked the knowledge or confidence to advocate for the needs of her patient. This demonstrated that she could not bear to see the patient suffer.

While another participant shared about her lack of knowledge of symptom management: 'I think it's not just about the communication with the relatives, it's also about knowing about the different symptomatic treatment for the patient for different condition. I'm not so confident to suggest what medicines to give' (P11, Lines 87–88).

Apart from knowledge deficits, participants also believed that poor communication skills prevented them from providing optimum care to their patients. Their lack of self-confidence in advocating for the early initiation of palliative care was apparent. Family members who expected restorative care had different opinions to nurses who wished to provide comfort care. Feelings of inadequacy and incompetency in managing complex symptoms, affecting the provision of care, were unanimous. Another barrier to providing optimum palliative care was the misconceptions held by patients' families and the medical team. The misconception about palliative care is discussed in the following section.

5.4.2 Misconceptions about palliative care

The majority of nurses in this study expressed the desire to introduce palliative care earlier rather than later. Participants explained that the late initiation of palliative care may have been the result of misconceptions held by relatives and doctors, who often regard palliative care as taboo and offer it as a last resort only. One participant worked in a medical unit commented:

But I find that palliative, I think, maybe, across all hospitals, is often referred quite late. It's only when one has pain, then you refer. But I'm sure palliative is not about pain . . . I think it's maybe a taboo. Let's say if a patient is newly diagnosed, then go through treatment, and you want her to . . . talk about palliation, I think, they may have a misconception. I think, I'm sure that many people are not very sure about palliative care. They always associate palliative with end of life, I think even the doctors (P4, Lines 106–111).

Misunderstandings about palliative care by patients and relatives creates challenges for nurses in initiating EOL care. Patients and relatives equate adequate pain control with hastening death. Many nurses shared this sentiment, adding to their frustration when providing care. The following quotations provide two examples of these misunderstandings of models of care:

The family members cannot really come up with the conclusion whether to bring the patient back or who's going to care for the patient. I feel that it's also stopping us. Like, if we want to proceed with something, they [the family] don't allow us. I have a patient who we give a PCA [patient-controlled analgesia] pump, but the family stopped her from using. They [the family] said, 'If you use this, you're going to die'. So, sometimes I really feel that they don't understand our treatment (P4, Lines 108–111).

They are from different ethnic group, have different kind of culture, sometimes certain patients... some patients doesn't think... some patients think that morphine is addictive. Family don't want it given to them [patients]. We [nurses] have to explain to them [family] that mist morphine is a breakthrough pain and it will help to promote their [patients'] quality of life, but they [family] don't understand that this treatment is meeting the needs of the patient (P8, Lines 55–57).

Another participant reported her emotion on the lack of confidence a patient had in general practice nurses when administering treatment:

Even though we nurses continue to give medication as what the doctors ordered, the patient still have no confidence in us. They still prefer to talk to the doctors. They [patients] assume we are only good at doing physical care. They [patients] don't understand what we are doing (P11, Lines 93–96).

These narratives suggest that relatives expected active treatment interventions and failed to understand the goals of palliative care. Managing families' conflicting values and misconceptions of palliative care can create dilemmas and frustrations for nurses in providing optimum care. The narratives also revealed that doctors managing patients in acute wards lack adequate knowledge or training in palliative care. Participant 11 suggested that patients trust doctors more than they do nurses, implying that nurses play a subservient role, are not highly regarded or are considered unprofessional. Participants who initiated discussions about palliative care were regarded negatively by patients and their families, and conversations were seen as unproductive. Other participants believed that only physicians had the authority to initiate palliative care. In addition, nurses felt frustrated and tense when they witnessed conflict between healthcare professionals and families, impeding their ability to provide care. The medicalisation of care with the intent to cure appeared to supersede palliative care, creating a barrier to providing optimum care to dying patients. The following section presents participant accounts of conflicts between healthcare professionals and family members.

5.4.3 Conflicts of interest between healthcare professionals and family members

The nurses discussed the conflicts arising in care management among the multidisciplinary team, patients and families. Participants reported witnessing a shift of responsibility of care among resident ward doctors who fail to initiate or delay referring patients to palliative care. This delay of referral to palliative team added to the frustration of the nurses, who expected resident doctors to initiate palliative care. However, some nurses believed that for them to provide quality care, doctors should be proactive in initiating palliative care:

When you looked at the changes, you can see three pages of changes, but we do not know who to follow and we have the palliative set of changes, we have the doctor's [resident] set of changes and when they speak to the family, we looked at the communication sheet, there's another expectation, so, we nurses are very confused sometimes. We do not know which team to follow. So, when we informed them [doctors] about the symptoms and . . . sometimes they would say, 'Okay, let the palliative team decide, let the palliative team decide'. So, we have to wait for the palliative team to come and so there will be a delay to the treatment provided to the patient at that time (P4, Lines 120–123).

Conflicts of interest were further aggravated when doctors focused on cure rather than comfort. Participants expressed differences between doctors and nurses with respect to the approach taken. For example, Participant 3 commented, 'In our hospital setting, you see a lot of aggressive approach. Sometimes, some doctors, they will keep on doing until the patient go. It depends on the consultant' (P3, Lines 226–227). Similarly, one participant expressed the following:

But the problem was, the doctor already knows the prognosis for the patient, but then the children were not with him at all times, they were in Russia. Doctor was giving a false hope to the family. When, we already know, as nurses we already know, with his treatment plans, with his prognosis, with his investigations that was done, nothing gonna happen to him, nothing good gonna happen to him. But the doctor keep on telling . . . that he will be okay and taken care of (P9, Lines 178–181).

Six participants reported conflicts of interest between healthcare professionals and family members, which frequently occurred when doctors provided information about a patient's prognosis. Family members expect nurses to provide active interventions even after receiving a patient's prognosis. The following excerpt highlights the obstacles faced by a nurse who was unable to provide optimum comfort care:

The doctors told the family at family conference the prognosis of the patient. Family members actually accepted the condition of the patient. But they still want us [healthcare professionals] to actively resuscitate the patient. I could not participate in the resuscitation—it's kind of no use and I felt for the dying patient. Can't they [family] just

let go and don't make him suffer? I am more happy to assist the family to surround him [patient] before he stop breathing (P8, Lines 163–168).

Another participant from a geriatric unit, shared a situation in which a family member was finding it difficult to let go and was not receptive to comfort measures, preventing her from providing optimum palliative care: 'They are not prepared . . . to bid farewell to their loved ones, so they still want to try. It's so hard to tell them that you're actually making your family suffer, and they [family] will get defensive' (P11, Lines 108–109).

Participants found it difficult to incorporate palliative care into the scope of acute care, especially when general practice doctors (as opposed to palliative care specialists) did not understand the goals of palliative care. Patients and families were resistant to palliative care because the culture of acute care implies the possibility of cure. There continues to be a lack of collaboration within interdisciplinary teams to better manage the symptoms of dying patients. Doctors can be evasive about prognosis and continue active medical interventions, even when they are futile, to avoid EOL care conversations. The environment of acute care instils hope, and families expect miraculous recoveries. The majority of participants were concerned about the false hopes instilled by resident doctors. They described having to act as mediators between doctors and families. Nurses often felt frustrated having to fill in the gaps when doctors did not provide adequate information to patients, creating stress when they feel unprepared to share information. Indeed, the narratives revealed the diversity of barriers the participants faced in acute hospitals when events are unpredictable. The challenges are significant when participants had to juggle and adapt to multiple roles. This further barrier is discussed in the following section.

5.4.4 Switching between multiple roles

Some nurses expressed that working in an acute care setting while simultaneously caring for dying patients was overwhelming and that they had to separate and prioritise their tasks. Participants had to switch roles constantly, moving from acute and active treatment to palliative care. They felt incompetent when moving between different situations because they believed it prevented them from meeting the needs of their patients. At times, a minimal amount of time was spent with dying patients just to fulfil routine tasks. During night duties, when staffing was minimal and staff members are often inexperienced, it became even more challenging to provide optimum care for dying patients.

A senior nurse participant with 18 years of experience narrated her experience of having to separate and prioritise her work tasks, feeling that, at times, adequate care was impossible in the acute care setting:

I mean, experienced nurses versus those who just joined may pose many difficulties. Handling existing patients and seeing to the dying patients can be overwhelming at times. There are so many things happening in the ward. But this dying patient is grieving and dying so I will attend to him. I will divide my work. We will help each other, and I have to prioritise my work. If I have the time, I will sit and talk to the patient. But I have to face reality. I do not have all the time. I am always changing lanes and seeing many other existing patients who also need my attention. If I have the time and I know how to manage them, I like to talk to them, touch them and say a few words of comfort, when especially the family is not there. But in reality, this is what I like to. But working in the acute ward, sometimes this is impossible (P1, Lines 112–125).

Likewise, another two participants shared similar sentiments, highlighting the difficulties they experienced when they were unable to give their full attention to a dying patient and how their priorities were shifted to acute care:

Time factor-wise, as much as I want to give her the comforting words, I have other responsibilities towards other patients. Time factor-wise, mostly in the ward we are very shortage of staff. To care for her and at the same time care for another, although others don't suffer so much but they also needed that attention. I wish I could spend a little more time with her (P10, Lines 39–43).

I think would be nurses juggling with palliative care and palliative treatment in an acute setting. I think when nurses are overwhelmed, including me sometimes, we [nurses] tend to neglect the patient who is dying because he/she can't voice their discomfort. So, we [nurses] are always busy with those who are actively seeking treatment (P11, Lines 143–145).

In addition, one participant related that to comply with families' requests, dying patients were nursed in the 'Lily room' where they are separated from other patients. Although she considered this approach good practice, dying patients were nursed away from the busyness of the ward, meaning that they were isolated. Nurses entered the room only to check on the patient: 'There is this . . . room called 'Lily room', so it's actually an isolated room at the corner of our ward, is to provide care for the dying patient. But often nurses enter to do their routine checks' (P11, Lines 101–102).

In contrast, another participant expressed her difficulties when nursing acutely ill patients along with those needing palliative care. She was unable to attend and provide comfort care to the dying. It felt like a 'rush' attending to acutely ill patients, and she relied on junior nurses to fulfil routine tasks. Her time was consumed attending to the acutely ill and she

expressed her disappointment as follows: 'I feel I am moving about from cubicle to cubicle attending to the urgent cases. I can't give my attention to the dying' (P4, Lines 71–72).

The above examples of switching between multiple roles or changing lanes (G.N. Thompson, 2006) clearly demonstrated that participants struggled to fulfil their professional roles as caring nurses. Coordinating care, spending time with dying patients and completing tasks within their shifts prevented nurses in this study from providing optimal palliative care. Participants were aware of the need for therapeutic conversations and interactions when death was imminent but felt inadequately resourced to do so. They felt as if they were neglectful or had failed to provide meaningful support for dying patients under their care. Thus, another barrier to providing optimal palliative care was staffing constraints. The participants described how they had to juggle meeting the needs of the patients with minimum staffing levels.

5.4.5 Staffing constraints

One of the barriers encountered by all participants in providing palliative care was the lack of staffing. The nurses in this study reported that care could be demanding when there was limited staff on certain shifts. Participant 13 indicated the difficulties she faced when attending to three dying patients when there was limited staff on night duty, compromising her overall care to the rest of her patients. She reported that, as well as attending to the dying, her routine tasks were disrupted and there was limited time to spend with each patient:

I can't forget this night duty—I had to nurse three dying patients and some patients needing round-the-clock antibiotics. I worked with one junior nurse and one assistant. In the middle of the night, one patient died, and one died in the early morning. We were so busy attending to the dying patients and juggling with routine work (P13, Lines 60–63).

The following excerpts highlight the shortage of RNs to care for the dying in the acute care setting, adding to the participants' dissatisfaction:

Not enough people to care for the dying. Yes... and we will have a lot of dying patients lying around in one cubicle. Only one registered nurse and the rest are enrolled nurses. It is just not fair for them [patients], you know. Simply shortage of staff (P14, Lines 245–249).

One participant indicated that 'the routine is endless. I find it so difficult to give one-to-one care for the patient because at that point of time, there wasn't enough staff in the ward' (P12, Line 65). Similarly, another participant commented, 'I think we only have one or two

palliative care doctor, then, and one sister [ward manager] who is an APN trained for palliative. Sometimes they won't be able to come down personally to see patient' (P8, Lines 72–73).

These narratives revealed the difficulties arising from placing dying patients in separate cubicles, the lack of staff and nurses and doctors inadequately trained in palliative care. According to participants, responses to calls after hours were not prompt, further limiting the provision of optimal care to dying patients. The lack of staffing at night, the need to complete routine tasks, the high acuity of care and attending to the needs of dying patients were challenging for all participants.

The theme pertaining to emotional labour revealed that participants faced diverse challenges when providing palliative care in acute care hospitals. Emotional labour and barriers to providing optimum palliative care resulted from not knowing how disclose or share information, feelings of powerlessness, witnessing the physical deterioration of dying patients and dealing with conflicts between patients and families. These issues also arose from participants witnessing the futility of medical care and the misconceptions of palliative care held by patients, families and physicians. The emotional labour continued when participants lacked confidence in advocating for their patients for fear that relatives may have misunderstood their intentions. Moreover, participants had to prioritise the provision of acute and comfort care when the ward was understaffed. These challenges led to participants frequently experiencing emotional labour in an unpredictable and volatile environment. However, the multiple challenges faced by participants also brought clarity to their practice and increased their sensitivity when interacting with patients and families. Participants' understandings of EOL care evolved.

In summary, chapter five presented the demographics of study participants and the findings of Part 1, which was related to two themes, 'emotional labour' and 'barriers to providing optimum palliative care'. It depicted participant's personal and professional struggles and the multiple barriers participants faced in meeting the needs of dying patients in an acute hospital. Moral distress included feelings of sadness, helplessness, dealing with unanticipated sudden deaths and guilt. Participants also expressed concerns about disclosure, communication challenges, cultural factors, personal barriers and discomfort with conversations about death and dying. Along with the emotional consequences, there were barriers that impeded nurses

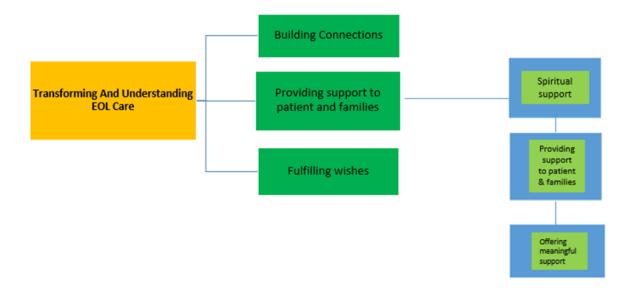
to provide optimum palliative care which was highlighted in the sub-themes (knowledge of symptom control, misconceptions about palliative care, conflicts of interest among health care professionals and family members, switching between multiple roles, and staffing constraints). The second theme that emerged from the findings was 'barriers to providing optimum palliative care'. This theme revealed a culture of acute care that impeded the provision of EOL care. It highlighted on the switching between multiple roles and the difficulties nurses encountered in meeting the expectations of both patients and families. The discussion also revealed participants' lack of knowledge of palliative care and the need for practical support for nurses in acute care settings. All participants mentioned the issues of biomedical dominance and misconceptions about palliative care for from health providers, nurses, medical officers, patients and families. The biomedical perspective was reported to take precedence over a patient-centred approach, which is inclusive of family and is the focus of palliative care. The next chapter presents Theme 3, 'transforming and understanding EOL care' and Theme 4, 'ways of managing care effectively'.

Chapter 6: Findings: Part 2

6.1 Introduction: Theme 3: Transforming and Understanding End-of-Life Care

Chapter 6 presents the findings related to Theme 3 and Theme 4: transforming and understanding EOL with its three sub-themes from participants' encounters with dying patients and their relatives. Figure 6.1 is a diagrammatic representation of Theme 3. This diagram is followed with the last Theme 4: 'ways of managing care effectively'.

Figure 6.1: Theme 3: Transforming and understanding end-of-life care



The transcripts revealed participants' understandings of effective EOL care practices in the acute care setting. Effective practices include the provision of space and privacy, sharing information, being an advocate for patients, showing sympathy and empathy and supporting religious rituals in the hospital environment. The transcripts clarified how participants met the needs of and built connections with patients and families. The majority of participants highlighted that their daily experiences helped them to learn and deepen their understanding and to accept the demands and expectations of patients and families as reasonable. The texts describe how the participants understood caring in the context of EOL care and how they

could create positive outcomes from caregiving. Participants experienced collaboration, understanding, appreciation and acceptance from families and patients. The texts revealed a deeply caring approach to patients and families. The theme on understanding EOL care has three subthemes: (1) building connections, (2) providing support to patients and families and (3) fulfilling wishes. Subtheme 2 also has three subthemes: (1) spiritual support, (2) alleviating physical suffering and symptoms and (3) offering meaningful support. The following section presents a summary of the findings related to the first subtheme, 'building connections'.

6.2 Building Connections

When narrating their care experiences, the majority of participants acknowledged that it was important to build connections with patients and families. The following quotations emphasise how participants provided emotional support by listening to, embracing and acknowledging patients' and families' feelings of sadness, responding appropriately and building rapport over the illness trajectory. Although participants described building rapport as challenging, they were able to cultivate a sense of acceptance for patients and relatives. The following quotations demonstrate these sentiments:

I mean, we have built this rapport with the patient and family. Is like a closeness of a family. When they cry, you can't be like a robot without feelings! If you see them cry, you don't hold your feelings, so I also will hug them and show my feelings (P1, Lines 39–41).

Participant 1 expressed that building connection meant constantly building rapport, being empathic to the situation, actively listening and genuinely showing her feelings. Building rapport gave her confidence in delivering care and assisting the grieving family effectively, but she expressed that it was challenging:

It is very challenging to convey it to the relatives. If after building rapport with the relatives, when we start to explain the prognosis care plan to the patients' relatives, I can see they begin to accept slowly. When you explain the illness burden to the relatives, and their loved ones are not responding, they slowly begin to accept. When nurses continue to give support to relatives, it makes our job easier (P1, Lines 68–71).

Participants became more receptive to information sharing once they had built rapport with relatives. For example, one participant reported that when she provided information on prognosis and care, relatives were able to understand as they slowly absorbed the news. Information sharing eased the approach to care. Demonstrating care and compassion fostered

ongoing trust and acceptance. A similar sentiment was echoed by another participant, who nursed an Arabian patient following a bone marrow transplant:

I nursed him. He was a gem of a guy. He opened up to me. He said, 'I don't wish to die now because I am young. But if death is going to come upon me, I will take it in a positive way of my sickness' (P2, Lines 13–17).

The above participant 2 was able to engage in conversation with her patient, who expressed his thoughts about dying. Connections were built through the use of effective listening skills and paying attention to the patient's overt verbal expressions. This rapport building was crucial because it revealed to Participant 2 the patient's preparatory grief. Connecting with the patient and his family meant that the nurse was able to understand how she was affected by the experience of her patient dying. The patient was able to open up to the nurse about his feelings of dying, which was possible because of the personal connection between them. The support the patient received from Participant 2 made it possible for him to express his inner thoughts about impending death.

Participant 2 further expressed that extending this support and showing genuine interest in the concerns of patients and families helped their relationship to evolve. Positive professional socialisation was built on trust, acceptance and confidence in the care delivered:

The lady [patient's mother] especially will hug and hug and then will say, 'Goodbye and take care of my son. I will come tomorrow'. They [family] have interpreters and they will tell us what they trying to say. I have no issues with the family support and with the little English the Arab man knows—he is able to translate what the mother is telling. It is like a family among family. I am in the family. I don't find any difficulty, but except maybe I don't understand the Arab language—there may be a communication barrier. But I try to understand with the facial expression and the meaning of the little English he speaks to me that whatever he says to me, I have delivered him the best care (P2, Lines 75–82).

This text implied that building relationships with patients and families required effort and demonstrated that language is not necessarily a barrier for building personal connections. The ongoing interactions between the nurse and the patient and his family enabled a 'chemistry' to develop between them. The patient could comfortably express his inner thoughts of impending death with no fear. The building of connections also extended to the family. Besides fostering ongoing trust and acceptance and sharing of information, some participants also expressed that the physical presence of nurses and their support of religious and spiritual practices in the final moments helped to build strong connections with patients and families.

The following quotations demonstrate this element of being present for the patient and family, both physically and psychologically:

I feel that human touch, there should be somebody there for him [physically]. Be it family members or even nurses, to be there as far as possible. We would try to maybe just touch him, there should be some human touch going on. Sometimes with that touch, they [patients] will be calmed down. They [patients] will feel that somebody caring for them at that difficult moment (P4, Lines 67–71).

Similarly, another participant stated:

Some family members I think, especially the Muslims, they would like to keep the patient in the cubicle for a while. I think, certain hours, so we [nurses] will try to accommodate to their [family] request. Like maybe wait certain hours for the priest to come and pray for the patient before we can shift the patient to . . . we try to facilitate their needs and it helps them to cope as well with the loss (P8, Lines 175–177).

These narratives emphasised the importance of the physical presence of the nurse to facilitate patients' and families' requests and offer meaningful support at crucial moments to strengthen the connections between them. Nurses can also help create closure for patients and families by participating in spiritual and religious rituals. Finding out what matters most to patients is crucial to care. Reassuring family members that they need not fear and continuing to engage with dying patients are important aspects of care, as is educating the family to spend as much time as needed to support their dying relative. The transcripts also revealed that touch, listening, facilitating family rituals and not leaving patients alone helped participants to strengthen connections. Participants were mindful of cultural rituals, including giving families more time to grieve and accept death. Care did not cease following the death of a patient, and participants preserved the dignity of patients and exercised discretion regarding the spiritual wishes of patients and grieving families. Building rapport and creating an atmosphere of tolerance, privacy, respect, understanding and acceptance of cultural, religious and spiritual practices helped to foster connections and understanding between nurses, patients and families.

In summary of this theme, the texts emphasised the importance of building connections for understanding EOL care practices that affect patients and families. They also highlight how nurses played a pivotal role in meeting the needs of patients and families. Spending time, maintaining open communication, being tolerant of patients' cultural practices, supporting family members and responding appropriately to grief were all important means of demonstrating the connections between nurses, patients and families. Participants'

understanding of EOL care was further enhanced when they described the various ways in which they provided meaningful support. The next section discusses the findings pertaining to the second subtheme—providing support to patients and families.

6.3 Providing Support to Patients and Families

Participants' understandings of EOL care practices involved providing support to patients and families. Participants spoke about how their practices in EOL care were transformed and how they integrated EOL care into their practice. Addressing the diverse and unique individual needs of patients was important in providing support in the hospital environment. Three connecting themes were identified for this subtheme: i) spiritual support, ii) alleviating physical suffering and symptoms and iii) offering meaningful support.

6.3.1 Spiritual support

The participants reported that spiritual expression was an important need for dying patients. The majority of participants acknowledged the freedom of spiritual expression of individual patients and recognised that it had enhanced their understanding of EOL care practices. The following passages from three participants demonstrate how they recognised and attempted to fulfil the spiritual aspects of care. One participant outlined the importance of spiritual care in establishing a connection with her patient:

I have done most is counselling. Mostly spiritual. Like, you know, prepare him in a spiritual way that he can feel the ease. He doesn't bother whether I am an Indian, Chinese or Christian, and if he [patient] feels like sharing the Quran words, he [patient] will share with us (P9, Lines 62–65).

Another participant was prepared to offer spiritual care when she shared a common faith with patients:

Spirituality is a very grey area, but if you have the same religion with the family, it's okay. I did ask one of my director of nursing regarding this, and she said if the patient is okay, you can pray with him, you can even read with him [patient] the Bible and all that. Usually the patient was receptive, and they are more courageous. I feel when it comes to end of life, I did pray with a patient when he cried . . . when he was going to pass on . . . He appeared calm and they [family] really appreciate and when you come in, they [family] really looked at you differently. They really smiled, even the patient would more, they [family] really trust you when you do that, when it comes to this spiritual support. I think they feel that you are no longer a nurse that was caring for me, you became my friend, You [I] became part of my [their] spiritual family, something like that, building the trust in care with

spirituality. Getting the family trust and bonding. Acceptance of care readily when the belief system is similar. Accepting the nurse as a friend (P4, Lines 212–221).

Similarly, another participant felt comfortable when patients were receptive to spiritual care: 'For this man [Arabian patient], he already brought up the subject of spirituality. When I brought this up, it just gels very well. Even though there was a language barrier, they [family and patient] just receive it' (P2, Lines 125, 132).

These texts implied that when nurses and their patients have a common faith, it was easier to broach the topic of spiritual needs. Although spirituality is individual, patients and families demonstrated acceptance and appreciation. Connections with patients were further enhanced and participants learned how they could better support dying patients' existential needs. Moreover, another participant from surgical unit, elaborated that the provision of spiritual support was easier if rapport with the patient and family had been strongly established:

Recently, I went to attachment in Assisi Hospice. They do have spirituality support and like . . . the priest will come around to give them support . . . I thought this is good . . . we need to build that rapport with the family. We don't ask, we don't know (P6, Line 191).

Building connection also implied that when nurses build strong interpersonal relationships with patients and families, providing spiritual support added meaning to their work. Offering spiritual support is similar to building a relationship based on trust. Building relationship implied that nurses should be proactive in learning the faith of their patients and supporting patients' spiritual expressions should the need arise. Participant 6 understood the value of discovering the unexpressed spiritual needs of patients, believing that it was her professional obligation to ask if necessary. She felt that this was proactive and offered something meaningful for her patient, facilitating the patient's existential needs. However, spiritual connections did not always occur. The following quotation describes a situation in which the family was not receptive to a participant's offer of spiritual support:

Most of the patients whom I nursed, when I spoke about spiritual care, when I spoke about prayers, their mindset will be different. I am not sure why. The issue here is they [patients] were not opening up, they don't open up. They find that the disease is a process. They come to hospital is to cure the disease and not about spirituality or the care concern or love. I have come across a group of family who are Christians but never sit in to converse with the patient. They just come in saying 'hi', 'ok' and 'bye'. That's it. When I go in, I tell them [the family], 'Why not you share about the good times with patient?' They said to me, 'Oh, we have no time'. They just walked out (P2, Lines 126–136).

It appeared that the spiritual aspect of care was secondary for some families. Families may be more focused on cure than on care or may not have a good relationship with the patient and, therefore, failed to see the relevance of spirituality or fostering a positive relationship.

Another participant related how nurses were generally not proactive in offering spiritual support:

There is this room called Lily room we used for patients with prognosis of less than three days. After that, they [patient and family] will be requested to come out from the room. In this room, the patient and the family members can be inside instead [of] at the main acute care. That room has a radio with different religious cassette. So, I think the only thing that we [hospital] provide is that particular radio with the music. I think that's the least that our hospital provide for the patient, that's all we did. Besides that, I don't feel there's any spiritual care that we provide to the patient in the Lily room unless the family ask for their own religious pastors to come. It has to come from the family, because normally I don't see nurses making active effort on spiritual care (P11, Lines 136–139, 163–166).

The above quote showed that in general, nurses do not actively engage in spiritual care but facilitate it by providing a supportive environment for the family to express their spirituality and practise their rituals. Participants' played a supportive role by removing barriers to the expression of spirituality.

Nurses in this study demonstrated their understanding of EOL care practices when they acknowledged the existential needs of patients. Gradual rapport building increased the nurses' confidence levels. Some participants were confident in mediating and sharing information, enabling them to connect with families. Several participants reported upholding and honouring the dignity of their patients by respecting their cultural and spiritual practices. Thus, spiritual support is a component of holistic EOL care. Participants attempted to meet the individual needs of patients and create a comfortable and conducive environment in which families could grieve. Although participants showed respect to patients and families, they found it challenging to provide or facilitate spiritual aspects of care to the dying in the acute hospital setting. Participants also strived to exercise cultural sensitivity. Participants acknowledged that their understanding of EOL care practices also involved alleviating patients' physical suffering and symptoms. This is discussed in the following section.

6.3.2 Alleviating physical suffering and symptoms

All participants in this study acknowledged the many ways of providing meaningful support and that the needs of patients and families were equally diverse and complex in nature. The following quotations demonstrated that participants understood that alleviating the physical suffering, distress and symptoms of the patients was profoundly important in EOL care. These sentiments were common to many participants. The following is an example provided by a participant witnessing relief from faecal impaction:

I've seen this particular palliative nurse, where she goes around, she makes sure that her patients are very comfortable. She will check for any faecal overload. Then, she will go and do the manual evacuation without any help. She will just go forward, and she won't feel... She will just go forward and she will do the manual evacuation. And she will come and tell us, this much of faeces... So, I feel that she has this... the passion for this type of patient (P13, Lines 155–159).

Another participant observed how senior nurses took steps to relieve symptoms. Senior nurses provided comfort care through touch and acted as companions, reassuring patients until their families arrived. Senior nurses minimised fear and suffering by their physical presence:

I do see a lot of patients at the respiratory ward. I do see a lot of seniors giving comfort care when patients are breathless. They come forward to relieve their pain and involve in some form of touch. Assisting them by being there, reassuring the patient and calming them down in their symptoms. Nurses come forward to comfort them until the patients feel better. These nurses are not oncology trained, but they really know how to take care of the patients. I see patients with renal failure in all acute care settings. I have seen nurses holding their hands and sit with them until their family arrive or until the patient feels better. It is like being there as a companion till their last lap (P7, Lines 70–78).

The empathy displayed by senior nurses demonstrates another means of building connections with families and patients. Senior nurses responded appropriately and maturely as they demonstrated their understanding of the losses experienced by patients and families. Senior nurses often remained after hours to provide support, and some took time out from their busy schedules to offer a listening ear. Senior nurses made their presence felt by being present at crucial moments.

Similarly, another two participants spoke about how they ensured dignified painless deaths and explained the importance of relieving physical suffering: 'I will say comfort measures for the dying patient is an important care. I try to make them comfortable' (P5, Line 178). Another participant stated:

I would say that it's really important as a nurse, as nurses, even to send the patient off with dignity. I feel very satisfied. Ya, it's not just seeing patient getting well, go home, even when they died well, died with less suffering. As a nurse, I feel that I did a great job. Ya, I'm okay, I believed that the family would sense that this nurse is different, would sense that

with the support of the nurses, my father is in good hands, you know, and all that. And I feel . . . rewarded (P4, Lines 220–224).

The above two participants felt satisfied and acknowledged by the family when they helped provide a dignified death. This could also be interpreted as striving for a 'good death' with less physical suffering for the patient. Likewise, one participant collaborated with the palliative team to meet the needs of patients and families. Comfort care and hygiene needs were important aspects for this participant:

Maybe our part, we are trying to improve patients' quality of life by doing whatever patients' family members want . . . and also what the doctor's palliative care team they actually want to reduce the pain. So, we started her on syringe driver. Also, we try to maintain hygiene, do sponging for patients and oral toilet care. We are just making the patient comfortable (P8, Lines 19–22).

These narratives demonstrate that making the patient comfortable and seeing to their activities of daily living are regarded as important aspects of EOL care. Participants indicated that it was rewarding when the suffering of patients was alleviated while upholding their dignity and respecting their choices. This highlighted how quality care was delivered to maintain quality of life for dying patients. Participants attained a sense of fulfilment and professional satisfaction when meeting the individual needs of patients. This demonstrated the therapeutic importance of nurses being physically present and allowing time for patients when the situation is unfavourable. The narratives also showed the importance of alleviating physical distress and managing symptoms. Moreover, participants believed their understanding of EOL care practice was enhanced when they could offer other types of meaningful support. The next section elaborates on the findings related to the subtheme 'offering meaningful support'.

6.3.3 Offering meaningful support

The majority of participants in this study acknowledged that patients and family members had diverse and complex needs. All participants believed in offering meaningful support that was unique to patients and families. Participant 9 expressed that it was crucial to communicate effectively to show her compassion for and support of dying patients and their families:

At that moment, when he [the patient] was dying, I and my colleagues were there, and we were very close to him and to the wife. We usually do a lot of talking with the wife, give her motivation, and also we always try to spend our time with her and her husband. When I'm

nursing him [the patient], to spend more time with him, so that he will be back motivated as before, at the point when he's giving up (P9, Lines 16–18).

Providing support meant keeping the lines of communication open, spending time with the patient and their family and promoting gradual acceptance. Participant 9 further expressed that she attempted to be present for patients, even outside of her work hours:

I mean, after our working time, once we know this patient is dying, and when we get closer to the family, we will spend our time extra. This will not count as an OT [overtime] or what, it's really from our [nurses] heart. We will be there with the patient and also with the family. But, overall, that is the good practice that we [nurses] are doing (P9, Lines 100–103).

These narratives emphasised that the physical presence of nurses and that care accompanied by compassion adds meaning to nursing practice. Voluntarily spending time with patients beyond the call of duty portrayed the compassion of participants. Participants also described the need to support family members to be present with the patient, believing that help from the palliative care team was vital. Participants expressed the need for multidisciplinary care and teamwork:

After the interdisciplinary team or medical team [had] spoken to [the] family to stop treatment, they [the family] agreed to stop treatment, and family accepted it. I will try to tell them [family members] at least, keep him comfortable now. I think what he/she [patient] wants now is by their bedside, so you [family] come down more often, spend more time with him, even though he [the patient] may not be able to communicate. He will know that you're here, so I will, in a way, reassure them [family members] that to just keep patient comfortable (P11, Lines 114–115).

Another participant commented on the value of the palliative care team for families:

I would think, if let's say, during the period when they [patients] are going to pass on, that last moment, when the family is all there, this team [palliative] can come down. Because they see the patients enough and they read more about this patient. If they [the palliative team] are there to help to actually communicate with them, it will be a great help for us as well. Somebody is there (P13, Lines 65–68).

These narratives showed that ongoing communication and reassurance from nurses and the palliative care team transformed the atmosphere to one of gradual acceptance by family members. Facilitating and allowing the family to spend time with the patient in a quiet reverent way added meaning to nursing practice and provided for better care. Ongoing communication allayed the anxiety of the family regarding the patient's condition and kept family members updated. Offering meaningful support to families helped them prepare for the further decline of their loved one's condition.

Participant 5 expressed how she offered meaningful support by playing the role of an advocate:

I will cry if I see the patient suffer. It upsets me. It just breaks my heart to see them [family] crying. So, I will do it indirectly. I cannot do it directly because it's very sad, to know, to stop their [family's] hope to see patient recover . . . it's really very sad to know that so many things going on for dying patient, and there's a lot of emotional breakdown, especially if you've build rapport with the patient. I will slowly tell them and educate them to stop. I will be honest with them. (P5, Lines 222–225, 235)

This narrative revealed that Participant 5 communicated honestly with families, subtly informing them that further interventions may be futile. She assisted family members in the decision-making process by educating them about the futility of ongoing treatment. In this way, she was able to alleviate the family's distress.

Other participants offered meaningful support by providing a comfortable environment away from the busyness of the ward. Three participants supported families in different ways by providing privacy and space or by seeking out volunteers in cases where there was no family: 'When we know the condition [of the patient] is turning bad, we will try to place the patient in a single room. It can accommodate quite a lot of relatives. We try to facilitate the family's request' (P8, Lines 158–159).

I feel privacy is very important. Like I mentioned in my first case, the male patient, we actually try to put him in a single room, we will allow more visitors to come and visit him. The single room is very big, about 20 people it can hold (P6, Lines 64–65).

There is this room called 'Lily room' we used for patients with prognosis of less than three days. After that, they will be requested to come out from the room. In this room, the patient and the family members can be inside instead [of] at the main acute care (P11, Line 136).

These nurses helped families to grieve and say goodbye in an environment away from the busy ward. They provide space and privacy for families to grieve. Participant 4 commented that she sought the support of volunteers for patients without family support:

In our hospital, let's say if we see that the patient is going, but he's always alone with no family members, there is this thing called 'no one dies alone'. We can get the service. They [management] will get people [volunteers] to come and sit with them or just talk to them at their last stage while they are alive and all that (P4, Lines 75–77).

The above text revealed that even when nurses were unable to spend time with dying patients, they actively sought the support of volunteers to be physically present. It also revealed that nurse participants are vigilant and aware of the situation and constantly evaluated various

means of supporting dying patients. While another participant took on the role of a mediator to build a meaningful relationship and to treasure the final moments before the death of a patient:

Especially with renal patients, when they have a six-month prognosis, we work very closely with patients and family members before they go into a state of unconsciousness due to their creatinine level. Within that period, we want them to treasure and appreciate the time they have and for nurses to prepare time to say goodbyes. It is like our final farewell (P7, Lines 111–112).

Working closely with family highlighted that nurses take time to say goodbye to patients. Participants further commented that they could provide meaningful support by explaining AMDs and ACPs. Participant 11 commented that 'After the doctor made known to them, you know, that they are stopping all treatment and they [the family] agreed to it, I find it helps me to speak more comfortably about ACP' (P11, Lines 117–118), while Participant 16 stated that 'When the DNR[Do Not Resuscitate] was conveyed to the family, I felt it was easy for me to support the patients and relatives. We get the medical social worker and they will explain more about ACP' (P16, Line 105–106). Another participant expressed it is as follows:

I think he actually accepted that he's going to go, he did verbalise to the doctor and said that, 'Please, just let me go'. I took the opportunity, spoke to the wife and explained all about ACP. She accepted the patient's wish (P9, Lines 123–124).

Active conversations with patients and family members enabled participants to offer meaningful support in relation to care planning. Participants were also able to care for patients more easily when families were educated about care options. Conversations about EOL care were more comfortable for participants when the family was actively involved in care, helping them with gradual acceptance. Some participants also shared vital information with and supported the family after the death of the patient. The following quotations describe how participants provided assistance to the family regarding hospital protocols and administrative practices. They also show how other kinds of meaningful support were offered to families in terms of what they should expect in the patient's final moments and arrangements with undertakers for transporting the body home:

We pass the brochures to the family, which help them to decide how to order the coffin with the undertakers. We move the process along, and what are the channels are available if they need to speak to someone, I think, that's how we support (P16, Lines 72–73).

Other than that, my ward sister talked to the main spokesperson, the caregiver, will encourage and support them. Give them brochure and . . . probably talked to them about how to handle, you know, the upcoming [death] (P6, Lines 68–69).

I remembered calling the pastor, offered my assistance. The family were appreciative. I spoke to them about hospital practices and how long the body can remain in the ward. There are brochures we share with the family for their arrangements (P4, Lines 211–214).

These narratives showed that care for the dying extends beyond death. Nurses offered continuous support, allayed anxieties and assisted in funeral arrangements. They also reveal the anticipatory quality of nurses in providing support to grief-stricken families, adding meaning to their practice.

All participants in this study shared similar sentiments about their understanding of EOL care practices. The direct quotations provide rich insights on nurses' understanding of EOL care practices and that building connections and providing support to patients and families developed their understanding of EOL care. Offering meaningful support enhanced nurses' EOL care practices. This included facilitating families to be physically present, spending time with patients and families, keeping families updated on a patient's condition, actively engaging in communication and respecting choices. Participants tailored their care appropriately and individually when the need arose. Their insights into EOL care also deepened when they were able to fulfil the wishes of patients and families. The next section presents the findings related to the subtheme about fulfilling wishes.

6.4 Fulfilling wishes

Participants spoke of their experiences with dying patients and that they further developed their understanding of EOL care when they were able to fulfil the wishes of patients and families. The following quotations described how maintaining human dignity, providing focused and individualised care and addressing hidden and anticipatory needs helped participants fulfil the wishes of dying patients and families. Participants also spoke about their moral and ethical dilemmas regarding fulfilling the wishes of the patients and relatives. Despite these challenges, participants attempted to fulfil the wishes of patients and families by respecting the care options, the personhood and the values and beliefs of the patient and their families. The following quotations demonstrate how participants honoured the wishes of their patients: 'The patient is for maximum comfort care. We never do any CPR[cardio pulmonary resuscitation] and that was according to the patient's and family wish as well'

(P1, Lines 29–30). This showed that Participant 1 and the team of doctors were able to honour the patient's and family's choices. Conversations regarding EOL care options were discussed with family members and the patient prior to deterioration. The patient and family requested a peaceful death with no active intervention, and their wishes were respected, showing no contradiction in care.

One participant worked in a medical unit, added that satisfaction increases when relationships are encouraged:

This old man, 84 years, was having Ca [cancer] lung. Prognosis no good. A lot of people visited him. Sometimes he wakes up and see around and sometimes falling asleep. It was like draggy [poor prognosis] case. Relatives were informed and they were all prepared. They kept asking me, 'Why is he like that?' I asked the relatives is there anyone need to see him, or he is looking forward to see? Then the daughter said his elder son not in town. Maybe call the son to visit his father. Then, I came back for night shift and my colleagues told me the old man is gone. One of my colleague told me, the elder son managed to visit him on the day you were off duty. I wondered was this what the old man longing for! Somehow, I felt good and satisfied (P12, Lines 88–101).

The above participant exercised her intuition in deciphering the inner needs of her dying patient and felt that she had done the 'right thing' for the patient. Another participant valued patients' needs to remain conscious and lucid:

He wants to maintain his consciousness actually for the sake of his mother. So, he doesn't want his mother to see him like always being unconscious or sedated and not be able to talk to her. So, he actually requested for us to titrate such that . . . he actually still has pain. He verbalised that he still has pain but he rather bear with the pain and be conscious so that he could actually talked to the mother, the girlfriend and as well as his family members. So, he actually remained lucid, if I'm not wrong, till just a day before he passed away (P16, Lines 65–68).

Participant 16 assisted her patient to remain lucid. She honoured his last wishes by collaborating with the team doctors to reduce his sedation so that he could communicate with his mother before he died. She facilitated the patient's wish within the sociocultural context. This developed her understanding and optimised her priority of care.

Some participants narrated that they had to be mindful, realistic and practical in fulfilling the wishes of their patients. Three participants shared their limitations in not always being able to fulfil the wishes of patients:

Sometimes, especially when family is so protective and they don't want the patient to know what is happening to them, they [family] know the patient is dying and the patient knows she is dying, and they don't want to reveal to the patient is so challenging for me. Patient

keeps on asking, 'What is wrong with me? Why am I feeling like that? Am I dying?' I find it so difficult to handle. I had to juggle with family and patient's wishes at the same time. Patient knows they are dying but the family too protective and don't want to tell them. Family don't want to involve the patient in the decision-making. Patient kept on asking what is going on with me. As a nurse it was a struggle to me whether to tell or not to tell; on the other hand, relatives kept reminding me not to reveal diagnosis (P1, Lines 47–54).

Participant 1 had to remain cognisant of her ethical and professional boundaries and objective in meeting the patient's and family's wishes. It was not easy to find a balance in a situation involving collusion. In this instance, the family's wishes were fulfilled but the patient's wishes were not. Truth and collusion were seen differently from the family's and patient's perspectives, and Participant 1 had to become the mediator. The text implies that the family was protecting the patient from physical and psychological harm. However, the situation cultivated deeper insights for Participant 1.

The other two participants reported that although their patients' wishes were important, they acknowledged that some circumstances may be out of their control. One participant relayed a situation in which a patient insisted on performing her own activities of daily living, even after her condition had significantly deteriorated:

I nursed another patient, she is also a case of colon cancer. I think she is like 40 to 50 years old. She's alone, she don't really have friends to visit her, but for her she not mentally prepared for her death. She cannot accept it. Her Ca [cancer] already spread a lot already. She lost a lot of weight. She really couldn't accept it, she wants to stand up herself, she keeps telling me, 'I can do it, I can do it' [activities of daily living]. For her to get up from the bed to the commode, to pass motion, is very difficult already. She refused to pass in the diapers, so she will force herself, all her strength, using all her strength to get up. After that, she will be sitting in the toilet, on the commode for like 30 minutes, and she will cry, she said, 'I can do it'. At that moment, I just tell her, 'If you can do it, go ahead, otherwise do not force'. I tried not to discourage her, but I know she can't (P6, Lines 40–51).

The above texts relayed participant's limitations and how she practised being non-judgemental when attempting to fulfil the wishes of her patient. She exercised discretion when helping the patient with her functional abilities. Although she knew her patient was unable to independently perform the activities of daily living, she continued to empower her patient without causing offence, helping her to accept her physical deterioration. In this situation, she respected and supported the patient's choice. Similarly, Participant 9 spoke of the limitations that can occur in practice:

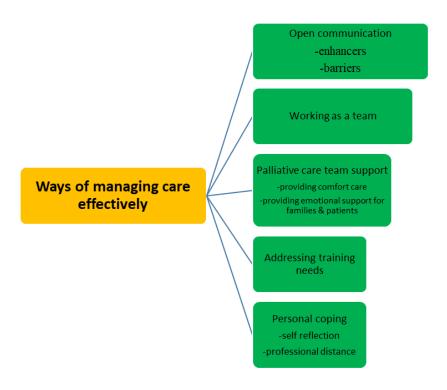
I had a patient, he's a Sri Lankan, he was working in Singapore. He has two kids, and the wife was here. He was 42 and had Ca [cancer] kidney that was diagnosed within six months. It's already the end stage. He was very ill, so, his last wish was to go to ICA

(Immigration) and to sign the consent for the two kids to get the citizenship. He has to present on that particular day, but doctor already told the family that he will not last even for 24 hours. He was that ill, but he knows, he keeps on telling that he needs to go to ICA, he said this is his last wish because he was waiting for this moment for many, many years, and now that he was dying, he feels that he needs to do something to keep the wife and the kids. I mean, security here after he goes. But then, when we [the organisation], we tried many ways to help him, but then when we called the ICA, they [ICA officers] actually did not understand the situation. They said the person [the patient] has to go down there to sign, otherwise it will be rejected. No doubt, even with the doctor's letter [with doctors signature and note]. So, that was very upsetting for him. At last, he passed away without doing. That was actually, I think his desire or wish did not come true (P9, Lines 78–90).

Participant 9 revealed that attending to the patient's personal matters in this case was beyond the control of the nurses or organisation. There were also ethical and legal implications of the patient's request. Participant 9 wished to fulfil her patient's wish, but the organisation and medical team faced practical constraints. Fulfilling patient's wishes may not be achievable in all cases. Participant 9 experienced some dissatisfaction when patients' wishes could not be fulfilled.

All nurses in this study had individual accounts of understanding practices related to EOL care. Nurses increased their understanding of valuable practices related to EOL care and journeyed with their dying patients. Alleviating physical discomfort and suffering and offering various types of meaningful support shows that the nurses in this study provided care outside of their scope. The meaningful support offered by nurses facilitated families in accepting a peaceful and dignified death. Notable findings included coming to terms with decision-making, being ready to let go and accepting the deteriorating condition of patients. The involvement of families in patient care, spending more time with dying patients, the ongoing interactions between families and nurses, providing private rooms for grieving families, providing physical aspects of care, alleviating physical distress and obtaining support from the palliative care team were all revealed as requirements for a 'good' death. The findings of Theme 4, 'ways of managing care effectively' and its associated themes are illustrated Figure 6.2 below.

Figure 6.2: Theme 4: Ways of managing care effectively



6.5 Theme 4: Ways of Managing Care Effectively

In Theme 4, providing individualised care was demonstrated by several common threads. This care highlighted the essence of integrated nursing practice in EOL care. Participants expressed that their accumulated professional experience had taught them the most effective ways of interacting with dying patients and their families. They felt that senior nurses acted as role models, who supported them and influenced their practice. They understood that continually building rapport with patients and families was pivotal in delivering personcentred care. Additionally, keeping the lines of communication open and transparent was essential for positive outcomes, including the acceptance of the deteriorating condition and impending death of patients. Participants also reported that inadequacies in communication, such as that between doctors and nurses, posed a barrier to effective care. Further, participants voiced that they lacked the therapeutic communication skills needed when patients continued to hope for recovery when it was no longer viable. Participants also expressed that continual education and training was important for developing critical skills in EOL care. Participants spoke about how they coped with everyday encounters when caring for dying patients and their families. The subthemes identified for managing care effectively were i) 'keeping

communication open', ii)'working as a team', iii)'palliative team support', iv)'addressing training needs' and v)'personal coping'. The next section presents a summary of the findings related to the subtheme 'open communication'.

6.6 Open Communication

Common narratives demonstrate that open communication helped participants manage their EOL care practice. Sharing of information between patients, families and healthcare professionals, including providing updates on treatment plans and prognosis, and displaying empathy were regarded as important by participants when providing care to dying patients. This enabled them to manage their care and support patients and families appropriately and effectively. Participants regarded these aspects of communication as helping them perform their roles. The following section presents the enhancers of open communication that helped participants sensibly manage care.

6.6.1 Open communication enhancers

The following quotations demonstrate the importance of open communication with respect to treatment plans and care options for patients and relatives. All participants recognised that being open to refusing futile treatment was crucial when death was imminent. When this aspect of care is communicated, participants felt they could reasonably manage patients' and families' expectations. The following quotations portray the importance of open communication about prognosis. Participant 1 indicated:

As for this patient, I don't face many challenges. In this case, the management is very clear what they [medical team and family] wanted for the patient. What the family want, what the patient want is very clear. There is no contradiction among them (P1, Lines 143–146).

She further elaborated: 'I feel this will give time for the patient to prepare well before death. At least the patient will know how much time is left for them to resolve the unfinished businesses' (P1, Lines 52-53). She was able to handle a crucial situation when communications regarding the care plan and prognosis were clear, well documented and conveyed to the family. Open communication was not only about communicating treatment options but also giving them time to prepare and resolve unfinished business. Open communication gave this participant confidence to provide bereavement support. Most participants shared the importance of open communication from team doctors regarding

prognosis. Participants recognised that empathy was helpful when there was acceptance by the family and the patient. Another two participants (P1&P2) agreed when there was clear documentation, they could handle relatives' concerns effectively. Effective communication improved families' expectations and acceptance: 'So, if it is written very clearly end-of-life care management, as a nurse I find it easier to handle the relatives and patients'(P1, Line 56) and 'Communication—without it, it is a failure. The family is more accepting' (P2, Lines 130–131).

However, another three participants (P4, P6 & P9) managed EOL care by understanding families' anxieties, assessing their readiness to accept the truth and communicating the truth gently and tactfully. Participant 6 commented, 'The family's emotions are stabilised; they [are] aware of the outcome and it makes our job easy' (P6, Line 27), while Participant 9 expressed it as 'The doctors already communicated with him the prognosis and he also accepted it. It makes our job easy because we don't have to explain and explain' (P9, Lines 123–124). Participant 4 stated:

I tried to be very understanding, and then I would tell them that he's not doing well, but I would not say the exact time and all that because I also don't know. The family also wanted to know [the prognosis] and I will tell them (P4, Lines 149–150).

These narratives also demonstrated that participants felt more confident in communicating when the prognosis and treatment plans were communicated to all staff, patient and family members. Further, when families were accepting of the situation, participants felt more in control. Participants could switch seamlessly between acute care and EOL care without being confronted by families. Open communication reduced the burden of care by keeping all parties updated with information. Transparency enhanced the building of connections between nurses, patients and their families. All participants agreed that open communication was positive, meaningful that they did not have to speak all the time.

Some participants shared that they provided non-verbal support by showing empathy. For example, this participant commented, 'I know on the day that he passed on, I also cried with the family members . . . because it's such a loss . . . I don't know what to say, but I hugged his wife' (P6, Line 43). Another participant expressed this as follows:

I took care of him for four nights. He was purging and I kept changing. He felt awkward. I always smiled at him after each time I changed him. I knew why he was purging often. He broke the silence on my last night duty by saying thank you (P16, Lines 45–50).

Both of these transcripts show that participants demonstrate empathy and were able to interact with the family and patient at the same emotional level. Participant 6 was able to display her feelings in an empathic manner, while Participant 16 focused not only on technical care but engaged with the patient in a trusting and empathic way. Both participants interacted with patients and relatives at the human level, showing respect for their dignity. Given that much was shared about the importance of open communication, most participants also talked about communication barriers that posed difficulties when providing care for the dying. Some of these barriers are discussed below.

6.6.2 Open communication barriers

The majority of participants recalled that they dreaded communicating with dying patients and their families. Participants felt that their communication skills were limited. Although open communication was regarded as important, participants felt that it was challenging because they lacked the confidence and experience to use effective communication skills. Participants often felt unprepared when confronted with truth telling, collusion or emotional situations such as the provision of futile care and believed they did not have the skills to empower patients and families. Others chose to take a neutral stance by not revealing the truth. Many common threads depicted the communication challenges faced by participants. Most participants expressed that it was difficult to communicate the truth about a patient's deteriorating condition at critical moments. For example, Participant 3 commented, 'I don't really know how to console the person, so don't talk about it better' (P3, Line 220). This thread implied that Participant 3 showed avoidance by refraining from talking to the patient and also reflected her inadequate communication skills in dealing with loss and grief. Similarly, Participant 10 stated, 'I find it very challenging and at the same time the patient's condition is deteriorating and . . . I wish that I know how to handle the family members by providing some comfort words' (P10, Line 82), while Participant 12 expressed it as, 'I'm scared that the family members have the perception of me... if I said the extra things or something... like... it might hurt their feelings... ya... that is my personal concern' (P12, Line 148). Participant 5 narrated it as follows:

I mean, medically his prognosis is really bad, he may not be able to make it. But it's difficult to express it to someone who's so dear to him, you know. So, all we say is, 'We'll try our best, we are doing our best' (P5, Lines 120–122).

These statements highlighted some of the communication barriers participants face, which included not knowing how to communicate therapeutically when patients and relatives were faced with a devastating situation such as impending death or futile treatment. Participants were unable to engage in empathic conversations because they lacked the skills to do so. It is also possible that stress or the fear of being reprimanded for saying the wrong thing contributed to these barriers. Although participants may have wished to educate patients and families about futile treatments, their ability to converse confidently was lacking. Some participants experienced disconnectedness, the inability to build rapport or the lack of self-trust. Truth telling was less about revealing the hard facts and more about understanding, acceptance and the social relationships between participants and families.

Arguably, in Asian societies, speaking about death is regarded as taboo. Withholding the truth can further compound communication barriers. Another two participants (P6 & P8) had similar difficulties with communication and chose to remain neutral: 'I won't encourage by telling, "I'm sure you can recover", neither do I tell her, "You cannot recover". I just follow the flow, you see' (P6, Line 50), and 'But end-of-life issue, I don't really bring up to them, I am not comfortable, I will leave it to the doctors to deal with it' (P8, Line 75).

These narratives demonstrated participants' lack of confidence, hesitancy, apprehension and ambivalent feelings towards how families might receive negative news. They also demonstrated the unwillingness to disclose prognoses or how to express bad news. This communication barrier shows that participants recognised their limitations and accepted their personal values, beliefs and concerns. However, communication barriers may result from participants failing to take a leading role in giving bad news to families hoping for recovery. This implied that a lack of collaboration between participants and doctors may also be a communication barrier. Overall, the lack of professional experience in communicating with dying patients and their relatives may have caused difficulty for participants, and it appeared as though they did not want to take responsibility for truth telling.

In summary of this major theme, participants unanimously acknowledged that open communication was an important element in effectively caring for dying patients, allowing them to further develop collaborative care with doctors, patients and relatives. Open communication resulted in transparency, interpersonal connections and trusting relationships between nurses, patients and relatives. Patients and relatives could have a mutual

understanding of the desirable delivery of EOL care. However, participants also acknowledged that hospital care was ineffective in the presence of communication barriers. These participant-centred barriers included the lack of experience, confidence and ability to use effective communication skills, the personal fear of becoming too deeply involved with the emotions of patients and families, the lack of collaboration between doctors, families and patients and managing unrealistic treatment expectations of patients and families. Part of open communication included working as a team and this is discussed in the following theme.

6.7 Working as a Team

The majority of participants stated that they were able to perform their roles effectively in the acute hospital setting when they received team support. Participants stated that when they felt part of a team, they could provide care more proficiently. This sentiment was captured in many participants' narratives. Participant 1 felt she could cope better with her work when her colleagues provided support: 'My colleagues are very supportive to one another. If I have many patients under my care who are dying, with clear management instructions, if the patients die, colleagues render support to one another' (P1, Lines 78–79). Participant 1 felt able to reach out to her peers for support, and the rapport she built with her colleagues sustained her in caring for dying patients. Team camaraderie was exhibited in moments when there were more patients to handle. They came together as one team to function and sustain each other's wellbeing. Participant 2 shared an experience that had built her confidence when caring for dying patients. She and her colleagues had taken care of the same dying patient, and she narrated the importance of sharing:

The three of us who always will communicate because we were nursing this patient. Accidentally we came by as we were nursing this guy. When I started sharing my experiences, they start sharing theirs too. We support each other when caring for this patient (P2, Lines 142–145).

Informal sharing was vital in this situation to validate their emotions. In sharing her emotions with her peers, Participant 2 felt less alone and more supported when her peers' experiences resonated with hers. In this way, they provided emotional support for one another, demonstrating that sharing helps to improve the effectiveness of care for dying patients. Apart from peer support, some participants indicated how they managed their care successfully when senior nurses provided assistance. Participant 4 expressed it in this manner: 'With the older nurses' guidance and support, I am able to build rapport, and it

really helps me' (P4, Lines 37–38). Likewise, Participants 5, 6 and 11 reported how they received support and guidance from senior nurses. Participant 11 commented, 'I will talk to my colleagues, especially the seniors; they experienced these things before, so normally we will talk about it during break or after work' (P11, Line 125). Other examples included:

Whenever, I am not sure what to do when a patient died, this senior nurse will make her rounds and I will take the opportunity to ask. Most of the times, she is so nice and helped me because she knew I was new to the ward. She taught me step by step and that is how I could complete my work (P12, Lines 106-108).

I haven't encountered any situation that is so challenging but then . . . for me, because my ward has a lot of really, really seniors, and whenever I encountered anything, like... something that I feel like not right or I'm not confident, I will go and ask, and I will carry out whatever I want to do. I will always ask first. I think the support I received from the senior nurses helped me, you know, we can help one another (P6, Lines 116–120).

The above narratives revealed how junior nurses manage their care and handled contextual situations effectively with the timely interception and guidance from senior nurses. They also showed that senior nurses, who had valuable experience in caring for dying patients, demonstrated their knowledge to junior nurses and provided timely help by normalising a tense atmosphere. The senior nurses demonstrated proactive behaviours, while the junior nurses demonstrated receptive acceptance and appreciated guidance from the seniors. Junior participants felt encouraged and developed maturity and confidence in their communication skills by observing how the seniors interacted during shifts and at crucial moments. The text highlighted the team cooperation between senior and junior nurses and demonstrated how complex situations were more effectively handled when collaboration between seniors and juniors was well established. The senior nurses alleviated stressful situations for junior nurses and were respected for their professional expertise. The narratives also demonstrated that experienced nurses' informal approach to bereavement support may result in positive coping outcomes for junior participants. Senior participants acted as role models for junior nurses.

Other narratives indicate that informal support from ward managers was vital in managing care effectively. Two participants recalled how they had been informally debriefed by their ward sisters, highlighting the sharing opportunities:

She [ward sister] is supportive. She sat down and talked to me and said this is a normal thing, every nurse goes through this. Try to keep a fine line; as a nurse you need to keep a fine line between a nurse and the patient. When you are offering care is a nursing care but don't get emotionally involved; maybe you can empathise but not more than that (P2, Lines 107–110).

If the staff is very down, if the sisters or seniors see that you are down, they talked to you over a short while. If the staff is really down and depends over a few days, they will refer you to the MSW [Medical Social Worker] in the hospital to have a talk with you (P8, Line 98).

These texts further illustrated that participants could manage their emotions and care adequately when ward managers demonstrate genuine concern about their repeated exposure to challenging emotional situations. They were strongly supported by ward managers listening to their concerns. The narratives also demonstrate how ward managers offer suggestions about how to maintain professional balance and boundaries when delivering care. For Participant 8, formal emotional support was also provided when the need arose, showing that caring for dying patients in acute care hospitals can be well managed if participants have access to appropriate internal and external support to address their emotional needs. The narratives also demonstrate the caring and nurturing culture of ward managers.

In summary of this sub-theme, working as a team provided learning opportunities for junior nurses. Junior nurses who were unable to cope with challenging death encounters could overcome these hurdles when they received support from more experienced senior nurses. Further, the support they received from ward sisters helped develop their self-confidence and bolstered their spirits when caring for dying patients. The sharing of common experiences between peers provided helpful insights to all participants on managing similar situations in the future. Working in a team was important and it was also realised with working alongside a palliative care team. The next section on managing care effectively discusses the support provided by the palliative care team.

6.8 Palliative Care Team Support

Most participants had similar sentiments about the timely referral to palliative care. Participants felt supported and guided in carrying out their patients' care effectively from the palliative care point of view. Participants expressed that the intervention of the palliative care team helped them in a variety of ways to manage the expectations of dying patients and their families. All participants regarded comfort care and emotional support as important elements in providing effective, high-quality care.

6.8.1 Providing comfort care

Comfort care was captured in many threads, reflecting the importance of participants to understand how to provide quality care for dying patients. Participants' personal encounters with patients and their families deepened their understanding of the support provided by the palliative care team and its valuable contribution in assisting them to manage care constructively. However, some threads depicted that referrals to palliative care were sometimes too late. Participants often witnessed the futility of ongoing treatment and felt frustrated when physicians delayed referring patients to the palliative care team for comfort care. Overall, the majority of participants emphasised the need for palliative care, particularly personalised comfort care, at the beginning of a patient's journey of illness. Participant 3 narrated if referrals to palliative team were made earlier, nurses could alleviate patients' distress sooner: 'I think palliative team should come early. Ward doctors need to refer early so that we can render care and distress their pain. Sometimes it is late' (P3, Lines 84–86). This implied that with early palliative care referrals, patients' comfort needs could be addressed more promptly. Moreover, resident doctors needed to be more open to seeking palliative care expert services. With early referrals and timely collaborations between acute and palliative care, patient outcomes would be improved.

This participant felt frustrated when aggressive medical treatment was continued, even when it would not change the outcome for dying patients:

I think in the acute care setting, if you know that the patient is not going to make it, comfort measures are very essential to the patient. Instead of just taking blood . . . all you [medical doctors] think about is blood, blood, blood. Medications are important, but all you think about is just poking the patient, taking the blood, doing blood cultures for one or two reasons like this, you know, there is no point to it (P5, Lines 206–208).

This text revealed that Participant 5 was opposed to the treatment because it unnecessarily exacerbated the patient's suffering and she believed that the doctor should have focused his efforts on providing comfort care. To alleviate the patient's suffering, Participant 5 felt that support from the palliative care team was vital. The text also implied that in the acute care setting, doctors typically respond to patients' needs from an objective, rational, biomedical perspective and could fail to recognise the futility of medical treatment, address the existential needs of patients or embrace the palliative care team's expertise. Acute care physicians may liken palliative care to terminal care, considering it a failure of restorative

care, or may have misconceptions about the meaning of total care or palliative care, regarding it as counterproductive. It appeared that physicians tended to operate alone rather than as part of a team and that palliative care was often offered as a last resort and only when death is imminent. There appeared to be a lack of collaboration between the acute care and palliative care teams. The timely intervention of the palliative care team was of great concern for Participant 5. However, she may also have lacked confidence in advocating for her patients. Another participant echoed a similar sentiment: 'To change the end-of-life care ... probably ... I think... to me, comfort [care] is still the most important one (P6, Line 175).

Participants agreed that comfort care was necessary at the end of a patient's life, expressing that palliative care team support was vital in managing care effectively. All participants expressed that the palliative care team was able to assess the needs of individual patients effectively. Three participants (P4, P8, & P14) shared their experiences of positive support from the palliative care team, ensuring the dignity of patients and alleviating discomfort. One of the participants commented that she had witnessed the palliative care team providing comfort care and removing unnecessary interventions:

They [the palliative care team] will really remove all unnecessary medications, and only those symptomatic ones. Let's say if patient's in pain, they will prescribe painkillers, sometimes even patch and subcutaneous instead of intravenous to minimise lots of injections. They will ensure the dietary support for the patient is sufficient also and all that. So, I think mostly their symptoms management well taken care of (P4, Lines 64–67).

The above narrative showed the importance of the palliative care team in providing comfort measures for patients and alleviating their suffering. For the majority of participants, high-quality patient-centred care was a primary concern in managing care effectively. The palliative care team involved families in care and filled the gaps when participant nurses were busy with patients in acute care. This demonstrated the time and energy required to meet the intricate needs of the dying patient, assisted by the timely support of the palliative care team. Participants felt that care of the dying should have a focus on quality. They emphasised how the palliative care team upheld the individuality and unique needs of their patients and families. Observing the palliative care team directly or indirectly taught participants how to pay attention to and manage the needs of their patients, leading to personal growth and increased knowledge for participants.

The participants deeply appreciated the support they received from the palliative care team and felt relieved when a patient's distress was alleviated. Palliative care is strongly focused on holistic, person-centred, high-quality care at the end of a patient's life. Comfort care for dying patients is provided through the appropriate management of physical symptoms and the provision of adequate nutritional support. Comfort care was an important aspect of care for all participants. The palliative care team's focus on human-centred care resonated with the nursing ethics of participants. Participants also reported how the palliative care team extended emotional support to the families of dying patients. The next section discusses how this aspect of care helped participants to manage care successfully.

6.8.2 Providing emotional support for families and patients

The majority of participants believed that, besides providing comfort care measures, the palliative care team also provided valuable emotional support. The following narratives exemplify the involvement of the palliative care team in supporting families with decision-making:

The [palliative] team also find out like who's going to take care of the patient. Are they [family] capable, let's say, if patient passed away, are the family supportive enough to care for him at the last stage of his life and all that? They [palliative team] will really do family conferences. I believed even though I might not be trained in palliative care, but I feel the support they give for our dying patients and family is really good. While working hand in hand with all these palliative nurses, I feel very supported to manage the dying patients (P4, Lines 67–71).

The support from palliative care team illustrated that the palliative care team provided essential emotional support to anxious families. Discovering families' coping mechanisms and involvement in care added valuable insights for participants. Participant 14 relayed how palliative care nurses demonstrate empathy: 'Palliative nurses are more... they can feel for the patient, they will touch the patient. They spend time talking to patient and family. They share their contact details if family needed help' (P14, Lines 261–263). The above showed that palliative care team nurses adopt empathic and non-judgemental behaviours by being open to situations faced by patients and families. By being non-judgemental, palliative care nurses strive to make a conscious effort to be receptive to patients' and their families feelings, showing respect and patience and spending time listening to their opinions. Many participants in this study felt that they did not have the time to provide adequate emotional support. Therefore, the emotional support provided by the palliative care nurses assisted

participants in connecting with their patients. The following excerpt expressed how the palliative care team helped the participants to manage care effectively in the final moments of death:

The general medical trained doctors do not pay much attention to the patient wellbeing holistically. Their management is totally different. Unlike the palliative-trained doctors, a lot of care and emphasis is placed on the patients' emotional concerns and wellbeing. The palliative team look into patients concerns, comfort and the family concerns and work well with the nurses and family (P1, Lines 54–57).

These narratives revealed that the palliative care team support was pivotal for all participants because they appreciated the value the team added to patient care. The participants acknowledged the extraordinary care and emotional strength provided by the palliative care nurses. Participants drew strength from the work and compassion of palliative care nurses when they felt overburdened with their existing workloads. The narratives implied that the resilience of the palliative care team and the support it provides to ward nurses indirectly helps participants to manage care equitably in acute hospitals. They also revealed that the physical presence of the palliative care team reassured participants about how to engage with dying patients. Undoubtedly, support from the palliative care team was effective in addressing patients' physical, social, spiritual and psychological wellbeing and it also taught the participants about a palliative care approach.

In summary, palliative care team support not only addressed physical distress but extended to meeting the emotional needs of patients and families. Being fully present assisted participants in alleviating the gaps in care delivery. Participants were able to focus their care and prioritise acute and EOL care effectively. Participants regarded the importance of early palliative care team support and how it helped guide and provide the family and the patient with holistic quality care towards the end of life. The many threads acknowledged the involvement of the palliative team care as a vital component in managing care effectively. However, participants also reported that they could manage care better if more training was offered to general practice nurses as discussed in the following sub-theme.

6.9 Addressing Training Needs

Threads common to this subtheme demonstrated that participants wished to improve their knowledge and skills in managing the care of the dying. Participants wanted more training at

the foundational and post-registration levels on communication and how to disclose truths. They also shared how knowledge deficits in symptom control made it difficult to provide adequate care. All participants reported they had received little training on addressing existential issues in their nursing education. In addition, there were gaps in how to communicate effectively when patients or relatives raised concerns, and participants had minimal exposure to how palliative care nurses handled such difficult and sensitive situations. This participant expressed her concerns as follows:

I feel end-of-life care must be taught first. It should be taught when you enter nursing course. I picked up caring for the dying through my personal experiences. I was never taught in school how to deliver. I was introduced to some forms where I have to tick whether it is for active or comfort measure. Otherwise I am not aware how to deliver effectively the care for the dying. I am not exposed to ACP or care for the dying during my nursing training. I feel inadequate in this aspect. I feel end-of-life care must be taught in the nursing school at the beginning of the course and throughout different levels at the course (P1, Lines 92–99).

Another participant stated, 'In my diploma training right, actually end-of-life issues were not commonly discussed. I was not trained how to assess deeper issues. We nurses do not know how to console or what is right to say now' (P3, Lines 207–209). Another three participants voiced their opinions on the need for more exposure on experiential learning, training at the foundation and at post-registration levels. One example of the quotation is:

In the foundation program, nothing about end-of-life care. Such training is necessary at foundation and post-registration level. Only in palliative care courses they [trainers] talk about end-of-life care. Normally it is done in the oncology wards but not in the acute care. But people are dying in all settings, I strongly feel this area is missing among nurses. Acute care nurses must go for palliative care courses and ACP which will give them some training on how to deal with end-of-life care (P7, Lines 132–137).

These narratives emphasised participants' inabilities to address psychosocial needs and the need for continual training for nurses working in acute hospitals. Written documentation of care preferences did not equip Participant 1 sufficiently to care for her dying patient. Participant 1 believed that both physical and emotional skills were essential to care for the dying. The text reveals the importance of training at different levels for different grades of nurses, including the need for training in ACP and AMD facilitation for patients and families. The texts show that training in EOL care involves many dimensions.

Similarly, Participant 10 shared her perceived inadequacies: 'I feel that for palliative care, experiential learning is more important than theoretical knowledge. If I get more exposure

working and learning from the palliative team, that would make me a little confident. It is about getting the training' (P11, Lines 81–82).

The above participants were deeply concerned about how to engage in open conversations about topics not related to the illness or what to say at appropriate moments. Their fear of offending families and patients revealed their lack of confidence in handling difficult circumstances. The narratives portrayed that education and training in these aspects of communication were vital to care management. The majority of participants believed that more training in communicating with patients about existential issues, cultural diversity and how to manage patient and family expectations is necessary.

Many participants also reported that they lacked the knowledge to adequately manage patients' physical symptoms, which is important to enhance the quality of care of dying patients. Participant 14 expressed it in this manner: 'I have to change the cannula every three days. When I am inserting or change the cannula, I don't even know whether he is in pain, what he is going through. I just don't know what is distressing him' (P14, Lines 37–39).

Participant 16 explained a situation in which despite following the medical team's orders to administer analgesia, she was unable to relieve a patient's pain. She witnessed the patient's distress but struggled to understand how to help the patient beyond symptom control: 'Except for medication administration, until now I have no idea on how to console a patient' (P16, Line 40).

The above quotations revealed that participants had inadequate knowledge about care management beyond alleviating physical symptoms. Participants struggled with the intangible aspects of care such as how to engage in soothing conversations or offer other means of compassionate therapeutic care for dying patients. This knowledge deficit also implied that participants lacked exposure to be even support or dealing with somatic complaints or emotional responses of patients and families.

In summary of this sub-theme, participants unanimously acknowledged that education and training in managing physical symptoms, offering bereavement support and managing patient and family emotions would give them important insights into effectively managing EOL care. Thus, the findings highlight the importance of equipping participants with appropriate education and training with respect to different dimensions of care for dying

patients. The physical presence of palliative care nurses alleviated the distress of participants by providing supportive, holistic and personalised care to dying patients in the absence of the ward nurses. Although participants struggled to provide appropriate care because of the various challenges they faced, most managed to care effectively by adopting personal coping strategies. The next section discusses participants' personal coping mechanisms in managing EOL care and caring for themselves emotionally.

6.10 Personal Coping

For this subtheme, there were common threads that captured how participants coped with caring for dying patients and their families. Most participants expressed that they had to disconnect from their emotions and undertake self-reflection. These participants kept a professional and emotional distance from their patients and had learned how to adapt to changing situations, acknowledging that this was part of their job. Others exercised personal coping by accepting that death was part of a spiritual journey.

Participant 7 reported how she exercised emotional distance and maintained professionalism:

When I am at work, I put away my emotions and just try to act professionally. I am blocking myself from entering this patient room because I feel I will be able to minimise my interaction emotionally with the care and may not exercise professional judgement in the course of my duty. (P7, Lines 106–107).

This professional distance showed that a strategy employed by Participant 7 was to exercise emotional disconnection to maintain her professional boundaries, deliver care professionally and avoid being affected by the patient. It appeared that she used these strategies as a shield to protect herself from emotional exhaustion. Emotional detachment allowed Participant 7 to exercise her professional judgement and enabled her to block other distractions.

Participant 1 cultivated a similar coping mechanism by accepting that patients were not going to live indefinitely:

It does not affect me, but patients come and go. The emotion of caring for the patient is definitely there. As a professional nurse, it does affect me because I have flashback of other experiences and it will come along with me (P1, Lines 41–43).

Participant 1 adopted and reflected on her previous experiences and encounters to develop strategies to emotionally cope with the passing of her patients. She further elaborated:

Those patients who die suddenly, colleagues are also shocked of what to do. Emotions involved. Patient is so nice: Why, why, what happened? But we also feel comfortable that patient had died and a stop to their suffering. We feel peaceful too. That is the way we cope (P1, Lines 79–84).

This encounter showed that sudden deaths can also be a relief for participants because patients were no longer suffering. The participant reflected that she had to find some emotional balance between effectively managing the care of patients and her personal coping mechanisms, illustrating that nurses' relationships with patients may elicit positive, negative and mixed feelings. Participants reflected on their own emotional attachments and meaningful engagements with patients to draw from their inner strength.

Similar to Participant 1's coping strategy of accepting the death of her patient. Participant 6 reported that death could not be avoided and was something that all people must eventually face: 'As for me, I see that dying is part of a process... and I do feel sad for .[the patients]... mmm... I have learned to accept it. One day we all going to die anyway' (P6, Lines 140–141). This shows that Participant 6 had reflected on human mortality, accepting that death was an inevitable part of life. It is also possible that she coped and managed care constructively from the perspective of spiritual acceptance. Participant 6 had her own sense of mortality and acknowledged the fragility of life.

Many participants reported how they balanced coping and caring by avoiding encounters with patients and families and disconnecting from their emotional responses. Participant 2 expressed her coping strategies as follows:

At one point of time, I refused to enter his room for three days. As a person after I know him for eight months, when I go home, I do think a lot. I go back and reflected myself. Yup, I should not have gone overboard. Not being emotionally involved with this patient. Especially this patient, I build rapport. I was also thinking that if every patient under my care, if I get emotionally involved, I will be crying all the time (P2, Lines 95–101).

This text showed how Participant 2 avoided caring and built an emotional barrier for herself in an attempt to keep things in perspective. Her personal coping mechanisms were to emotionally detach and set professional boundaries to continue providing effective care. She used separation to avoid the significant negative impact of thinking about her patient at home. Her self-realisation gave her insight into how she would care for patients in future. She

further elaborated that she coped better when this participant turned to her personal spiritual beliefs.

To tell the truth, I prayed, I go to Jesus and tell him this is what is happening. Give me the light and guide on how to handle such patients who need my service. When I open up like that, I feel the next day I have more confident. Yes, more confidence and, yes, I can deal with it (P2, Lines 111–114).

This support from personal spiritual beliefs showed that Participant 2 coped well when she was involved in personal reflection and prayer and relied on divine help for guidance. She embraced and found meaning in her work through the spiritual component. Prayer increased her self-confidence and motivation, enabling her to face the situation at hand. Spiritual beliefs resonated with her own intrinsic values on life and death.

The majority of participants in this study also indicated that they could balance care and coping when they accepted that caring for dying patients was part of their professional duties. Participant 3 cited how she coped with an aggressive patient who was dying: 'He's really very angry with everyone. What to do? It is part and parcel of facing in my job' (P3, Lines 201–202). Likewise, Participant 9 shared how she had learned to accept that caring for the dying can be emotional and was an inevitable part of her job: 'So, when I see all these [suffering], it's really very emotional for me, but as time goes, I tell myself that this is my profession, I cannot run away from it' (P9, Lines 115–116). This self-realisation implied that Participant 9 coped with the situation and gradually accepted that it was her responsibility to accept things as they were, enabling her to develop personal strength and improve her performance.

In summary of this sub-theme, all participants in this study adopted various coping mechanisms. Individual coping mechanisms involved self-reflection, professional detachment, maintaining an emotional balance, staying neutral, relying on divine guidance and drawing on inner strengths. The death of patients evoked feelings as well as contributing to participants' personal growth. Participants' individual responses also highlighted their ability to function and face future deaths. These concepts together led to participants' resilience, personal and professional growth.

In summary of this chapter on two major themes on 'transforming and understanding EOL care' and 'ways of managing care effectively' it depicted the positive experiences of caring

for dying patients and showed how participants cultivated personal meaning. In theme 3, it demonstrated how participants felt motivated when they were able to fulfil the wishes of patients. Through their advocacy roles, they were able to achieve positive outcomes for their patients, the families and for themselves. The findings highlighted how care practices may be transformed through personal daily interactions with patients and families. This transformation of EOL is associated with personal growth and increased knowledge of EOL care, despite the moral distress felt by nurses. It is somewhat paradoxical that the acute care environment causes emotional distress for participants while simultaneously triggering personal growth.

The fourth theme that emerged from the findings was 'ways of managing care effectively'. Open communication, working as a team, palliative care team support, addressing training needs and personal coping emerged from the data analysis. Participants' experiences were unique and varied in terms of their experiences in caring for the dying in acute care hospitals. This theme also illustrated how participants performed their roles while finding the strength to deal with the daily challenges at work. It highlighted how participants cope with death through meditation and by maintaining professional, physical and emotional distance. Open communication and support from senior and palliative care nurses made caring for dying patients manageable for participants. Participants believed that ongoing training and education in EOL care would make care more productive and equitable. The next chapter seven discusses the salient issues that emerged from the study findings.

Chapter 7: Discussion

7.1 Introduction

The aim of this study was to describe the experiences of RNs caring for dying patients in the acute care hospital setting in Singapore. This chapter presents the findings that emerged from participants' rich accounts of their experiences. This study was unique because, despite their difficulties, participants had experienced significant personal and professional growth through their recounted experiences. This personal and professional growth is portrayed in the findings of this study, which are organised under four major themes (presented in Chapters 5, 6 and 7). Adopting the hermeneutic circle helped to elicit four major discussion points, revealing an understanding of the nurse participants' experiences of caring for dying patients. All participants recounted that being involved in EOL care had affected them personally and that EOL care could be distressing, onerous and demanding. In general, participants lacked knowledge in the field of palliative care, but many were satisfied that the care they provided was personal and holistic and fulfilled all essential dimensions of EOL care. Participants' experiences reflected how their care practices had evolved and had explicitly and implicitly contributed to their personal and professional growth.

The results of this study in the Singaporean context support the findings in the published literature. However, this study identified previously unrecognised positive and negative aspects in relation to caring for dying patients. Participants were affected emotionally and felt unprepared to care for dying patients because of their lack of communication skills and knowledge about palliative care. Despite these difficulties, they were able to draw on their inner strength and find resources to cope with the situation. These issues emotionally affected participants. Therefore, this chapter covers: (1) the moral distress of nurses and its impact on caring for dying patients, include managing disclosures, communication challenges and cultural differences on death and dying; (2) the culture of acute care, includes the role of nurses and their challenges; (3) organisational barriers, (4) transforming care, include development of personal and professional growth, providing spiritual care and personal coping; and (5) the fusion of horizons- resilience, personal and professional growth through moral distress. The discussion of the study findings focus on the relation to the literature on the Gadamerian hermeneutic understanding of EOL care, awareness of being in the world,

attention to the historicity of others including my own reflections, the conscious human connection and the development of holistic human relationships.

7.2 Moral Distress of Nurses and its Impact on Caring for Dying Patients

A range of complex demands contributed to participants' experiences of moral distress and tension. Participants experienced enormous frustration, fear, guilt, helplessness, ongoing distress, emotional detachment, professional distancing and the inability to provide best-practice care. Although participants had a strong desire to offer quality care, the societal taboos associated with death and dying in a multicultural society such as Singapore hindered them in providing optimal care for dying patients and their families. Moral distress is defined as a painful psychological disequilibrium that results from being unable to take ethically appropriate actions because of obstacles (e.g. lack of time, supervisory reluctance, institutional policy or legal considerations) (Rice et al., 2008, p. 361).

Some studies have reported that moral distress arising from time constraints is an obstacle to providing quality EOL care (Ingwu et al., 2016; McCallum & McConigley, 2013; Peterson et al., 2010a). Other studies also illustrated that the moral distress was attributed to nurses who struggled to find time and space to deal with their own grief, witnessed fragmentation in care, unable to allocate time caring for palliative and curative patients, having to deal with conflicting family demands, and having to deal with the psychological distress of patient and family (E. Anderson et al., 2016; N. E. Anderson et al., 2015; Banerjee et al., 2016; Becker et al., 2017; Croxon & Deravin, 2017; X. B. Lai et al., 2018; J.). In this study, emotional and moral distress affected participants' ability to provide quality care to dying patients and disrupted the quality of care when participants experienced the physical decline of patients alongside aggressive demands from families when further treatment was futile. This conflict of care made participants feel helpless and inadequate to address patients' wishes and emotions. Moral distress also affected the quality of care when participants encountered sudden unanticipated deaths.

In this thesis, the terms 'moral distress' and 'emotional distress' are used interchangeably to show how one affects the other in a causal relationship. In other words, nurses' moral imperatives to care and their inability to do so caused them emotional distress. In the literature, the term 'moral distress' is also known as 'emotional distress' (Wallerstedt &

Andershed, 2007). In this phenomenological study, nurses reported taking their burdens home, even after a patient had died. Participants also recounted feelings of frustration, inadequacy and sorrow after building close relationships with patients and their families. Participants reported that the interpersonal connections and bonds they built with patients and families from their constant interactions held powerful personal meanings for them. This in turn developed their personal strength even though they faced frustration.

As Gadamer (2003) identified, participants were connected by a common human consciousness that had evolved through their practice. Further, Gadamer (2003) believed this connection was possible because of the history and mutual understanding of being in the world by participants, patients and families. The regard for human relationship ensures a sense of connectedness (Prince-Paul, 2008). Participants had developed this relationship building unknowingly and unconditionally, regardless of language, culture or race. Participants gained affirmation in their relationships with patients and families, emphasising that EOL care brought wholeness to their relationships (Farber, Egnew, Herman-Bertsch, Taylor, & Guldin, 2006; Ferrell & Coyle, 2008; Prince-Paul, 2008). 'Being in the world' was a shared experience for all participants, who journeyed with patients and families to uphold trust, respect and dignity until death. This human connection fostered adaptation, strength and coping for family members (Heidari & Norouzadeh, 2014; Silverman, 2005).

Participants who had witnessed the death of young patients reported feeling helpless and unsure of how to provide bereavement support to families. The lack of education and the emotional effect had on them limited their ability to provide what they believed to be adequate care. For some participants, memories of deceased parents and siblings who had suffered life-threatening conditions reminded them of a similar feeling of helplessness. Therefore, caring for dying patients was associated with emotional exhaustion and was compounded by witnessing sudden deaths, prolonged suffering or the death of young patients. These experiences reflected their own mortality and that of their loved ones. Physical and emotional exhaustion demonstrated participants' inability to handle their own distress at times. Participants were affected as they thought of their own mortality and feared the outcome. Participants needed support to handle their own grief while sustaining their caregiving roles. The literature revealed that regular debriefing, grief counselling sessions

and workplace support were important for nurses to fulfil a positive caregiving role (Gerow et al., 2010; Powazki et al., 2014; J. Wilson, 2014; Zheng, Lee, & Bloomer, 2016).

As such, other studies have reported both similar and different accounts of symbolic experiences reported by nurses in various acute care settings. For example, Shimoinaba, O'Connor, Lee and Kissane (2014) found that Japanese nurses experienced intense grief after a patient's death because of the interpersonal relationships they had built with their patients. This account is similar to those of nurses in the present study. In contrast, the outcomes for nurses working in an acute medical setting in the UK were slightly different. Although the deaths of their patients reminded them of their relatives' deaths, nurses were able to continue working despite it being difficult, and some were able to manage their emotions because of personal life experiences, even when organisational support was lacking (J. Wilson, 2014). This finding is also similar to that of the present study pertaining to the lack of organisational support for nurses. However, in the present study, junior nurses expressed difficulty coping, while senior nurses appeared to cope better. Another study found that critical care nurses felt less exhausted when they openly communicated with and educated families about dying, which may come with experience (Heidari & Norouzadeh, 2014). In contrast, experienced nurses who worked in a multidisciplinary medical facility in Canada reported becoming emotionally exhausted when they took time to support junior staff. These nurses felt that they had less time to meet patient and family needs, which they believed was more important than supporting junior staff (Funk et al., 2017). The findings of the present study differ to this outcome-senior nurse were willing to support and guide junior nurses while rendering emotional support to grieving families. Younger nurses built their personal strength and took the opportunity to grow professionally from the guidance of the senior nurses.

Further distress was apparent in the accounts of three participants who had experienced family members demanding explanations about their relative's treatment. The increasing tension between family members and nurses was a traumatic experience for these participants. Other studies have shown that ongoing exposure to unreasonable human demands for futile treatments can affect nurses' wellbeing, including their self-confidence, emotional and spiritual wellbeing and their ability to cope with stressful situations (Clemans, 2004; Dunkley & Whelan, 2006). Participants in the present study reported that the management of patients' and families' expectations of EOL care decision-making was an

important component of EOL care. However, participants stated that decision-making became difficult when family members refused to accept alternative options of care and insisted on active treatment, overtaking patients' sense of control and autonomy.

In summary, this study revealed that moral distress affected the quality of care provided by nurses. Nurse participants felt frustrated, emotionally exhausted, helpless and lacked confidence. They had to deal with multiple complex situations with minimal support from their organisation, adding further distress. Despite the negative outcomes, younger nurses built their strength and learned from the senior nurses to handle complex situations. It was also shown that younger and senior nurses coped differently. However, one salient issue was, overall participants cultivated resilience which contributed to their personal, professional growth, and development.

7.2.1 Managing disclosures

Family-centred models of medical decision-making protects patients from receiving bad news (Foo, Zheng, Kwee, Yang, & Krishna, 2013). Patient autonomy, an important concept in palliative care, is well established in Western societies (Cherny, 2011; F. Wilson, Ingleton, Gott, & Gardiner, 2014). However, in Singapore, although death is not necessarily denied, EOL care decision-making can be more complex when families intervene and disclose selective information to patients (H. M. Chan, 2004; Kwak & Haley, 2005). Although a family may have good intentions, their decisions may not align with the patient's wishes or with the principles of palliative and EOL care (Foo et al., 2013). Singapore is a multiracial and multicultural society, and diverse cultural and religious practices have a strong influence on EOL care practices. Patient autonomy is encouraged in Singapore (Jeyaretnam, 2001). However, according to the participants in this study, major decision-making is often left to a patient's family and doctors. The notion of filial piety (respect for one's parents, elders and ancestors) poses a barrier to EOL care decision-making by the person who is actually dying.

The moral dilemma in balancing the emotions of patients and families while making ethical EOL care decisions posed problems for participants. Decisions were often based on the emotions of family members. Understanding human behaviour is an essential skill because it can reflect the deep social and cultural meanings from the perspectives of patient and families (Newman, 2002). This understanding also means that paying attention to the

preferences, values and lifeworld of the patient and family may be problematic. It also meant that initiating EOL decision making connoted disrespect and basically nurses were aware that children in Asian societies, according to filial piety are expected to do everything that can prolong life (M. Lee, Hinderer, Kehl, 2014; Zou, O'Conner, Peters & Jiejun, 2013). Gadamer (2006) argues that horizons constantly evolve and will come together when they are seen from different vantage points. Likewise, the nurse participants had had their own horizons shaped by their individual histories and cultures. Participants were not confined to their own understandings but had been altered by what they could see in their patients and families (Gadamer, 2001). 'Being in the world' of patient implied that nurse participants can broaden their understanding and be able to move back and forth between different worlds (i.e. those of themselves and their patients and families).

Studies have reported that revealing a cancer diagnosis causes psychological distress to patients (Tavoli et al., 2007). However, in the diverse Singapore culture there is an element of truth telling that mimics the Western belief in open and honest communication. Prior to the 1960s, physicians rarely discussed diagnosis and prognosis with patients because of paternalism and the stigmas associated with terminal illness (K. Taylor, 1988). Since the 1960s and 1970s, there has been a dramatic shift to full disclosure arising from the growth in consumer rights and bioethical principles of patient autonomy. 'Truth telling' is defined as total openness about diagnosis and prognosis (Kazdaglis et al., 2010). However, the literature suggests that truth telling is complicated and the truth may not always be received positively by patients, drastically and negatively altering their view of their illness (Buckman & Kason, 1992). Truth telling is viewed by healthcare professionals as a moral obligation, but it does not appear to serve all patients and families in the same manner, especially when there are cultural influences (Kazemi, Poorsoleimani & Fakhari, 2010). Truth telling occurs when there is a common understanding of dialogue between the physician and patient. It is not about who is in power to disclose the truth but rather, in hermeneutic understanding, the subject matter must be in common. According to Gadamer (2004, 2006), individual prejudices must be set aside to arrive at a common understanding.

Each patient reacts to a diagnosis of a life-threatening condition differently (Schattner, 2002). The literature also suggests that the perspectives of physicians, nurses and patients on truth telling also differ (Kazdaglis et al., 2010). Physicians find it difficult to disclose the truth,

nurses believe it is the doctors' duty to reveal the truth, and patients who want to know the truth may not be psychologically prepared to receive negative news (Kirk, Kirk, & Kristjanson, 2004). The full realisation of the ethical tenet of patient autonomy in Singapore is complex because of the diversity of cultures. Family-centred care and decision-making takes precedence over and influences the EOL care that patients receive. Therefore, according to the participants, a collective cultural approach is taken by physicians in considering the family's central role in decision-making for EOL care. While some patients may prefer non-disclosure, they are happy to receive constant attention and care from their families. The predominant activities performed by families include frequent visits to the hospital, engaging in conversation with physicians and covering costs to alleviate the financial burden of hospitalisation.

Other studies have also shown that the disclosure of negative news or a poor prognosis is not readily accepted in many countries and cultures (E. Anderson et al., 2016; L. S, Chan et al., 2018; Heidari & Norouzadeh, 2014; Lai et al., 2018; Zheng et al., 2015). Studies have reported the moral distress faced by nurses in acute care settings (E. Anderson et al., 2016; Lai et al., 2018; Zheng et al., 2015), similar to that expressed by participants in this study. Moral distress arose from witnessing patients' physical deterioration, the implementation of futile treatments, feeling inadequate in the nursing role and the difficulties related to disclosure of a poor prognosis. According to participants, distress, in turn, affected the quality of EOL care they provided. From the hermeneutic perspective, the phenomenon of distress increased participants' self-awareness. Self-awareness of distress created a boundary and limited their ability to align with the needs of patients and families (Ferrell & Coyle, 2010; Halifax, 2008). Bearing witness to patients' distress was a means of 'being in the world' of patient suffering. According to Gadamer, (2004) one has to put aside prejudice or judgement to understand the situation, as such it allowed the participants to be aware of the history and culture of patients to make understanding possible.

In summary, the disclosure of a diagnosis more complex than it might seem because of differences in cultural, patient and family perspectives with respect to accepting the truth, impeding the quality of nursing care.

7.2.2 Communication challenges

Participants in this study who had built close relationships with patients reported that they struggled with advocating for patients and their families regarding futile treatments. They also experienced communication barriers and rarely spoke to patients about death and dying to avoid eroding their hope of living (Schattner, 2002). A moral dilemma arose with regard to being honest with patients when treatment was viewed as futile (Bach, Ploeg, & Black, 2009; Silen, Svantesson, & Ahlstrom, 2008; Sorensen & Iedema, 2007). Participants were also concerned about how to start EOL care discussions to assist patients and families in decision-making and were overly cautious not to cause offence or conflict. This dilemma was tackled differently by critical care nurses, who processed information in an organised constructive way and presented a realistic picture of patients' conditions. However, this information sharing failed to change patients' perceptions about the futility of their treatment, and they remained hopeful for cure (Bach et al., 2009; Liaschenko, O'Conner-Von, & Peden-McAlpine, 2009; Robichaux & Clark, 2006). Further, it has also been reported that the lack of skills to communicate with dying patients negatively affects nurses' capacity or, to some extent, impedes the quality of care they provide (N. E. Anderson et al., 2015; Zheng et al., 2015). Communication with patients is important for decision-making. However, information can also be misunderstood by patients who are selective about what they hear (Erichsen, Danielsson, & Friedrichsen, 2010; Friedrichsen, Strang, & Carlsson, 2002). The findings of this study highlight the importance of training nurses in effective communication skills.

In relation to the present study, the pre-understandings of patients receiving treatment in an acute care setting must be understood by nurses and doctors. Gadamer (2006) believed that understanding is impossible if one cannot enter the other person's world. Moreover, there was the need to address the pre-understandings of patients with the perception that the acute care setting can offer them the possibility of recovery and cure. Therefore, patients' presuppositions about acute care indirectly led to participants being reticent to communicate the futility of treatment or the need for palliative care to patients and families. Participants, patients and family members all had their own presuppositions about the futility of treatment. From the participants' perspectives, there was a gap in how to respond sensitively in such situations. According to Gadamer (2004), the ability to accept the futility of treatment arises

from managing one's prejudices, presuppositions and judgements, searching for meaning and understanding the patient's perspective of EOL decision-making. Other studies have highlighted that patients and families must have their concerns acknowledged and their emotions validated, and that information sharing should not exclusively focus on diagnosis and prognosis (Farber et al., 2006; Wenrich et al., 2003).

It is evident from the literature that nurses play three key roles in EOL care decisions, being information brokers, emotional supporters and advocators in EOL care decision-making with physicians and family members (J. A. Adams, Bailey, Anderson, & Docherty, 2011). However, these findings revealed that nurses lacked the skills to break negative news or advocate for patients' needs. Participants constantly adapted to patients' situations, consciously or subconsciously. Participants strived to 'enter the patients' worlds' to have a better understanding of patients' values, beliefs and prejudices related to death and dying. The ability to enter a patient's world and alter oneself is characteristic of being a nurse. According to Gadamer (2004), this ability meant being open to experience in which one can gain knowledge that is enriching. Even though participants faced with frustrating situation their resilience directly or indirectly shaped their adaptability to the changing needs of their patients.

Advocating for truth may not be easy in acute care settings in Singapore because nurses must constantly align themselves with the needs of patients and families. In this study, truth telling was individual for each participant depending on their experience and the interpersonal relationships they had established with patients and their families. Moreover, participants reported that their training in communication skills was inadequate to help them deal with daily complex situations, particularly with respect to disclosure of diagnosis and prognosis. Consistent with the findings of earlier studies (Beyraghi et al., 2011; Chuah et al., 2017; R.K. Frank 2009; X. B. Lai et al., 2018; Valiee et al., 2012), participants preferred medical officers to share those intricate details. The literature on truth telling highlights that, traditionally, nurses dislike disclosing diagnoses and prognoses, believing it to be the role of physicians. Further, nurses often feel powerless and experience ethical conflicts when physicians avoid disclosure (J. A. Adams et al., 2011; Clark & Volker, 2003; Engstrom & Soderberg, 2007; Georgaki, Kalaidopoulou, Liarmakopoulos, & Mystakidou, 2002; Lind, Lorem, Norvedt, & Hevroy, 2011).

Trust is an integral element in truth telling; however, it is often the family who requests collusion in non-disclosure (Cherny, 2011; Kazdaglis et al., 2010). EOL care decisionmaking also involves being supportive of collective family cultural norms rather than individualism and patient autonomy. Intercultural awareness and assessing one's own cultural biases broaden healthcare professionals' understanding of patients' and families' preferences and values regarding disclosure (Rising, 2017). Therefore, truth telling should be tailored according to patients' needs (Gold, 2004). Gadamer (2004, 2006) argues that one's prejudices limits total understanding—in this instance, understanding cultural values and preferences and a person's historicity can lead to multiple interpretations of the reality of disclosure. Studies have shown that training on simply how to disclose diagnoses and prognoses is not sufficient and that it must include how to provide psychological support for patients after disclosure (Freedman, 2003; Kazdaglis et al., 2010). Nurses often act as mediators between doctors and patients but are not comfortable engaging in such conversations (Bloomer et al., 2013; Casey et al., 2011; Espinosa et al., 2010; Peterson et al., 2010a). Therefore, the findings of the present study suggest that more training on communication skills is required to care for dying patients and their families effectively. It is not about how nurses need to uphold patient's autonomy but rather how to reconcile with their own values and exercise cultural sensitivity (Fowler, 2008).

In summary, the communication challenges faced by nurse participants were multifaceted and complex. Nurses faced challenges related to advocacy, EOL decision-making, truth telling and managing care expectations of patients and families. The need for effective communication skills, and how to provide psychological support to patients after breaking bad news need to be addressed.

7.2.3 Cultural differences on death and dying

Participants in this study were from diverse cultural backgrounds, including Chinese, Malay, Indian and Filipino. These studies have illustrated that engaging in conversations about EOL care meant that nurses needed to exercise cultural sensitivity in their practice (Casey et al., 2011; Chuah et al., 2017; M. L. Fang, Sixsmith, Sinclair, & Horst, 2016; Lai et al., 2018; Wu & Volker, 2009). This study revealed that the majority of participants were not adequately prepared to deal with cultural nuances in patient and family expectations or ACP. In Singapore, the legislation pertaining to AMDs was enacted in 1996. To address Singapore's

rapidly ageing population, the Agency for Integrated Care was formed in 2009 as the national healthcare integrator, the aim of which was to seamlessly connect services across different sectors. One of its initiatives was ACP. The literature on ACP suggests that challenges in initiating ACP may arise from disparities between the beliefs and values of healthcare providers and those of patients and families (M. L. Fang et al., 2016). Cultural barriers, such as an individual's level of acceptance and meaning of suffering, and the healthcare system both influence EOL care decision-making (Bullock, 2006; Morita et al., 2004).

Even when there is an ACP in place, participants were hesitant to talk about death and dying and prefer doctors to initiate these conversations. Nurses expressed they were not confident engaging in EOL care discussions because they were mindful of the cultural diversity and values of the patient and family. Nevertheless, they continued to provide physical aspects of care. In contrast, other studies have shown that therapeutic communication is the cornerstone of EOL care (Agustinus et al., 2014; Aslakson et al., 2012; Becker et al., 2017; Edo-Gual et al., 2014; Ferrell & Coyle, 2010; Powazki et al., 2014; White & Coyne, 2011; Zheng et al., 2015). Thus, education on EOL care communication skills is a finding from this study that should be addressed.

In addition, they faced difficulty having conversations with patients and family on dying (Croxon, Deravin, & E. Anderson, 2016). Similarly, Zheng et al. (2015) found that young Chinese nurses who cared for the dying experienced difficulty having conversations with family members on EOL care issues. Although they understood the Western principles of EOL care, strong Chinese cultural taboos limited their abilities to talk about death. Thus, although they were not open to communication, they continued to respect Chinese cultural beliefs and provide individualised care, which was meaningful to them (Zheng et al., 2015). Moreover, younger participants who lacked experience in EOL care and communication skills were more hesitant to engage in conversation with patients and families. This finding is similar for newly graduated nurses who have difficulty engaging in conversations about the dying process, particularly with family members. Newly graduated nurses lacked knowledge of palliative care and felt unsupported in their role by senior nurses.

The studies discussed above imply the need for ongoing training and support for young nurses to develop their communication skills so they may openly discuss EOL care with patients and families. The literature highlights that training on grief, bereavement and self-

coping strategies may optimise young nurses' roles in clinical practice (Omansky, 2010; P. M. Wright, 2011). The literature also shows that experienced nurses must be proactive in mentoring young inexperienced nurses and that ongoing clinical mentoring and reflective discussion is needed for young nurses to transit effectively into practice (Croxon et al., 2018; Gillett, O'Neill, & Bloomfield, 2016; Zheng et al., 2016; Zheng, Lee, & Bloomer, 2018). Informal mentoring has been found to be beneficial for nurses in understanding death and helping with clinical decision-making (Gerow et al., 2010). It is also imperative that ongoing nursing education on EOL care communication skills is recognised as an area that requires constant attention at the undergraduate and postgraduate levels as well as in professional development.

Previous studies have reported that experience is important. Nurses who have spent more time with terminally ill or dying patients were able to cope better and have more positive attitudes towards death and dying. The literature shows that grief is personally constructed—its duration and intensity vary depending on the depth of a relationship (Schultz & Bruce, 2005). The literature also shows that older nurses with longer clinical experience and specialist training have more positive attitudes and are comfortable, knowledgeable and capable in providing psychosocial aspects of care (Iranmanesh et al., 2009; Lange, Thom, & Kline, 2008; Peters et al., 2013; Powazki et al., 2014). In its broadest sense, interpretive phenomenology implies that each participant brings their own unique contextual meanings, as was the case for participants in this study. The nature of being, grounded in temporality, was meaningful for each participant. According to Gadamer (2004, 2006), a fusion of horizons takes place when one (e.g. a nurse) becomes self-aware of the nature of being and connects with patients and families in a meaningful and compassionate way. This appeared to be the case with the experienced nurses in this study.

Herdman (2004) and Stayt (2009) have emphasised that nurses should be empathic but not sympathetic. In contrast, E. Taylor (2007) and Brown and Wood (2009) believe that nurses should remain professional to ensure they pay attention to the needs of families. It is acceptable for nurses to demonstrate their emotions but need to distinguish their own emotions and respond to the grieving families appropriately (E. Taylor, 2007). Gadamer (1976) argues that without an understanding of tradition and history, blockages will occur in the understanding of being. In this study, 'being' relates to the connections between

participants and patients and their families at meaningful moments. Feelings of empathy and emotional distress are significant across all Western and Eastern studies (Bloomer et al., 2013; Funk et al., 2017; Kongsuwan et al., 2010; Mak et al., 2013). Feeling empathetic may be because nurses have dealt with similar circumstances with their loved ones, relatives or friends. Ultimately, participants struggled with their own existential issues on death and dying.

The intensity of emotions reported by all participants across various acute care settings may be termed 'professional compassion fatigue'. This term was first used by Joinson (1992) in the context of health care among emergency nurses. Joinson (1992) and Ledoux (2015) attempted to establish a causal relationship between compassion fatigue and burnout but were unable to provide a rationale. Figley (1995) described 'compassion fatigue' as the 'cost of caring' and 'professional compassion fatigue' as the cumulative effects of physical and emotional caring for dying patients. According to some researchers, compassion fatigue occurs when compassion is obstructed, giving rise to moral distress (Fernando & Consedine, 2014; Ledoux, 2015). In the current study, all participants internalised the emotions of their patients and experienced the cumulative effects of internalisation. Compassion fatigue illustrated the intensity participants experienced as they entered the world of their patients' suffering and EOL care. Other studies have also found that in palliative care settings, nurses face ethical dilemmas when information is withheld from patients or when aggressive treatment is deemed futile (Dunne, Sullivan, & Kernohan, 2005; Ferrell, 2006). It is challenging for nurses to accommodate diverse EOL cultural needs in Singapore, however, through continuous training it can broaden their understanding on how to meet the diverse cultural needs of their patients at EOL. There is no one formula, a collective effort from all health care professionals is required to meet the needs of their patients.

In summary of this discussion on moral distress, it was a significant element that affected nurses' practice of EOL care in the acute care setting. Unique to this study were the diverse cultural backgrounds, beliefs and values that nurses needed to manage when faced with dying patients. The acute care culture prioritises cure over comfort care. Participants in this study had to juggle their priorities between acutely ill and terminal patients, which was consistent with the findings of other studies on caring for dying patients in the context of acute care. Participants identified emotions of sadness, frustration, helplessness and guilt, expressing

that death and sorrow affected their performance and quality of care for the dying. Similar to other studies, all participants in this study found that poor communication related to information sharing and disclosure was a barrier. Young nurses were more hesitant and not confident to engage in EOL care conversation as opposed to senior nurses. Gadamer (2006) states that each participant assigned personal meaning to the care of dying patients in the acute care setting, which enhanced their existential understanding of how to be mindful of patients' horizons so that they could understand the vulnerabilities of patients and families in the face of death. This 'being in the world' was related to the moral distress felt by participants.

The next section covers the barriers to providing optimum palliative care under the culture of acute care. It discusses the biomedical dominance of acute care coupled with the practical difficulties that limited the provision of best-practice palliative care. It also highlights how acute care priorities shifted the nurses' roles. In addition, within the spectrum of biomedical dominance, the discussion also focuses on the misconceptions about palliative care among physicians, patients and family members.

7.3 The Culture of Acute Care

The second major discussion point is on how the culture of acute care shaped nurses' roles, creating practical and emotional difficulties. According to participants, biomedical dominance (i.e. medical management with a 'cure at all cost' mandate) overlooked the holistic patient-centred care approach. This dominance also shaped the expectations of families and patients in the acute care setting, in turn affecting how participants approached EOL care. Misconceptions about palliative care among physicians, patients and family members, which posed a barrier to EOL care in the acute care setting, are also discussed.

7.3.1 The role of nurses and their challenges

All participants discussed the multiple challenges they faced on a daily basis in the acute care setting. One such challenge was related to palliative care. A fundamental concept of palliative care is its holistic approach (Bach et al., 2009; Lind et al., 2011; Roche-Fahy & Dowling, 2009). The distinctive characteristics of palliative care include its interdisciplinary, personcentred (including families) approach to symptom relief and, particularly, the psychosocial and spiritual needs of the dying patient (WHO, 2018). In this study, participants unanimously

desired to provide comfort care but, in practice, their lack of experience affected the quality of care, and they encountered practical difficulties such as how to communicate effectively with patients and families about EOL care issues or provide palliative care support. This lack of experience in palliative care is comparable to that found in other studies that have reported as well as poor knowledge in palliative care, nurses have a heavy workload and can be overly focused on tasks, causing dissatisfaction and affecting their roles (E. Anderson et al., 2016; Becker et al., 2017; L. S, Chan et al., 2018; Funk et al., 2017; Lai et al., 2018).

Participants revealed they tended to be task oriented and to overlook the holistic aspects of care for dying patients. EOL nursing in the acute care unit was about facilitating care but involved constantly switching between multiple roles. 'Switching between multiple roles' or 'changing lanes' meant paying attention to active treatment aimed at curing some patients while simultaneously striving to provide comfort care for those with a terminal illness (Ingwu et al., 2016; Sasahara et al., 2003; G. N. Thompson et al., 2006a, 2006b). Narratives on switching between multiple roles and workforce constraints in this study showed that participants' roles were multifaceted and complex but there was limited availability of resources.

Other studies have reported that nurses working in acute care settings were unable to provide satisfactory care because of staff shortages, heavy workloads, lack of time, poor knowledge leading to poor performance and lack of support supervisors (Betriana & Kongsuwan, 2019; Gélinas, Fillion, Robitaille, & Truchon, 2012; Ingwu et al., 2016; Mak et al., 2013; Melvin, 2012; Rice et al., 2008; Thacker, 2008; H. U. Yu & Chan, 2010). Having to juggle with multiple roles, shifted participants' care priorities to patients who required constant attention. The culture of acute care shaped, directed and caused dissatisfaction for participants, who felt unable to meet the imminent needs of dying patients. EOL care conversations, discussing options of care, providing bereavement support for patients and families and referral to palliative care appeared to be secondary needs. Adding to the moral distress participants experienced, their roles were challenged when they had to divide their attention between palliative and curative approaches to care, and there was an unequal allocation of resources for nurses to provide palliative care to patients in need.

Participants also stated they had difficulty advocating for their patients. The literature suggests that it is important to include patient's wishes, values and preferences to deliver

respectful and dignified EOL care (Becker et al., 2017; Detering, Hancock, Reade, & Silvester, 2010). The Singapore Nursing Board's (2018) *Code for Nurses and Midwives* states that nurses must respect a patient's right to privacy, ensure dignity and respond to the physical, social and psychospiritual needs of patients. These patient-centred processes were difficult to achieve for participants in this study because of what they believed was a knowledge gap. Participants recognised the needs of patients, acknowledged their own inadequacies and identified the need to be educated in basic palliative care. These findings were consistent with studies that have indicated that more education on EOL and palliative care is required to prepare nurses adequately (L. S, Chan et al., 2018; Lai et al., 2018; Mak et al., 2013; Todaro-Franceschi, 2013; White & Coyne, 2011).

Participants did not feel confident discussing death or patient prognoses or offering compassionate support to family and relatives. In addition, the lack of palliative care education meant they were unprepared or unable to provide bereavement support to families in need. Bereavement support is important because it helps family members to address physical, emotional, psychological and spiritual aspects after experiencing a significant loss (Zerwekh, 2006). Bereavement support in the context of acute care was not provided to participants nor to the families of dying patients. Gadamer (1976) asserted that the person who expresses and the person who understands are connected by a common human consciousness, which makes understanding possible. Participants were not confident to provide bereavement support to family and relatives, and they brought their own values and beliefs with them, in turn affecting their perceptions about EOL care and how to provide bereavement support.

Another challenge affecting participants was related to unaddressed grief, which the literature suggests can lead to burnout (Bailey, Murphy, & Porock, 2011; Kent, Anderson, & Owens, 2012; Khalaf et al., 2018; Shorter & Stayt, 2010). Nurses' grief is intensified when they have prolonged engagement with patients or frequently witness unanticipated sudden deaths and do not receive adequate support (Gerow et al., 2010; O'Connor, Watts, Bloomer, & Larkins, 2010; Wisekal, 2015). The findings in this study signal the need for bereavement support for nurses in the acute care setting in Singapore. The importance of interprofessional collaboration in EOL care decision-making is crucial before death becomes imminent (Ho, Jameson, & Pavlish, 2016; Pavlish & Ceronsky, 2009). Participants witnessed conflicts in

care management between the multidisciplinary team, patients and families and felt excluded from the decision-making process on the patient's care. Medical doctors were less proactive and delayed referring patients to palliative care. This study highlights the unmet needs in the multicultural acute care setting in Singapore and that the provision of appropriate EOL care is still in its infancy. This knowledge gap in palliative care prevented participants from providing individualised care to dying patients or advocating for them.

Similar findings on the deficient knowledge of symptom control in palliative care have been reported (Turan, Mankan, & Polat, 2017; Ugur et al., 2017). A Lien Foundation (2014) report highlighted that 74% of doctors and 46% of nurses had insufficient knowledge of palliative and EOL care. Although the participants in this study believed in the need for early palliative care, they spent more time focusing on acute care tasks than on caring for dying patients and their families. Participants juggled their workload between these two worlds but strived to be present in both by going back and forth between patients being actively treated and those who were dying. The literature shows that nurses must structure their care in accordance with the culture of the patient and family (Y. L. Huang, Yates, & Prior, 2009; Turgay & Kav, 2012).

In this study, understanding a patient's cultural practices was important because nurses entered the 'lived space' and 'lived time' of the patient and family members, moving between these 'two worlds'. According to Gadamer (2004), moving between two worlds is about connecting to the world consciously or unknowingly and being open to deeper understanding and meaning, which is similar to what the participants in this study described. Participants strived to understand the cultural nuances and its association to illness, death and dying in relation to the care of their patients.

The reality of care in the context of the acute setting seemed to be logical to participants. However, it also challenged their values and practices because their care of dying patients was marginalised and undervalued. Similarly, other studies have reported that the knowledge gaps in palliative care causes frustration for nurses and affects their communication skills in EOL care (E. Anderson et al., 2016; Becker et al., 2017; L. S, Chan et al., 2018; Croxon et al., 2018; Funk et al., 2017; Lai et al., 2018). This phenomenon of the acute care culture in Singapore typically shaped the care practices of participants.

In summary, this section discussed the culture of acute care in Singapore and the practical and professional difficulties encountered by nurses in providing EOL care. The culture of acute care that focused less on palliative care, the lack of knowledge of palliative care among medical doctors, difficulty in advocating for patients, juggling task-oriented and holistic care, the inability to provide bereavement support to patients and families and not receiving bereavement support for themselves were highlighted.

7.4 Organisational Barriers

The following section discusses the effect of organisational barriers, including biomedical dominance, on patients' and families' perceptions of palliative care, as well as structural and space challenges, which hindered the provision of quality care for dying patients. According to participants in this study, the culture of acute care means that biomedical dominance impedes patient-centred care. In the literature, physicians have equated palliative care with terminal care and have considered it a failure of restorative and curative treatment (Aslakson et al., 2012; L. S, Chan et al., 2018; Chapple, 2010). Participants believed that acute care physicians had misconceptions about and lacked understanding of palliative care. Nurse participants reported dissatisfaction when physicians were evasive about prognosis, continued with active medical interventions and instilled false hope when it appeared futile. They also tended to refer patients to the palliative care team for supportive management only in the later stages. Other studies have reported similar findings (Gardiner, Cobb, Gott, & Ingleton, 2011; Mahtani-Chugani et al., 2010; McCallum & McConigley, 2013). Participants strongly expressed the need to incorporate palliative care early as a component of routine care.

The literature on physicians' perceptions of palliative care highlights that general practitioners often equate palliative care with dying and referrals are delayed (Perrin, 2015; Synder, Hazelett, Allen & Radwany, 2012). Therefore, the medicalisation of care with intent to cure appears to supersede palliative care. According to participants, there is a tendency for physicians to compartmentalise non-malignant disease management and EOL care. Although the evidence shows that patients with advanced non-malignant diseases can benefit from palliative care, nurses are frustrated when physicians continue with futile treatments and avoid being honest with family members (Boland, Martin, Wells, & Ross, 2013; Calvin, Lindy, & Clingon, 2009; McClendon & Buckner, 2007; Traue & Ross, 2005; Zuzelo, 2007).

Participants expressed that the care of dying patients became ambiguous when patients transitioned to acute care. Participants narrated that it was not their duty to initiate EOL care conversations. Other studies have had similar findings, reporting that healthcare professionals discuss EOL care issues less frequently than they report. Studies have found that nurses avoid questions from families or take the role of mediation, preferring physicians to handle inquiries (Calvin et al., 2009; Tobler et al., 2012).

This study showed that several factors may impede the quality of patient-centric care according to participants. These factors include the failure of physicians to initiate EOL care conversations; the lack of interprofessional coordinated care; patient and family misconceptions about palliative care; cultural taboos associated with conversations about death and dying; the assumption that acute treatment will lead to recovery; and the reluctance of physicians to advise the withdrawal of futile treatments. These findings appear to be consistent with those of other studies, which have revealed the lack of nurse education on EOL care communication skills, the inadequate preparation of nurses in their basic education to care and initiate EOL conversations, the focus on task-oriented care and families dominating the decision-making about care options, all of which may impede EOL care (Calvin et al., 2009; X. B. Lai et al., 2018; Todaro-Franceschi, 2013; Zheng et al., 2015).

The findings revealed that there were issues with space in the acute care setting. More single rooms were needed because it was challenging providing emotional and spiritual care for dying patients in open cubicles. Other studies have acknowledged these difficulties and have recommended the provision of privacy and a peaceful environment (Becker et al., 2017; Bloomer et al., 2013; Roche-Fahy & Dowling, 2009; Smyth & Allen, 2011). The literature suggested that important factors in the wellbeing of patients and family members included privacy, the provision of calm designated spaces and teaching families about the end of life (Hajradinovic, Tishelman, Lindqvist, & Goliath, 2018; Johansson & Lindahl, 2012; Slatyer, Pienaar, Williams, Proctor, & Hewitt, 2015). Participants in this study struggled to find solutions for designated spaces to alleviate family distress and offer privacy.

In summary, organisational barriers include biomedical dominance and a paternalistic culture in which aggressive treatments continue to dominate, despite the futility of care. Physicians overlooked what palliative care could offer for high-quality, patient-centred EOL care. Biomedical dominance and the poor acceptance of palliative care in the multicultural context

led to misconceptions about palliative care for patients, families and staff. Biomedical dominance also challenged participants' values in providing quality EOL care. Participants recognised the importance of space and privacy for the wellbeing of patients and families in interaction and personal connection. These factors are also supported by the literature. Despite these challenges, a distinctive feature of this study was the evolution of EOL care practices among participants. The next section discusses how participants' EOL care practices were transformed, and how their experiences led to personal growth, meaning and the development of personal coping.

7.5 Transforming Care

Participants' reflected that their unique experiences in changing their approach from being task focused to providing individualised care were transformative for them both personally and professionally. According to Gadamer (2006), understanding takes place through dialogue, openness and relationship. Participants allowed themselves to be transformed through critical reflection, indicating their readiness to embrace change in practice. Baumgartner (2001) argues that transformation of practice can occur through a process of critical reflection. Connections with patients and family members led to the development of maturity and meaningfulness of 'being' for nurses in demanding situations. 'Being in the world' evolved as participants brought their historicity to their caring encounters. E. W. Taylor (2008) has argued that personal transformation and change can occur with cumulative experiences of death and that this change is personal in nature. Participants kept communication lines open, spent time with patients and families and supported them to gradually accept the reality of death. Some participants stayed after work hours to be physically and emotionally present with patients, going beyond the call of duty. These meaningful connections helped them develop both personally and professionally.

7.5.1 Development of personal and professional growth

The participants' experiences contributed to their personal growth in several ways, positively influencing their practice. In caring for dying patients, some participants used holistic rather than task-focused nursing practices, developing a new meaning of death and dying. Cumbie (2001) has claimed that human relationships built on trust and understanding are necessary for authentic connections. Despite their moral distress, personal challenges and practical

difficulties in the acute care culture, participants showed resilience when encountering challenges.

According to Rushton (2016), moral resilience is the capacity to sustain or restore integrity in response to moral complexity, confusion, distress or setbacks. Moral resilience is cultivated through reflection and meaning making (Lutzen & Ewalds-Kvist, 2013). Participants were able to moderate their unpleasant feelings and convert them to something meaningful, helping to foster psychological resilience. Participants were able to carry on with their work because it provided meaning for them in distressing situations. According to Monteverde (2014), moral resilience in response to moral distress can be cultivated in three different ways: (a) situational reconstruction, which is the process of reliving a traumatic experience to gain new perspectives; (b) focusing on the somatic responses to memories of trauma; and (c) compensatory self-improvement in which reviews one's present actions to help develop confidence for the future.

In relation to the participants' experiences, situational reconstruction was the meaning they made for themselves. This fusion of horizons by the nurses provided a different meaning and experience when caring for dying patients. Rushton (2016) argues that moral resilience also relates to one's adaptability to a given situation arising from a positive personality. Moral resilience is not necessarily about negative feelings but how professional growth is fostered through positive thinking (Crigger & Godfrey, 2014; Tse, Hung & Pang, 2016). The literature also highlighted that clinicians who worked in palliative care settings developed moral resilience through empathy, moral sensitivity and compassion. Palliative care nurses mitigated their distress through focused awareness and maintaining a balance of spiritual and emotional wellbeing (Rushton, Kaszniak, & Halifax, 2013). Participants built their moral resilience by establishing trusting relationships with patients and families. Each encounter with a patient and his or her family brought invaluable experience in how to deal with complex situations. Participants reflected on their own personal experiences, creating awareness of the various facets of life situations that they witnessed in the acute setting and contributing to their professional and personal development. Even when nurses felt helpless, inadequate, sad or guilty, these demanding and frustrating experiences provided strength and helped them to continue with care.

According to Fulton (2014), critical reflection involved identifying one's support systems, reflecting on distressing events and obtaining supervision and feedback from colleagues or supervisors. Constructive feedback can build self-esteem by providing greater awareness and opportunities for learning. For the participants in this study, senior nurses nurtured younger participants through role modelling and behaviours. Senior participants were able to balance professionalism with emotional exhaustion. Younger nurses received assistance and guidance from their seniors. As a result, they learned to cope and develop professionally.

The literature also suggested that through reflective practice, one can connect and engage more deeply with oneself as well as with others (Bulman & Schutz, 2013; Jacobs, 2016; Schon, 1987). Schon (1987) has asserted that practitioners must not allow scientific knowledge to completely override their experiences of working with clients. J. A. Johnson (2013) considered experiential knowledge a conscious process of understanding oneself through recognising one's skills, addressing one's limitations, taking steps to enhance knowledge and engaging in continuous learning. Critical reflection may be likened to a constant voyage of discovery that is never complete and has no saturation point (Burnard, 1988, 1992; Rungapadiachy, 1999).

In summary of this discussion point, the development of personal and professional growth of participants occurred through the building of trusting relationship with their patients and families. With resilience, participants adapted, reflected and reconstructed personal meaning for themselves. As the participants in this study discovered, this ontological process can create a deeper humanistic meaning and understanding of death and dying, positively influencing the spiritual care provided by nurses.

7.5.2 Providing spiritual care

In this study, some participants expressed their satisfaction when they were able to provide spiritual care. Gadamer (2004) advocates that one must view the phenomenon of experience in its totality rather than in parts. The richness of experience provided personal meaning and growth for participants as they became aware of what it meant to care for dying patients. Spiritual care is regarded an essential component of holistic care (Narayanasamy, 2006a). In providing spiritual care to patients from diverse cultural and religious backgrounds, many participants experienced personal growth. In the literature, the meaning of spiritual care

varies among healthcare professionals; however, it is universally regarded as a fundamental component of quality palliative care. Spiritual care is applicable irrespective of the setting, culture, religious tradition or stage of illness (National Consensus Project for Quality Palliative Care, 2018). Nevertheless, in this study, some participants felt more comfortable than others when discussing spirituality. This outcome may be because participants were unprepared and unsure of how to engage in spiritual communication or lack the skills to assess patients' readiness for spiritual conversations.

Puchalski et al. (2009) has defined spirituality as the 'aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, self, others nature and to the significant or sacred' (p. 887). Chochinov (2006) states that 'spirituality evokes a sense of searching or yearning for significance or meaning in life' (p. 88). Spiritual care is associated with connection and building relationships, addressing patients' and families' values and preferences and showing empathy and a sense of responsibility for others on health, disease and death (McEwen, 2005; Yılmaz & Okyay, 2009). In contrast, religion is associated with behaviours that facilitate ritual practices (Overstreet, 2010). Participants in this study claimed there may be positive and negative outcomes of spiritual care. Some participants had witnessed negative reactions or refusals from families when they suggested having a priest attend and pray for a dying patient. As a result, they felt awkward, and the negative reaction of the family posed an obstacle to alleviating the spiritual distress of the patient.

On a positive note, participants created space, respected the privacy of grieving patients and families and assisted in closure or acceptance of the situation. Some participants honoured patients' wishes to remain lucid and aware of their impending death and wishing to be surrounded by family members. The literature highlighted the interconnections between spiritual care, fulfilling wishes and providing dignity in EOL care (Christensen, 2008; Gurdogan, Kurt, Aksoy, Kinici, & Sen, 2017; McSherry & Jamieson, 2013; Paddy, 2011). However, younger nurses had reservations about when to initiate spiritual care and appreciated the guidance shown by senior nurses, choosing instead to be physically present to support patients and families. Nevertheless, younger participants spoke less about their physical presence adding value for patients and families. Younger participants were self-aware, acknowledged their limitations and made a conscious effort to provide care that was

meaningful to them. The literature also highlighted that while nurses could not completely alleviate patients' suffering, their physical presence provided therapeutic assurance to patients that they are not abandoned in their time of need (Lai et al., 2018; Tornøe, Danbolt, Kvigne, & Sørlie, 2015).

One of the dimensions of supportive spiritual care is to display empathy, which has been shown to improve quality of life and reduce anxiety for dying patients (Carpenter, Girvin, Kitner, & Ruth-Sahd, 2008; N. Davies, 2014). Participants' care practices transformed as they developed maturity and empathy through their cumulative experiences with dying patients. In this instance, the cumulative experiences were related to participants' interactions with patients and families who were less hostile to receiving the truth about a patient's condition. Participants who had knowledge of symptom control were better able to identify the needs of patients, were more empathic and were able to alleviate their pain. Glaser and Strauss (1965) have reported that a patient's awareness of death and dying and his or her understanding and acceptance of impending death provides an opportunity for the nurse to fulfil his or her needs. According to Dinkins (2011), when nurses are more aware of the present situation, they can emerge from their 'veil of ignorance' to connect and show empathy. Mount, Boston and Cohen (2007) considers this connection a dynamic supportive relationship between patients, families and nurses, helping to foster an environment of healing with a meaningful purpose.

As Gadamer (2004) purports, a fusion of horizons is shaped by the past and awareness of the present that holds meaning for participants. For the participants in this study, personal growth was evident as they were able to connect with their patients. The majority of participants who self-reflected on their practices and experiences were able to find greater value in their life and work. Self-reflection promoted professional growth and reduced the impact of death (E. Anderson et al., 2016; Evans & Hallet, 2007; Rushton, 2016). Professional growth occurred for hospice and community palliative nurses who drew meaning when they were actively involved in the care of the dying patients (Gaydos, 2004; Olthuis, Leget, & Dekkers, 2007). Although the context of care was different in this study, personal and professional growth was evident for many participants, who had brought their previous care experiences to the care of dying patients. Bradby (1990) has described this convergence of caring as the 'collective passage' of people starting at the same time and being 'all in the same boat' (p.

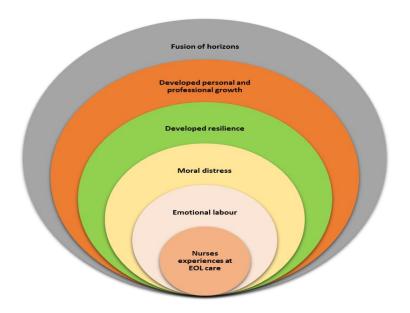
1223). According to Gadamer (2004, 2006), participants bring their own prejudices and develop personal understanding, meaning and self-coping as they care for dying patients.

7.5.3 Personal coping

The participants in this study stated a number of ways in which they coped with distressing situations. Participants identified how they were able to disconnect by establishing professional, physical and emotional boundaries. This finding is consistent with earlier studies on professional distancing, which allows nurses to focus on basic needs, prepare themselves to face the next patient, build resilience, prevent burnout and be less sensitive to death encounters (Funk et al., 2017; Hinderer, 2012; Melvin, 2012; Peterson et al., 2010b; Zheng et al., 2018). The nurses coped with stress and distress in various ways, some through meditation or attending church and others by engaging in self-reflection on how they could provide better care in future. The literature showed that nurses coped by taking time out from their clinical areas, seeking support from colleagues, setting clear boundaries at work, being involved in physical care only, emotionally distancing themselves and remaining professional (Bailey et al., 2011; Barrere & Durkin, 2014; Betriana & Kongsuwan, 2019; Gerow et al., 2010; Hinderer, 2012; A. Johnson, 2011; Mak et al., 2013; Stayt, 2009). Similarly, participants in this study were professional, distant and disconnected, accepted the fragility of life, supported by their colleagues and used a spiritual approach as ways of coping.

In summary of this discussion point, the transformation of care involved critical reflection, striving and connecting with patients and families through holistic nursing practice. Nurse participants displayed empathy and provided a spiritual dimension of care to a certain extent. Younger nurses strived to emulate their seniors. Their professional and personal growth developed as they drew on their resilience and cultivated personal coping mechanisms. Gadamer (2006) has written about being open to understanding. In this instance, participants' means of coping through various dimensions illustrated the broader meaning and understanding of caring for a dying person. This study also challenged my pre-understanding of what it means to be a nurse, shifting to one of focusing on all dimensions of care. The next section presents the fusion of horizons — it discusses what it means to care for a dying person and how a fusion of horizons was reached in the context of acute care in Singapore. Figure 7.1 illustrates the fusion of horizons below.

Figure 7.1: Fusion of horizons- EOL care in the acute care context in Singapore



7.6 Fusion of Horizons

All participants experienced moral distress in one way or another to whom they had contact with which was evident from the interpretation of texts. Within the context of moral distress participants also developed resilience which contributed to their personal and professional growth. A fusion of horizons was obtained through the interpretation of texts within the hermeneutic circle. The experiences of the nurse participants offered a new possibility of understanding and meaning of what it is to care for dying patients in an acute care setting in Singapore. Nurse participants' experiences were interwoven.

Gadamer's (2006) concept of fusion of horizons relates to the superior range of vision reached by one who attempts to understand a phenomenon. In other words, it involves gaining a clearer understanding from the perspective of others in a given time, history and culture. Old and new understandings merge, providing new meaning. The interpretation of the findings of this study was guided by the Gadamerian interpretive framework, which was the central context of this study (Gadamer, 2004, 2006). Hence, my personal history and pre-

understandings served to widen my interpretive gaze via the hermeneutic circle. Through dialogue with participants, understanding was gained by moving between the whole conversation to individual parts and back again (Gadamer, 2001). My own experiences merged with those of participants and other researchers, shedding light on the fusion of horizons.

The meanings derived from participants' experiences were filtered through the lenses of individual participant experiences, bringing an emic understanding of the meaning of caring for dying patients in the acute care setting in Singapore. This perspective, extrapolated from the analysis of nurses' meanings, is unique for many reasons. In Singapore, patients have diverse cultural backgrounds, and understanding the intricacies of each patient's unique needs is a challenge. Endurance and resilience are required to continue with EOL care, despite the cultural and organisational barriers and misconceptions in the delivery of EOL care in Singapore. I developed an understanding through dialogue with the text by being open to the viewpoints of participants, resulting in the emergence of one of the main major discussion point on moral distress.

Transforming through resilience was a noteworthy finding from this study. All participants expressed that each situation imparted new meaning, knowledge and coping skills. Although situations could be challenging, they provided opportunities for growth in unpredictable situations. They learned to manage patient and family expectations while striving to remain positive in a stressful environment. Participants learned to modulate their emotions and responded positively to volatile situations, building and shaping their horizon of understanding on EOL care. Subconsciously, participants developed individual coping strategies in response to work distress. They were transformed as they developed resilience.

According to Masten and Powell (2003), resilience results from the positive adjustment to challenges. In this study, nurse participants adjusted, adapted and sustained professionalism in an environment in which they faced distress. A review of literature on personal resilience highlighted that resilience is necessary to succeed in nursing (Jackson, Firtko, & Edenborough, 2007). Jackson et al. (2007) identified strategies to develop resilience, including building positive professional relationships through mentoring, maintaining positive emotions, developing emotional insights, achieving life balance and spirituality and engaging in self-reflection. These characteristics are similar to those found in this study in

which nurse participants subconsciously developed resilience through peer support, building trusting relationships with patients and families, self-reflecting to transcend challenging situations and being mentored by senior nurses.

My own experience as a nurse involved taking care of one patient at a time in a bone marrow transplant unit. In contrast, participants in this study took care of many patients in an acute hospital ward. A fusion of horizons occurred when participants faced emotional exhaustion and witnessed the consequences of futile care. Amid these challenges, personal and professional growth took place through resilience. Participants continued to provide EOL care as they emulated the strengths of their seniors and learned how to thrive in the acute care setting.

Personalising care enabled participants to view the 'person in the patient', which resulted from establishing meaningful connections. Through self-reflection, the nurses grew professionally and acknowledged that care of the dying patients involved psychological, sociocultural, spiritual and organisational needs. The experiences of the participants were interwoven with my own and they must be seen in totality. The fusion of horizons was a transformation that provided new meaning for nurses who provided EOL care in an acute care setting in Singapore. In providing EOL care, nurses became resilient and continued to be professional and to cope with their emotions. Participants gained emotional resilience through peer support and self-reflection, strengthening their practice.

This chapter highlighted the impact of moral distress on the care of dying patients. It further discussed the personal, communication and cultural challenges faced by participants in EOL care in an acute care setting. Challenges were related to time constraints, managing disclosures, dealing with cultural differences on death and dying, the limitations and extend of information sharing on futile care and challenges faced related to advocacy role. In addition, the chapter discussed the acute care culture, biomedical dominance, the lack of palliative care knowledge, misconceptions about palliative care among medical officers, patients and families and organisational barriers to the quality of care. Despite these challenges, nurses were able to provide spiritual care, cope, transform their practices, grow personally and professionally and build resilience through critical reflection and guidance from senior nurses. The interpretation of texts via hermeneutic circle aided in the fusion of horizons that cultivated resilience through moral distress. The concluding chapter revisits the

research questions, objectives and discusses the implications for practice, research and education. Suggestions for improving EOL care are presented.

Chapter 8: Conclusion

8.1 Introduction

The discussion points discussed in the previous chapter highlighted the phenomenon of caring for dying patients and the challenges faced by nurses in an acute hospital setting in Singapore. They were moral distress, culture of acute care, organisational barriers, transforming care, and the fusion of horizons. Of which, the main discussion was on the moral distress and how participants in this study cultivated resilience that contributed to their personal and professional growth. Given their experiences, senior nurses in this study handled complex situations better than younger nurses. Generally, nurses in this study faced obstacles in the provision of quality EOL care, not only emanating from patients, family and relatives but also from within the organisation. These obstacles all affected their practice. This study also highlighted the tenets of Gadamer (2006), who urged one to explore all possibilities of understanding from various vantage points. This approach means moving beyond what is at hand to arrive at a conclusion that is clearer, set within a larger context and is in 'truer proportion' (Gadamer, 2006, p. 304).

To undertake this task, I had to look beyond my own pre-understandings, converse with colleagues and participants and analyse the conversational texts within the circular movement of the hermeneutic circle. My pre-understandings influenced my interpretations and helped me to visualise the broader horizon of the phenomenon with as little bias as possible. Conducting this study challenged my pre-understandings and helped both me and the participants to adopt a broader understanding, fusing our horizons. The fusion of horizons enabled me to see the bigger picture-that nurse participants in this study cultivated resilience and carried on with the care of dying patients in the volatile acute hospital setting. Participants engaged in critical reflection, guided by the senior nurses and coped with distressing situations.

The primary aim of this study was to understand the EOL care practices and experiences of general practice RNs working in an acute care hospital in Singapore. This study was designed to answer the following research question: What are the everyday experiences of general practice RNs caring for the dying in an acute care hospital in Singapore? Interviews with 16

nurses from various acute care settings provided a deeper understanding of the challenges they encountered with patients and families. Four key themes emerged, offering a deeper understanding of EOL care practices in acute care hospital. The themes on ('experiencing emotional labour', 'barriers to providing optimum palliative care', 'transforming and understanding EOL care' and 'ways of managing care effectively') described the common challenges, frustrations, moral distress and barriers encountered by nurses that challenged their holistic nursing practices. The fusion of my horizon with that of participants provides implications for education practice, policy and future research in the next section. Finally, the strengths and limitations of the study and concluding remarks are also presented in the subsequent section.

8.2 Implications and Recommendations

The study's findings have important implications and provide recommendations in the areas of nursing education and practice, health policies and future research on EOL care in acute care settings in Singapore. These recommendations provide a strategic focus on how to improve EOL care practices along the care continuum in this context.

8.2.1 Implications for end-of-life care education

The findings from this study have strong implications for the need to address the formal and continuing education of nurses through tertiary institutions and in acute care hospitals. The education gap identified highlights the need for educational institutions and hospitals in Singapore to consider including programs on EOL care in the nursing curriculum. There is a need for increased curriculum hours in pre-employment training as well as continuing education and training in EOL care to educate nurses, make EOL more visible, and ensure best-practice in EOL care. All nurses are faced with death and dying; thus, education is essential.

Currently, an average of only four to six hours is allocated to EOL care in both preemployment training and continuing education and training courses. Although it may vary across teaching institutions, the time allocated to EOL care should be considerably increased to give nurses a better understanding and ensure that new graduates have the ability to manage complex needs in providing EOL care. Consistent with the literature, training in advanced communication skills at tertiary education institutions and by healthcare industry partners is recommended. These skills must go beyond those recommended by the End-of-Life Nursing Education Consortium project. An increase in training hours and role play is needed to equip nurses working in acute care to be confident in dealing with diverse cultural and religious practices pertaining to death and dying. It is important to include strategies in educational programs that nurses can adopt to manage distressed patients and families in EOL care. To include inter-professional education, collaboration and communication especially between doctors and nurses.

More nurses should be educated at the advanced diploma and advanced practitioner nurse in palliative care levels. Acute care hospitals should identify nurses who are interested in the field of palliative care and support them to pursue further education in palliative care practices. This aligns with the Lien Foundation (2014) report, which indicates that 74% of doctors and 46% of nurses believe that they do not know enough about this area of care. In the words of the Lien Foundation CEO, 'We've got to make palliative care part of our health care system's DNA. Clinicians need greater competence, confidence and inspiration to provide the kind of end-of-life care we would wish for ourselves and our loved ones' (Lien Foundation, 2014, p. 1). Cross-training of nurses on a rotational basis across various settings such as oncology, critical care, geriatric and palliative care hospices will improve communication skills, symptom management, bereavement and spiritual support. More nurses should be trained as ACP facilitators to initiate conversations on EOL care preferences.

8.2.2 Implications for practice

Currently, all acute care hospitals in Singapore have a preceptor program catering for newly graduated and foreign nurses to induct them into the hospital system and Singaporean culture. A mentorship program led by experienced senior nurses in the acute care setting is warranted. This program would facilitate and guide newly graduated and foreign nurses to attend inhouse training program on EOL care on a continuing basis. Mentoring of younger nurses may contribute to their professional growth, develop their coping skills and dispel their fear of caring for the dying (Dunn, Otten, & Stephens, 2005; Nordgren & Olsson, 2004). There is also a critical need to incorporate EOL care in mainstream medical education. Medical officers clearly need to distinguish between palliative care and EOL care models. Medical education could lead to a better integration of these models when treatment is futile. This

paradigm shift would help nurses provide care that does not conflict with their professional ethics.

Nurses in acute care settings would benefit from regular focus group discussions led by experienced nurses. These focus groups could create a platform upon which nurses could share information, thoughts and coping skills and provide emotional support for each other. Debriefing sessions led by nurse clinicians or ward managers should be considered for nurses experiencing emotional distress to increase their confidence, improve their wellbeing and provide a range of coping mechanisms. Bereavement support for all nurses would be beneficial, both personally and professionally (Mak et al., 2013; Shimoinaba, O'Connor, & Lee, 2010).

Further, public hospitals should implement campaigns to raise public awareness of EOL care preferences and palliative and hospice care. This awareness would help in dispelling misconceptions about palliative and EOL care and educate the public that everyone has the right to make autonomous decisions pertaining to EOL care. Raising awareness will foster empowerment, openness and acknowledgement that conversations about life and death are crucial and a normal part of life. In addition, a cultural and societal shift must begin with the media, including public forums facilitating conversations about death and dying.

The study also revealed that in acute care hospitals, there are no specialised units for patients who required palliative care. Having a specialised unit for patients who require palliative care with educated staff and support from the multidisciplinary team is recommended. Palliative care should be implemented earlier rather than near the end of life. Given the increased numbers of people dying from chronic and malignant disease, this time is to consider the provision of designated wards, which may help minimise the distress faced by nurses who must juggle acute, palliative and EOL care. Further, the principles and values of palliative care should be better integrated into specialised units.

8.2.3 Implications for policy

Currently, there is no national framework for EOL care in Singapore. There should be a collaboration between the MOH, healthcare partners, medical and nurse educators, sociologists and anthropologists to develop and implement a national framework on EOL care to meet the needs of the multicultural Singaporean population. This guideline would

help to standardise care across various healthcare settings and address the needs of patients, regardless of race, language, religion or ethnicity. Although cultural practices differ, a framework would assist in guiding healthcare professionals, including nurses, to deliver care appropriately while considering the cultural and religious values of patients and families.

8.2.4 Recommendations for future research

Future research is recommended to examine the care experiences of foreign nurses in acute, intermediate and long-term care settings in Singapore. This research would provide knowledge on care practices and coping mechanisms of foreign nurses and their similarities and differences in caring for the dying across various health care settings. Strategies with respect to socialisation and education on EOL may address the unmet needs of foreign nurses when providing EOL care.

Research should also focus on the EOL care needs of patients and families. Although patients are the recipients of care, families and medical officers often take control over major decision-making. It is critical to examine the experiences of patients and family caregivers of EOL care. Further, it is necessary to examine the cultural differences and perceptions of EOL care among various ethnic groups in Singapore.

8.3 Study Limitations

Singapore is a multicultural society, and this study did not examine the experiences of nurses from different cultural groups. It is recommended that future studies consider multicultural experiences of nurses in their investigations. This study focused on RNs practising in acute hospitals who were not trained in palliative or EOL care. The inclusion of RNs, Enrolled Nurses and interdisciplinary healthcare professionals who are exposed to palliative and hospice care may provide more detailed information about the care delivered to dying patients. Moreover, all participants in this study were female, and the lack of male participants sharing their experiences may be considered a limitation.

With respect to methodology, Gadamer (2006) argued that developing a horizon requires an awareness of one's current horizon. Although this study aligns with the tenets of qualitative research, it may be considered a form of bias by quantitative researchers, who tend to focus on objectivity. This study was qualitative in nature and because of the small numbers inherent

in the design, the generalisability of findings is not part of the paradigm. However, findings may be transferable and common to the experiences of nurses in other settings (see section 4.3.5.4).

In keeping with V. Fleming et al.'s (2003) method of data analysis, trustworthiness was ensured (see section 4.3.5), and it is expected that the reader will be able to understand the interpretations. Given that this study explored the possibilities of understandings, readers can bring their own horizons to the interpretation, preventing the achievement of objective understanding (V. Fleming et al., 2003). However, the varied experiences of the nurse participants add richness to the experiences of EOL care.

8.4 Strengths of the Study

The strength of this study was in its close adherence to Gadamer's philosophy. Utilising the hermeneutic circle, going back and forth and examining the language of expression created an openness to analysis of the text. This form of reiterative analysis involved a continual process of re-examination to ensure that small nuances of expression were not missed. The choice of V. Fleming et al.'s (2003) framework of analysis was appropriate because it offered a clear direction for analysis and upheld the tenets of Gadamer's philosophy. It provided rich insights and broadened my horizons of what it is like to care for dying patients.

All interviews were undertaken in the nurses' preferred areas, allowing them to speak freely. The use of an interview topic guide helped me to remain focused. Given that I had no personal or working relationships with participants, there were no conflicts of interest or power differentials with participants, adding strength to the study. My supervisors verified the data by reading the interview transcripts and results to check that my interpretations were valid. The credibility of the data resulting from verification revealed the intended focus of the research (Creswell, 2007).

8.5 Researcher's Personal Reflections

This thesis is the first of its kind to adopt a Gadamerian hermeneutic phenomenology to explore the everyday lived experiences of nurses caring for dying patients in an acute care hospital in Singapore. Although there are studies in Western literature, there is a dearth of studies in the Singaporean context. This study also portrayed the range of experiences of

nurses who worked in a multicultural acute healthcare setting in Singapore. The study provided an opportunity to reveal the meaning and lived experiences of nurses who worked in a variety of different care specialties across the acute care setting. It assisted in the understanding of what it was like for nurses from diverse cultural backgrounds caring for dying patients also from diverse cultural backgrounds.

To understand what these themes meant in terms of caring for dying patients, I needed to consider them against my own pre-understandings. It was necessary for me to look beyond my own understanding from my novice practice days of what it means to care for the dying. Through self-reflection, it broadened my understanding of practice. I could identify with the struggles of participants, and, perhaps unknowingly, both I and the participants have grown both personally and professionally. The study expanded my horizon of what it is to care for dying patients. A new understanding of resilience contributed to the personal development and professional growth of nurse participants.

Reflecting on my horizons as a novice nurse, I was unable to see the many dimensions and multifaceted challenges involved with care of the dying. My focus was more on the physical aspects of care, and I was highly task oriented and lacked training and knowledge in palliative care. My pre-understandings of EOL care as a novice were restricted to the limited scope of my experience and history. This undertaking has fused my horizon with that of my participants, leading to a new understanding and the transformation of care through resilience. Simultaneously, this study enabled me as the researcher to acknowledge this new understanding as temporal because knowledge gained about resilience is not finite but continues to develop through hermeneutics.

The philosophical hermeneutics lens of Gadamer (1976, 2004) was adopted from the beginning to the end of this thesis journey. The dialogues with participants were transcribed verbatim and represent their thoughts and feelings about caring for dying patients. Viewing these experiences from a wider perspective has transformed my personal prejudices. In Gadamerian terms, prejudices and biases are integral to interpretation, and here they were transformed by the accounts of participants. Gadamer (1976) states that 'Prejudices are biases of our openness to the world. They are simply conditions whereby we experience something—whereby what we encounter says something to us' (p. 9).

The pre-understandings that I brought to the interviews were transformed into a new understanding. It was through the interpretation of the dialogues with participants that my horizon fused with the horizons of participants, giving me a more in-depth understanding and shaping a new horizon that nursing dying patients requires resilience. Gadamer (1976, 2004, 2006) has reported that understanding is gained through dialogue and a common language. To understand the nurses' dialogues and conversational texts, I had to move in a circular motion through the hermeneutic circle, from the whole conversation to individual parts and back to the whole again. It was through this hermeneutic circle that I developed an understanding about caring for the dying through the emergence of four themes: experiencing emotional labour, barriers to providing optimal EOL care, understanding EOL care and ways of managing care effectively.

This approach would not have been possible without understanding the common language I had with participants. Gadamer (1976, 2004) asserted that understanding can only come about through language. The dialogue was open, and participants were free to engage without being conscious of it. Throughout the interview process, dialogue moved back and forth until a common agreement was reached. I felt reassured by Gadamer that this movement back and forth was about the possibility of understanding. Others who read the transcripts may have a different interpretation, but interpretation is open and temporal, and the text may be reinterpreted by others. Therefore, Gadamer (1976) asserted:

Nowhere does understanding mean the mere recovery of what the author 'meant', whether he was the creator of the work of act, the doer of a deed, the writer of a law book, or anything else. The mens auctoris does not limit the horizon of understanding in which the interpreter has to move, indeed, in which he is necessarily moved, if, instead of merely repeating, he really wants to understand. (p. 210)

This research journey helped me to better understand the experiences of nurses caring for dying patients and their families in the acute care setting. It broadened my horizon and gave me a broad helicopter view of what nurses were experiencing on the ground. Through resilience, EOL care transformed nurse participants, in turn contributing to their personal and professional growth.

In summary, this concluding chapter has highlighted that the environment of acute care may not be appropriate for EOL care because of the juggle between cure, care and family expectations. Normalising death and dying within the spectrum of acute care will take time and require a shift in paradigm for doctors, patients and families. This shift would dispel the misconceptions about palliative care and facilitate open communication with respect to prognosis and disclosure of death and dying. Although it may take some time, through ongoing education, palliative care may be more readily accepted and normalised in medical care.

In a multicultural society, decision-making is often collective, and patients may not be able to fully exercise autonomous decision-making. In contrast to Western cultures, open conversations about death are not as forthcoming. Disclosure of a patient's diagnosis and prognosis are considered detrimental to a patient's condition, and nurses tend to be evasive because they lack effective communication skills. The findings of this study add knowledge and significant areas for consideration to address emotional labour and develop resilience of nurses caring for dying patients in acute care settings. Misconceptions about palliative care in Singapore and the futility of medical treatment, which prevent people from dying with dignity, must be challenged. The focus on cure, the failure to accept death as part of life and the lack of support and resources for nurses to address emotional exhaustion must all be addressed. The multiple realities of participants provided meaning and understanding of the full spectrum of the EOL care experiences of nurses in this study. The fusion of horizons enlarged a broader of view of nurses' experiences at EOL care that participants were able to cultivate resilience which contributed to their personal and professional growth. I have found closure to a certain extent on my unprocessed grief over my father's and sister's death encounters. The experiences I witnessed on my father's and sister's deaths periodically revisit me and to move forward is to build my own inner resilience.

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Appendix 1: Summary of Quantitative and Qualitative Studies

| | | | Study design | Analytical themes: Associated with the nurses' experiences of caring for dying patients | | | | | | | |
|--|---|---------------|--|---|-------------------------|--------------|-----------------------------------|------------------------------------|--|-----------------------|--|
| Author, year (country) | Title | Type of study | | Lack of education & knowledge | Personal development | Lack of time | Lack of bereavement support | Cultural & physical barriers | Communication barriers (disclosure, treatment options, palliative care) | Symptom management | Personal challenges/ emotional labour |
| Hopkinson et al., 2003 (UK) | Caring for dying people in hospital | Qualitative | Phenomenology | | | × | | | × | × | × |
| Jack et al., 2003 (UK) | Nurses' perceptions of the Liverpool Care Pathway for dying patient in the acute hospital setting | Qualitative | | × | | | | | × | × | |
| Sasahara et al., 2003 (Japan) | Difficulties encountered by nurses in the care of terminally ill cancer patients in general hospitals in Japan | Quantitative | Cross-sectional | × | × | × | × | × | × | | × |
| Toscani et al., 2005 (Italy) | How people die in hospital general wards: A descriptive study | Quantitative | Descriptive questionnaire & interviews | × | | | | | × | × | |
| Thompson et al., 2006b (Canada) | Nurses' perceptions of quality end-of-life care on an acute medical ward | Qualitative | Grounded theory | × | | × | | | | × | × |
| Costello, 2006 (UK) | Dying well: Nurses' experiences of 'good and bad' deaths in hospital | Qualitative | Ethnography | | × | × | | | × | × | × |
| Wallerstedt & Andershed, 2007 (Sweden) | Caring for dying patients outside special palliative care settings: Experiences from a nursing perspective | Qualitative | Descriptive phenomenology | | × | × | × | | × | | × |
| Rice et al., 2008 (USA) | Determinants of moral distress in medical and surgical nurses at an adult | Quantitative | Descriptive prospective cross-sectional survey | | | | | × | × | × | × |

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| | | | | Analytical themes: Associated with the nurses' experiences of caring for dying patients | | | | | | | |
|---|---|---------------|---|---|-------------------------|--------------|-----------------------------------|------------------------------------|--|-----------------------|--|
| Author, year (country) | Title | Type of study | Study design | Lack of education & knowledge | Personal development | Lack of time | Lack of bereavement support | Cultural & physical barriers | Communication barriers (disclosure, treatment options, palliative care) | Symptom management | Personal challenges/ emotional labour |
| | acute tertiary care hospital | | | | | | | | | | |
| Boroujeni et al., 2008 (Iran) | Iranian nurses' preparation for loss: Finding a balance in end-of-life care | Qualitative | Grounded theory | | | | | × | | × | × |
| Terry & Carroll, 2008 (UK) | Dealing with death: First year nursing students | Qualitative | Descriptive phenomenology focus group | | | | × | × | | | × |
| Iranmanesh et al., 2009 (Sweden) | Swedish nurses' experiences of caring for dying people | Qualitative | Phenomenological hermeneutic approach | | × | | | | | | × |
| Roche-Fahy & Dowling, 2009 (Ireland) | Providing comfort to patients in their palliative care trajectory: Experiences of female nurses working in an acute setting | Qualitative | Gadamerian hermeneutic | × | | × | | | × | × | × |
| Peterson et al., 2010 (USA) | What is so stressful about caring for a dying patient? A qualitative study of nurses' experiences | Qualitative | Grounded theory approach using mixed methods | | | × | | | × | × | × |
| Kongsuwan et al., 2010 (Thailand) | Thai Buddhist intensive care unit nurses' perspective of a peaceful death: An empirical study | Qualitative | Descriptive qualitative study | × | × | | | × | | | |
| Mahtani- Chugani et al., 2010 (Spain) | How to provide care for patients suffering from terminal non- oncological diseases: Barriers to a palliative care approach | Qualitative | Descriptive qualitative study Focus group & individual interviews | × | | | | × | × | | × |
| Espinosa et al., 2010 (USA) | ICU nurses' experiences in providing terminal care | Qualitative | Phenomenological study | × | × | | | | × | | × |

| | | | | Analytical themes: Associated with the nurses' experiences of caring for dying patients | | | | | | | |
|--|--|------------------------|--|---|-------------------------|--------------|-----------------------------------|------------------------------------|--|-----------------------|--|
| Author, year (country) | Title | Type of study | Study design | Lack of education & knowledge | Personal development | Lack of time | Lack of bereavement support | Cultural & physical barriers | Communication barriers (disclosure, treatment options, palliative care) | Symptom management | Personal challenges/ emotional labour |
| White & Coyne, 2011 (USA) | Nurses' perceptions of educational gaps in delivering end-of-life care | Quantitative | Descriptive, cross-sectional study | × | | | | | × | × | × |
| Johnson, 2011 (Australia) | Nursing the dying: A mixed-method study | Mixed methods study | Descriptive questionnaire & interview guided by van Manen | × | × | | | × | | | × |
| Casey et al., 2011 (Ireland) | Dying well: Factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland | Qualitative | Grounded theory approach | × | | × | × | × | × | | × |
| Valiee et al., 2012 (Iran) | Exploration of Iranian intensive care nurses' experience of end-of- life care: A qualitative study | Qualitative | Descriptive qualitative approach | × | | | × | | × | | × |
| Aslakson et al., 2012 (USA) | Nurse-perceived barriers to effective communication regarding prognosis and optimal end-of- life care for surgical ICU patients: A qualitative exploration | Qualitative | Descriptive qualitative approach using focus group interview | × | | | | × | × | | × |
| Johansson & Lindahl, 2012 (Sweden) | Moving between rooms—moving between life and death: Nurses' experiences of caring for terminally ill patients in hospitals | Qualitative | Phenomenological study | × | × | × | | | | | × |
| Mak et al., 2013 (Hong Kong) | Experiences and perceptions of nurses caring for dying patients and families in the acute medical admission setting | Qualitative | Interpretive phenomenology | × | | × | | | × | | × |

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| | | | | Analytical themes: Associated with the nurses' experiences of caring for dying patients | | | | | | | |
|--|---|---------------|--|---|-------------------------|--------------|-----------------------------------|------------------------------------|--|-----------------------|--|
| Author, year (country) | Title | Type of study | Study design | Lack of education & knowledge | Personal development | Lack of time | Lack of bereavement support | Cultural & physical barriers | Communication barriers (disclosure, treatment options, palliative care) | Symptom management | Personal challenges/ emotional labour |
| McCallum & McConigley, 2013 (Australia) | Nurses' perceptions of caring for dying patients in an open critical care unit: A descriptive exploratory study | Qualitative | Descriptive exploratory approach | | | | | × | × | | × |
| King & Thomas, 2013 (USA) | Phenomenological study of ICU nurses' experiences caring for dying patients | Qualitative | Phenomenological study based on Merleau-Ponty works | × | | × | | | × | | × |
| Bloomer et al., 2013 (Australia) | The 'dis-ease' of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study | Qualitative | Qualitative non- participant approach followed by focus group & individual interview | | | | | × | × | | × |
| Todaro- Franceschi, 2013 (USA) | Critical care nurses' perceptions of preparedness and ability to care for the dying and their professional quality of life | Quantitative | Mixed methods questionnaire survey based on two instruments and themes identified from open-ended responses | × | × | | | | | | × |
| Powazki et al., 20144 (USA) | The care of the actively dying in an academic medical center: A survey of registered nurses' professional capability and comfort | Quantitative | Cross-sectional, mixed methods prospective study | | | | × | | × | | × |
| Edo-Gual et al., 2014 (Spain) | The impact of death and dying on nursing students: An explanatory model | Qualitative | Descriptive hermeneutic study | × | × | | | × | | | × |
| Wilson, 2014 (UK) | Ward staff experiences of patient death in an acute medical setting | Qualitative | A Heideggerian phenomenological approach | | × | | × | | | | × |

| | | | | Analytical themes: Associated with the nurses' experiences of caring for dying patients | | | | | | | |
|---|---|---------------|--|---|-------------------------|--------------|-----------------------------------|------------------------------------|--|-----------------------|--|
| Author, year (country) | Title | Type of study | Study design | Lack of education & knowledge | Personal development | Lack of time | Lack of bereavement support | Cultural & physical barriers | Communication barriers (disclosure, treatment options, palliative care) | Symptom management | Personal challenges/ emotional labour |
| Agustinus et al., 2014 (Singapore) | Research in brief— Attitudes of nurses in Singapore towards palliative care | Quantitative | Descriptive cross- sectional survey | × | | × | | | × | | × |
| Decker et al., 2015 (Australia) | The experiences of emergency nurses in providing end-of-life care to patients in the emergency department | Qualitative | Grounded theory | × | | × | | × | | | x |
| Anderson et al., 2015 (New Zealand) | Experiencing patient death in clinical practice: Nurses' recollections of their earliest memorable patient death | Qualitative | Interpretive phenomenology | × | × | | × | | | | x |
| Zheng et al., 2015 (China) | Chinese oncology nurses' experiences on caring for dying patients who are in their final days: A qualitative study | Qualitative | Descriptive approach | × | × | | | | × | | × |
| Anderson et al., 2016 (Sweden) | To be involved: A qualitative study of nurses' experiences of caring for dying patients | Qualitative | Descriptive approach | × | | × | | | × | × | × |
| Ingwu et al., 2016 (Nigeria) | Knowledge and practice of end-of-life care among nurses in a teaching hospital in Nigeria | Quantitative | Descriptive survey | × | | × | | × | | | × |
| Becker et al., 2017 (USA) | Perceptions of dying well and distressing death by acute care nurses | Qualitative | Qualitative questionnaire | | | | × | | | | × |
| Funk et al., 2017 (Canada) | The emotional labor of personal grief in palliative care: Balancing caring and professional identities | Qualitative | Descriptive qualitative approach | | × | | × | | | | × |

| | | | | | Analyt | tical themes: Asse | ociated with the n | urses' experien | ces of caring for dying pa | atients | |
|--------------------------------------|---|---------------|--|-------------------------------------|-------------------------|--------------------|-----------------------------------|------------------------------------|--|-----------------------|--|
| Author, year (country) | Title | Type of study | Study design | Lack of education & knowledge | Personal development | Lack of time | Lack of bereavement support | Cultural & physical barriers | Communication barriers (disclosure, treatment options, palliative care) | Symptom management | Personal challenges/ emotional labour |
| Chuah et al., 2017 (Singapore) | A qualitative study on oncology nurses' experiences of providing palliative care in the acute care setting | Qualitative | Descriptive exploratory study | × | | | | × | × | | × |
| Lai et al., 2018 (China) | The experience of caring for patients at the end-of-life stage in non-palliative care settings: A qualitative study | Qualitative | Descriptive qualitative approach | × | | | | × | × | | × |
| Chan et al., 2018 (Canada) | 'I'm only dealing with the acute issues': How medical ward 'busyness' constrains care of the dying | Qualitative | Ethnography | | | × | | | × | | × |

Appendix 2: Aims, Methods and Key Findings

| Author, year | Aims | Methods | Key findings |
|---------------------------------|--|--|---|
| Hopkinson et al. 2003 | To develop an understanding of care for dying people in hospital, from the perspective of newly qualified staff nurses in the UK. The purpose was to build a theory of how nurses might be helped to deliver quality care to dying people in hospital | Design: qualitative, in-depth interviews, audio recorded Data collection: 28 newly qualified nurses from two acute hospitals | All the nurses' stories were found to be built around six essences: the personal ideal, the actual, the unknown, the alone, tension and anti-tension. These essences, and the relationships between them, were used to build a model of the experience of caring for dying people in hospital. |
| Jack et al. 2003 | To explore nurses' perceptions of using the Liverpool Care Pathway in the acute hospital setting | Design: qualitative approach Data collection: 15 nurses, two focus group interviews, semi- structured and audio recorded | Generally, a positive impact on the use of Liverpool Care Pathway. It provided guidance to nurses on symptom control, communication with relatives, increased work confidence & knowledge. A reduction in documentation. Barriers: some staff resistant to using Liverpool Care Pathway. |
| Sasahara et al. 2003 | To investigate the difficulties encountered by nurses who have cared for terminally ill cancer patients at general hospitals | Design: quantitative Data collection: questionnaire survey of 534 nurses from the general wards. 450 responded (84.3%) | Eight domains emerged from the questionnaire response. They were communication with patients and their families, knowledge & skills of nurses, treatment & areas of concerns, personal issues, collaboration as a team including patient and family, environment & system, collaboration among nurses and near-death issues. |
| Toscani et al. 2005 | To describe how adults die in hospital general wards, focusing on treatments, management and care proximity of death To assess differences in management and care of severely ill patients whose death was expected and patients whose death was unexpected | Design: quantitative, likely mixed method Data collection: clinical records and interviews of nurses post patient deaths | Symptom control was inadequate for the most severely ill patients Family expected better quality of care Palliative care was not referred early enough |
| Thompson et al. 2006 Canada | To develop an understanding of the process nurses undertake in providing quality EOL care and to develop an emerging theory grounded in the reality of the participants that captured their experiences in providing such care on an acute adult medical unit | Design: qualitative approach, grounded theory Data collection: semi-structured interviews conducted on ten nurses from 30 minutes to hours. Data analysed using the constant comparative method | The basic social problem uncovered in the data was that of nurses striving to provide high-quality end-of-life care but being pulled in all directions. Facilitating and maintaining a lane change, getting what is needed, being there and manipulating the care environment were the psychological processes they experienced. |
| Costello 2006 | To investigate hospital nurses' experiences of death and dying | Design: qualitative approach Data collection: in-depth interviews on 29 nurses for 40–50 minutes | Findings suggested that the experiences of nurses were based on their level of control over the dying process 'Good and bad death' focused less on patients' needs but more on the nurse's ability to manage organisational demands |
| Wallerstedt & Andershed 2007 | To describe nurses' experiences in caring for gravely ill and dying patients outside special palliative care settings | Design: qualitative approach Data collection: interviews conducted on nine nurses in primary care, community care and hospitals | The results indicate that nurses need resources such as time and improved methods of communication and cooperation as well as more support to give quality palliative care and achieve satisfaction with the outcome. The need for discussion about the conditions for giving palliative care outside the hospices and other special palliative care settings is also elucidated. |
| Boroujeni et al. 2008 | Aim: to explore the nurse-patient interaction in terminally ill situations in | Design: qualitative, grounded theory approach Data collection: three teaching hospitals in Isfahan, Iran. Two acute care & one cancer care. Eighteen nurses were interviewed | 13 conceptual categories emerged The core themes were striking a balance between restorative & palliative care, information & hope, expectations & abilities, intimacy and distance |

| Author, year | Aims | Methods | Key findings |
|-----------------------------|--|---|--|
| | acute care, focusing on the nurses' preparation for loss | up to three times. Semi-structured interviews were conducted (total three interviews) Data analysed using Strauss & Corbin (1998) & Carpenter (2003) model of analysis | |
| Terry & Carroll | To investigate first-year nursing students' | Design: qualitative descriptive | The research found that, to the student, every death in clinical practice is a learning experience |
| 2008 | encounters with patients' deaths | Data collection: mixed method. Semi-structured questionnaire and three focus group interviews. Fourteen student nurses participated in one of the focus groups | and potentially a source of emotional distress; some students reported experiencing flashbacks afterwards and were developing avoidance behaviours. Students sometimes felt unsupported by mentors and felt that dying patients and families were sometimes inadequately cared for. The theme of abandonment was evident in the students' stories. The authors conclude that there is still room for improvement in EOL care. Good role modelling and pastoral care is vital to student development. |
| Rice et al. 2008 | To determine the prevalence and | Design: quantitative | The intensity of moral distress was uniformly high in situations related to physician practice, |
| | contributing factors of moral distress in medical surgical nurses | Data collection: questionnaire survey on 260 nurses | nursing practice, institutional factors, futile care, deception & euthanasia |
| Iranmanesh et al. | To elucidate the meaning of nurses' | Design: qualitative | Three themes emerged: meeting patients and family members as unique persons, learning in a |
| 2009 | experiences of caring for dying persons at home and in a special unit in a hospital | Data collection: interviews were conducted on eight nurses for 55 to 65 minutes | challenging environment and gaining personal strength. It was about reflecting on their personal experiences and appreciating the caring context. Building trusting connections. |
| Roche-Fahy & | To explore the lived experience of nurses | Design: qualitative, using Gadamerian hermeneutic | The main findings revealed four major themes (with subthemes) that describe the lived experience of providing comfort to palliative care patients in an acute setting: time needed to |
| Dowling 2009 | who provide comfort to palliative care patients in an acute setting in a small urban | phenomenology Data collection: 13 interviews were conducted for 20 to 70 | provide comfort, emotional cost to the nurse in providing comfort, a holistic approach in the |
| | hospital in the west of Ireland | minutes. Data analysed using Colaizzi's method | provision of comfort, and the role of education and the expert team in providing comfort |
| Peterson et al. 2010 | To explore the specific aspects of caring for | Design: qualitative | Nurses expressed personal concerns about the patients and their families, including challenges |
| | a dying patient that concern nurses | Data collection: 15 nurses and nursing students using mixed method. Questionnaire survey on the Multidimensional Fear of Death Scale and the Frommelt scale and followed by interview | in communication with both patients and families |
| Kongsuwan et al. | To describe the concept of a peaceful death | Design: qualitative descriptive approach | Four core qualities of a peaceful death emerged as described by Thai Buddhist nurses who |
| 2010 | from Thai Buddhist ICU nurses' perspectives | Data collection: ten nurses from adult ICUs were interviewed | practised in the ICUs. These core qualities were peaceful mind, no suffering, family's acceptance of patient's death and being with others rather than alone. Thai Buddhist nurses described a peaceful death as 'a situation in which persons who are dying have peace of mind, and do not show signs and symptoms of suffering. Peaceful death occurs when family members declare acceptance of their loved one's dying and eventual death. Such a death is witnessed by relatives and friends and the dying person is not alone'. The findings encourage nurses to be with, and provide palliative care for, dying patients and families. |
| Mahtani-Chugani et al. 2010 | To explore palliative care service provision for patients in Spain | Design: qualitative descriptive approach Data collection: patients, family caregivers and healthcare | The barriers identified were as follows: lack of clarity about prognosis, the hegemony of the curative approach, avoiding words and the desire to cheat death. |
| | | professionals were interviewed, individually or in a group, with the aim of identifying barriers in the provision of care and | Lack of clarity about prognosis: relatives and patients often linked palliative care to terminal illnesses, and this posed as an obstacle to care of other life-limiting conditions. |
| | | strategies to overcome them. Focus group and ten interviews conducted on professional caregivers | The hegemony of the curative approach: professionals admit they lacked training in palliative care. The focus was on cure as opposed to care. Lack of shared understanding between patient, relatives and professional caregivers. |
| | | | Avoiding words: difficulties encountered when sharing information with relatives. Non-acceptance of disease progression by relatives. Fragmented care within the interdisciplinary team. |

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| Author, year | Aims | Methods | Key findings |
|-----------------------|--|--|---|
| | | | Cheating death: speaking of death and palliative care was considered taboo. It delayed the palliative care approach. Non-acceptance of caregivers on prognosis as they connoted palliative care meant giving up. |
| Espinosa et al. 2010 | To explore the experiences of intensive care | Design: qualitative phenomenological approach | Three major themes identified. |
| | nurses who provide terminal care in the ICU | Data collection: 18 registered nurses participated in focus and individual interviews | Barriers to optimal care were lack of involvement in the plan of care, differences between the medical and nursing practice models, disagreement among physicians and other health care team members, perception of futile care and unnecessary suffering, unrealistic expectations of the family and lack of experience and education of the nurse. |
| | | | Internal conflict: feelings of relief when care moved to palliative approach. The desire for the patient to be comfortable and good memories for the family. Abandonment and powerlessness when nurses felt it was their failure when patient did not get well. Conflict with medication administration regarding dosage. Difficulty with younger patients who belong to the same age group. |
| | | | Coping: the ICU nurses described their coping strategies. They included building trust with the family, crying, humour, talking to others about terminal care and avoiding care for the terminal patients. |
| White & Coyne 2011 | To assess EOL care core competencies deemed most important with corresponding educational needs from oncology nurses and to describe the characteristics of the respondents that are associated with selection of the top-ranked core competencies | Design: descriptive, cross-sectional Data collection: responses to a mailed or emailed researcher- developed questionnaire during a six-month period were collated and analysed | Almost all the respondents indicated that EOL care was a part of their practice and that continuing education was important, but more than half of the respondents had had fewer than two hours of continuing education regarding EOL care in the past two years. Twenty-five percent of the respondents did not believe they were adequately prepared to effectively care for a dying patient. Symptom management was the top-rated core competency, consistent across age, education level, practice role and practice setting. How to talk to patients and families about dying and what comprises palliative care also was selected frequently. |
| | | | Symptom management is the number one core competency, and the quantity and quality of EOI continuing education is inadequate. |
| Johnson 2011 | To understand the experience of caring for | Design: mixed methods longitudinal study | Phase 1: 72% response rate. Education on death and dying among Australian undergraduate |
| | an adult dying patient and their family in an acute care hospital | Data collection: descriptive survey and phenomenological interviews | nursing programs is consistently presented. Minimum emphasis on death and dying in the nursing curricula. Poor pedagogy. Clinical placement not well structured on palliative care. |
| | | Phase 1: descriptive survey of Australian undergraduate nursing curricula | Phase 2: four themes emerged. Confronting death has three subthemes. They were being repulsed at the physicality of death, being intimate with the dying and being lost. |
| | | Phase 2: conducted interviews on 14 postgraduate students | Theme 2: being transformed by death |
| | | 1 0 | Theme 3: grieving the loss of a patient |
| | | | Theme 4: the buck stops with you: being responsible for the care of the dying |
| Casey et al. 2011 | To explore key stakeholders and direct care | Design: grounded theory was used | Factors that influence provision of end-of-life care in Ireland were identified. The core category |
| | managers' perspectives on the current provision of end-of-life care for older people in acute and long-stay care settings | Data collection: semi-structured interviews were employed to collect data between 2007 and 2008. In total, 33 people participated, of whom 19 were registered nurses. Interviews | was 'dying well'. The potential to 'die well' was influenced by three factors, namely philosophy, culture and organisation of care, knowing the person and physical environment and resources. |
| | in Ireland and to construct a model of these | lasted between 45 and 60 minutes | Philosophy, culture and organisation: the need to incorporate holistic palliative care for the comfort of patient. Organisational support is needed for staff to address emotional labour and staffing constraints. |
| | | | Knowing the person: building a trusting relationship. Additionally, the lack of knowledge was a hindrance to care. |
| | | | Physical environment and resources: space needed for privacy. Knowledge of palliative care was found to be important. |

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| Author, year | Aims | Methods | Key findings |
|-------------------------------|--|---|---|
| Valiee et al. 2012 | To explore the experiences of intensive care | Design: qualitative approach. | Two themes emerged: emotional burden and values and beliefs. |
| | nurses providing care for EOL patients | Data collection: ten nurses from the ICU were interviewed. Interviews lasted between 45 and 60 minutes. Conventional | Emotional burden was related to the psychological pressure in providing care, the nature of patient family's reaction and the effect of patient's conditions |
| | | content analysis on data | Values and beliefs related to the hereafter and being an advocate for the patient |
| Aslakson et al. 2012 | To explore the barriers to optimal | Design: qualitative approach | Thirty-four barriers identified to optimal communication regarding prognosis, which were |
| | communication and EOL care in SICUs as perceived by the bedside nurses | Data collection: conducted four focus group discussions on 32 SICU nurses. Each focus group lasted about an hour and dealt with the topic of communication regarding prognosis and was followed by the discussion of EOL care. | summarised into four domains: logistics, clinician discomfort with discussing prognosis, inadequate skill and training and fear of conflict. For optimal EOL care, the groups identified 24 barriers in four domains: logistics, inability to acknowledge an EOL situation, inadequate skill and training and cultural differences relating to EOL care. |
| | | Using content analysis, responses were organised into themes validated by independent observers and a subset of participating nurses | |
| Johansson & Lindahl | To describe the meanings of generalist | Design: qualitative, descriptive and interpretive study | Seven themes were identified. |
| 2012 | registered nurses' experiences of caring for palliative care patients on general wards in hospitals | Data collection: eight registered nurses. Interviews lasted between 30 and 60 minutes. The interviews were analysed using | Being grateful to be able to share in the end of another's life: being involved in the care and feeling satisfied |
| | nospitais | a phenomenological hermeneutical approach inspired by Ricoeur's philosophy | Being touched by physical and existential meaning: being touched by and aware of patient's bodily changes and to be struck by existential thoughts |
| | | | To exist in place and space: creating a place and longing for sheltered place |
| | | | To give and receive energy: being drained of energy and being in an existential void and experiencing rest in the acute care setting |
| | | | Being open in relation to patient and colleagues: striving for continuity of care and sharing of feelings with each other |
| | | | Being in embodied knowledge: having good self-knowledge and knowledge of others and altering oneself before each encounter |
| | | | Time that does not exist: feelings of stress and dissatisfaction, feelings of inadequacy |
| Mak et al. 2013 | To explore the experiences and perceptions of nurses caring for dying patients and their families in the acute medical admission setting | Design: qualitative interpretive descriptive | Four themes were identified. |
| | | Data collection: 15 nurses were interviewed for 90 minutes. Boyatzis's (1998) thematic analysis adopted | Theme 1: lack of preparedness for patients' deaths. There were three subthemes: sudden and unanticipated deaths, families' intense responses to patients' deaths and emotional responses and somatic complaints. |
| | | | Theme 2: reflecting on own nursing roles for dying patients. This was supported by three subthemes: disappointment & helplessness related to inadequacy in the role, satisfaction with their positive supportive role and learning mutually for better care of dying patients and their families. |
| | | | Theme 3: reflecting on the meaning of death and personal experiences of the death of their own family members |
| | | | Theme 4: coping with caring for dying patients has two subthemes: having an easy-going attitude to life and exercising self-caring |
| McCallum & McConigley 2013 | To describe the provision of EOL care in an open high-dependency unit | Design: A descriptive exploratory approach Data collection: five registered nurses working in the high- dependency area at a major teaching hospital were interviewed. Thematic analysis was used to code the data and identify themes. Interviews lasted between 21 and 54 minutes | Three themes emerged from the data. The core theme was 'the nurse as protector'. The two other themes were 'conflict of care' and 'peace and quiet'. Within these themes, characteristics of an ideal death were identified and barriers to providing an ideal death were acknowledged. In particular, relief of suffering, not letting the patient die alone, awareness of end of life, spiritual wishes, maintaining dignity and providing peace and a quiet environment. |

| Author, year | Aims | Methods | Key findings |
|---------------------------|---|---|---|
| King & Thomas 2013 | To explore critical care nurses' experiences caring for the dying | Design: qualitative phenomenological approach based on Merleau-Ponty works Data collection: 14 nurses were interviewed. Thematic analysis conducted | The theme on promises to keep emerged. It has five subthemes: promise to be truthful, promise to provide comfort, promise to be an advocate, promise that could not be kept and promise to remain connected. |
| Bloomer et al. 2013 | The aims were to explore nurses' 'recognition of' and 'responsiveness to' dying patients and to understand the nurses' influence on EOL care | Design: qualitative approach utilising non-participant approach Data collection: focus group discussion followed by individual semi-structured interviews for clarification. Twenty-five nurses participated and 20 episodes of observation were conducted | Four core themes were derived from observation and affirmed through focus group discussion: recognition of dying, nursing care challenges, the impact of single rooms, and clinician preparedness and coping. Nurses took a passive role in recognising dying, providing active care until a medical officer's declaration of dying. Ward design, nurse allocation and nurses' attitude to death affects patient care. EOL care in a single room can have negative consequences for the dying. Nurses demonstrated varying degrees of discomfort, indicating that they were underprepared for this role. |
| Todaro-Franceschi 2013 | To explore whether critical care nurses perceive that they have been adequately prepared during basic nursing education to care for the dying and their loved ones To identify if there is a relationship between their perceptions of preparedness and ability to provide EOL care and professional quality of life. | Design: mixed methods approach using web-based survey Data collection: survey conducted using two instruments. Perceptions of preparedness and ability to care (PPACD)—13- item questionnaire with a 6-item subscale. Next was the professional quality of life (PQOL) instrument with 30 items and three subscales, each with ten items of measurement on compassion satisfaction, compassion fatigue/traumatic stress and burnout. A 6-point Likert scale was used to rate each experience. 473 critical care nurses participated in total. Narrative responses were grouped by question | Findings indicate that there is a relationship between critical care nurse perceptions of preparedness and ability to care for the dying and their PQOL, with higher compassion satisfaction scores, lower compassion fatigue scores and lower burnout scores for those who perceive themselves more prepared and better able to provide EOL care (N = 473). Thus, pedagogic interventions to enhance perceptions of preparedness and ability to care for the dying can potentially improve PQOL for nurses working in critical care areas, possibly diminishing the incidence of compassion fatigue and burnout. Two themes were identified from the narrative questions: facing death unprepared hurts more and appreciating moments with patients nearing EOL and helping their loved ones through the transition feels good |
| Powazki et al. 2014 | To assess nurses' self-perceived capability and comfort in the care of the actively dying. To determine whether professional capability and comfort was associated with any of the six demographics characteristics (age, gender, clinical experience, education level, nursing unit, continuing education). To identify areas of clinical challenge to promote educational initiatives to stimulate best nursing practices | Design: quantitative, cross-sectional, mixed methods prospective study Data collection: questionnaire has two parts. Part 1 measures the demographic profile with one open-ended question. Part 2 comprises 20 questions, nine of which deal with perceived personal capability and 11 with comfort. Data analysed using descriptive statistics software. Written responses were analysed qualitatively | Older age and greater clinical experience were associated with greater levels of capability/comfort. Most nurses felt professionally capable and comfortable in domains such as knowledge, physical and psychosocial care but bioethics, communication, cultural, spiritual and bereavement issues challenged ≥ 40%. Nurses' self-perceived professional capability and comfort levels in caring for the dying were positively influenced by older age, greater clinical experience and extensive continuing education. Bioethics, communication and grief affected nurses personally and emotionally. Continuing education, organised debriefing, grief counselling and preceptor's support should be routine for nurses who work in units with predictable high mortality. |
| Edo-Gual et al. 2014 | To explore nursing students' experiences of deaths and dying in clinical practice | Design: qualitative descriptive and hermeneutics Data collection: semi-structured interviews on 12 nursing students. Data analysed using Colaizzi's (1978) seven-step procedure | The analysis identified five themes: impact, training in end-of-life care, ethical issues, coping and learning/growth/healing connections Impact related to three subthemes: impact of what death implies, impact of seeing the dead body and fear of emotional contagion Training in EOL care has four subthemes: managing emotions, how to break bad news, palliative sedation and the concepts of euthanasia and withdrawal of life support The ethical issues theme has four subthemes: ethical care, ethical dilemmas, beliefs and 'good' and 'bad' deaths: being allowed to die Coping has five subthemes: accepting death as part of life, support from qualified staff, talking about death, being involved in patient care and beliefs The learning, growth and healing connections theme has three subthemes: professional learning, personal growth and healing connections |

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| Author, year | Aims | Methods | Key findings | | |
|-----------------------|---|---|---|--|--|
| | | | The central theme was the enormous impact the encounter with death had, while the other themes were a response to and/or modulators of this impact. An explanatory model was derived based on the relationship between all these emergent themes. | | |
| Wilson 2014 | To explore how ward staff, including nurses and healthcare support workers, experience patient death in an acute medical setting | Design: qualitative; a Heideggerian phenomenological approach was used Data collection: 13 staff from two acute medical wards for patients with respiratory conditions were interviewed about their experiences of patient death. Interviews lasted between 30 and 60 minutes. Data were analysed using van Manen's phenomenological approach | Three main themes were identified: responses, influences and support. These themes were further subdivided into preliminary themes that reflected the social psychology literature. Participants often experienced grief following the death of a patient and the effects on staff were not always recognised or acknowledged by managers. | | |
| Agustinus et al. 2014 | To explore the attitudes of nurses in Singapore towards palliative care and the factors affecting such attitudes | Design: quantitative, descriptive, cross-sectional, correlational survey Data collection: 512 participants targeted, 418 participated with 82% of response rate. Questionnaire survey included demographic profile and clinicians' attitudes towards care at EOL (CACEL). A 12-item instrument with a 5-point Likert scale and a death attitude profile/revised (DAP-R) 32-item with a 7-point Likert scale was used | The findings indicated nurses were less inclined to communicate with terminally ill patients. This could be due to lack of time, EOL communication skills or self-confidence. Older nurses and nurses who had more experience had more positive attitude towards palliative care. | | |
| Decker et al. 2015 | To describe the experiences of emergency nurses in providing EOL care, which is the care delivered to a patient during the time directly preceding death | Design: qualitative, grounded theory approach Data collection: data collected from 25 emergency nurses during three focus group interviews. The interviews were transcribed and analysed using the qualitative techniques of grounded theory | Ten categories emerged from the data that described a social process for managing death in the emergency department. The categories were linked by the core category labelled 'dying in the emergency department is not ideal', which described how the emergency department was an inappropriate place for death to occur. To help manage the influence of the environment on EOL care, nurses reported strategies that included moving dying patients out of the emergency department and providing the best care that they could. | | |
| Anderson et al. 2015 | To explore the earliest memorable patient death experiences of New Zealand registered nurses. This is the second phase of the study | Design: qualitative, interpretative phenomenology Data collection: 20 semi-structured interviews were conducted on RNs for 40 minutes. Data analysed using the interpretive approach | Seven emergent themes, and features of more positive or negative experiences were identified: event significance; emotional challenges; sharing the experience; learning; feeling unprepared, responses to death and finding benefits | | |
| Zheng et al. 2015 | To elucidate Chinese oncology nurses' experience of caring for dying cancer patients | Design: qualitative descriptive study Data collection: 28 nurses were interviewed for 30 to 60 minutes. Data were analysed using the NVivo 10.0 and Colaizzi's seven-step approach | Five main themes were identified: EOL care for dying cancer patients, EOL care for family members, cultural sensitivity and communication, moral distress and self-limitations, self-reflection and benefit-finding. Death is taboo in traditional Chinese culture. This increases the difficulty of effective communication between nurses, patients and families. Although nurses suffered emotional distress when caring for dying cancer patients, these experiences helped them to reflect on the meaning of death and life, and positively influenced their daily lives, attitudes and behaviours towards caring for the dying. Chinese nurses had strong willingness to offer quality EOL care to patients and families, however, they suffered moral distress because of self-limitation, lack of knowledge and confidence and inexperience in psychological care | | |
| Anderson et al. 2016 | To describe nurses' experiences (> two years) of caring for dying patients in surgical wards | Design: a qualitative descriptive study was carried out in two surgical wards in the southern part of Sweden Data collection: six interviews with registered nurses for 30 to 60 minutes. Data were analysed using qualitative content analysis | The results formed one category (caring to be involved) and three subcategories (being supportive, being frustrated and being sensitive in the caring processes). Nurses were personally affected and felt unprepared to face dying patients because of a lack of knowledge about the field of palliative care. Their experiences could be described as processes of transition from theory to practice by trial and error. | | |
| Ingwu et al. 2016 | To examine the knowledge and practice of EOLC among nurses working at the | Design: quantitative, descriptive survey, cross-sectional | The results showed that 123 respondents (94.6%) had knowledge of EOLC as care given at a terminal state of life and/or a dying person. Findings also showed the practice of EOLC with a | | |

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|----------|--------------------|---|---|---|
| | Becker et al. 2017 | To identify perceptions of nurses practicing in four adult inpatient units regarding their actions to provide quality EOL care for dying patients, their definitions of dying well, and their symptoms of distress and actions they took for relief | Design: descriptive, mixed methods approach Data collection: qualitative questionnaire data were collected from 49 nurses on four adult inpatient nursing units to analyse nurse perceptions of distressing death and dying well. Data analysed using grounded theory approach | Three main concepts emerged describing the nurses' definitions of dying well: emotional and spiritual support for the patient and family, patient and family control and promotion of a peaceful environment. Eight categories of nursing actions to promote dying well were identified, including communication with disciplinary team/nursing staff, provision of optimal physical care, demonstration of caring and compassion, supporting dignity in death for patient/family, education of patient/family to support dying well, emotional support for patient/family, advocacy for dying well and fostering a peaceful environment. Symptoms of distress among nurses and actions for relief were also indicated by participants. |
| 3 | Funk et al. 2017 | To explore how health care employees interpret personal grief related to patient death | Design: qualitative, interpretive approach Data collection: interviews with 12 health care aides and 13 nurses. Data were analysed collaboratively using an interpretively embedded thematic coding approach and constant comparison | Participant accounts of preventing, postponing, suppressing and coping with grief revealed implicit meanings about the nature of grief and the appropriateness of grief display. Employees often struggled to find the time and space to deal with grief and faced normative constraints on grief expression at work. Findings illustrate the complex ways health care employees negotiate and maintain both caring and professional identities in the context of cultural and material constraints. Implications of emotional labour for discourse and practice in health care settings are discussed. |
| 21 | Chuah et al. 2017 | To explore nurses' experiences of providing palliative care in the acute oncology care unit | Design: qualitative descriptive approach Data collection: focus group interviews involving a total of 24 nurses were conducted. Interviews were audiotaped and transcribed verbatim. Data were analysed using an inductive content analysis approach | Five key themes emerged from the analysis: nurses' perceptions of palliative care, multiple roles of nurses in palliative care, emotional burden of providing palliative care, misconceptions of palliative care and challenges in providing palliative care |
| | Lai et al. 2018 | To explore the experiences of health care providers in caring for patients at the EOL stage in non-palliative care settings | Design: qualitative exploratory Data collection: 26 health care providers from eight health care institutions based in Shanghai were interviewed individually between August 2016 and February 2017. Three levels of health care, i.e. acute care, sub-acute care or primary care were provided in the health care institutions. The interviews were analysed using qualitative content analysis | Three themes emerged from the interviews. (1) Definition of the EOL stage. This is mainly defined based on a change in treatment. (2) Health care at the EOL stage. Most patients spent their last weeks in tertiary/secondary hospitals, transferring from one location to another and receiving disease- and symptom-focused treatment. Family-dominated decision-making was common when discussing treatment options. Nurses instinctively provided extra care and attention to patients, but nursing care was still task oriented. (3) Challenges, difficulties and the future. From the interviews, it was found that pressure from families was the main challenge faced by health care providers. Three urgent tasks before EOL care can become widely available in the future were identified from the interviews, including educating the public on death, extending government support and creating a better health care environment. |
| | Chan et al. 2018 | To better understand how this curative/life- | Design: qualitative, ethnography | Staff experienced overwhelming workload. The culture of busyness, managing care priorities, |

Data collection: participant observation, field work, formal and

informal interviews and chart reviews. Three groups were interviewed: patients (N=10), family members (N=11) and staff members (N=14), of whom six were nurses

Data collection: questionnaire on 130 nurses from oncology,

medical and surgical wards. Data analysed using descriptive

Key findings

approach.

time with dying patients.

mean score of 3.6 ± 2.8 and inadequate labour and lack of experience with the mean 2.9 ± 1.6

reported inadequate time, lack of experience to practice and feeling guilty for not having enough

and 2.9 ± 1.5 , respectively, as factors negatively influenced their practice of EOLC. Nurses

cure versus care and palliative care. Less attention to palliative care. Delay in palliative care

Methods

statistics

Author, year

Aims

Enugu

University of Nigeria Teaching Hospital, in

prolonging care environment shapes the

care of dying patients

Appendix 3: Assessment of Primary Qualitative Research

Critical Appraisal Checklist (Joanna Briggs Institute, 2011)

Roche-Fahy & Dowling (2009)

Title: Providing comfort to patients in their palliative care trajectory: Experiences of female nurses working in an acute setting

| No. | Criteria | Yes | No | Unclear | Not applicable | Comments |
|-----|---|--------------|----|--------------|----------------|---|
| 1. | There is congruity between the stated philosophical perspective and the research methodology | √ | | | | Gadamerian hermeneutic approach |
| 2. | There is congruity between the research methodology and the research question or objectives | √ | | | | |
| 3. | There is congruity between the research methodology and the methods used to collect data | \checkmark | | | | |
| 4. | There is congruity between the research methodology and the representation and analysis of data | \checkmark | | | | |
| 5. | There is congruity between the research methodology and the interpretation of results | \checkmark | | | | |
| 6. | There is a statement locating the researcher culturally or theoretically | \checkmark | | | | |
| 7. | The influence of the researcher, and vice versa, is addressed | | | \checkmark | | Only mentioned one author from the department of palliative care, clinical coordinator for graduate studies |
| 8. | Participants and their voices are adequately represented | \checkmark | | | | |
| 9. | The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body | √ | | | | |
| 10. | Conclusions drawn in the research report appear to flow from the analysis, or interpretation, of the data | √ | | | | |

Peterson et al. (2010)

Title: What is so stressful about caring for a dying patient? A qualitative study of nurses' experiences

| No. | Criteria | Yes | No | Unclear | Not applicable | Comments |
|-----|---|--------------|----|---------|----------------|---|
| 1. | There is congruity between the stated philosophical perspective and the research methodology | V | | | | Mentioned grounded theory approach |
| 2. | There is congruity between the research methodology and the research question or objectives | \checkmark | | | | |
| 3. | There is congruity between the research methodology and the methods used to collect data | √ | | | | Mixed methods used to collect data: 1. multidimensional fear of death 2. Frommelt attitudes towards nursing the dying 3. followed by interviews. |
| 4. | There is congruity between the research methodology and the representation and analysis of data | $\sqrt{}$ | | | | |
| 5. | There is congruity between the research methodology and the interpretation of results | √ | | | | |
| 6. | There is a statement locating the researcher culturally or theoretically | \checkmark | | | | |
| 7. | The influence of the researcher, and vice versa, is addressed | $\sqrt{}$ | | | | |
| 8. | Participants, and their voices, are adequately represented | $\sqrt{}$ | | | | |
| 9. | The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body | \checkmark | | | | |
| 10. | Conclusions drawn in the research report appear to flow from the analysis, or interpretation, of the data | \checkmark | | | | |

Mak et al. (2013)

Title: Experiences and perceptions of nurses caring for dying patients and families in the acute medical admission setting

| No. | Criteria | Yes | No | Unclear | Not applicable | Comments |
|-----|---|--------------|----|---------|----------------|--|
| 1. | There is congruity between the stated philosophical perspective and the research methodology | √ | | | | Descriptive interpretive phenomenology |
| 2. | There is congruity between the research methodology and the research question or objectives | \checkmark | | | | |
| 3. | There is congruity between the research methodology and the methods used to collect data | √ | | | | |
| 4. | There is congruity between the research methodology and the representation and analysis of data | $\sqrt{}$ | | | | |
| 5. | There is congruity between the research methodology and the interpretation of results | \checkmark | | | | Two bilingual translators interpreted the quotes |
| 6. | There is a statement locating the researcher culturally or theoretically | \checkmark | | | | |
| 7. | The influence of the researcher, and vice versa, is addressed | \checkmark | | | | |
| 8. | Participants, and their voices, are adequately represented | \checkmark | | | | |
| 9. | The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body | √ | | | | |
| 10. | Conclusions drawn in the research report appear to flow from the analysis, or interpretation, of the data | V | | | | |

Anderson et al. (2016)

Title: To be involved: A qualitative study of nurses' experiences of caring for dying patients

| No. | Criteria | Yes | No | Unclear | Not applicable | Comments |
|-----|---|--------------|----|---------|----------------|--|
| 1. | There is congruity between the stated philosophical perspective and the research methodology | √ | | | | Qualitative descriptive |
| 2. | There is congruity between the research methodology and the research question or objectives | V | | | | |
| 3. | There is congruity between the research methodology and the methods used to collect data | \checkmark | | | | |
| 4. | There is congruity between the research methodology and the representation and analysis of data | \checkmark | | | | Though qualitative data, a scientific systematic analysis was conducted. Further it was mentioned content analysis was conducted |
| 5. | There is congruity between the research methodology and the interpretation of results | \checkmark | | | | |
| 6. | There is a statement locating the researcher culturally or theoretically | \checkmark | | | | |
| 7. | The influence of the researcher, and vice versa, is addressed | \checkmark | | | | |
| 8. | Participants, and their voices, are adequately represented | \checkmark | | | | |
| 9. | The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body | √ | | | | Permission sought from the ward managers |
| 10. | Conclusions drawn in the research report appear to flow from the analysis, or interpretation, of the data | √ | | | | |

Lai et al. (2018)

Title: The experience of caring for patients at the end-of-life stage in non-palliative care settings: a qualitative study

| No. | Criteria | Yes | No | Unclear | Not applicable | Comments |
|-----|---|--------------|--------------|---------|----------------|--|
| 1. | There is congruity between the stated philosophical perspective and the research methodology. | V | | | | Qualitative descriptive approach |
| 2. | There is congruity between the research methodology and the research question or objectives. | √ | | | | |
| 3. | There is congruity between the research methodology and the methods used to collect data. | √ | | | | |
| 4. | There is congruity between the research methodology and the representation and analysis of data. | √ | | | | Verbatim in Mandarin—no mention of translation of data |
| 5. | There is congruity between the research methodology and the interpretation of results. | √ | | | | |
| 6. | There is a statement locating the researcher culturally or theoretically. | √ | | | | |
| 7. | The influence of the researcher, and vice versa, is addressed. | \checkmark | | | | |
| 8. | Participants, and their voices, are adequately represented. | | \checkmark | | | More physicians' voices than nurses' voices |
| 9. | The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body. | √ | | | | |
| 10. | Conclusions drawn in the research report appear to flow from the analysis, or interpretation, of the data. | √ | | | | |

Appendix 4: Assessment of Primary Quantitative Research

Todaro-Franceschi (2013)

Title: Critical care nurses' perceptions of preparedness and ability to care for the dying and their professional quality of life

Level of Evidence: 3

| No. | Criteria | Yes | No | Unclear | Not applicable | Comments |
|-----|--|--------------|----|----------|-------------------|--|
| 1. | Is sample representative of patients in the population as a whole? | | | V | | Members recruited from AACC—these are nurses. Total number of members in the association not mentioned. Only mentioned how many responded |
| 2. | Are the patients at a similar point in the course of their condition/illness? | | | | \checkmark | Study on critical care nurses |
| 3. | Has bias been minimised in relation to selection of cases and of controls? | | | | \checkmark | |
| 4. | Are confounding factors identified and strategies to deal with them stated? | | | | \checkmark | |
| 5. | Are outcomes assessed using objective criteria? | \checkmark | | | | |
| 6. | Was follow-up carried out over sufficient time? | | | | \checkmark | |
| 7. | Were the outcomes of people who withdrew described and included in the analysis? | | | | | 5 critical care nurses' responses were not taken into account—no reasons given |
| 8. | Were outcomes measured in a reliable way? | √ | | | | Data collection: survey conducted using two instruments. Perceptions of preparedness and ability to care (PPACD), a 13-item questionnaire that has a 6-item subscale. Next was the PQOL instrument, which has 30 items with three subscales, and each has ten items of measurement on compassion satisfaction, compassion fatigue/traumatic stress and |
| 9. | Was appropriate statistical analysis | | | | | burnout. A 6-point Likert scale was used to rate each experience |
| 9. | Was appropriate statistical analysis used? | \checkmark | | | | |

Appendix 5: Social and Behavioural Research Ethics Final Approval

Dear Ambelorfam,

The Chair of the <u>Social and Behavioural Research Ethics Committee (SBREC)</u> 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. | 6950 | | | |
|----------------------|--|------------------------------|------------------|--|
| Project Title | Registered nurses' experiences of end-of-life care in the acute setting in Singapore | | | |
| Principal Researcher | Ms Ambelorfam Manikam | | | |
| Email | mani0055@flinders.edu.au | | | |
| Approval Date | 10 August 2015 | Ethics Approval Expiry Date: | 31 December 2019 | |

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):

Appendix 6: NYP Institutional Review Board Approval



180 Ang Mo Kio Ave 8, Singapore 569830 Tel: (65) 6451 5115 www.nyp.edu.sg www.nyp.edu.sg

NYP IRB Ref: SHS-2015-007

28 Aug 2015

Ms Ambelorfam d/o Manikam (LTR/SHS)

Thru' DSHS(N) pur

Dear Ms Ambelorfam,

NYP INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL

STUDY TITLE: Registered nurses' experiences of end-of-life care in the acute care

We are pleased to inform you that the NYP Institutional Review Board has approved the application as titled above to be conducted in Nanyang Polytechnic.

The approval period is from 28 Aug 2015 to 27 Aug 2016. The NYP IRB reference number for this study is SHS-2015-007. Please use this reference number for all future correspondence.

The documents reviewed are:

- NYP IRB Application Form: Version No. 4, dated 27 Aug 2015 Informed Consent Form: Version No. 4, dated 27 Aug 2015 Interview Guide: Version No. 2, dated 27 Aug 2015 Verbal Script: Version No. 2, dated 27 Aug 2015

- Acceptance Form: Version No. 1, dated 16 Jul 2015

The NYP IRB acknowledges the receipt of the following document:

Final Approval Notice (SBREC) Flinders University: Project No.6950.

Continued approval is conditional upon your compliance with the following requirements:

1) Only the approved Informed Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.

NYP IRB Letter of Approval SHS-2015-007 Dated 28 Aug 2015

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THE INNOVATIVE POLYTECHNIC



- No deviation from or changes to the study should be implemented without documented approval from the NYP IRB, except where necessary to eliminate apparent immediate hazard(s) to the study subjects.
- Any deviation from or changes to the study to eliminate an immediate hazard should be promptly reported to the NYP IRB within <u>seven</u> calendar days.
- 4) Please note that for studies requiring Clinical Trial Certificate, apart from the approval from NYP IRB, no deviation from, or changes of the Research Protocol and Informed Consent Form should be implemented without documented approval from the Health Sciences Authority unless otherwise advised by the Health Sciences Authority.

Please submit the following to the NYP IRB:

- All Unanticipated Problems Involving Risk To Subjects Or Others (UPIRTSOs) must be reported to the NYP IRB. All problems involving local deaths must be reported immediately within 24 hours after first knowledge by the Investigator, regardless of the causality and expectedness of the death. All other problems must be reported as soon as possible but not later than seven calendar days after first knowledge by the Investigator.
- Report(s) on any new information that may adversely affect the safety of the subject or the conduct of the study.
- NYP IRB Study Status Report Form this is to be submitted 4 to 6 weeks prior to expiry of the approval period. The study cannot continue beyond <u>27</u> <u>Aug 2016</u> until approval is renewed by the NYP IRB.
- Study completion this is to be submitted using the NYP IRB Study Status Report Form within 4 to 6 weeks of study completion.

Thank you.

Yours Sincerely

Dr Mathew Lau Chairperson

NYP Institutional Review Board

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Appendix 7: Participant Information Sheet



INFORMATION SHEET

Title: Registered Nurses' experiences of end-of-life care in the acute care setting in Singapore

Investigator:

Ms Ambelorfam d/o Manikam

School of Nursing & Midwifery

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Ph: +65 98312162

Supervisor(s):

Associate Professor, Ann Harrington (Principal Supervisor)

School of Nursing & Midwifery

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Dr Anita De Bellis (Associate Supervisor)

Senior Lecturer in Nursing

School of Nursing & Midwifery

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Description of the study:

The study will investigate Registered Nurses' experiences of end-of-life care in the acute care setting in Singapore. The study will investigate and explore Registered Nurses' experiences and perspectives and how caring for the dying affects Registered Nurses' role in the acute care setting in Singapore.

Purpose of the study:

Singapore's approach to end-of-life care is evolving due to a rapidly ageing population. Registered Nurses who provide end-of-life care face challenges in integrating with the system to realise patients' hope of attaining a good quality EOL care. However, little is known or highlighted about the Registered Nurses'

challenges when dealing with end-of-life care in Singapore. Registered Nurses' experiences in the context of Singapore will provide information for the development of growth in the care of the dying through education and research that informs practice in the acute care setting.

What will I be asked to do?

You will be asked to take part in a face-to-face audiotaped interview led by the researcher, at a mutually convenient location. The interview will take about 60 minutes. The interview will be transcribed and analysed qualitatively to identify the issues associated with end-of-life care in acute settings in Singapore. You will be given an opportunity to view the transcribed data upon request and to seek clarification the transcribed interview will be send to you for verification. Your participation is entirely voluntary.

What benefit will I gain from being involved in this study?

While there may be no direct benefit to you in taking part, it is expected the information you provide will enable a more in-depth understanding on the nurses' experiences of end-of-life care. Your experiences and views are important to the future practice developments for a National Framework in end-of-life care in Singapore, to re-evaluate nursing education curricula in particular to end-of-life care in acute settings that are not focused on palliative care. The study will further prepare nurses to effectively care for the dying patients. Your views are very important for the future practice developments in the care of dying. The benefit to you will be an opportunity to share your views concerning care in an acute care setting, your experiences and approaches and how practice can be improved.

Will I be identifiable by being involved in this study?

You will be given a pseudonym and you will not be able to be identified by anyone other than the researcher. Any personal identifiable information will remain confidential and all data will be de-identified. Any identifying information will be removed, and the typed-up file stored on a password-protected computer that only the researcher will have access to. Your comments will not be linked directly to you or any individual. During transcription you will be given a pseudonym and only the researcher will have access to your contact email and the consent form, ensuring your confidentiality and anonymity at all times in accordance with the Data Protection Act 1998 and NHMRC guidelines (2007).

The protocol for this research follows the Ethical Guidelines for research as set down by Flinders University, Social and Behavioural Research Ethics Committee (SBREC). The research has been reviewed by Flinders University, Social and Behavioural Research Ethics Committee. You can decide at any time to withdraw from this study and any details or information already gathered will be destroyed.

Are there any risks or discomforts if I am involved?

There are some possible burdens or risks to you through your involvement in this study where you will be talking about your professional practice. You may feel uncomfortable or get distressed from relating your experiences and if this occurs the interview will be stopped and not commenced until you are ready. You can withdraw from the study at any time. If you wish to see the school counsellor, referral will be initiated, and this is a free service.

The school counsellors can be contacted at Student Affairs Office, Block E, Student Development Centre, Level 4.

Hours: Mondays-Thursdays 8.30am-6.00pm

Fridays 8.30am-5.30pm

Email: nyp_counsel@nyp.edu.sg or contact

Ms Amy Lee Tel: 6550 1904

Mr Arshad Mail Tel: 6550 19056550 1904 or 6550 1905.

At any one time you can choose to cease the interview or refuse to answer any question. If you have any concerns about this study, please contact the supervisors, Associate Professor, Ann Harrington (ann.harrington@flinders.edu.au) (+61 8 8201 3483) or Dr Anita De Bellis (anita.debellis@flinders.edu.au) (+61 8 8201 3441).

How do I agree to participate?

Participation is voluntary. It is your decision whether or not to take part. If you decide to take part, you will need to indicate on the response form your name and contact details and the researcher will then contact you to arrange the interview. At the interview, the researcher will give you a copy of this information sheet to keep and ask you to sign a consent form. You will be free to withdraw at any time without penalty or consequence. Participation in the research or withdrawal from it will not affect your rights in any way. If you decide to take part all you have to do is deposit the response slip to the box provided and the researcher will contact you to make an appointment with you for the interview. The interview will take place away from your work environment on a date and at a time convenient for you and will take approximately 30 to 60 minutes of your time. It is suggested you talk to a friend or relative about participating in the research prior to the interview.

How will I receive feedback?

The results will be presented as a PhD thesis upon completion and published in a peer reviewed professional nursing journal.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6950). 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 at human.researchethics@flinders.edu.au.

Appendix 8: Recruitment Letter

Verbal Script to Recruit

Dear Nurses,

On behalf of my colleague, Ambelorfam Manikam, senior lecturer and a PhD research student from Flinders University, who is expected to complete a dissertation as part of her fulfilment of this programme, I am here to assist in the recruitment. She is conducting a qualitative research looking into the nurses' experiences of caring for the dying patients in an acute care setting in Singapore. She is inviting and hoping to interview registered nurses who have worked in the acute care settings in Singapore for more than one year. The interview will take about 30 to 60 minutes. If you fit these criteria and wish to participate in this study, please complete the response slip, place it in the self-seal envelope provided and drop it in the box provided at Level 3 reception counter, J block. Further information about this study can be found in the information leaflet enclosed. Your participation is voluntary. She will contact arrange a mutually convenient time and place to meet. In the meantime, please do not hesitate to contact her if you have any queries about the study. She can be contacted either by email at mani0055@flinders.edu.au,

<u>Ambelorfam MANIKAM@nyp.edu.sg</u> or by telephone on +65 98312162/ 65501413. On behalf of Ambel, I thank you and look forward to your participation.

Appendix 9: Consent Form



CONSENT FORM FOR PARTICIPATION IN RESEARCH

(by interview)

| Registered nurses' experiences of end-of-life care in the acute care setting in Singapore |
|--|
| I being over the age of 18 years hereby consent to participate as requested in the Information Sheet for the research above. |
| 1. I have read the information provided. |
| 2. Details of procedures and any risks have been explained to my satisfaction. |
| 3. I agree to audio recording of my information and participation in an interview. |
| 4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference. |
| 5. I understand that: |
| I may not directly benefit from taking part in this research. |
| • I am free to withdraw from the project at any time and am free to decline to answer particular questions. |
| • While the information gained in this study will be published as explained, I will not be identified, and |
| individual information will remain confidential. |
| • Whether I participate or not, or withdraw after participating, will have no effect on my progress in my |
| course of study, or results gained. |
| • I may ask that the recording be stopped at any time, and that I may withdraw at any time from the |
| session or the research without disadvantage. |
| I have had the opportunity to talk about the research to a relative or friend. |
| Participant's signature: Date: |
| I certify that I have explained the study to the volunteer and consider that she/he understands what is involved |
| and freely consents to participation. |
| Researcher's name: Date: |
| Researcher's signature: Date: |

Appendix 10: Interview Guide

Interview Guide

Outline of Interview Guide

Equipment Required:

- Quiet room without distractions with comfortable seating and a table
- Consent forms
- Paper copies of the information sheet for registered nurses
- Refreshment and comfort articles for participants water, coffee or tea and tissues
- Digital recorder and spare batteries
- Notebook with questions guide and to make observations

Interview Schedule:

- Introduce self as a researcher
- Re-emphasise voluntary nature of participation
- Re-emphasise protection of confidential information and anonymity
- Obtain written consent and provide paper copies of information and signed consent
- Remind participant of their freedom to leave at any time
- Commence digital recorder

To put the participant at ease, the interview will commence with some general and easy to answer closed questions about their work:

- How long have you been a nurse?
- What is your role in this department?
- Before I proceed further, are you comfortable to share your experiences when caring for the dying? Please feel free to stop the interview if you feel uncomfortable.

To explore their thoughts and experiences about end-of-life care, some of the following open-ended questions will be used:

- 1. Without revealing who the patient is, tell me about the last patient you cared for who was dying.
- 2. What do you think are his/her key concerns about dying?
- 3. What do you think are your challenges when caring for the dying?
- 4. What do you think prevents you from meeting the needs of the dying patients?
- 5. What would you say are examples of good practices in meeting the needs of dying patients in your ward?
- 6. How do you feel about talking about your concerns relating to EOL care?
- 7. In your area of practice, what would you say is positive/negative about EOL care?
- 8. Can you describe a situation when you were involved in a challenging situation?
- 9. If there is anything you would change about EOL care, what would it be?
- 10. Is there anything you would like to discuss in relation to this issue?

Finally, the participant will be thanked for their time and for sharing their experiences and thoughts with the researcher.

Appendix 11: Interview Transcript

Interview 1

The participant is a female RN; a pseudo name Martha was given*I denotes Researcher and *M denotes participant

- I: Hi Martha, thank you for coming and showing interest in this interview. I am looking at your experiences when caring for the dying patients.
- I: Can you describe to me your area of work?
- M: I have been working in a multi-disciplinary ward for the past 18 years. It is involving the CVM/medical/surgical and geriatric patients. I am a SSN.
- I: Wow, oic. Martha before I go further, are you comfortable to share your experiences when caring for the dying patients?
- M: Oh yes. I am alright with that
- I: At any time if you feel uncomfortable you can choose to stop the interview, Martha. Are you ok with this?
- M: Yes yes. Sure sure.
- I: Without revealing the patient's identity, when was the last time you cared for a patient who was dying?
- M: That was in March this year. I cared for two patients who were dying. I will talk about the first one who was 70 years old. She has her husband and taken care by the maid and she suffered from stroke, unable to feed and has NGT. Another patient was a male who is also 70 years old who had good family support.
- I: That means you have nursed two elderly patients. One is a female and the other a male. Am I right?
- M: Yes Yes
- I: What actually happen to them?
- M: The female patient had stroke, bedridden for almost 5 years and was on NGT. Her main carer was her husband and her maid. If I am not wrong some of her children were in overseas.
- I: Oic. Is this a Chinese patient?
- M: Both are Chinese.
- I: What do you think was her key concerns about dying?
- M: In the female one, I cannot say anything because she can't speak. I can relate to you the male patient who is able to talk, and he has moderate assistance from the maid and has good family support. So that man although 70 plus, he mentioned that he wanted to die at home. He wants to be discharged from the hospital and die at home.

I: Oic. Who did he verbalise?

M: He was a very chatty man and his family also very supportive and loving. We have also built rapport with them. Often the patient talks to us during feeding and the family is very open about patient's wishes. They always talk to us casually. The family is very open about the view of the patient. I: You mean the family is very involved in the patient's care?

M: Ya, to them whatever the dad wants they will support.

I: Looks like you had a good interaction with family and patient.

M: yes yes

I: Is his concerns of dying at home fulfilled?

M: In this patient, it was not fulfilled. He came in because of severe shortness of breath and fluid overload. At that time, the doctors knew that his progress was not good. But I think under geriatric care, the team wanted to make him comfortable and then discharge him later. That was their plan, to discharge once his condition settle. To keep him for 3 days and then to discharge.

I: Oic that was their discharge plan once breathlessness settles?

M: Ya, but unfortunately, I dunno what happen, the doctors also said there was underlying pneumonia. So, as elderly they are fragile, one moment they are ok, one moment they are not ok you know. On that day it was during morning medication round. He asked my colleague for a cup of milo. My colleague just went off to pantry to get milo. When she came back, the patient is gone!

I: Oh...

M: It was very sad. Yes, it was sad. But the good thing is the doctors have prepared well and documented during admission on the nursing notes that should this patient collapse no active resuscitation, a DNR status was well written. The patient is for maximum comfort care. We never do any CPR and that was according to the patient's and family wish as well. Everything happened so fast.

M: One moment my colleague went to get a drink for him and the next moment, he is gone. For both of us it was really shocking.

I: How did you feel about this situation?

M: (Hmmm...) ... (Long Pause.... Participant tearing) Gave her a tissue paper to wipe her tears. There was silence for 25seconds.

M: I think (sobbing) if I am the family member, it will be shocking. Because I never get to see the last breath. Like there is no preparation for myself if I am the family member (Still sobbing) of course as a family member you want to respect the wishes of your father. In this way you won't feel guilty as you respected the patient's wish. But But

I: What do you mean by guilty? As a nurse did you feel guilty?

M: As a nurse I did not feel guilty because I did what he requested for. As I was giving the drink he was gone. Family also find it strange because patient requested for milo but he is gone. Family felt patient's wish was attended to but he was gone quickly before he could drink.

M: The family accepted his death and importantly their father did not suffer. But kept saying he just gone so fast.

M: As a nurse I felt very emotional because this elderly man resembled my father, the closeness of a family. My dad died two years ago. If I see such situation my memories of my dad comes. This patient was so kind and loving and reminding me of my dad. Of course in front of relatives I want to be strong

but sometimes I can't help it. My tears are welled up and most importantly I want to respect what the patient wants. As a nurse you want to be strong but sometimes can be carried away with their emotions.

I: Do you feel inappropriate to show your feelings?

M: No La..I mean we have built this rapport with the patient and family. Is like a closeness of a family. When they cry, you can't be like a robot without feelings!! If you see them cry, you don't hold your feelings so I also will hug them and show my feelings.

I: How this patient's death does affect you?

M: It does not affect me. But patients come and go. The emotion of caring for the patient is definitely there. As a professional nurse it does affect me, because I have flashback of other experiences and it will come along with me.

I: What are your challenges when caring for this patient?

M: As for this patient, I don't face many challenges. In this case, the management is very clear what they (Medical & Family) wanted for the patient. What the family want, what they patient want is very clear. There is no contradiction among them.

M: The way how I want to take care of this patient is very smooth. Unlike another patient, who is unable to speak and could not verbalise her wants and dislikes.

M: This is a female patient and the main carer is her husband and his only son is in overseas. So, there was a struggle of what actually they wanted because the patient could not communicate. The husband wanted comfort care, but the son wanted full treatment. So, there was a dispute of whom the team doctors will liaise with. Eventually, it was the husband who was the main carer and the team doctors collaborated with him for the patients care.

M: Furthermore, it was at night-time I faced this challenge, all I could rely on was what the patient's husband told the team doctors. As a nurse I find it so difficult to manage at night. There was clear instruction on the care plan, so I referred to the last 24-hour care plan and I relied on that and carried on with my care. Luckily in the case of this woman, the husband was there throughout the night and when she was about to pass on, he was able to tell us exactly what he wanted. The family support and instructions were clear for me.

I: Is there any situation that you encountered that you were unable to meet the needs of the dying patient?

M: Ahemm, yes, I do. Sometimes, especially when family is so protective and they don't want the patient to know what is happening with them, they know the patient is dying and the patient knows she is dying and they don't want to reveal to the patient is so challenging for me. Patent keeps on asking what is wrong with me, why am I feeling like that, am I dying? I find it so difficult to handle. I had to juggle with family and patients' wishes at the same time.

M: Patient knows they are dying but the family too protective and don't want to tell them. Family don't want to involve the patient in the decision making. Patient kept on asking what is going on with me. As a nurse it was a struggle to me whether to tell or not to tell, on the other hand relatives kept reminding me not to reveal diagnosis.

M: This is so contradicting, I want to tell and yet I can't open my mouth

I: How do you feel about this?

M: As a nurse I work very closely with the team doctors. I encourage my team doctors to reveal the diagnosis and prognosis to patient. It will help the patient and the nurses to prepare better before dying. So that there will be enough time for preparation. I feel this will give time for the patient to prepare

well before death. At least the patient will know how much time is left for them to resolve the unfinished businesses.

M: We try to suggest to team doctors to reveal. More so if the team doctors are not geriatric trained, we encounter more difficulties. The general medical trained doctors don not pay much attention to the patient well-being holistically. Their management is totally different. Unlike the geriatric trained doctors, a lot of care and emphasis is placed on the patients' emotional concerns and well-being. The geriatric team look into patients concerns, comfort and the family concerns and work well with the nurses and family.

I: In the ward that you are working can you describe some of the good practices that you encounter when nursing the dying patients?

M: Yes, in terms of clear management. Clear management involving patients and families. For example, family and patients want only comfort care and if this is written and documented in the nursing notes clearly, it gives all nurses the necessary preparation on how to deliver the care should the patient reaching the end of life stage.

M: However, sometimes, it is so difficult in my ward where it is a multi-disciplinary, if doctors did not document clear care plan, maximum care will be given till the patient sent to ICU care setting. So, if it is written very clearly end of life care management, as a nurse I find it easier to handle the relatives and patients.

M: Clear documentation and instruction is important especially if death occurs at night.

I: So, what about your concerns when you speak about end-of life care?

M: I often find difficulty when the care plan is not clear. It is difficult to fulfil and juggle with family and patients wishes. So, often when I face dilemma, I will initiate family conference.

M: With family conference it will help me and my fellow nursing colleagues from having to to witness any conflicts disputes from family and medical team. So that we are clear what directions we are heading for the dying patient.

I: Oh, I see...In your area of practice what is positive about end of life care? Can you share some of your encounters?

M: In end of life care if there is clear instruction like DNR, no fluids, maximum comfort care and clear management of patient is well documented. Most of the time is practiced in my area. Everybody knows what to do. This is very positive which I often witnessed.

M: The negative aspects are if clear instructions are not well written I faced many problems. For example; when a patient who is 80 years old admitted in the middle of the night with no clear instructions and with poor prognosis, it leaves us with no options but to resuscitate all the way. I feel very uncomfortable about it. Patient is bedridden with poor quality of life with poor prognosis and with poor documentation it makes very uncomfortable to participate actively in the resuscitation.

M: Family wants active treatment even with such poor prognosis and quality of life.

I: How did you feel about this?

M: As a nurse I want to respect what the family wants. But when I look at the patient his eyes is speaking to me with different message. I also can feel what the patient wants. He wants to die peacefully but the family wants a different outcome.

I: By looking at the patient you knew what he wanted. Do you have difficulty conveying it to the relatives?

M: It is very challenging to convey it to the relatives. If after building rapport with the relatives, when we start to explain the prognosis care plan to the patients' relatives, I can see they begin to accept slowly. When you explain the illness burden to the relatives and their loved ones are not responding, they slowly begin to accept. When nurses continue to give support to relatives, it makes our job easier.

M: From the family perspective, I can understand why they don't want to let go. As a nurse I felt the patient is suffering with poor quality of life. I felt I will support the relatives and explain to them what actually their mum wants. Again, this is very individualistic.

I: In such situation how can the nurse prepare herself well?

M: preparation comes from case to case basis. My previous experiences also help me how to deal with relatives. If you don't have any experience and facing the first time, I feel it is very challenging. Some young patients even when prognosis is poor don't want to let go and die. When they verbalise to you, my heart is broken but I feel helpless on how to help them.

M: So, it is case to case basis. How much can I comfort them? I am not in their shoes!! I feel helpless.

I: Do you feel that the nurses are well prepared to take care of the dying?

M: Hmmmm (pause) some yes, some may not

I: Can you describe?

M: As for me, if I were to face many dying patients, more or less I can handle the situations. Because I am involved in comfort care. But if death comes once in a while, then it is difficult. As long as I can provide comfort care, I can manage the situation. But if patients are grieving and in pain and restless, I also feel restless of what else can I do for this patient.

I: How supportive is your ward management/environment when caring for the dying patients?

M: Yes, management is supportive. My colleagues are very supportive to one another. If I have many patients under my care who are dying, with clear management instructions, if the patients die, colleagues render support to one another.

M: Those patients who die suddenly, colleagues are also shocked of what to do. Emotions involved. Patient is so nice: Why why what happened? Bu we also feel comfortable that patient had died and a stop to their suffering. We feel peaceful too. That is the way we cope.

I: When you have your own team to support....

M: Yes, own team to support and guide make us comfortable, but we are sad and happy that patient passed away. It is not in our hands. Especially sudden death like heart attack and especially young ones, it is beyond our control. We feel helpless.

I: In your opinion what are other things as a nurse you could offer to the dying patients?

M: If the relatives and patient are comfortable and acceptable, I will offer pastoral care regardless of whatever religion the patient may have. It is on a case to case basis. So long, they are comfortable. Even if the patent is gasping, I will wait patiently and ask is there any relatives coming. I try to offer whatever I could to ease the family tension. I do offer spiritual care only if the relatives and patient are comfortable.

M: sometimes I do witness a patient draggy and gasping for a long time. I will ask the relative is there any unfulfilled wishes of the patient or do you need to call someone to pray for the patient to die peacefully.

I: In your acute care ward, do you feel the nurses can offer more or are they doing enough for the dying patients?

M: I think the senior experienced nurses can handle. I am not sure of the junior ones. There are so many new nurses now in the ward. But we support one another even if it is new staffs who are handling the dying patient, we will support one another.

I: Are the new staff afraid to handle?

M: Perhaps they don't have the experience to handle the family. I will normally step in and explain to the family should the need arise.

I: Can the teaching on end of life care be carried out in the ward? Do you think it is basically hands on rather than teaching?

M: Well, I am glad I am trained in gerontology. I bring my experiential learning and experiences when I care for the dying patients. It is very helpful to me. Learning can be theoretical but it compliments with my personal experiences. Therefore, I feel I am more prepared to face challenging situations.

M: But even if you have knowledge and you do not know how to apply then it is difficult. I still feel my prior experiences dealing with dying patients have given me some confidence. Even if you do not have the knowledge when encountering such situations will eventually make you better ready to handle situations.

M: I feel end of life care must be taught first. It should be taught when you enter nursing course. I picked up caring for the dying through my personal experiences. I was never taught in school how to deliver. I was introduced to some forms where I have to tick whether it is for active or comfort measure. Otherwise I am not aware how to deliver effectively the care for the dying.

M: I am not exposed to ACP or care for the dying during my nursing training.

Do you think this is an important aspect for you to be trained in?

M: Of course, then I can prepare myself and understand what are the patients and family preferences. I feel inadequate in this aspect. I want to give more but I don't know how

Maria, I am approaching the last 5minutes of the interview. Is there anything you want to share with me that is important for nurses to care for the dying?

M: Ya, I feel end of life care must be taught in the nursing school at the beginning of the course and throughout different levels at the course. Continue at the advanced diploma (post-graduate level) to reflect what they have missed out and what can be added on. How they can deliver care better.

I: Oh I see

M: The guidelines that I see in the form at the hospital only mentioned about relatives' preferences and nothing about patient's decision making.

M: I think we should include patients' preferences like, is it comfort care etc etc, so that nurses can deliver care better without fear or being reprimanded by the relatives.

I: I see... What about your organisation? How can your organisation support the nurses when caring for the dying?

M: I think, this is case to case basis. If your supervisor is very supportive then she is able to support u in the care delivery. If he/she is not supportive then it is difficult.

I: What do you mean by supervisor not being supportive?

M: If there is a conflict or contradictory management issues, then the supervisor will step in to help. If the supervisor chooses not to help resolve, then it becomes your problem.

I: Oh, I see...

I: How do you juggle this situation?

M: Err..it is very difficult. Again, it is case to case basis. If it is a dying patient and it is a comfort measure, you go all the way out to make things easier for the patient and family.

M: You to handle the relatives and patients' emotions. You give space and allow them to grief.

I: Do you have enough nurses to help you in the shift?

M: I think if you have a good team of nurses, then everything will run smoothly. If your team is not good enough, you end up struggling.

I: What do you mean by not good team of nurses?

M: I mean experience nurses versus those who just joined may pose many difficulties. Handling existing patients and seeing to the dying patients can be overwhelming at times.

M: Luckily in my ward we help each other. If I have a dying patient my entire shift is surrounding him/her. I will ask my colleagues to help me with other patients. But if I have a poor team of nurses, then it is a struggle. There are so many things happening in the ward. But this dying patient is grieving and dying so I will attend to him. I will divide my work. We will help each other, and I have to prioritise my work.

I: Last but not least, do you feel the way you are handling the dying, are you satisfied?

M: Sometimes yes and sometimes no. Yes, if I have the time I will sit and talk to the patient. But I have to face reality. I do not have all the time. When comes to dying patients, I talk to the family first, stay for a while at the bedside and make sure the patient is receiving comfort care. I will follow what the patient, family management want and then truly I can say I am satisfied.

M: But those patients that I actively resuscitate did not revive I feel less satisfied. It is not our team fault but simply we could not revive the patient. For those who are dying at least I will be there at the bedside for a while until the patient pass on. I have the time and I know how to manage them. I like to talk to them, touch them and say a few words of comfort when especially the family is not there. But in reality this is what I like to. But working in the acute ward sometimes this is impossible.

M: This is what I wish to do. It will be even better if the dying is accepted by the family and patient. This makes my comfort measures easy to deliver. Unlike those who don't accept the condition, facing their demands adds the care demands. It becomes more challenging.

M: Most of the time they are referred to palliative care and their comfort is well taken care of. Some patients even ask me to bathe them in the middle of the night. I will fulfil their wishes. I take him for a shower and later about 15minutes later he died. Some even want to smoke in the ward; I just give the cigarette without lighting it, just to give him the feeling of smoking. I do what I can within my capacity.

I: Oh, I see...

M: I think end of life care, must have clear instructions, clear management, clear patients' preferences and relative wishes documented. More emphasis on patient perspectives rather than the relatives. Then we can give and deliver better patient care.

I: Thank you M for your time. Have a good evening.

Appendix 12: Transcript Analysis

Analysis of Transcriptions- Participant 1

| Interview | Meaningful descriptions- Overall expression | Possible elements- Meaning | Essential structural elements – meaning of sentence | Final Elements-Shared Understanding Identification of Themes & Sub-themes |
|-----------|---|--|--|--|
| 1 | | | | |
| L17 | So that man although 70 plus, he mentioned that he wanted to die at home. He wants to be discharged from the hospital and die at home. (2) | Clear open communication Clear decision making Preferred place of death Clear care plan | Communication Open communication Clear decision making | Effective Communication Advance care planning |
| L19 | He was a very chatty man and his family also very supportive and loving. We have also built rapport with them. Often the patient talks to us during feeding and the family is very open about patient's wishes. They always talk to us casually. The family is very open about the view of the patient. (5) | open communication of death and dying by relatives and patients nurses building of rapport with patient & relatives.(Positive) Family who is very supportive to patient's autonomy decision making nusring role made easy when there is open communication Respect Dignity of care the nurse as a facilitator/listener interpersonal/interaction build up when rapport is established | Open communication Rapport building Supportive family Dignity of care Patient's preference | Effective communication Clear care plan Maintaining dignity of care Family support Consistent rapport building |
| L25 | In this patient, it was not fulfilled. He came in because of severe shortness of breath and fluid overload. At that time, the doctors knew that his progress was | symptomatic management versus the need to tell the truth versus fulfilling patient's desire to go home. | Symptomatic management Truth telling | |

| | not good. But I think under geriatric care, the team wanted to make him comfortable and then discharge him later. | comfort care fulfilling wish | | |
|-----|--|--|---|---|
| L27 | So, as elderly they are fragile, one moment they are ok, one moment they are not ok you know. On that day it was during morning medication round. He asked my colleague for a cup of milo. My colleague just went off to pantry to get milo. When she came back, the patient is gone | volatility of the illness trajectory unpredictable situation and changing physical condition of the patient. good and bad days for patient facing sudden death when the nurse does not have the anticipatory quality of assessing that the patient is dying. Nurses personal challenges: acceptying sudden death | Facing Sudden death Turbulent moments Acceptance of the situation | Personal challenges Coping mechanism |
| L29 | But the good thing is the doctors have prepared well and documented during admission on the nursing notes that should this patient collapse no active resuscitation, a DNR status was well written. The patient is for maximum comfort care. We never do any CPR and that was according to the patient's and family wish as well. Everything happened so fast. (4) | Clear care plan Clear instructions communication via wrtitten documentation by doctors well established. Care is executed without barriers. Fulfilling patient's & family's wish Team approach | Managing care well Written communication Team understanding | Effective communication |
| L30 | One moment my colleague went to get a drink for him and the next moment, he is gone. For both of us it was really shocking. (2) | expectation versus anticipation that patient will die. Too fast to handle the changing condition and situation surrounding patients death. Shock that it happened too fast without fulfilling the patient's last desire for a drink. (sudden death) sadness engulfing the nurse needed to compose herself as reality set in to accept the fragility of life. unable to witness the last breath. Nurse feeling the distraught, and shock that the last | Handling sudden death Lack of anticipation Emotional imbalance | Managing care effectively/ineffectively |

| | | wish was unfufill, feeling of uneasiness. Associating her family events where she reflected similar situation with her father | | |
|-----|--|---|---|--|
| L35 | As I was giving the drink he was gone. Family also find it strange because patient requested for milo but he is gone. Family felt patient's wish was attended to but he was gone quickly before he could drink.(3) | acceptance is made easy when there is ample preparation. death is fast and unagonising. good but stiil too soon it came. No time for closure | Fulfilling wishes Establishing closure Handling Sudden death | |
| L37 | As a nurse I felt very emotional because this elderly man resembled my father, the closeness of a family. My dad died two years ago. If I see such situation my memories of my dad comes. This patient was so kind and loving and reminding me of my dad. Of course in front of relatives I want to be strong but sometimes I can't help it. My tears are welled up and most importantly I want to respect what the patient wants. As a nurse you want to be strong but sometimes can be carried away with their emotions. | Trying to be emotionally strong Keeping calm and composed infront of the relatives reflecting own personal sorrows space and time of death occurred in her family (Personal emotions, challenges & burden) | Coping stress Managing challenges Being emotionally steady Trying to balance emotions in the care | Managing emotions Displaying emotions Handling own emotions with that of relatives |
| L39 | I mean we have built this rapport with the patient and family. Is like a closeness of a family. When they cry, you can't be like a robot without feelings!! If you see them cry, you don't hold your feelings so I also will hug them and show my feelings. | building of rapport with patient and family members makes the caring easier. The expressions becomes a natural response to the situations. Highlighting that even though she is a professional nurse the humane factor is embedded in the care delivery. you dont work like a automaton. ([personal emotions] | Building rapport Holistic care Display of emotions Giving support to relative Grief and loss Humanistic nursing bereavement | Delivery of care |

| L41 | It does not affect me. But patients come and go. The emotion of caring for the patient is definitely there. As a professional nurse it does affect me, because I have flashback of other experiences and it will come along with me. | aware of the changing situation of patients condition and is acceptance of the fragility of life. Other experiences comes along (personal emotions) | Nurses personal emotions Managing personal emotions | Managing personal emotions Personal reflection |
|-----|---|--|---|--|
| L43 | M: As for this patient, I don't face many challenges. In this case, the management is very clear what they (Medical & Family) wanted for the patient. What the family want, what they patient want is very clear. There is no contradiction among them. (3) | Clear care plan and documentation Clear preparation Clear understanding among the team & family Clear direction No conflict of management | Collaborative management | Managing Care effectively Clear communication |