

UNIVERSITY OF CAPE TOWN



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**Intensive care nurses' experiences of death in the ICU and
the implications for postgraduate nursing pedagogy:
A Heideggerian phenomenological study.**

**Submitted to the University of Cape Town
in Fulfillment of the Requirements for the
Degree Doctor of Philosophy in Education**

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IN MEMORIAM

In memory of my parents who died during my PhD journey.



*What peaceful hours I once enjoyed!
How sweet their memory still!
But they have left an aching void
The world can never fill.*

William Cowper (1731-1800). *Olney Hymns, I.*

REMEMBERING OTHERS

Sally (Sal) Stonehouse (nee Rhoades). Died January 2010. Special friend.

Joanne (Jo) Spencer (nee Wilcox). Died July 2010. Dear friend.

Daisy - Staffordshire Bull Terrier. Died July 2010. Ian and Camilla and George (Pitbull Cross). Friends and neighbours.

Sweetie-Pie - Maltese Poodle. Died April 2011. Rina - Friend and neighbour.

Robert (Bob) Stonehouse - Died May 2011. Dear friend.

George - Pitbull Cross - Died January 2012. Ian and Camilla - Friends and neighbours.

Graham Adams - Died April 2012. Friend and neighbour.

Jimmy (Jim-Jim) - Border Collie - Died February 2013. Mark, Wendy, Connor, Brennan and Sassie (Jack Russell) - Friends and neighbours.

Nelson Mandela - Died December 2013. Father of the Republic of South Africa.

Nibbles (Nibbie) - Cat - Died March 2014. Mark, Wendy, Connor, Brennan and Sassie (Jack Russell) and Charlie (Border Collie) - Friends and neighbours.

Keetak - Cat - Died July 2014. Wendy and Ben - Friends and neighbours.

Jasper - Cat - Died August 2014. Ian and Camilla - Friends and neighbours.

DECLARATION

I, Nicola Anne Fouché, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being or is to be submitted for another degree in this or any other university.

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All the ICU nurses/students with whom I have had the privilege of teaching
- For trusting me to tell your stories.

Not least, remembering patients that have died during my nursing career spanning 34 years.

'Those who learned to know death, rather than to fear and fight it, become our teachers about life' (Kübler-Ross, 1983).

ABSTRACT

Intensive care nurses' experiences of death in the ICU and the implications for a postgraduate nursing pedagogy: A Heideggerian phenomenological study.

The study sought to understand the phenomenon of the experiences of ICU nurses dealing with the deaths of patients under their care who die in the ICU.

Heideggerian hermeneutic phenomenology was used as the philosophical underpinning of the study. Methodologically, van Manen's (1990) six research stages in searching for the essence of a lived experience offered opportunities to inquire further about pedagogical issues.

Information gathering was in the form of phenomenological conversations with a sample of ICU nurses and lived experience themes emerged during the unravelling of the ICU nurses' narratives. Using Heidegger's concept of the three modes of *being*: *authenticity*, *inauthenticity* and *undifferentiatedness*, five lived experience themes were recognised:

1. **Care** - *authenticity*
2. **Suffering, Disenfranchisement and Cultural/religious unpreparedness** - *inauthenticity*
3. **Living with dying** - *undifferentiatedness*

Based on an analysis of the phenomenological conversations, motivation is made for the inclusion of death education into the current Postgraduate Critical Care Nursing curriculum to meet the need for improving, not only the professional nursing care for patients dying in the ICU, but also facilitating and supporting the self-care of the ICU student him/herself.

Barnett and Coate's (2005) concept of the '**Engaged Curriculum in Higher Education**', utilising the schema of knowing, acting and *being*, was used as the educational framework within which to identify pedagogical offerings for introducing death education. Such pedagogical offerings would include the teaching and learning of the theories of death and dying; aspects of the dying process; cultural/spiritual/religious issues such as post-mortem care and bereavement self-care.

The study contributes new knowledge about ICU nurses' lived experiences of the deaths of patients under their care in the ICU resulting in the recognition of the need for the inclusion of death education into a Postgraduate Critical Care Nursing curriculum.

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CHAPTER ONE

Intensive care nurses' experiences of death in the ICU and the implications for postgraduate nursing pedagogy: A Heideggerian phenomenological study.

Introduction

Background to the study

The impetus for the study arose from student comments in module evaluations (2009 - 2012) and from reflective drawing tasks from both adult and paediatric Critical Care Nursing¹ students registered for the Postgraduate Diploma in Nursing Critical Care (General) and Critical Care Child Nursing at the University of Cape Town, South Africa. Some of these comments and drawings (with signed permission from the ICU students) are illustrated to give a background to the research question itself.

'I just can't handle it anymore. I am having nightmares... thinking of that baby dying.'

'Why don't we do more death education? The last time I did anything on death was when I was training to be a nurse 12 years ago.'

'I found the reflective drawings that you gave us to do about our experiences of death really hard to do. We don't talk about death in our culture - it is bad luck.'

¹ Formally known as Intensive Care (ICU) Nursing but is now listed as Critical Care Nursing with the nursing professional body, the South African Nursing Council (SANC) as a result of advances in medical technology and life-sustaining therapies and interventions which have resulted in Critical Care Units (CCU) being established. This requires highly skilled nurses to work in the various disciplines of Critical Care Nursing. For example Paediatric (Child) ICU, Adult Surgical and Medical ICU. However, CCUs in this context are not to be confused with Coronary Care Units (CCUs). This is a sub-speciality in the Critical Care setting which deals with persons afflicted with cardiac conditions. To avoid confusion between Coronary Care Units and Critical Care Units, I will use ICU and ICU nurses/nursing. In the context of the current Postgraduate Critical Care Nursing Curriculum, this will remain unchanged.



'The mother is so angry (black hearted) and the doctor's hands are tied as there is nothing more that can be done to save this baby. I am in the middle feeling lost, hopeless and useless.'



'Come, little one, fight, fight! You can do it. Then I saw the breath leave the body.'



At the end of the dissertation, I have included a collection of the ICU nurses drawings which served to highlight their distress when caring for patients that are dying or had died in the ICU while under their care. These drawing exercises were presented in class while the ICU nurses were studying for the postgraduate critical care adult/child diploma and are not considered or offered as part of data collection or analysis.

From these reflective drawing tasks done in class, it appears as though the ICU students described significant distress about their experiences of the dying and deaths of patients under their care in the ICU. This was underlined in student comments found in the evaluation done on completion the module. Here the ICU students expressed their sense that they needed an education intervention to better able them to cope with their experiences.

This prompted me to explore the ICU students' experiences of the dying and deaths of patients in the ICU and to identify pedagogical issues that required attention, and to put forth interventions to address the ICU students' educational and ontological needs.

My interest in ICU nurses' experiences of the dying and deaths of patients under their care also dates back to 2006 when I wrote an editorial entitled **'What a Critical Care Nursing Curriculum does not teach us':**

‘Caring for a person facing death is not an easy undertaking, but it is a privilege. Providing a good and dignified death in the ICU will help the patients, their families and the moral responsiveness of nurses themselves (Fouché, 2006, p. 46).

Intensive/Critical Care Nursing in South Africa

The inception of an acute care setting for caring for critically ill patients in South Africa was first established in Cape Town and Durban in the early 1970s (Scribante, Schmollgruber & Nel, 2004). The discipline of critical care as a speciality in both medicine and nursing required an academic organisation to promote safe evidence-based practice in the interest of quality patient care. The Critical Care Society of Southern Africa was established in 1978 and is now represented within the World Federation of Societies of Intensive and Critical Care and the World Federation of Critical Care Nurses. It was deemed necessary to provide for specialised nurse training in this field and the South African Nursing Council (SANC) advocated that a post-registration qualification² for registered nurses be implemented.

The Origin of Intensive Care Medicine

The discipline of intensive care medicine and much later, nursing, is rooted in the mechanical support of ventilation when respiratory failure ensues (Grenvik & Pinsky, 2009). The classical work of Versalius in 1543, ‘***De Humano Corporis Fabrica***’, describes a number of experiments in which animals were kept alive by regular insufflation of air through the trachea using a fire bellows. Historically, this has become the first known application of intermittent positive pressure ventilation (IPPV)³ (Grenvik & Pinsky, 2009). The use of a low-pressure chamber for thoracic surgery was introduced by Sauerbruch in 1904. The surgeon and the patient were placed in the chamber with the patient’s head exposed via an airtight collar sealed at the neck. This method became known as continuous positive pressure ventilation (CPAP)⁴ and soon proved to be ineffective as a continuous flow of oxygen was needed to prevent cyanosis of the patient (Grenvik & Pinsky, 2009).

2. SANC Regulation R212 (19 February 1993, as amended).

3. IPPV. Also known as mechanical ventilation. A ventilator (respirator) delivers a mixture of oxygen and air and passes it into the lungs via a tube referred to as an endotracheal tube (ETT).

4. CPAP. This non-invasive mode of ventilation works in the same way as IPPV but does not require the patient to be intubated using an ETT.

All images referenced will be found on page 278.

The recommendation of a continuous oxygen supply was supported in 1918 by Volhard who also claimed that the patient's spontaneous breathing effort was vital to move sufficient air in and out of the lungs.

In 1927 the iron lung was invented by medical researchers from Harvard University (Image 1.). The iron lung supported ventilation by negative pressure and was very similar to the design of Sauerbruch, but only the patient was placed in the chamber.

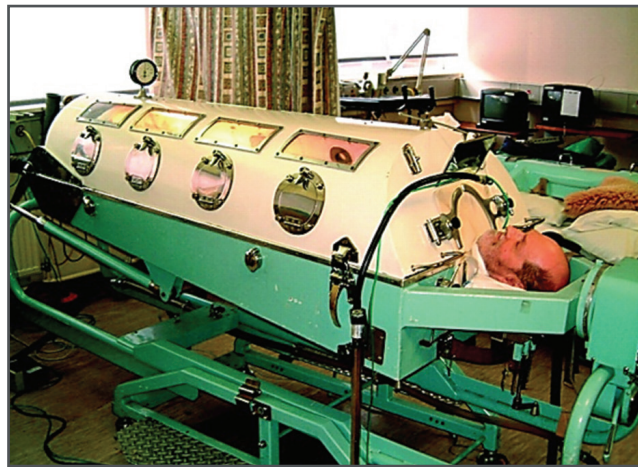


Image 1. The Iron Lung.

The system was deemed useless in patients who were paralysed, which prompted Ibsen, a Danish anaesthesiologist to make use of a tracheostomy⁵ and manual bag insufflation with IPPV. During the polio epidemic in Denmark in the 1950s, paralysed patients were brought to the University Hospital in Copenhagen and, following closure of the medical school, all medical students were instructed to manually ventilate the patients on a shift basis. This was to become the birth of the Respiratory ICU (Grenvik & Pinsky, 2009).

In 1947 Mörch designed the piston ventilator which was primarily for the use of patients undergoing thoracic surgery however it was Bjork and Engström who introduced the long-term use of mechanical ventilation in 1955 following the Copenhagen polio epidemic.

⁵. This is a surgical opening into the trachea for the insertion of an airway that is made of plastic or metal. It is usually performed to facilitate ventilation especially in patients who require long-term ventilation.

Great advances in mechanical ventilation and technology especially invasive haemodynamic monitoring and pharmacological support have taken place since the polio epidemic. These advances make it necessary to have special environments known as ICUs in which highly skilled doctors and nurses and other allied health professionals work in.

The Origin of Intensive Care Nursing

Florence Nightingale has traditionally been considered the pioneer of the first ICU. During the Crimean War (1854-1856), she placed the most ill and injured British soldiers in a dedicated area near the nursing station in order to provide continuous observation of their condition. In doing so, she was able to intervene quickly when the soldiers' condition deteriorated.

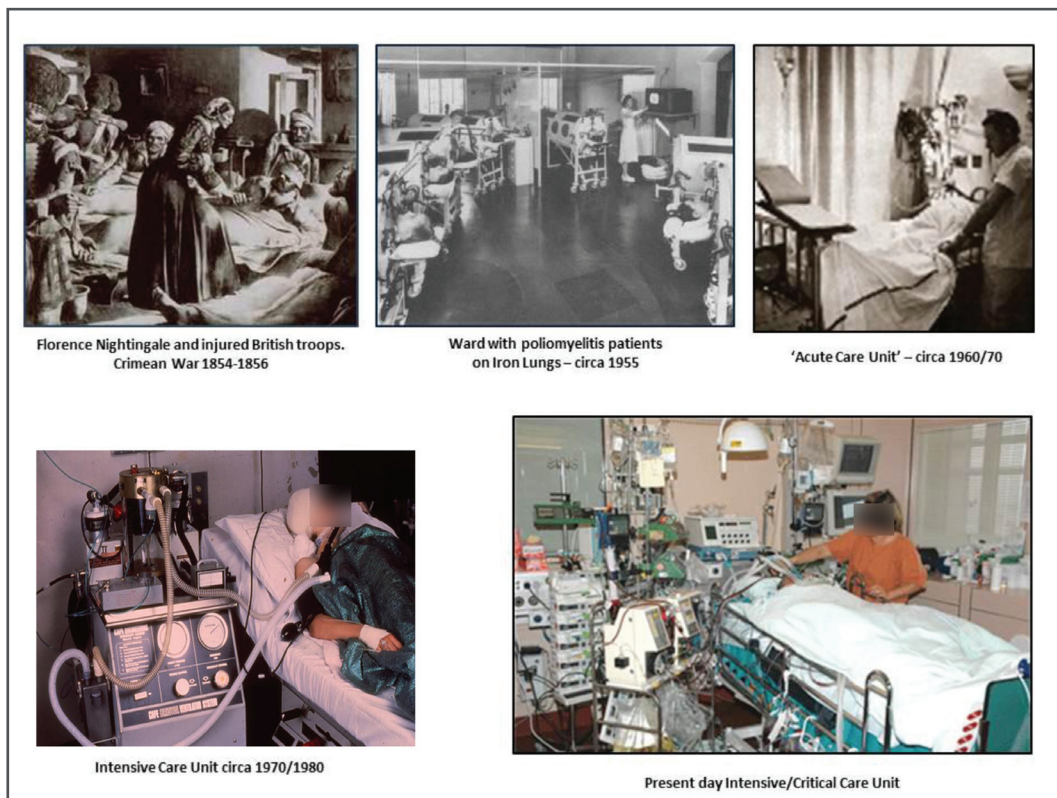


Image 2. Evolution of Intensive Care Units.

As in critical care medicine, ICU nursing made great advances in the care of critically ill patients and are regarded as the most important personnel in an environment which calls for continuous vigilant care of the critically ill. Critically ill people require

ICU nurses with specialised knowledge, skills and experience to provide care and create environments that are healing, humane and caring.

The ICU Environment

The ICU is dominated by technology and biomedical perspectives on *care* that serve as background to the *being*⁶ of the people involved, both patient and other multi-disciplinary health-care professionals (Bush & Barr, 1997; Cooper, 1994; Rushton, 1992; Wilkin, 2003).

This complex environment is not without challenges which are common both in South Africa and elsewhere in the world⁷.

Challenges Facing Intensive Care

The mortality rate for patients who are admitted and die in ICU varies worldwide. In so called first world countries such as the United Kingdom (UK), a review done of a large case mix of several intensive care units, revealed a mortality rate of 20.3% (Harrison, Brady & Rowan, 2004). Angus, Barnato and Linde-Zwirble (2004) report a comparable mortality rate in American intensive care units of 22.4%. In South Africa, the mortality rate for adults admitted to ICU is 31.5% (Mathivha, 2002) and for children is 7% (Argent, Ahrens, Morrow et al., 2014). This high mortality rate may possibly result from a different disease profile. Hodgson refers to 'two epidemics that have a profound impact on the provision of intensive care services in South Africa':

1. HIV/AIDS
2. Trauma due to motor vehicle accidents and interpersonal violence (Hodgson, 2006, p. 73).

Tables 1 and 2 provide information on the two epidemics that Hodgson refers to.

⁶. For this dissertation, when a Heideggerian phenomenological term is used, I have used an italicised font to draw the reader to the unique language of Heideggerian phenomenology. Italicising is in keeping with most literature in existential phenomenological philosophy and higher education.

⁷. The ICU environment is discussed in more detail in both chapters pertaining to nursing and the philosophical underpinning of the study.

Rank	Males n = 45 237		Females n = 14 698		Persons n = 59 935	
	Cause injury/death	%	Cause injury/death	%	Cause injury/death	%
1	Homicide/interpersonal violence ^a	50.9	Road traffic injuries	32.6	Homicide/interpersonal violence ^a	46.0
2	Road traffic injuries	24.8	Homicide/interpersonal violence ^a	30.8	Road traffic injuries	26.7
3	Suicide/self-induced violence	9.3	Fire ^b	12.5	Suicide/self-induced violence	9.2
4	Fire ^b	5.1	Suicide/self-induced violence	8.6	Fire ^b	6.9
5	Drowning	2.4	Surgical/medical misadventure	4.3	Drowning	2.3
6	Other transport injuries	1.7	Falls	2.6	Surgical/medical misadventure	2.0
7	Falls	1.4	Drowning	2.2	Falls	1.7
8	Other unintentional injuries	1.3	Other unintentional injuries	1.7	Other transport injuries	1.7
9	Surgical/medical misadventure	1.2	Poisoning	1.7	Other unintentional injuries	1.4
10	Poisoning	0.8	Other transport injuries	1.5	Poisoning	1.2
11	Mining injuries	0.5	Suffocation and foreign bodies	0.9	Suffocation and foreign bodies	0.4
12	Suffocation and foreign bodies	0.3	Natural and environmental causes	0.4	Mining injuries	0.4
13	Natural and environmental causes	0.3	Mining injuries	0.0	Natural and environmental causes	0.3
14	War ^c	0.0	War ^c	0.0	War ^c	0.0

Table 1. Percentage of Injury Death by Cause

(Norman, Matzopoulos, Groenewald & Bradshaw, 2007, pp. 695-702).

a. Using NIMSS data (National Injury Mortality Surveillance System), it was possible to distinguish deaths due to legal intervention from homicide/interpersonal violence-related deaths, as all of these deaths are coded as homicide. Although the proportion of deaths from legal intervention is probably small, it was necessary to combine homicide and legal intervention (other intentional) injuries when comparing this with data from WHO regions.

b. It was possible to differentiate deaths from fire-related burns (flame burns and respiratory damage due to smoke inhalation) from other burns. The majority of burn deaths are fire-related. It was possible, however, to distinguish between different burn categories in the Cape Metropole Study (CMS) data.

c. There were no war related deaths in South Africa 2000.

Year	Prevalence				Incidence	HIV
	Women 15-49	Men 15-49	Total Youth 15-24	Total population	Adult 15-49	population (millions)
2008	16,7	15,4	10,1	9,3	1,12	4,59
2009	16,9	15,5	9,7	9,5	1,03	4,74
2010	17,1	15,6	9,3	9,6	0,98	4,88
2011	17,2	15,7	9,0	9,8	0,96	5,01
2012	17,3	15,8	8,7	9,9	0,87	5,13
2013	17,4	15,9	8,5	10,0	0,85	5,26

Table 2. HIV Prevalence and the Number of People Living with HIV 2008 – 2013

(StatsSA, 2013, p. 4).

Year	Number of Births	Total number of deaths	Total number of AIDS deaths	% AIDS deaths
2008	1 107 603	618 324	240 309	38,9
2009	1 114 301	591 135	211 903	35,8
2010	1 123 409	580 673	201 174	34,6
2011	1 109 926	579 371	200 259	34,6
2012	1 095 669	572 600	191 620	33,5
2013	1 084 397	559 631	178 373	31,9

Table 3. Births and Deaths for the Period 2008 – 2013 (StatsSA, 2013, p. 7).

The Global Burden of Disease (GBD) for a particular country may influence which critically ill patients could possibly require intensive care intervention and who are very likely to die in the ICU (See Tables 4 and 5).

COUNTRY	Rank 1	Rank 2	Rank 3	Leading risk factor
Australia	Ischaemic heart disease	Diseases of trachea, bronchus and lungs	Cerebrovascular disease	Dietary
Canada	Ischaemic heart disease	Diseases of trachea, bronchus and lungs	Cerebrovascular disease	Dietary
UK	Ischaemic heart disease	Diseases of trachea, bronchus and lungs	Cerebrovascular disease	Dietary
USA	Ischaemic heart disease	Diseases of trachea, bronchus and lungs	Cerebrovascular disease	Dietary
The Netherlands	Ischaemic heart disease	Diseases of trachea, bronchus and lungs	Cerebrovascular disease	Tobacco smoking
India	Diarrhoeal diseases	Ischaemic heart disease	Diseases of trachea, bronchus and lungs	Dietary
South Africa	HIV/AIDS	Diarrhoeal diseases	Interpersonal violence	Alcohol

Table 4. Global Burden of Disease for Adults
(Institute for Health Metrics and Evaluation (IHME), 2013).

COUNTRY	Rank 1	Rank 2	Rank 3	Rank 4
Australia	Congenital abnormalities	Prematurity	Birth trauma or asphyxia	Respiratory infections
Canada	Prematurity	Congenital abnormalities	Birth trauma or asphyxia	Sepsis/other infectious conditions
UK	Prematurity	Congenital abnormalities	Birth trauma or asphyxia	Respiratory infections
USA	Congenital abnormalities	Prematurity	Birth trauma or asphyxia	Respiratory infections
The Netherlands	Congenital abnormalities	Prematurity	Birth trauma or asphyxia	Respiratory infections
India	Respiratory infections	Prematurity	Diarrhoeal diseases	Birth trauma or asphyxia
South Africa	HIV/AIDS	Prematurity	Respiratory infections	Birth trauma or asphyxia

Table 5. Global Burden of Disease for Children (IHME, 2013).

End-of-life care (EoLC)⁸ is receiving much attention in a many other disciplines such as trauma and emergency and oncology. Aspects of EoLC such as legality, morality and culture are also being deliberated.

In the UK, a national EoLC policy has been implemented by adopting the Liverpool Care Pathway (LCP) which is used in acute care settings (Coombs & Long, 2008). The Marie Curie Palliative Care Institute in London has been found to be useful in further development of the EoLC tool aimed particularly at critical care. The issues of respiratory care (withdrawal of respiratory assistance), discontinuation of pharmacological interventions, cardiac and renal support and supplementary symptom control are issues which require consensus in order to incorporate into an EoLC guideline (Coombs & Long, 2008).

During my search of the nursing literature, I could not find any evidence that 'palliative nursing care' is being implemented in the SA ICUs. The medical personnel in the ICU that manage critically ill patients, may use 'palliative care' glibly but really focus on pain and symptom management and non-escalation of further medical or surgical interventions. From my experience of working in both public and private ICUs, the ICU nurse's responsibilities remain unchanged and should there be a request to allow for some involvement by the family in the care of their dying loved one, this is often frowned upon or outrightly rejected.

Established good practice guidelines in withdrawal of invasive monitoring and the use of analgesia and sedation as well as family involvement are in use in the United States of America (USA) (Rubenfield & Crawford, 2001), New Zealand (Ryder-Lewis, 2005) and in the UK (Longden & Mayer, 2007).

Currently, in South Africa, there are no EoLC guidelines that are in use and this may be because that there is a dichotomy of ICU services: the 'open ICUs' and the 'closed ICUs.' The 'open' or private ICUs have facilities that are comparable to those in non-teaching ICUs in the USA and are not specialist intensivists led. As a result of this, there is limited experience in initiating EoLC decisions specifically relating to withholding or withdrawing therapy (Hodgson, 2006, p. 74). 'Closed ICUs' are mostly government run but are not without problems. There are staff shortages due to attrition and loss to private hospitals or countries, resource shortages because

⁸ There is no exact definition of end-of-life; however, the evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate, and (2) the symptoms or impairments resulting from the underlying irreversible disease requiring formal (paid, professional) or informal (unpaid) care and that can lead to death (NIH, 2004).

of limited budget for health care thus reducing the number of ICU beds and most significantly, the HIV/AIDS and trauma epidemics (Hodgson, 2006).

Dying and Deaths of Patients in the ICU and the ICU Nurse

Intensive care nurses will experience the dying and deaths of patients in the various environments in which they work. These deaths may range from neonatal deaths to deaths of children, adolescents and adults from trauma or acute and chronic illnesses.

It has been suggested by Madfes that western society has been guilty of refuting the experience of death and that social skills related to death and dying have yet to be mastered (Madfes, 1990). Subsequently, the death experience evokes anxiety and fear leading to responses of denial, repression and avoidance. Intensive care nurses, who are not prepared to manage the dying process and the eventual deaths of patients under their care, may withdraw from the dying patient and family. Such coping behaviour through distancing has the potential to influence the delivery of good nursing care negatively and threaten the moral and professional behaviour required of any nurse. The death of a patient in the ICU often leads to what is referred to as the 'Stress Cascade' as illustrated in Figure 1 below.

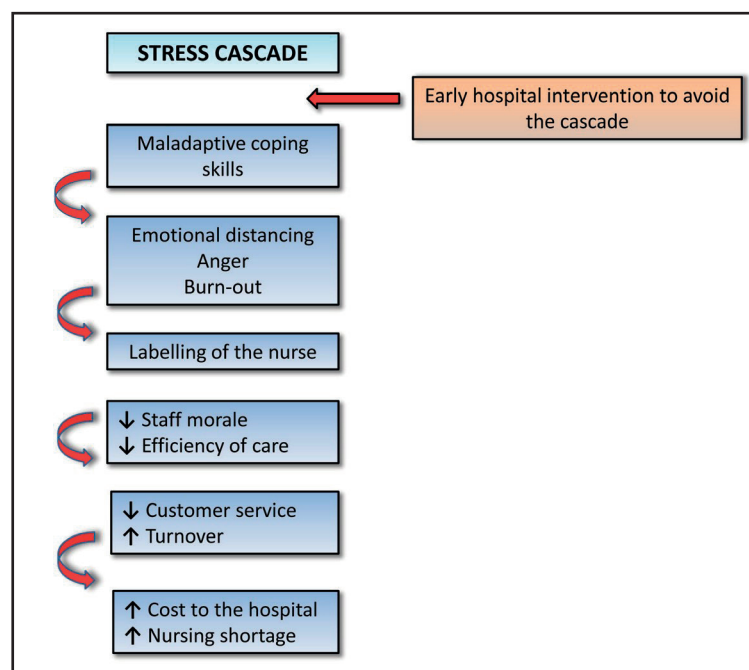


Figure 1. The Stress Cascade (Brosche, 2003, p. 177).

Once the cascade is in motion following the ICU nurse's experience of death, the stress of the ICU nurse becomes further heightened by a highly technological environment and the need to maintain care towards living patients. Although the deaths of patients in the ICU are a reality, the ICU nurse does not have adequate support or time for a grieving process (Lenart, Bauer, Brighton, Johnson & Stringer, 1998).

As important, Ehrenfeld and Bar-Tal (1995) and Sawatzky (1996) assert that if ICU nurses do not have coping skills learned through education programmes or experience or do not make use of available coping resources effectively at the place of employment, the ICU nurse is more likely to develop ineffective and maladaptive coping skills. Once these skills are embedded, emotional distancing, depression (both of which are described as a non-caring attitude), anger and burn-out may ensue see § [Review of the Nursing Literature on page 36](#). Non-caring or *inauthentic* (Heideggerian term meaning to be *self not properly*, behaviours may result in the ICU nurse being labelled as inconsiderate and apathetic see § [Philosophical Underpinning of the Study on page 16](#). Should these *inauthentic* behaviours continue, there is a real possibility that drug and alcohol abuse or thoughts of suicide and death may develop (Mealer, Burnham, Goode, Rothbaum, & Moss, 2009).

Preparing ICU Nurses for the Dying and Deaths of Patients under their Care in the ICU

Planning an educational response by preparing ICU nurses to care for the dying and deal with the deaths of patients under their care as well as their own ontological confrontation with death, requires nurse educators to be emotionally sensitive to this pedagogical challenge. In conventional approaches to higher education programmes, ontology has tended to be subordinated to epistemological concerns (Dall'Alba & Barnacle, 2007). While there are exceptions, higher education programmes emphasising knowledge and skills acquisition still remain prevalent. Their design raises the question of how such knowledge and skills are to be integrated into skilful practice or, more broadly, contribute to the transformation of the learner (Dall'Alba & Barnacle, 2007).

I will return to this pedagogic task that recognises the three dimensions of knowing, acting and *being* as proposed by Barnett and Coate (Barnett & Coate, 2005, p. 246) in Chapter Seven.

The Aim of the Research Study

This study sets out to better understand ICU nurses' lived experiences of dying and deaths of patients under their care in the ICU. In the light of such an understanding, and based on the experiences of ICU nurses in training noted above, the possibility will be explored as to whether there is a need for deliberate attention to the ontological impact of their care of people who die whilst in the ICUs. Furthermore, the importance of the provision of a caring environment should include caring for him or herself is also anticipated.

The Phenomenon under Investigation

In this study, I attended to a phenomenon that appears self-evident in the *lifeworld* of ICU nursing: the process of dying and the deaths of patients. My intention was to explore and uncover meaning of the experiences of ICU nurses whilst dealing with the dying and deaths of patients in their care in an ICU.

The Research Question

Attending to the ICU nurses' stories of the dying and deaths of patients under their care in the ICU may answer or respond to the research question I pose: 'are these nurses ontologically and educationally prepared to cope with the types of deaths that they experience in the ICU?'

The ICU nurses' accounts of their experiences may offer insights for the development of pedagogical strategies that address the epistemological and ontological challenges that ICU nurses face in their everyday world of caring for the dying and dealing with the deaths of patients in the ICU.

The following chapter, entitled *The Philosophical Underpinning of the Study*, provides an account of phenomenology⁹, which accepts that human experience is the source of knowledge and provides a valuable basis for researching *inter alia* the practice of nursing.

⁹The phenomenological method aims to describe, understand and interpret the meanings of experiences of human life. It focuses on research questions such as what it is like to experience a particular situation (Bloor & Wood, 2006, p. 128).

The choice of Heideggerian hermeneutic phenomenology was made as this provides a way 'of approaching research which focuses on the person' (*being*) and the 'context of their existence' (*to be*) (Mackey, 2005, p. 184). Furthermore, Heidegger's philosophy engages with the metaphysical in a way that appears to support research into understanding the phenomenon of care-givers' experience of death as an ontological rather than merely an epistemological phenomenon.

This study attempts to demonstrate that the nature of the setting and of the professional role of the nurse in the ICU confronts the nurse with challenges to his/her *being* that differ in significant ways from the experiences of nurses in other contexts, including those of palliative care¹⁰.

¹⁰. Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems: physical, psychosocial and spiritual (WHO, 2009).

CHAPTER TWO

The Philosophical Underpinning of the Study

Phenomenological inquiry offers nursing scholars an approach to better understand individuals' (families, patients, nurses and communities) experiences in order to answer questions that inform the art and science of nursing practice (Gullickson, 1993; James & Chapman, 2009; Robertson-Malt, 1999; Walters, 1994). Due to the unique integration of art and science in nursing, 'specialised knowledge for the practice of nursing must reflect the lived, contextual realities and concerns' of patients and families for whom nurses provide care (Lopez & Willis, 2004, p. 726). Meleis (1996) stresses that the development of nursing knowledge that is culturally relevant and sensitive of those living in the situation is equally as important.

The Concept of Phenomenology

Phenomenology is concerned with *being* (the subject of ontology) and the self-showing or disclosure of a phenomenon. In '**Being and Time**' ('*Sein und Zeit*')¹¹ (1927/1996), Heidegger calls phenomenology the laying bare or exhibiting (*Aufweisen*) of *Dasein*¹² or '*what shows itself in itself*' (BT, p. 28. Italics original). There are various ways in which things can show themselves and it is possible that things show themselves as they are not, but only appear to be.

To make Heidegger's question about *being* more understandable, he asks '*was heist Sein?*' (BT, p. 26. Italics original). The translated phrase means 'what is called *being*' or as King proposes 'what do we mean by "to be?"' (King, 2001, p. 5). Heidegger maintains that phenomenology could serve to address his concern that modern philosophy has overlooked the question of *being* and that philosophy is more interested in the ontic reality, or entities of the world, with the focus on the person's everyday existence (*Existenz*) in their lifeworld (*Lebenswelt*). Heidegger explains very simply that '*we are dealing with something self-evident which we want to get closer to*' (BT, p. 28. Italics original).

¹¹ All references to '**Being and Time**' by Martin Heidegger are taken from the translated version by Joan Stambaugh 1953/1996 unless otherwise stated. References are to the page numbers of the 1927 German original '*Sein und Zeit*.'

¹² It was Heidegger's expressed wish that in future translations the word *Dasein* should be hyphenated throughout '**Being and Time**' in order to make the reader less prone to assume he or she understands it to refer to 'existence' which may bring along a number of psychological connotations (Stambaugh, 1996, p. xiv). I acknowledge that Stambaugh offers the latest translated version of '**Being and Time**' and uses a hyphenated 'Da-sein.' I have used *Dasein* in an unhyphenated form as my references predominately have not followed Heidegger's request.

Heidegger and 'Meaning'

Meaning for Heidegger, 'is that from which something is understandable as the thing it is' (King, 2001, p. 6). For example, we enquire what a particular building is and are told that it is a museum. The building has come to our understanding as a museum – that is, as the thing it is. When understanding something as the thing it is, we now understand it in its essential *being* and hence its *meaning*. In Heidegger's thinking, the world is not a thing nor is it the number of *entities* that exist in our everyday world. Johnson explains this as 'the world is the interconnected context of involvements that give *meaning* to everything that one encounters within one's individual world' (Johnson, 2000, p. 137). The experiences that humans confront in the world do not simply exist in a detached form 'out there,' waiting to be explored, but their experiences are all part of an interrelated world of investment and significance.

For nursing, Heidegger's thinking on the *meaning* of life's experiences may have positive outcomes on caring and healing. Willis, Grace and Roy (2008) describe three modes of *meaning* within the context of nursing practice namely: (i) 'the nurse attending to and helping recipients of nursing care, or their proxies and making sense of health and healing concerns; (ii) the nurse constructing meaning(s) related to nursing practice within the larger healthcare and socio-political environment, including perceptions of both positive and negative human-natural world conditions, affecting the facilitation of humanisation, meaning, choice, quality of life and healing and (iii) the nurse's reflection on nursing concepts, ways of knowing and practical knowledge and the relational use of self and the natural world in forming effective healing relationships and other healing modalities' (Willis, Grace & Roy 2008, p. 35).

Living in our own world is the *horizon*¹³ by which we identify our everyday existence and understand things and in doing so is *meaning giving*. In order to better understand Heidegger's use of *meaning*, King (2001) suggests that we turn away from our everyday world and enter into a world that is not familiar to us. In the context of ICU nurses and the ICU environment, the *horizon* from which things are understood is nursing and care of critically ill patients. In this scenario, buildings and museums are now meaningless or just *entities*.

13. A horizon, for Heidegger is an advantage point from which one can view certain matters, ask and answer appropriate questions about them (Inwood, 1999, p.98).

The *horizon* from which things are understood by ICU nurses is modified and re-articulated into categories or concepts of life-saving modalities such as technological life-support and complex pharmacological assistance.

It is also modified by ICU nurses' experiences of witnessing the death and dying of patients.

The world of ICU nursing for ICU nurses is the *horizon* from which they understand things as relevant to a purpose. Modifications to the *horizon* of ICU nurses' understanding of death and dying in the ICU enable them to understand things in different ways, but in each case only in one or another of their possibilities. King adds 'the *horizon* which makes it possible for us (in this instance ICU nurses) to understand *being* as *being* is itself the *meaning of being*' (King, 2001, p. 7).

To answer the questions about the meaning of *being*, Heidegger introduces the concept of *Dasein* or *being-there*. Although *Dasein* has no direct translation into English, *Dasein* simply means 'human existence with the entity to ask what it means to be' (Waterhouse, 1981). McConnell-Henry, Chapman and Francis (2009) picture *Dasein* as the glue that binds a nurse and a patient. Consequently my study aims to uncover *Dasein* that exists when ICU nurses experience the dying and deaths of patients in the ICU.

Heidegger's 'Dasein' ('being-there')

The German word *Dasein* is composed of the prefix *da* which means 'there' and the root word *sein* which means 'to be.' Hence the word *Dasein* is formed meaning 'to be there' (Inwood, 1999).

Heidegger's term *being-there* refers to a being which understands its own *being* or *Dasein*. Heidegger makes this concept clearer by explaining that humans do not have *Dasein* but each is *Dasein* which understands how to *comport* itself or behave within its *Dasein* of *being-in-the-world* (Wrathall, 2005). Gerner adds that '*being-in-the-world* is *being-with-others-in-the-world*' and hence the world is shared (Gerner, 2007, p. 5).

‘Being-in-the-world’ (In-der-Welt-sein)

‘The being of *Dasein*, its existence, is *being-in-the-world*’ (Gorner, 2007, p. 91). *Care*¹⁴ (*Sorge*) is the name Heidegger gives for ‘how the whole of *Dasein* is and how *Dasein* wholly is’ (King, 2001, p. 36). It is through *care* that *Dasein* becomes engaged with life situations and possibilities. This engagement of *Dasein* with the world and the numerous possibilities that make up *Dasein*’s experience of *being*, unifies its *being* with the past, present and future (temporality). King (2001) elucidates that *Dasein* not only cares, but *Dasein*’s *being* is *care*.

For Heidegger, the world is ‘a web of significance which makes it possible for entities¹⁵ to show themselves or to be encountered’ (Gorner, 2007, p. 5).

In an attempt to understand this concept, I found it useful to make constant reference to my own experiences of my *being* or *Dasein* in situations of *being-there* when patients are dying or in witnessing the deaths of patients in the world of the ICU. On reflection, questions that came to mind were: ‘*what was my Dasein’s comportment towards the unexpected and traumatic death of a patient in the ICU?*’; ‘*did I behave appropriately as a professional nurse and show no emotion?*’ or ‘*did I share my inner most feelings of disappointment and failure as an ICU nurse?*’

This brings into view Heidegger’s philosophy of *mineness* or ‘*always-being-my-own-being*’ (*Jemeinigkeit*) (BT, pp. 42-43. Italics original). *Dasein* is mine – it belongs to me and with this in mind, *Dasein* has the possibility of choosing ways of existing which may be *authentic* (*eigentlichkeit*), *inauthentic* (*uneigentlichkeit*) or *undifferentiated* (*Alltäglichkeit*).

Heidegger interchangeably uses the *owned self* for *authenticity* of *Dasein* and the *disowned self* for *inauthenticity*. To understand this concept, King suggests that the reader rather use phrases such as ‘to be self properly’ or ‘self not properly’ (King, 2001, p. 40).

In *Dasein*’s *authentic* mode (‘to be self properly’), *Dasein* is aware of what it means

¹⁴ *Sorge* (*care*) serves as an umbrella term that provides a kind of structural unity for the aspects of *Besorgen* (*concern*) and *Fürsorge* (*solicitude*) of *Dasein*’s existence (Cerbone, 2008, p. 57). ‘Care is the dominant member of the triad but inseparable from the others’ (Inwood, 1999, p. 209).

¹⁵ An entity or a being (*ein Seiendes*) is anything that in any sense ‘is’ (Gorner, 2007, p. 15).

to exist in terms of human relationships. Krasner (1996) elaborates that an *authentic* relationship involves responding to the presence of other *Dasein*.

Taking Krasner's explanation further, Carman (2005), states *Dasein* is not in isolation but it is absorbed within a relationship with others, which Heidegger refers to as *thrownness* (*Geworfenheit*) and is closely related to *facticity* (*Faktizität*).

Facticity comprises the conditions in which 'Dasein finds itself that affect its possibilities and is thrown into situations' (Cass, 1998, p. 330).

For the most part, *Dasein* understands itself by what others think and say and not from his or her *being*. King goes on to explain that *Dasein* exists in public disclosedness whose very 'publicity is a way of covering over each *Dasein's being*' (King, 2001, p. 41). This is *Dasein's everydayness* (*Alltäglichkeit*) or *undifferentiated* mode of existence in which *Dasein* exists for most of its lifetime. In this mode, *Dasein* lives its life without questioning any events, successes or circumstances and as a result, the possibility of understanding his or her self's *being* is concealed. Heidegger does not mean in that living an *undifferentiated* mode of existence *Dasein* stops caring, but that the distinction between an *owned* and *disowned* self is not disclosed but remains *undifferentiated*.

In contrast, *inauthentic* mode (self not properly) 'Dasein conforms its life to fit the expectations of the *They*' or *das Man*'¹⁶ by attempting to force its existence into pre-articulated roles and structures' (Cass, 1998, p. 330). For example, the ways in which ICU nurses *comport* themselves in the ICU when patients are dying or have died may be dictated by *das Man* or *They*, in this case, the professional code of conduct and curriculum as governed by the South African Nursing Council. There are some ICU nurses who go out of their way to *comport* themselves differently but will never be free of the dictatorship of *das Man* or *They*. So the freedom of *Dasein* becomes forgotten by getting lost 'in what the *They*' presents as possibilities' and *Dasein* 'either defines life mechanistically and tries to dominate its circumstances or withdraw into fantasy, delusion and self-pity' (Cass, 1998, p. 330). In these circumstances possibilities for expressing one's *being* may be impeded and reduced by becoming detached from the *everydayness* of life experiences and fall within the expectations of *das Man*.

¹⁶ In *'Being and Time'* (BT, pp. 121-139), Heidegger explains that the 'everyday world is a public world, within which everyday *Dasein* orients itself in a public and common manner'. For Heidegger, *das Man* is the answer to the question of the 'who' of everyday *Dasein*: 'The self of everyday *Dasein* is the *Man-self* which we distinguish from the *authentic* self, the self which has explicitly grasped itself' (Cerbone, 2008, p. 51).

Care, Nursing and Heidegger

The topic of caring is extensively discussed within nursing literature (Benner & Wrubel, 1989; Dunlop, 1986; Kuhse, 1997; Leininger, 1984; Watson, 1979). Caring is an essential function of nursing and is built on human interaction. Agreeing with this sentiment, Heidegger states that to be with another is to care (Heidegger, 1927/1996). Care and caring can be classified as either intentional caring or ontological caring. Acts of intentional caring are voluntary, deliberate actions on the part of human beings and seem to lie unquestionably in the moral sphere (Edwards, 2001, p. 167).

Benner and Wrubel, both nurse theorists, claim 'caring is a basic way of *being-in-the-world*' (Benner & Wrubel, 1989, p. 368). However, this is not to be interpreted as that all humans are caring in the intentional sense, which is improbable as not all humans care or are caring. Notwithstanding, Benner and Wrubel point to a sense of care appropriately described as ontological care, a form of care that is in the very make-up and constitution of human beings (Benner & Wrubel, 1989). Their thinking was derived from Heidegger who claims that '*Dasein, when understood ontologically is care*' (BT, p. 57. Italics original). Care for Heidegger is *Sorge* (loosely translated as 'care for'): that which signifies a person's existence and makes it meaningful; such care is ontological in character.

Recently, some nursing authors have criticised the appropriation of Heidegger's philosophy into nursing, especially with respect to the accuracy of the interpretation of Heidegger.

Horrocks (2000) makes a strong case that Benner's (1985) philosophy is not grounded in Heidegger but in Dreyfus's (1991) interpretation of Heidegger's *everydayness* and that her application to nursing may not be as innovative as nurse academics think. Benner claims that she is using Heideggerian hermeneutics to understand everyday nursing practice, knowledge and meaning which will impact on health and illness.

Heidegger does not focus on human beings and their *everydayness* in the world. He instead uses this approach to find out the *meaning of being* in general. However, Heidegger does start his enquiry into human *everydayness*, without wanting to disclose the shared meanings of human activities. Dreyfus's commentary on Heidegger's '**Division One**' of '**Being and Time**' attempts to do this in order to reveal the essential structures of *Dasein* and eventually the *meaning of being*. Benner, on the

other hand, is using Heidegger's concept of *everydayness* to reveal the everyday practices and meanings of nursing by using hermeneutics as a method and talking about it as though she is following Heidegger.

Cash enters the Benner debate and argues that 'the underlying philosophy is that of Heidegger', especially as it has been interpreted by Dreyfus' (Cash, 1995, p. 527). By using Dreyfus' interpretation of Heidegger, Cash defends Benner by stating 'practical understanding entails beliefs that are only meaningful in the context of underlying shared practices within specific domains' (Cash, 1995, p. 528). This debate illustrates that Heidegger is rarely referred to as a primary source, but that much of the nursing literature relies on secondary and tertiary interpretations, such as Benner's interpretation of a Dreyfusian explanation of Heidegger. One possible consequence in a nursing context is that Heidegger's ontological emphases are distorted and Benner's ideas and their application to nursing theory and practice may be weakened because of this.

On the other hand, Crotty (1996) and Paley (1998) do not regard Dreyfus' interpretation of Heidegger as wrong. They state that it may be more correct to emphasise that Dreyfus focuses on '**Division One**' of '**Being and Time**' and, as a result, his interpretation lacks 'the richness that would have been gained from an understanding of '**Division Two**' (Johnson, 2000, p. 138).

Such debates illustrate how important theoretical arguments 'can be hidden due to the use of secondary sources' (Horrocks, 2000, p. 237). Despite criticisms of the author's interpretation of *care*, Heidegger's philosophy of hermeneutical phenomenology remains useful for nursing research as it provides a framework for exploring the *meaning* of individuals' experiences.

Van Hooft (1996) approaches caring from a bioethical perspective and takes the work of Heidegger and Levinas (1994) as a starting point, arguing that caring is an 'ontological structure of human existence' of which there are two forms:

1. Caring about oneself.
2. Caring about others.

Taking his argument further, Van Hooft includes the Aristotelian forms of human existence and proposes that the dimensions of integrity and ethically principled care may be the only way of embracing the concept (w)holistically. From a moral

standpoint, care incorporates the attributes of respect, trustworthiness and honesty. MacLeod (2001) notes that care can start when a person enters the *lifeworld* of another and attempts to understand what it is like to be that other person.

Heidegger's concept of *Sorge* (*care*) can contribute to understanding nursing *care* in two important ways. Heidegger asserts that each concept of *care* is related to our *being* and *becoming* and that this is the essential *existential* mode of human *being* (Scudder, 1990). Firstly, by 'leaping in', nurses may 'take over' or 'take away' *care* from patients and this could be seen as a form of domination and dependence. Scudder refers to this as dependent *care* as it 'fosters dependency on others' (Scudder, 1990, p. 59). Secondly, *authentic care* takes place when the nurse 'leaps ahead' in order not to take away *care* from the patient, but to give it back *authentically* and in so doing, the patient is helped through *care* for his/her *being*.

Using Heidegger's concept of *care*, one can see that ICU nurses may both hinder and/or even enhance the well-*being* of dying patients. Dying patients in ICU require *care* that will enable them to have a good death and in so doing, this makes them dependent on ICU nurses. Even in the ICU, nurses should strive to minimise dependent *care* and maximise *authentic care*, but often this is impossible.

Unfortunately though, nurses are required to administer *authentic care*, but are often neither able nor enabled to do so. Historically, nursing education placed a greater emphasis on the sciences and less on the humanities.

For Benner and Wrubel (1989), humanistic study explores human experience and therefore should assist nurses to deal with the experiences of ill patients. The lack of nurses' experience in the *authentic care* of ill patients, and of themselves, may find patients scientifically categorised as a disease entity to be treated (Bishop, 1990). The opportunity for nurses to experience patient illness also allows them to develop relationships with patients and families through better communication. Such strategies allow possibilities for patients to resume self-*care* and enable nurses to administer wholistic and *authentic care* which is essential to *authentic being*.

Wholistic care, health promotion and concern for the protection of basic human integrity are the prime focuses of a nursing/caring/healing relationship (Cumbie, 2001). From a relational context, all nurses must bring an *authentic* self in order

to engage with another human being. Watson believes that when the relationship with a patient and/or the family is harmonious, 'the capacity of one human being to receive another human being's expression of feelings for one-self' is the basic activity of nursing and caring (Watson, 1988, p. 5). In a nursing context, this may be what Heidegger was attempting to explain *Dasein's authentic mode*: *Dasein is being* the awareness of what it means to exist in terms of human relationships.

If ontological caring applies to all beings, in what sense is it particularly relevant to nursing? Edwards (2001) explains that in order to care for a patient ontologically, it is fundamental for the nurse to establish what it is that the patient is most concerned about. This is in order for the nurse to act *authentically* while balancing *care* for him or herself in the ontological sense as is claimed by Van Hooft (1996). Such an existential awareness calls for an *authenticity* with self and the other; in this case, a patient dying in an ICU.

A nurse's reflection on his/her experiences with patients dying in the ICU has the possibility to further integrate, augment and achieve the *authentic self*. Taking Edwards' point of view further, Watson states that the more a person (the ICU nurse in this case) is able to 'experience one's real self, the more harmony there will be within the mind, body and soul and the higher degree of health will exist' (Watson, 1988, p. 57).

The opposite may also be true: disharmony between the mind, body and soul may lead to a disconnected self, or in Heideggerian terms, an *inauthentic self*. In these circumstances, possibilities for expressing one's *being* may be impeded and reduced by becoming detached (*fallenness*) from the *everydayness* of patients dying in the ICU. A consequence of *fallenness* may result in *Dasein* becoming absorbed in its *lifeworld* and losing sight of its *being*.

How do ICU nurses come to this *authentic state of being-in-the-world* of patients dying in the ICU? Another question may be: 'What is necessary to enable an ICU nurse to competently and sensitively engage in his/her *authentic self* in caring for dying patients and their families in an ICU setting?'

My personal belief is that nursing needs to move beyond out-dated paradigms that insist nurses remain detached and objective in all situations in order for them to be an effective and competent health-care provider. One of my roles as an ICU

nurse educator is to provide guidance and structure that will enable ICU nurses to be secure in an *authentic way of being-in-the-world* of dying patients in the ICU.

Through the introduction of thanatology¹⁷ into a Postgraduate Critical Care Nursing curriculum, it is hoped that in the future, ICU nurses will participate more fully in a nursing-caring-healing relationship with dying patients and their families.

Heidegger also refers to another aspect of *inauthenticity* when *Dasein* struggles with the present which he calls *falling* or *fallenness* (*Verfallen*). A consequence of *fallenness* may result in *Dasein* becoming absorbed in its world and losing sight of its *being*. *Fallenness* is a dynamic activity of *Dasein* that 'entices *Dasein* to involve itself in the world in such a way as to forget about its challenge to live *authentically*' (Cass, 1998, p. 330). Heidegger emphasises that *Dasein* will be driven into anxiety (*Angst*) when it denies the *authentic* and *inauthentic* truth about its self and that the possibility of its existence is futile and meaningless.

In order for *Dasein* to escape this *Angst*, it fills itself with distractions which prevent *Dasein* from contending with its *authentic* possibilities. Zimmerman (1986) sums this up as *Dasein's* plight of being alienated from itself. Pascal and Endacott explain that *Angst* allows opportunities to 'redefine who we are in the world, and what relationships and tasks we will sustain and where we devote our time and energy' (Pascal & Endacott, 2010, p. 5). It would seem that *Angst* can lead to *authenticity*, to developing relationships of care for ourselves and for others in the world (Heidegger, 1996).

Looking at *Dasein* and *being* in another light, Heidegger was extremely concerned about the lack of interrogation regarding our relationship to technology especially, toward the essence¹⁸ of technology.

¹⁷. The academic study of death and dying among human beings which investigates the circumstances involving a person's death, the grief experienced by significant others and other social attitudes towards death and dying. Thanatology is an inter-disciplinary study undertaken by professionals in nursing, psychology, sociology, theology and various forms of social work (Wass, 2007, p. 263).

¹⁸. The inner nature or principle of a thing (Inwood, 1999, p. 2).

In **'The Question Concerning Technology'**, Heidegger asserts:

'Everywhere we remain unfree and chained to technology. But we are delivered over to it in the worst possible way when we regard it as something neutral; for this conception of it makes us utterly blind to the essence of technology' (Heidegger, 1953, p. 4. Italics original).

Heidegger and Technology

Heidegger describes the essence of technology as *'Ge-stell'* (enframing). *'Ge-stell'* is characterised by the revealing of what is as *'bestand'* (standing-reserve) or more simply, a resource or stockpile. Human beings ultimately are subjected to enframing and view themselves as just standing-reserve (Cerbone, 2008) – an *inauthentic being-in-the-world*.

In **'The Question Concerning Technology' (QCT)** Heidegger argues that technology is the supreme danger to understanding *being*. Heidegger describes the supreme danger as one of human beings becoming just additional resources to be effectively and efficiently ordered.

Heidegger (1962) refers to *ge-stell* – technology as *'ready-to-hand'* (*zuhanden*) – which is concerned with *'seeing and understanding the world as something practical to use'* (Walters, 1995, p. 341). Heidegger's futural thinking of *ge-stell* may have been realised especially with regards to medical technology. Cardiac pace-makers, artificial joints and genetic engineering regularly confront health-care professionals especially in the intensive care arena. Body organs such as hearts and kidneys are now used as therapeutic tools (Hogle, 1996). Cadavers, animal experiments and brain-dead-but-otherwise-alive organ donors contest and confuse human notions of person versus object versus natural versus artificial versus living (Casper, 1994; Ohnuki-Tierney, 1994; Pickstone, 1994). Timmermans eloquently states that *'devices substitute for and stand in for and hold the place of the actions of people'* (Timmermans, 1998, p. 428).

Technology can also exist as 'present-at-hand'¹⁹ (Heidegger, 1962). This is a relationship that arises from and depends upon ready-to-hand interactions.

It can be illustrated by technology representing a patient on a screen in the form of a heart-rate, an image such as an x-ray or even a virtual digitalised skeleton – see Image 3.

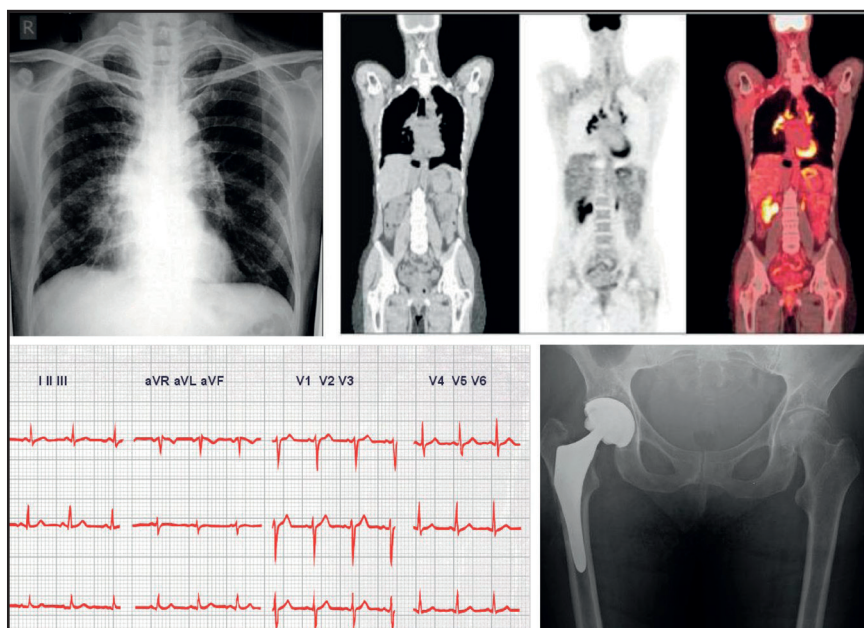


Image 3. Concepts of *Ge-stell*.

Such images may actually be seen as a stand-in or replacement for a patient with more life than the 'real thing' (Simon, 1999, p. 157). In the ICU, doctors and even ICU nurses look to the monitors to assess how well or close to death a patient is. It is common practice to treat bad x-rays or blood results, and not ill or dying patients. Heidegger explains that present-at-hand relationships are detached practices of interacting with the world and render technology undistinguishable.

Nursing and Technology

The topic of technology and nursing practice has been an area of concern for some time. As far back as the 1980s, Henderson (1980), a nurse theorist, warned professionals in the nursing field, that technology had resulted in a very impersonal

¹⁹ A Heideggerian term (*vorhanden*) used to describe '(to be) there, present, available'; it is used of things, not of people (Inwood, 1999, p. 209).

form of western health care, which originated from a 'technological way of understanding the world' (Walters, 1995, p. 342). The implication of this for nursing practice, education and research is that if this impersonal structure of health-care continues, nursing epistemology will contribute to an impersonal health care system. However, technology is currently at the centre of a fair deal of scholarly debate about technology and nurse-patient caring interactions.

Early debates depicted nursing and technology as opposing forces. Sandelowski (1988) viewed technology in nursing as a modality that resulted in fragmentation and distance which went against the philosophical foundations of nursing: to care. Leininger (1988) encouraged nurses to learn about technology in relation to caring. She hypothesised that technology may augment care, but that ran the risk of decreasing interpersonal care. The same may be said of the technological world of the ICU:

'Nowhere is the paradoxical nature of the relationship between technology, an offshoot of science, and care more evident than in the micro-culture of an intensive care unit, where the dominance of technology renders many experiences of care invisible or at best obscured' (Cooper, 1994, p. 402) aptly illustrated in Image 4.

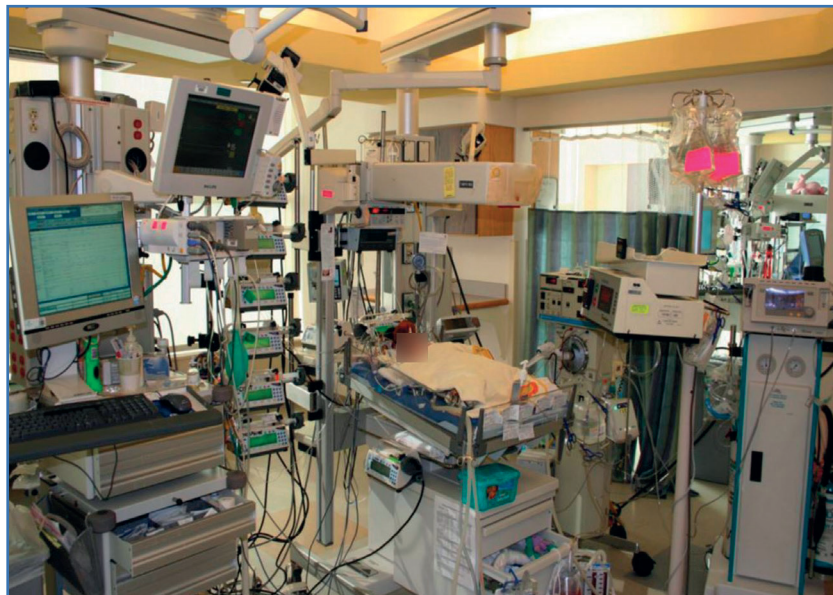


Image 4. The Dominance of Technology in the ICU.

Sandelowski continued to position herself against technology, as it dissociated nursing from humanising care (Sandelowski, 2000). She has also offered a historical perspective on the impact of technology on nursing care which demonstrated how technology had 'advanced and thwarted the fulfilment of nurses' desires' (McGrath, 2008). Locsin (2005) offered fresh insight into how technology might be appreciated and valued rather than frowned upon by demonstrating that technological competence could be viewed as caring. The various studies that informed Locsin's thinking also explained that the effects of using technology in nursing care could be positive or negative (Locsin, 2005).

More recently, from ICU patients' perspectives, Almerud, Alapack, Fridlund and Ekerbergh (2008), describe how ICU patients view themselves as invisible despite constant observation and monitoring. This state of invisibility makes ICU patients feel that they are 'mere organs, objects or just diagnoses' (Almerud et al., 2008, p. 56). Almerud et al. also claim that technological work in the ICU takes precedence over nursing care, resulting in almost a silence in response to ICU patients' uttered need for help and consolation.

Since the very essence of professional nursing is care, ICU nurses find themselves silenced as nurses at a moment when care is all that is left to give in the last stages of living. Such silence has the potential to cause high levels of death anxiety, which may negatively affect the attitudes and behaviours of nurses towards dying patients and their families and, as a result, create obstacles in providing quality nursing care for those living in the face of death (Eakes, 1985).

Expected trust and compassion towards ICU patients are only ministered after the technological tasks are completed. The caring hand of the nurse can be seen as an extended arm of technology which enhances the so-called invisibility experienced by ICU patients. One of the reflections by Almerud et al. was that of the meaning ascribed to technology. The wholistic²⁰ manner in which ICU patients are cared for as opposed to being objects treated with mechanical competence was what really matters (Almerud et al., 2008).

Walters (1995), using Heideggerian hermeneutic phenomenology as a methodology, demonstrate that ICU nurses can work in harmony with technology but also warns

²⁰. Holistic in nursing may be misinterpreted as spiritual care only; hence I have used 'wholistic' to signify the psychological, physiological, spiritual and multi-cultural care.

that an attempt to 'understand technology as an objective detached thing can channel the nurse's attention away from the transpersonal dimensions of caring for the patient' (Walters, 1995, p. 341).

Conversely, Little (2000), who also used Heideggerian hermeneutic phenomenology, found that professionally qualified ICU nurses were able to concentrate on nursing care only when they had developed technological competence. Barnard (2000) found that technology could alter and impede surgical nurses' ministering of wholistic care. Alasad (2002) demonstrated a similar finding with ICU nurses. McGrath contests the findings of Barnard (2000) and Alasad (2002) as the two authors concentrated on novice and inexperienced nurses working in the ICU. Had Barnard and Alasad used experienced ICU nurses as participants in both studies, the findings may have been very different.

Little (2000) is of the opinion that technology in medicine and nursing will only realise Heidegger's *authentic meaning* if 'described by nurses who make direct use of it and may elude practitioners who are not experienced in the critical care arena' (McGrath, 2008, p. 1097).

Another standpoint about technology is that of Carnevale (2005) who believes that there has been an emergence of 'death enhancement' initiatives which aim to make death less distressing. These include the works of Corr, Doka and Kastenbaum, 1999; Glaser and Strauss, 1968, and Kübler-Ross, 1969.

Carnevale refers to these death philosophies as 'death technologies' wherein death is seen as ontified (Carnevale, 2005, p. 2). Such death technologies may be viewed as a 'technologisation' of death – a turn towards technology to heal an ailment or to intervene in an imminent death.

For those who encounter the death of others as ICU nurses do, the inclination, dictated by *das Man* or *They*, is to leap in and attempt to try and take death away from a dying patient.

As a consequence, the technologisation of death threatens to conceal our understanding of the meaning of death and our relation to death that is necessary for *authentic dying and being*.

Heidegger and Death

Death is when *Dasein* is no longer *being-there* and can be seen as *Dasein's* non-*being*. When death is understood *authentically*, it is understood as the '*possibility of not having any more possibilities*' (BT, pp. 258-259. Italics original). Heidegger's phenomenological thinking is to rely on the phenomenon to disclose itself but no *Dasein* ever encounters its own death. Heidegger asks if we:

'genuinely experience the death of another. In one sense we do; we see the dying person, we see that they are still alive, we see that they are now dead. But do we experience the dying?' (BT, pp. 258-259. Italics original).

For Heidegger, 'only *Dasein* is capable of *authentic* dying' (Carnevale, 2005, p. 7). This 'makes it impossible to have a phenomenological understanding of death, however *Dasein* can 'relate to the death of others, whether as dying or as dead' (Mulhall, 2005, p. 123).

Heidegger implies that *Dasein* can be understood from the perspective of one's own death. The final *horizon* for *Dasein* is death and therefore our *being* is always on its way to death (Kruger, 1979). It would then make sense to say that death is not just a mere ending or termination, but a manner of *being*. This challenges us to discover our own death and make it our own in order for us to understand the infinitude of our lives (Kruger, 1979). Lavine explains Heidegger's thinking on *being* and death as the most *authentic* and significant moment which each *Dasein* must suffer alone. From Heidegger's books – '**Basic Writings from Being and Time**' (1927) and '**The Task of Thinking**' (1964), Lavine further clarifies *being* and death as that each *Dasein* must concede to death and embrace it. In doing so, *Dasein* will be freed from anxiety (*Angst*) and the triviality of life and consequently be free to *comport authentically* (Lavine, 1984). By understanding death in this way and by accepting it as my death, *Dasein* splits from its *inauthentic* existence and engages with its own *authentic* possibilities.

From this Heideggerian perspective, *being-toward-death* (*Sein-zum-Tode*) is *Dasein's* ultimate mode of *being* and therefore can make one's life truly *authentic*. It would seem that Heidegger's approach to death is to foster an introspective awareness of the dying of another and the significance for one's own experience rather than

striving to comfort or lessen the intense dread and anxiety that dying entails.

Using Heidegger's thinking of *being-towards-death*, it is hoped that an ontological awareness of the ICU nurse experiencing the death of a patient in the ICU will result from this study.

Heidegger and Death in Intensive Care Nursing

The *lifeworld* of ICU nurses is that death (the 'possibility of not having any more possibilities;' the end of *Dasein*) is always a possibility in the *everydayness* of ICU nurses' *being-there*. Heidegger explains that the death of *Dasein* is when it has run its course from its '*beginning to its end*' (BT, p. 233. Italics original). Heidegger explains that death is a mishap constantly occurring to others when *They* talk fleetingly that '*one of these days one will die too*' (BT, p. 297. Italics original). Such *idle talk* (BT, p. 297) may result in the *They* becoming concealed from their *being-toward-death*. In other words, as Cerbone explains:

'Experiencing the deaths of others contributes to *Dasein's* tendency to evade or cover up over its own finitude. The deaths of others are experienced as terminating events, something that happens at the end, and to end, a person's life. Such experiences contribute to a purely futural way of thinking about death, as something that will happen somewhere off in the distance, thereby encouraging the thought that '*one also dies at the end, but for now one is not involved*' (BT, p. 253. Italics original) (Cerbone, 2008, p. 87).

Nurses as well as doctors consider themselves to have failed if a patient dies (Pietroni, 1991) and as a consequence, withdraw from the bedside as they are unable to deal with their ontological confrontation with death (Kübler-Ross, 1969). Such fleeing in the face of death and defeat alienates ICU nurses from their potential for *being* and as a consequence, their *being-toward-death*, causes *Angst* and guilt. Intensive care nurses do not doubt that critically ill patients may die, but their own ontological confrontation with death and the inability to be *ready-at-hand* in the *lifeworld* of ICU nursing propels them into anxiety and fear.

Assumptions may be made that confrontation with death and dying has limited ICU nurses' involvement with dying patients and this has impacted on the care at end of life in the critically ill. This is highlighted more fully in the next chapter which reviews the nursing literature specifically at dying and death in the ICU.

In summary, this chapter addresses the philosophical underpinning of the study and Heidegger's concepts of *Dasein*, death and technology and their relationship with dying and death in ICU nursing.

CHAPTER THREE

Review of the Nursing Literature

Death Education and Nursing

In the USA, Quint's study on the education of nurses with dying patients highlighted the inadequacy of educational provision for nurses (Quint, 1967). The study highlighted the tendency of nurses to limit involvement with dying patients. One of the worrying reasons for such withdrawal behaviour has been identified as the lack of appropriate education (Quint 1967; Kübler-Ross, 1969). When health professionals identified when a patient was dying, they withdrew from the bedside because they were unable to cope with the process of death themselves, let alone support the patient in his or her final moments.

By the late 1970s and early 1980s, undergraduate training of nurses in the UK included some contribution towards death education. The training tended to focus on the practical and legal aspects of death and dying, with very little input on interpersonal skills, until the hospice movement was popularised in the late 1980s, linked to what was later to be known as palliative care (Doyle, 1991). Despite the inclusion of death education content in British nursing programmes, student nurses stated that their preparation to provide end-of-life care (EoLC) was inadequate (Doyle, 1991).

Nursing schools in the USA, Canada and in some Scandinavian countries spend on average nine to 14 hours on death and dying related topics using an integrated approach of didactic and experiential learning strategies (Wass, 2004). Likewise, in the USA offerings of death education (EoLC) have increased in nursing schools. But still large gaps in health-care professionals' knowledge and strategies in dealing with patients' end-of-life issues persist (Aulino & Foley, 2001). In the ICU arena, nurses do not receive extensive education on how to care for dying patients, their families and, in particular, the nurses themselves (Allchin, 2006; Ferrell, Virani, Grant, Coyne & Uman, 2000). This suggests that inadequate or inappropriate attention is being paid to death and dying.

This pedagogical concern has been reflected in an analysis of end-of life content in 14 critical care nursing textbooks that were identified from the libraries of Wisconsin-Madison and Brigham Young universities in the USA. My personal and collaborative experiences with tertiary postgraduate nursing institutions nationally and internationally, most of these textbooks are used by South African nurse academics and some are recommended by the South African Nursing Council (SANC)²¹. Furthermore, critical care nursing textbooks are authored mainly by nurse authors from the USA, Canada, the UK and Australia and therefore do not address the unique South African issues pertaining to death and dying. This includes multi-cultural societies and the different types of death that patients and ICU nurses are exposed to (Hodgson, 2006; Scribante, Schmollgruber & Nel, 2004).

These types of death experiences include horrific body disfiguring road accidents, violent crime, auto-immune deficiency syndrome (AIDS) related illness and severe sexual violations. The analysis by Kirchhoff and colleagues from the American Association of Colleges of Nursing (AACN) revealed that there was a significant need for improving EoLC content, especially the psychological processes that patients, families and nurses experiences so that they can be helped with their suffering, grief and loss (Kirchhoff, Beckstrand & Anumandla, 2003).

Although death education has been researched in the USA, Canada and the UK, I was unable to source any relevant literature during a search for South African-based research using the following databases: (i) Educational Research Information Center (**ERIC**); (ii) Dissertation Abstracts International (**DAI**); (iii) **MEDLINE**; (iv) Academic Search Premier via **EBSCO** Host and (v) Cumulative Index to Nursing and Allied Health (**CINHAL**) using key words such as *thanatology, death education, death and dying, end-of-life care, nursing education, critical care/ICU nursing curricula and the South African Nursing Council (SANC)*. In South Africa, the SANC stipulates the teaching, learning and clinical requirements for a postgraduate nursing specialisation such as Intensive/Critical Care nursing. Although dying and death and EoLC are topics that should be considered in adding into the critical care nursing curriculum, the SANC does not indicate how the subject content is to be taught and such prescription is to be expected.

²¹. The South African Nursing Council aims to serve and protect the public involving health services. Other functions of the SANC is to establish, improve and control conditions and standards of nursing education and training according to the Nursing Act (2005) and any other applicable laws (SANC, 2006). The Nursing Act. № 33 of 2005 regulates the nursing profession in South Africa.

Generic subject areas are based around: (i) health assessment; (ii) pharmacology; (iii) psychological care (patient and family); (iv) nursing care; (v) ethical/legal issues; (vi) cultural issues; (vii) resuscitation/brain death, organ transplantation and lastly withdrawal/withholding of treatment.

End-of-life care does not include any aspect of the ICU nurses themselves, but focuses primarily on the patient and to a lesser extent the family. For this reason, critical care nurse educators who are involved in curriculum design may have to revisit issues and address omissions regarding EoLC in curriculum design may have to revisit issues and address omissions regarding EoLC.

In my review of the literature on caring in the ICU, the strongest focus was on the role of family members in the care of critically ill patients. However, the literature is limited with regard to the dying and deaths of patients in the ICU and the ontological challenges facing the ICU nurse. For the purpose of this study, the literature reviewed is centred on the dying and deaths of patients in the ICU and the effect that it has on ICU nurses and the delivery of patient care.

Review of the Nursing Literature Centred on Dying and the Deaths of Patients in the ICU and ICU Nursing

Rushton maintains that professionals in ICUs, although overworked and overwhelmed, are diligent in their caring (Rushton, 1991). However, 'the ICU environment can be dehumanising for care-givers' by virtue of, among others, inconsistent philosophies about patient-care delivery and decision-making, lack of professional skill and increasing technology (Rushton, 1991, pp. 238-240). There is much published literature on the stressors experienced by ICU nurses (Bailey, Steffen, & Grout, 1980; Brosche, 2003; Buysen, 1996; Hay & Oken, 1972; Lally & Pearce, 1996).

Research into nurse-caring behaviours in the care of the dying patient in the ICU generated some interest as far back as 1971, albeit with no explicit Heideggerian philosophical underpinning. The research concentrated mainly on comfort care of the patient, patient feelings, support to colleagues, patient rights and family care. However, there were a few studies exploring nurses' feelings in coming to terms with their own fear of dying.

Michaels' (1971) study highlighted the strain that nurses experienced when exposed to repetitive deaths. Concurring with Quint's (1967) study, which is discussed in further detail below, McGory found that nurses developed self-protective strategies that diminished their ability to provide humane care (McGory, 1978). Learning to cope with the grief experienced by ICU nurses in caring for a dying patient received some attention by Simon (1980). In 1985, Alspach and Williams, in conjunction with the American Association of Critical Care Nurses, (AACCN) reviewed the **'Core Curriculum for Critical Care Nursing.'** The purpose of the authors' review was to evaluate nursing care based on whether or not the dying process was positively influenced. It was at this time that some content in end-of-life care was introduced into a Critical Care Nursing curriculum, although the curriculum centred on nursing care of the patient and to some extent the family. The ICU nurses' needs with regard to understanding and coping with death and dying were given minimal attention.

The ICU nurses' experiences of dying and death are discussed in detail in more recent studies. These will be dealt with here in chronological order and not in order of significance. This is to assist a diverse readership in engaging with the concept of dying and death and to take cognisance of the fact that there still remains little attention given to death and the ontological educational needs of ICU nurses.

In 1994, Spencer, a nurse educator in Manchester, England, conducted a study exploring how ICU nurses handled their own grief when a patient died in an ICU. From Spencer's experience of having worked in ICU for many years, the issue of grief amongst ICU nurses was not addressed directly nor was it recognised as needing any consideration. The study also set out to investigate whether the convenience sample of ICU nurses (N = 72) felt that they received adequate support from their colleagues and from nursing and hospital management, or whether they felt more help was required. Using a mixed methodology and methods of quantitative and qualitative approaches, information was first collected by using a questionnaire and analysed using a computer statistical programme. To explore the ICU nurses' feelings of grief in more depth, a semi-structured interview was used and the results were recorded manually.

A summary of the results is presented here under the headings of the questions asked of the ICU nurses.

1. How do nurses deal with their grief at present, following the death of a patient in ICU?

The majority of the ICU nurses experienced feelings of sadness, anger, shock and relief. Some of the ICU nurses (n = 21: 41%) expressed feelings of guilt when a patient died. Talking to colleagues or even the family of the deceased patient was a strategy used to deal with grief.

2. Is any support given to ICU nurses by their peer group? If so, what form does it take?

The results from this study suggested that the ICU nurses did receive some support from their peer group, mostly in the form of informal (tea-room) discussions.

3. Is any support given to ICU nurses by their managers to help them overcome their grief? If so, what form does it take?

In this particular study, there was a full-time nurse counsellor at the hospital. It was interesting to note that not all the ICU nurses were aware of her availability. Several authors have commented that nurses generally do not like to admit that they are unable to deal with their feelings (Casey, 1991; Charnock, 1985; Slater, 1988). Having a counsellor available could also be seen as a barrier to this support system as Adey (1987) found in her research. Nurses were reluctant to confide in outside personnel as it was felt that they were not experienced or not exposed to the pressures faced by nurses and therefore unqualified to offer support or advice.

4. Do ICU nurses feel that more information about how to deal with their own grief, given during their training, would have been useful?

The results showed that the majority of the study participants had received little or no training. Upon questioning the ICU nurses as to what training they felt would be beneficial, assertiveness training was identified as being valuable. This strategy could assist the ICU nurses to appreciate their own feelings and to know which feelings are normal. Bleazard (1984) ascertains that in order for any nurses to be effective counsellors, they need to be aware of their own feelings and emotions.

5. If more support is wanted by ICU nurses, in what form would they find it most helpful?

Only 15 participants (7%) felt that a counsellor would be helpful. This reiterates the results from Adey's (1987) study that counsellors may be seen as obstacles and hinder any form of grief support. Half of the ICU nurses requested more support from the workplace such as 'person-to-person chats' with another ICU nurse, a counsellor or even within a self-help group.

The results from Spencer's study highlight the need for support from the ICU nurses' peer group(s) and that more training in counselling skills, assertiveness training and self-awareness programmes should be included in post-registration nursing programmes.

Although not a study focusing on death and dying in the ICU, Copp's (1994) study exploring hospice²² patients' construction and management of their experiences in confronting impending death, and on the nurses' experiences in caring for them as they died, warrants some mention. The data was collected using unstructured interviews and participant observation.

The main finding in Copp's study was that patients and nurses persistently engaged in a process of encountering. Taking on a multitude of forms encountering may include, 'face-to-face contact,' 'direct or indirect action' in planning and 'manoeuvring' situations behind the scenes. Copp pointed out that patient-nurse/nurse-patient interactions were often antagonistic but were still seen as acts of caring. Acts of 'protecting and controlling,' 'watching and waiting' and 'holding on and letting go' were recognised and provided fundamental aspects in 'furthering an understanding of the complex strategies and interplays that are acted out in order to cope with the process of dying' (Copp, 1994, p. 388).

To identify expert nursing behaviours in the care of the dying adult in the ICU, a study was conducted by McClement and Degner (1995). The settings were one tertiary care hospital surgical ICU and one community hospital medical-surgical ICU in a western Canadian city. Ten expert ICU nurses were recruited and an exploratory and descriptive design was employed. The theoretical concept for this study was

22. In 1967, Dame Cicely Saunders at St. Christopher's Hospice in London first applied the term 'hospice' to specialised care for dying patients. Today, hospice care provides humane and compassionate care for people in the last phases of incurable illness or disease so that they may live as fully and comfortably as possible (American Cancer Society, 2009).

drawn from Quint's 1967 study of how nurses learned to care for the dying and the Dreyfus' Model of Skill Acquisition (Dreyfus & Dreyfus, 1980). Quint was of the opinion that nurses would assume the behaviours of other health-care professionals working in the same environment and would limit their involvement in death-related situations. For Quint, these behaviours were as a result of the nurses not receiving educational support when exposed to dying patients (see Figures 2 and 3).

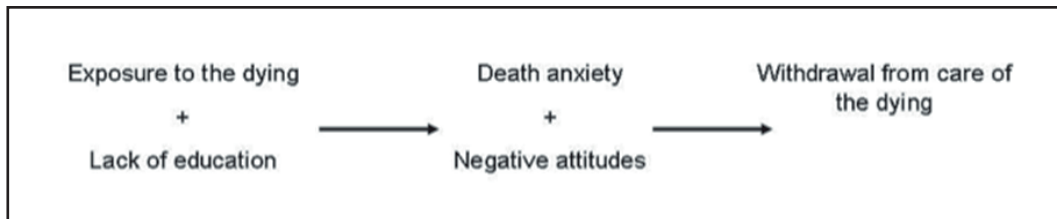


Figure 2. Quint's Theoretical Framework from McClement and Degner (1995, p. 409).

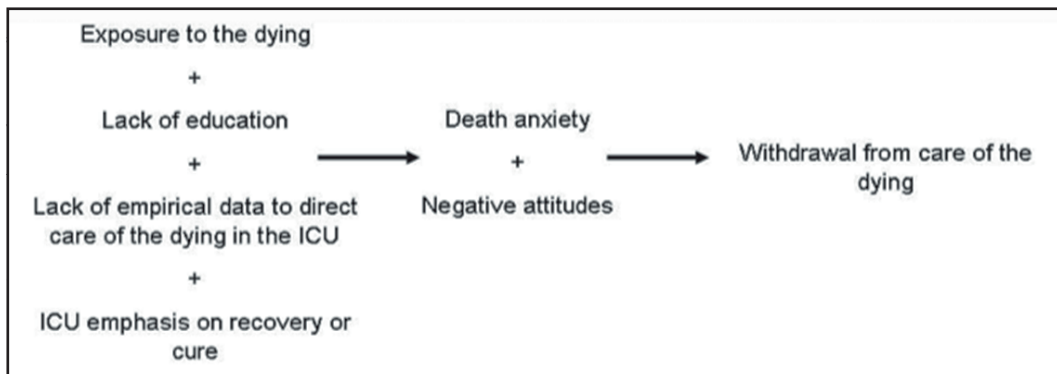


Figure 3. McClement and Degner's Revised Theoretical Framework (1995, p. 409).

Dreyfus and Dreyfus (1980) advocated that clinical judgement could be thought of as a cognitive skill and developed a theory of skill acquisition that consisted of five stages of performance based on increasing levels of experience. Benner (1984) asserted that the model could be generalised to apply to nursing by analysing data from interviews and participant observation of novice and experienced nurses (see Figure 4). Benner believed that a wealth of 'untapped knowledge is embedded in the practices and the know-how of expert nurse clinicians' and this systematic 'documentation of expert clinical performance in the care of the dying is the first step in clinical knowledge development' (McClement & Degner, 1995, p. 409).

<p>Stage 1: Novice</p> <p>The Novice or beginner has no experience in the situations in which they are expected to perform. The Novice lacks confidence to demonstrate safe practice and requires continual verbal and physical cues. Practice is within a prolonged time period and he/she is unable to use discretionary judgement.</p>
<p>Stage 2: Advanced Beginner</p> <p>Advanced Beginners demonstrate marginally acceptable performance because the nurse has had prior experience in actual situations. He/she is efficient and skilful in parts of the practice area, requiring occasional supportive cues. May/may not be within a delayed time period. Knowledge is developing.</p>
<p>Stage 3: Competent</p> <p>Competence is demonstrated by the nurse who has been on the job in the same or similar situations for two or three years. The nurse is able to demonstrate efficiency, is coordinated and has confidence in his/her actions. For the Competent nurse, a plan establishes a perspective, and the plan is based on considerable conscious, abstract, analytic contemplation of the problem. The conscious, deliberate planning that is characteristic of this skill level helps achieve efficiency and organisation. Care is completed within a suitable time frame without supporting cues.</p>
<p>Stage 4: Proficient</p> <p>The Proficient nurse perceives situations as wholes rather than in terms of chopped up parts or aspects. Proficient nurses understand a situation as a whole because they perceive its meaning in terms of long-term goals. The Proficient nurse learns from experience what typical events to expect in a given situation and how plans need to be modified in response to these events. The Proficient nurse can now recognise when the expected normal picture does not materialise. This holistic understanding improves the Proficient nurse's decision making; it becomes less laboured because the nurse now has a perspective on which of the many existing attributes and aspects in the present situation are the important ones.</p>
<p>Stage 5: The Expert</p> <p>The Expert nurse has an intuitive grasp of each situation and zeroes in on the accurate region of the problem without wasteful consideration of a large range of unfruitful, alternative diagnoses and solutions. The Expert operates from a deep understanding of the total situation. His/her performance becomes fluid and flexible and highly proficient. Highly skilled analytic ability is necessary for those situations with which the nurse has had no previous experience.</p>

Figure 4. A Summary of Benner's Stages of Clinical Competence (Benner, 1984, pp. 13-34).

The descriptions from the ICU nurses resulted in six categories of behaviour being identified by McClement and Degner (1995) which were analogous to the categories generated by palliative care nurses and nurse educators from the work of Degner, Gow and Thompson in 1991 (see Table 6). The six categories generated were: (i) responding during the death scene; (ii) responding to family; (iii) responding to anger; (iv) responding to colleagues; (v) providing comfort and (vi) enhancing personal growth. However, there were a number of significant differences between the studies of Degner et al. (1991) and McClement and Degner (1995).

Critical nursing behaviours in care for the dying. Degner, Gow & Thompson (1991). Palliative Care Nurses	Identifying nursing behaviours in care of the dying adult in ICU. McClement & Degner (1995) ICU Nurses
1. Responding during the death scene	1. Responding after death has occurred
2. Responding to the death scene	2. Responding to family
3. Responding to anger	3. Responding to anger
4. Responding to colleagues	4. Responding to colleagues
5. Providing comfort	5. Providing comfort care
6. Enhancing personal growth	6. Enhancing personal growth

Table 6. Comparison of Themes from Degner et al. (1991) and McClement and Degner (1995)

A sub-category of **enhancing the quality of life** while dying, which was a category identified by Degner et al. did not emerge in McClement and Degner’s study. In this sub-category, palliative care nurses are able to help patients do things for themselves. This requires an interval of time in which nurse-patient relationships can be established. This caring behaviour does not always exist in ICU settings because dying patients in the ICU often have a rapid-dying trajectory.

The second category in the study by Degner et al. identified the importance of palliative care nurses **maintaining a sense of calm and family involvement** during the death scene. By contrast, ICU nurses stated that responding after the death had taken place, was an important aspect for them. The ICU nurses stressed that they encouraged family involvement with the dying patient while the patient was still alive. However, they frequently elaborated that patients admitted into the ICU died soon after admission and that the conceptualisation of the ‘death scene’ rarely if ever had time to occur. In addition, the death scene in an ICU was regularly one of chaotic intervention aimed at instituting technological and complex pharmacological support in order to prolong life.

Thirdly, palliative care nurses and nurse educators did not emphasise the importance of the nurses creating a **bedside environment of dignity and peace** for the family once the patient had died. It was postulated that families were more able to be present at the death scene than in acute care settings such as the ICU. As there

were no life-saving interventions at the time of death, the bedside environment was never in a state of disorder.

Category four – **providing comfort for dying patients** by palliative care nurses in the Degner et al. study - highlighted a nursing behaviour of ‘a palliative care nurse’s avoidance that results in neglect’ and ‘poor symptom management due to poor knowledge base.’ Even though ICU nurses admitted that some neglect of the patients did occur, the neglect tended to be of a psychological nature rather than a physiological one. The management of a dying patient’s physiological care is carried out systematically and efficiently by ICU nurses but little time is available to minister psychological care or this type of care may be hindered by the patient receiving large doses of sedation or being in a comatose state. The symptom management of pain and discomfort, to name just two, was not seen as a problem by the ICU nurses in McClement and Degner’s (1995) study.

In both studies, the fifth category was one of **showing empathy and respect** for the patient and family who were angry. The palliative care nurses and ICU nurses both understood the source of anger and did not take the expression of anger personally. It was noted by Degner et al. that some of the ways that the palliative care nurses reacted was as a result of them not developing a philosophical approach to managing anger. The nursing behaviours by the palliative care nurses revealed that they avoided the patient’s room, spoke harshly or showed their frustrations to the patient and the family. For the ICU nurses who acknowledged that constantly avoiding angry patients and family and responding harshly were negative behaviours in care of the dying, short-term avoidance was an understandable and acceptable behaviour. Taking ‘time-out’ from intense anger situations was seen as a safety valve that prevented the ICU nurses from saying and doing things that they might regret at a later stage.

However, it was important to be aware that the negative reactive behaviour was short lived so as not to imply that the nurse was insensitive towards the patient and family needs. A study conducted by Vachon, Lyall and Freeman (1978) which looked at the measurement and management of stress experienced by health-care professionals working with patients with advanced cancer, noted that palliative care nurses who had been socialised to know that ‘the good nurse’ – one who never portrayed bad feelings - worked in isolation from their colleagues. This resulted in ‘bad nurses,’ who at times felt angry, depressed, helpless and hopeless.

Both the studies by Degner et al. (1991) and McClement and Degner (1995) revealed that it was important for palliative care nurses and ICU nurses to give critical feedback to colleagues. However, the literature reviewed by Degner et al. and the study participants of their study did not elaborate on the concept of timeliness in the provision of emotional support. By contrast, the ICU nurses expressed strongly that the timeliness of the feedback and support was very important.

There is minimal literature available about the domain of emotional and organisational support for ICU nurses and other health-care professionals working in the ICU environment (Clarke, Curtis, Luce et al., 2003). The need for formal debriefing sessions, particularly after life-support measures had been withdrawn has been highlighted by Jones and Fitzgerald (1998). Intensive care unit meetings focusing on counselling after a patient had died, seldom or never occurred (Puntillo, Benner, Drought et al., 2001).

The category of **responding to the family** was identified in both studies as an important caring/nursing behaviour. By responding to the families' need for information, the probability for future regret may be lessened. The ICU nurses also referred to the significance of responding to the families' need for information, but they indicated that they tried more to facilitate the process of emphasis on care being rather palliative than curative in cases where patients were not going to survive. It was highlighted by the ICU nurses that during this transition period they did not completely dash all hope of survival for the patient and also did not make the family feel abandoned when all treatment was withdrawn.

In McClement and Degner's study, negative nursing behaviours in care of the dying 'had their genesis in avoidance and withdrawal' (McClement & Degner, 1995, p. 418). Intensive care nurses find that caring for dying patients and grieving families in the ICU is very stressful. The failure of care-givers to drop the armour of professionalism has been viewed as synonymous with inhumane treatment of the dying (Ufema, 1998).

Concluding remarks in McClement and Degner's study pointed out that ICU nurses strongly believed that care-givers (including themselves) needed to risk being involved with dying patients and their families despite concerns about what to say or do. The consequences of minimal contact with dying patients and their families may affect ICU nurses' experience of the grieving and bereavement process and may have long-term implications for the wellness of their *being*.

The terms of grief, bereavement and mourning are often used interchangeably: grief is the personal response, bereavement is the loss itself and mourning is the social or public face of grief (Doka, 1999).

Lastly, the six nursing behaviours identified in this study could be considered as a framework for nurse educators to design programmes for care of the dying.

Critical care nurses' lived experience of unsuccessful resuscitation was explored by Isaak and Paterson in 1996. The research methodology was informed by the philosophical viewpoint of Benner (1984; 1994) using interpretive phenomenology. Critical care nurses (N=9) were recruited from intensive and cardiac units in a tertiary hospital in Vancouver, Canada. The participants' narratives were obtained through interviews and 'paradigm exemplars' described as 'a clinical episode that alters one's way of understanding and perceiving future clinical situations' (Benner, 1984, p. 296). The critical care nurses in the study were requested to relate a story about a significant event of an unsuccessful resuscitation. The narratives were transcribed verbatim and a transcript mailed to each individual critical care nurse. The nine transcribed interviews were analysed using Colaizzi's (1978) framework and three themes emerged.

1. Knowing what to expect was the theme that expressed the critical care nurses' coping abilities. They felt better prepared as a result of past 'learning' experiences. The sense of being technologically proficient in terms of 'smoothness, efficiency and control' gave them some purpose even when the resuscitation was unsuccessful and the patient died (Isaak & Paterson, 1996, p. 693). They felt that they were also able to protect themselves from anxiety and guilt by being technologically and clinically competent: *'You could tell when you looked at him that there was an imminent arrest. You could tell that he wasn't going to do well'* (Isaak & Paterson, 1996, p. 693).

The age of the patient also had some significance in that the younger patient was expected to survive the resuscitation efforts. In cases where resuscitation was unsuccessful, the critical care nurse was more affected by the death.

2. The aftermath was the next theme to emerge. This aftermath was characterised by attempting to normalise the environment, doing a 'post-mortem' of the experience, feeling the physiological effects (adrenaline rush) and caring

for the family and significant others. The environment was tidied up and made calm for outsiders. This entailed clearing away clutter from resuscitation and stocking up trolleys and cupboards, as well as preparing the body to be taken to the mortuary. Other normalising actions included protecting other patients and their families by drawing the bedside curtains closed and speaking quietly in an effort to avoid anxiety and fear about the outcome of the resuscitation.

The 'conducting of a post-mortem' after an unsuccessful resuscitation was seen as a learning opportunity. It involved the critical care nurses analysing their performance in terms of knowledge, skill and efficiency. At these post-mortem sessions, also many described how they felt weak and exhausted; some said they were unable *'to take in anything else'* and were generally *'numb'* for the rest of their shift (Isaak & Paterson, 1996, p. 695).

- 3. Care of significant others**, including the provision of information, emotional support and access to suitable resources was the last theme to emerge. The critical care nurses maintained that they were better able to care compassionately if they understood the significance of the patient's death on the family: *'This was more than just an 18 year old boy. This was someone's son.'* Another obstacle to compassionate care was that the critical care nurses may not have met the family prior to the resuscitation: *'It's a bit hard when you hardly know the family. If you've developed a bit of a relationship with the family, I find it a little easier to be supportive'* (Isaak & Paterson, 1996, p. 695).

A concern shared by the critical care nurses in this study was that of a sudden 'switch' from being focussed, assertive and emotionally detached during the resuscitation and having to show compassion and interaction with the family. One critical care nurse described this 'switch' as *'reaching inside of you to find your feelings.'* Another participant said it was like learning to *'be an actress'* (Isaak & Paterson, 1996, p. 695).

Grief, loss, guilt, anger and regret were identified by the participants following an unsuccessful resuscitation. Some of these emotions were triggered weeks after the resuscitation by a sound or smell, although the critical care nurses who reported such instances were more often than not more connected to the patient and family. Having a connection with a patient who did not survive resuscitation was viewed by the participants as a 'double-edged sword.' For these critical care nurses, feelings of helplessness, anxiety and emotional distress were highlighted.

Some of the critical care nurses particularly felt guilt, anger and regret following an unsuccessful resuscitation if the wishes of the patient that they had developed a 'connection' with were not respected. Intense grief was experienced when the critical care nurse had 'personalised' the loss of a patient because the patient's personality, situation and age reminded them of themselves or of a loved one.

The type of job that the participants were in, involved a number of demands which required on-going prioritisation. As a result the critical care nurses felt that they were unable to care for the patient and family adequately. Some of the participants then 'professionally distanced' themselves when they believed that the patient would die and that the death would be disturbing to the family and significant others.' Such 'professional distancing' did not mean that the critical care nurses stopped caring, but rather, that they 'shielded' themselves from the emotional consequences of an unsuccessful resuscitation: *'There was a part of me that also distanced myself from him because I knew he wasn't going to make it'* (Isaak & Paterson, 1996, p. 697).

The death of some patients was not always seen as a sad event by the critical care nurses. Many felt that the death was better than the patient surviving and having a poor quality of life.

In an attempt to minimise or negate the emotion connected with an unsuccessful resuscitation, the participants in this study emphasised the importance of 'letting go.' At times the 'letting go' started with preparing the body for the mortuary and seeing the patient as the 'shell' of his/her former being. Crying privately was another strategy employed by the critical care nurses in an attempt to put the event 'behind them': *'I grab a book or a hot bath and have a good cry, and that's it. I mean I leave it after that and usually go to bed early. I'm drained for the next day. But I leave it after that. I just don't want to talk to anybody. I don't want to live it again'* (Isaak & Paterson, 1996, p. 697).

In the study by Isaak and Paterson (1996), the key findings revealed that critical care nurses' experience of unsuccessful resuscitation was dynamic and multi-faceted. This required that they employ various coping strategies.

Simpson's (1997) grounded-theory study examined the experiences of 14 qualified ICU nurses caring for patients in an 18-bed ICU whom they did not believe were going to survive. The study was conducted in a public hospital in the UK.

The findings suggest that inexperienced ICU nurses often find it difficult to understand why decisions are made to continue or discontinue treatment. Simpson further suggests that in order for these patients to be cared for humanely and with dignity, an overt multi-disciplinary approach to care is necessary to ensure sound decision-making processes (Simpson, 1997, p. 196).

A study by Bush and Barr (1997) used a phenomenological approach to formulate the fundamental structure of caring as a lived experience of ICU nurses. They considered the experiences of 15 ICU nurses who were employed in six large metropolitan hospitals in the south-western region of the USA.

The results showed that caring was composed of affective, cognitive, action and outcome sub-processes. The process root of caring originated in the nurses' feelings and knowledge, and moved the nurse to competent actions that contributed to patient, family and nursing outcomes.

A phenomenological study exploring paediatric ICU nurses' experiences of grief when children died was undertaken by Rashotte, Fothergill-Bourbonnais and Chamberlain in 1997. The study setting was an ICU in a Canadian paediatric metropolitan university teaching hospital in Ottawa. Using a Heideggerian phenomenological approach, semi-structured interviews were conducted with six paediatric ICU nurses and analysed using Colaizzi's (1978) method of induction. From the data, three themes emerged: (i) grief reactions; (ii) contextual factors and (iii) coping strategies.

Under the theme of **grief reactions**, the sub-theme of hurting was identified. Some of the paediatric ICU nurses' anecdotes included: *'It left me with a really bad pain. I felt so rotten' and 'It tore me apart for a couple of weeks'* (Rashotte et al., 1997, p. 377). Further to the findings, the emotion of sadness or sorrow was expressed, which resulted from the paediatric ICU nurses' involvement and empathy with the family. The complexity and period of sadness were dependent on the attachment to the child and/or family and how visibly distressed the family were at the time of the child's death. Of note was that the less experienced nurses were overwhelmed by sadness, whereas the more experienced nurses were able to identify emotions that seemed to alleviate their sadness such as a sense of relief because the child had not died in pain. In Spencer's 1994 study (page 37) exploring grief of adult ICU nurses, all but one nurse acknowledged that they had experienced feelings of relief when a patient died.

Variations of hurting were dependent on the context of the death. These included accountability, anger, emptiness, powerlessness and vulnerability. The hurt associated with accountability was expressed in levels of guilt ranging from feelings of regret to feelings of culpability. Intertwined feelings of anger and guilt resulted from deaths that continued to haunt these study participants even after a considerable time following a child's death. Excerpts from the participants' narratives describe this: *'Did I do something? Did I miss something? Could I have made a difference? Should I have spoken up five hours earlier and been more aggressive and said: "Enough is enough. Stop this ridiculousness. Do you see what we are doing? Do you see what we are perpetuating here!" Then I feel anger. I feel frustrated. I feel self-recrimination from the fact that I didn't speak up'* (Rashotte et al., 1997, p. 378).

Anger was felt by all the participants, irrespective of their years of experience. However, it was less articulated by the inexperienced paediatric ICU nurses. It appeared that as the ICU nurses gained more experience, their guilt transformed to anger when they no longer felt accountable for the childrens' deaths that were beyond their control.

Contextual factors which involved the 'nature of the nurse-family unit' highlighted the closeness of the relationships in which the participants became 'emotionally bound' and 'attached,' especially if the family spent a great deal of time in the ICU. The longer the family were in the ICU, the longer and more intense the grief experienced by the nurses. The nurses' feelings of grief were even more pronounced when the 'emotional connectedness' had been made directly with the child as if the nurse became part of the family. The grief reaction was of long duration and great intensity when the child died' since the child had become such a significant figure in their lives' (Rashotte et al., 1997, p. 378).

From the nurses' narratives, the theme of **dissonance** emerged as an unassailable contextual factor affecting the intensity, type and duration of the nurses' grief reactions. The context of 'dissonance' in this study referred to the 'clashing of co-existing beliefs, values or expectations within themselves or others when the reality of the child's death contradicted their expectations about death and dying processes' (Rashotte et al., 1997, p. 379).

Some of the nurses' grief reactions were influenced by: (i) their beliefs about the ideal death; (ii) their philosophy of what intensive care nursing was and the how the delivery of nursing care to the dying child fitted into this philosophy and (iii) the nurses' professional responsibilities and their own emotional needs. Grief reactions were often affected by the nurses' powerlessness to reconcile their personal beliefs on the 'right way to die with the reality of how children often did die in the ICU' (Rashotte et al., 1997, p. 379). Children whose deaths were described as 'senseless' or 'preventable' were harder to accept. These types of deaths resulted from child abuse, drownings, being run over by cars and trucks and not wearing bicycle helmets.

The nurses in this study were very vocal about the manner of death for a child. In their minds, it should be peaceful or uneventful but the very nature of ICU environments interfered with this. The following anecdote illustrates the type of death that children in the ICU may have: *'Probably most kids who die are hooked up to all kinds of equipment and probably are not aware either because they're not cognitively developed to that level or they are sedated to such an extent. Does that bother me? I guess it comes back to I don't think that's a nice way to die but it clearly reflects the environment which I work in. And it reflects the type of health system that we have. I don't think being hooked up to 6 different pieces of equipment is a nice way to die'* (Rashotte et al., 1997, p. 379).

The same nurse describes a more acceptable scenario: *'I think that it would be nice if we could offer the parents and the child something more pleasurable. I guess from my perspective that would be not having them hooked up to all kinds of things and allowing the parents to hold the child if they want before the child dies, not after. But that's not usually the way it is and I guess maybe it's a bit of a fantasy. Maybe it presents a nice rosy picture to have the child feel comfortable in the mother's and father's arms. It's harder to envision that when they're hooked up to a respirator and that to see, you know the child and the parents cuddling is somehow comforting. It's a nice picture. It's a nicer picture than seeing parents kind of leaning over a bed where their child is lying. You don't get to see that on Hallmark cards you know. I guess it's my perception that it would, it's better'* (Rashotte et al., 1997, p. 379).

The institution's policies and procedures also interfered with these ICU nurses' values. If the child died under any circumstance that required a post-mortem (autopsy), the nurses felt that they were unable to still care for the deceased child as all tubes had to remain in place. This also did not allow for the parents to hold their child.

Another concern was the preparation of the body for transportation to the mortuary. The child's body had to be wrapped in a plastic shroud after the limbs were tied together. Placing the body in a suitcase-like structure for transportation was seen as disrespectful and inhumane. One participant describes her feelings when having to leave a dead infant at the mortuary: *'But the worst feeling I had was when I brought him to the morgue [shudders]. We went into the morgue where they put the bodies and there was nobody in there and it was cold. It was horrific. Like I put [child's name] down and I gave him a great big hug and a big kiss [crying], and he's going to be there alone in there all night [sniffles]. And there was no more respect, there was no more love, there was no more feeling. It was ruthless'* (Rashotte et al., 1997, p. 380).

One of the **coping mechanisms** used by the participants was 'self-expression' which appeared to have a public and private domain. Some of the participants had written articles or presented at conferences or became involved in projects associated with death and dying. By contrast, a considerable number of the nurses expressed their feelings more privately.

This was done by keeping a journal or diary, while others spoke of using humour (black or gallows humour)²³, especially when they felt emotionally challenged in their workplace.

Other coping strategies included talking with family, friends and colleagues but on many occasions reluctantly, as the nurses did not want to upset anybody. Of note was that the newer nurses who had less or no experience of death did not have an established support structure, and as a result, were unable to discuss the death processes and their own grief. This had a negative impact on the inexperienced ICU nurses as their grief was 'silenced' and it took them much longer to come to terms with a child's death.

Rashotte et al. (1997) point out that for some of the inexperienced nurses in their study, the interview was the first time that they had had an opportunity to openly deliberate on the details surrounding the child's death as well as on their grief responses.

²³. A humorous way of looking at or treating something that is serious or sad (Cambridge Dictionary Online, 2013).

The theme of **self-nurturance** emerged after the participants described their use of an assortment of activities to nurture themselves and re-establish a sense of stability in their grief, even if only temporarily. Self-nurturing activities included buying something for themselves, exercising or gardening. The activities chosen were seen as mindless, requiring minimal concentration and effort. Other participants preferred to surround themselves with things that were alive such as animals and plants.

The next theme to emerge was that of **termination of relationship** activities. Despite it not being a job requirement to follow up on the family after a death of a child, all the participants indicated that some form of follow-up took place.

These ranged from attending the funeral, writing a letter, making a phone call or even visiting the family. Studies exploring how hospice nurses coped with their stress (Eakes, 1990; Gray-Toft & Anderson, 1986; 1987) showed similar findings. Sheard (1984) acknowledged that follow-up with the deceased patient's family was a strategy for terminating the extended relationship that nurses often developed with families.

Developing control over certain aspects of their practice was also seen by nurses as a strategy for managing their grief. This apparently developed from the professional role of being a nurse and included: (i) establishing boundaries; (ii) withdrawing or distancing themselves and (iii) fulfilling personal death rituals.

The last theme of **self-reflection** revealed that the participants were still haunted by certain deaths. On one hand, this could be seen as re-affirming that the nurses were caring human beings in a highly technical and at times inhumane environment. In addition, it appeared that the nurses' accounts formed a significant component of their experiential learning. A necessary element of experiential learning is the ability to engage in self-reflection which may aid those to 'thrive and survive' in the ICU environment (Rashotte et al., 1997, p. 383). In this study, self-reflection helped the nurses to: (i) come to terms with a child's death; (ii) create meaning and (iii) accept their own feelings of emotional pain when a child died. In addition, the nurses learned to understand how they reacted to the death of a child and identify what factors of the death affected their grief reactions.

Conclusions derived from Rashotte, Fothergill-Bourbonnais and Chamberlain's (1997) study demonstrate that paediatric ICU nurses' grief is different from that of the dead child's family. More research is needed to document more thoroughly the

experiential learning process to manage and cope with multiple and accumulative deaths for paediatric ICU nurse. Additional research is recommended, examining interventions and strategies to enhance education and support in relation to the grief experiences of nurses in general.

Two studies that include consideration of the perceptions of ICU nurses involved in end-of-life care were conducted separately in the USA (Asch, Shea, Jedrzejewski & Bosk, 1997) and in Australia (Cartwright, Steinberg, Williams, Najman & Williams, 1997). The American study surveyed ICU nurses on issues of euthanasia and used a content analysis of text comments from the 468 respondents. Eight themes were generated, the main concepts of which were: (i) the ICU nurses wished that they could have more say in the care of the dying; (ii) there was no consistency in the way dying patients were cared for and (iii) the ICU environment did not adequately promote the compassion that dying patients needed.

The Australian study mailed a 30-page questionnaire to a random sample of 1 200 health-care professionals, of whom 299 (25%) were ICU nurses. The survey sought responses on a number of issues associated with the care of the dying in the ICU. The outcome of the study highlighted that the ICU nurses: (i) wished for better pain control for dying patients; (ii) saw the need for improved communication between physicians and patients and also between physicians and nurses and (iii) thought of themselves as advocates for the dying patient.

Neither study reported on the care of the ICU nurses themselves as proposed by Van Hoof's (1996) ontological structures regarding caring about oneself. Looking back to Aristotle's thinking of wholistic care - caring for one's self and caring for others - it is not clear in either study whether such care was given to the dying patients.

From the American study, the Institute of Medicine (IM) in 1997 recommended improving and strengthening the knowledge base of end-of-life care for health professionals. It must be noted that, during this period, research on approaches to make the ICU environment more compatible to facilitate improved care was limited (Ferrell, Virani, Grant, Coyne & Uman, 2000; Kirchhoff & Beckstrand, 2000; Kirchhoff, Spuhler, Walker, Hutton, Cole & Clemmer, 2000).

Taking the American and Australian studies further, Beckstrand, Callister and Kirchhoff (2006) embarked on a larger study in order to obtain ICU nurses' suggestions for providing a 'good death' for patients dying in the ICU. By conducting this study, it was hoped that the suggestions would facilitate appropriate end-of-life care. Questionnaires consisting of three mailings were sent to a geographically dispersed, random sample of 1409 members of the American Association of Critical Care Nurses (AACCN). The respondents had been registered nurses for a mean of 19.8 years and had worked in the ICU for a mean of 16 years. The response rate was 61% and the most important finding was the importance of having more time to care for dying patients (100% of the respondents).

The main theme identified by this study was that the respondents wanted to provide dying patients and their families with a 'good death' with an emphasis on dying with dignity and not dying alone. Barriers to facilitating a 'good death' included shortages of ICU nurses which consequently contributed to the lack of time to care for dying patients. Other barriers mentioned were communication challenges, unrealistic expectations held by patients' families, inappropriate treatment decisions and certain aspects of physicians' behaviours.

Recommendations from this study to make possible a 'good death' were: (i) making environmental changes to facilitate dying with dignity; (ii) managing pain and discomfort; (iii) knowing and following patients' wishes for end-of-life care; (iv) promoting earlier cessation of treatments or not initiating aggressive treatments especially when care seems futile and (v) communicating effectively as a health-care team.

Even though the study respondents mentioned that all members of the health-care team should receive education about end-of-life care, the nurses were particularly concerned as they thought that their nurse training had not adequately prepared them to care for dying patients. It was only by 'learning the hard way' that the nurses gained insight into caring for the dying and deaths of patients.

Continuing with nursing studies in the USA, Kirchhoff et al. (2000) investigated ICU nurses' experiences with end-of-life care. A cross-sectional descriptive design with four focus groups was used to assess 70 qualified ICU nurses from eight ICUs at two teaching hospitals in the western region of the USA. From each focus group, tapes were transcribed and analysed following the guidelines described by Morse

and Field (1995).

The results were similar to the Beckstrand, Callister and Kirchhoff (2006) study. However, a theme of self-care was evident. The researchers asked the ICU nurses what strategies they took to care for themselves. The nurses 'seemed to *grope for answers to this question.*' *Some of the comments from the ICU nurses were: 'You just manage,' unless you live it, you don't really understand it' and 'I had somebody die today, and people who don't do this, don't get it.'* The ICU nurses' own issues around death and dying also complicated their ability to provide quality end-of-life care to the patient(s). At times they felt that they did not always know the right way to care. This was supported by a comment made by one of the ICU nurses: *'I learnt how to care for the dying in ICU from "trial and error"'* (Kirchhoff et al., 2000, pp. 40-41).

The authors concluded that the uncertainty of prognosis, disagreement among patients' family members or among care-givers, and communication problems further complicate end-of-life care in intensive care units. Recommendations made to improve the care of dying patients and their families included changes in the physical environment, education about end-of-life care, staff support and better communication.

Kirchhoff and Beckstrand (2000) expressed interest in exploring ICU nurses' perceptions of obstacles and helpful behaviours in providing end-of-life care to dying patients. Nurse members of the AACCN were randomly selected from the membership roster (N=300). The AACCN developed the **National Survey of Critical Care Nurses Regarding End-of-Life Care** by using information derived from four focus groups of ICU nurses. From the four focus groups, a 64-item questionnaire with a Likert scale response (0 = no obstacle to 5 = extremely large obstacle) was developed. Using qualitative data software, the responses were entered and calculated. The results showed that there was no single obstacle identified as large or extremely large. The ICU nurses ranked caring for patients and following their wishes as a high priority. One of the highest ranked obstacles perceived by the study sample was the behaviour of patients' families that removed critical care nurses from caring for the dying patient.

Another highly ranked obstacle was having a dying patient's family request more technological life support than the patient had wanted. Other highly ranked obstacles included: (i) family members not understanding the care that was being

recommended; (ii) family members not accepting the patient's poor prognosis and (iii) family members being angry and fighting within their group about treatment options (Kirchhoff & Beckstrand, 2000, p. 104). The consequences of these obstacles impeded the ICU nurses from providing adequate nursing care to patients that were dying in ICU.

The highest ranked helpful behaviour identified in the study was that of agreement among physicians with regard to the direction of care. Other helpful behaviours were linked to supporting or communicating with patients' families. Addressing staffing concerns and providing ICU nurses with education were also considered as significant helpful behaviours.

In response to studies by Ferrell et al. (2000), Kirchhoff and Beckstrand, (2000), Kirchhoff et al. (2000) and the AACN has developed, **'Peaceful Death: Recommended Competencies and Curricular Guidelines for End of Life Nursing Care'** (2000). Further work has been done on these guidelines by the AACN resulting in the development of **'End of Life Nursing Education Curriculum'** (ELNEC) in 2001. The ELNEC is a comprehensive curriculum consisting of nine modules to prepare baccalaureate and associate degree nurse academics for integrating end-of-life care into the basic nursing curriculum. In addition, ELNEC offers an opportunity for continuing death education in colleges, universities and speciality nursing organisations, albeit only in America.

Studies mentioned previously have highlighted that suffering of nurses has received very little attention (Doka, Rushton & Thorstenson, 1994; Rushton, 1992). To gain further insight into the phenomena of emotional distress of critical care nurses with EOL and DNR decision-making, Jezuit conducted a study in 2000 in a large mid-western medical centre in Illinois (USA). Critical care nurses with a minimum of one year's ICU experience and who had experienced suffering in that role were invited to participate through an advertisement displayed in the medical centre. The sample consisted of six critical care nurses (one male, five females) who were interviewed and asked to describe the situations and circumstances which caused them emotional suffering. From the subsequent study, the following areas of concern were identified.

Suffering Experiences with EOL Care Decisions

All of the participants were able to recall and describe a number of incidents relating to decision-making at EOL. One of the most poignant statements was made by one of the participants who had been left to adjust a narcotic infusion during the withdrawal of life-support: *'I've suffered a lot of distress. I am concerned that I am causing their death. I have to actually tell myself that I am providing comfort to a patient rather than killing them.'* Another situation that was described was that of a patient in end-stage heart disease who wished to be removed from the ventilator. The patient's request was delayed and the participant revealed that: *'I felt like I betrayed him [patient] a little bit. I felt that I was participating in something that wasn't right'* (Jezuit, 2000, p. 147).

Conflict

Conflict was common to the situations described by the participants even though each situation was different. Rushton reminds us that 'many critical care nurses experience a variety of conflicts in their care-giver role' (Rushton, 1992, p. 303). Most of the conflicts experienced by the participants in Jezuit's study occurred around issues between critical care nurses and physicians, critical care nurses and family members and between other critical care nurses. Working closely in the ICU environment with multiple disciplines brings with it different values, experiences and threats, which is conducive to conflict. It has been identified by Rushton that care-givers (critical care nurses) 'struggle to balance their obligations to others with obligations to themselves' and as a result 'these conflicts culminate in personal suffering by the nurse who provides care' (Rushton, 1992, p. 303).

The Patient's Moral Beliefs

Clearly identified in the study was the importance of up-holding the moral beliefs of the patient. The participants were more than willing to put aside their individual beliefs in order to respect the patient's needs and wishes: *'This is a difficult decision that you've [the patient] has made. I'm here to support you in that decision. I'm not here to pass judgement on you'* (Jezuit, 2000, p. 148). A consequence for critical care nurses in the future may be their eventual inability to practice nursing as their own moral selves.

Doka, Rushton and Thorstenson found similar findings in their study in 1994. 'Moral distress also comes from acting in a manner contrary to our personal and professional values, which is an attack to our integrity' (Doka, Rushton and Thorstenson, 1992, p. 348). In their study it appeared that critical care nurses felt assaulted when the

moral beliefs of the patient were in conflict with their own. The authors concluded that the unending 'moral vacillation' that critical care nurses endure especially during EOL decision-making, may have an impact on their suffering.

Ideal of Care

The six participants that were interviewed were in agreement that all the patients they cared for may not recover. Despite the advances in technology, the participants emphasised that the patient should be comfortable, both physically and mentally, with one participant who felt it was important for everyone to be '*comfortable with the decision*' in EOL decisions (Jezuit, 2000, p. 148). Further emphasis was placed on the assurance to the patient and family that treatment would continue according to the wishes of the patient. This group of critical care nurses felt it important to keep the patient and family informed especially when the prognosis was poor. More important for one participant was not only keeping the patient informed of all the options available but also that: '*The family isn't selfish to the point of wanting to keep the person around just for themselves and ignoring the fact that the patient may be suffering*' (Jezuit, 2000, p. 148).

Role in End-of-life Decision Making

The key aspects in EOL decision-making identified by this group of critical care nurses were support, coordination and education/information. Many scenarios of suffering were discussed by the participants. However, no one solution to providing relief from their suffering was identified. The study highlighted that four out of the six critical care nurses expressed that they were going to leave critical care nursing: '*I'm getting tired of it, tired of worrying about people. I'm kind of feeling stressed out*' (Jezuit, 2000, p. 149). It is possible to extrapolate from this sample of critical care nurses to the general population of critical care nurses globally (four out of six is equivalent to 67%) that the attrition rate is very high in critical care nursing and may be in part related to struggling with EOL situations. Clearly other resources and interventions are needed to address the future loss of critical care nurses.

Jezuit concludes from this study that the literature still lacks a universal definition of suffering. However, it is evident from the descriptions of suffering experienced by critical care nurses caring for critically ill and dying patients in the study that it can be viewed as a form of suffering which is unique. A recommendation was that further research was needed to explore whether the suffering experienced by critical care nurses was related to the critical care environment, the discipline of critical

care nursing or the dying and deaths of patients. Jezuit states further that several in the sample group of critical care nurses interviewed, disclosed that they took their suffering home, indicating a spill-over from 'professional distress to personal distress and possibly the reverse' (Jezuit, 2000, p. 152).

Hospice nurses caring for dying cancer patients in hospital settings have been studied quite extensively (Corner, 1993; Degner, Gow & Thompson, 1991; Gray-Toft & Anderson, 1981; Gurfolino & Dumas, 1994; Levetown, 1998). Yang and McIlfatrick (2001) also identified that the ICU environment was an area in which dying patients were cared for, but that little research had been done at that time. The authors undertook a study exploring ICU nurses' experiences of caring for dying patients. Using a Husserlian phenomenological methodology, ten ICU nurses with experience of caring for dying patients were purposively selected from two teaching hospitals in Taiwan. Data was collected using a semi-structured interview which were tape-recorded and transcribed verbatim. Utilising Colaizzi's (1978) seven steps of induction, the participants' descriptions disclosed five major themes: (i) fear and guilt; (ii) frustration and a sense of powerlessness; (iii) understanding, compassion and empathy; (iv) grief reaction and (v) an opportunity for growth.

The first theme of **fear and guilt** was very apparent in nurses with less than two years' experience. Yang and McIlfatrick suggested that this could be as a result of the novice nurses accepting that 'cure' was no longer a possibility and that the goals of care had changed. It was anticipated that difficulties might be experienced by this group of ICU nurses as the primary goal of care is to save lives of the critically ill.

The theme of **frustration and powerlessness** was related to the ICU nurses' inability to change the final outcome of critically ill patients and to take away the grief experienced by the family. Lack of involvement in doctor-nurse decision-making was seen as a possible reason. This was supported by an earlier study by Erlen and Frost (1991), who proposed that even though ICU nurses had an enormous amount of responsibility towards patients and family, they had little or no influence on the decision-making processes, leaving them feeling powerless. Taking this theme further, the ICU nurses argued their stance of patient advocacy to uphold their questioning of decisions regarding patient treatment. This can be seen as another cause of stress with regard to the doctor-nurse relationship.

The third theme of **understanding, compassion and empathy** as the ICU nurses developed a bond with the patient was a prominent finding. Critically ill patients believe that ICU nurses are sources of immense emotional support and their presence is extremely reassuring (Stein-Parbury & McKinley, 2000). As highlighted previously, Kirchhoff et al. (2000) maintain that ICU nurses endeavour to provide compassion, empathy and quality nursing care to the dying in difficult circumstances. The stress thereof is exacerbated by the lack of transparency about prognosis, unpredictability of the patient's condition, work overload and the many people involved in decision-making.

Grief reaction and feelings of sadness was the fourth theme and was experienced by more than half of the participants. Some of the ICU nurses reverted to crying, both privately and with families, when patients died. A study by Isaak and Paterson (1996) examining critical care nurses' lived experience of failed resuscitation demonstrated that some of the ICU nurses' grief reaction was personalised when a patient died. A possible reason was that the patient's age, personality or circumstances reminded the ICU nurses of a family member or loved one or even themselves. This is supported by the following narrative in Yang and McIlfatrick's study: *'When I was a new nurse and caring for dying patients, I felt sadness and loss, especially when the patients were old. I always thought that the person in the bed could be a family member or even me'* (Yang & McIlfatrick, 2001, p. 438).

The fifth theme of an **opportunity for growth** highlighted that for some health-care professionals, caring for dying patients was stressful. In spite of this, some nurses developed positive attitudes to counterbalance negative experiences (Hedley & Anderson, 1989). Previous positive and professional experience, seniority and specialist training were seen as mediating attitudes towards death and dying (Corner, 1993).

A sub-theme of **stressors** was also identified under the theme of 'an opportunity for growth.'

The literature review thus far has recognised that nurses working in the ICU have multiple and varied demands made on them. A number of these factors include work overload, nurse-physician relationships and patient treatment issues. Under the sub-theme of 'stressors', four categories were identified by the ICU nurses caring for dying patients: (i) doctor-nurse relationship; (ii) coping with family reactions; (iii)

concealment of illness/prognosis and (iv) DNR (do-not-resuscitate) orders.

The family's emotional reactions and psychological needs are generally acknowledged by ICU nurses. In this study, more than half of the ICU nurses considered that dealing with the family's grief and bereavement was significantly stressful for them when dying patients were under their care. This was illustrated by the following quote: *'Some families could not accept that the patient's condition had deteriorated rapidly and that he or she would die soon. They denied or fought this situation. I felt stressed dealing with their emotional reactions'* (Yang & McIlfatrick, 2001, p. 439). This is in contrast to the findings of Mendoca and Warren (1998) who proposed that the family's needs for comfort care was not adequately met in the ICU. This was an important aspect which warranted further education as suggested by one of the study participants: *'I thought it was very important to educate nurses [on] how to deal with not only personal emotional reactions but also with families. It can reduce nurses' stress when they care for dying patient'* (Yang & McIlfatrick, 2001, p. 439).

The next category of **concealing illness/prognosis** from patients was highlighted as a stressful moral dilemma experienced by most of the participants. This caused the nurses to express certain 'moral tension' and a sense of discomfort with their inability to disclose their patient's prognosis when they were dying. The authors suggested that this issue could have potential educational implications for understanding social and cultural values of death and dying for both health-care professionals and the general public

The category of **do-not-resuscitate (DNR)** orders also resulted in ethical and moral tension, as demonstrated in an earlier study by Simpson (1997), on page 47. Simpson pointed out that ICU nurses continued to deliver good quality nursing care to patients even when all treatment was deemed futile and was consequently withdrawn. Yang and McIlfatrick's study revealed that the ICU nurses viewed obtaining consent and explaining to the family as their responsibility despite the distress that they experienced. This is poignantly illustrated by one of the ICU nurse's narrative: *'When I pushed or hinted that the families sign the permit for DNR, I felt cruel. I felt like I was the killer in this situation because I was indirectly dominating the life and death of the patient'* (Yang & McIlfatrick, 2001, p. 439).

One of the discussion points under the category of 'do not resuscitate' was that of ICU nurses' coping strategies. The ICU nurses identified two areas that helped them manage in stressful situations in ICU. These coping strategies are similar to a study conducted by O'Hara, Happer, Chartrand and Johnston (1996). The sample were nurses who were caring for dying patients in a long-term facility. The thought of having provided a good quality of nursing care to the patient during the dying process was seen as the primary coping strategy. Nurses in general felt responsible for providing a 'good death' which the majority of the study participants defined as 'dignified' and 'peaceful.' The ICU nurses in Yang and McIlfatrick's study believed that rendering comfort and compassion and respecting the patient's wishes could help nurses find a balance between their own emotions and reactions: *'I provide the optimal nursing care to the patients who are approaching death. I just want all of them to feel very comfortable and this is what I can do for them at this time. It can make me feel better when the patients die'* (Yang & McIlfatrick, 2001, pp. 439-440).

Of the ten ICU nurses, three had Taoist and Buddhist religious beliefs. These three nurses considered that religious support could decrease their distress and assist them in accepting the dying and deaths of patients under their care: *'Religion is very important to me when I am caring for dying patients. It helps me accept the fact of dying and death and then decrease the distress of death'* (Yang & McIlfatrick, 2001, p. 440). It did not appear that any specific religious ideology offered more support than others.

The study concludes that it is important to recognise and acknowledge that ICU nurses face dying and death daily in the ICU and it cannot be taken for granted that this will prepare them for this experience. Educational programmes that are tailored to address issues highlighted throughout the review of the literature this far, is essential in optimising patient care, family support and ontological care of the ICU nurses.

The University of Washington School of Nursing and the Massachusetts Institute of Health Professions offer a Tool-Kit for Nursing Excellence at End of Life Transition (TNEEL). This initiative provides an innovative package of electronically available tools distributed to American nurse educators and researchers in academic and clinical settings. It is now offered as a web-based self-study course. Topics include:

1. Comfort goals.
2. Assessment and management of pain.
3. Signs and symptoms of approaching death.
4. Decision-making at the end of life.
5. Communications and relationships supporting the patient and family-centered care at the end-of-life transition.
6. Grief, loss and bereavement.
7. Hope and well-being.
8. Spiritual and psychosocial needs.
9. Impact of dying (economics, resource utilisation).
10. Cultural, ethical, legal and quality of life concerns at this life stage.

The success of this course was evident through course evaluations which highlighted the usefulness of on-line learning in comparison to the more traditional didactic approach.

Currently, there are no similar end-of-life guidelines or curricula in South Africa to address death education concerns amongst ICU nurses.

Papadatou, Martinson and Chung's (2001) study warrants a mention despite being a comparative trans-cultural study of oncology and critical care nurses' experiences of caring for dying children in Athens and Hong Kong. Semi-structured interviews were used to collect data from 39 Greek and 24 Chinese nurses and analysed both qualitatively and quantitatively. The fundamental theme that emerged was the grieving process of nurses caring for critically ill children. The quantitative analysis compared the nurses' experiences in terms of unit variables (oncology versus critical care) and ethnic or cultural variables (Greek versus Chinese).

The findings revealed that, irrespective of the discipline of nursing or the cultural background of the nurses, the deaths of children deeply affected them. The nurses' stress levels were elevated as a result of them feeling, firstly, helpless in not being able to relieve the physical suffering of the dying children and secondly, the emotional and spiritual distress experienced by the children and family. Of note was that none of the nurses had any preparation in managing their grief and the conflict in their working environment. Again, as highlighted in many studies, there is the need for better communication between health-care professionals and the family of the

patient's disease condition and dying process (Beckstrand et al., 2006; Cartwright et al., 1997; Halcomb, Daly, Jackson and Davidson, 2004; Kirchhoff, 2000).

The other significant finding was that Greek and Chinese nurses expressed their grief differently. The Greek nurses were more open and demonstrative of their grief compared to the Chinese nurses who were more private and preoccupied with practical issues and duties in order to avoid their grief. The authors referred to this as 'conscious suppression' (Papadatou, Martinson and Chung, 2001, p. 410).

Most of the Greek and Chinese nurses made sense of children dying by attributing the death to divine beings or forces or to the seriousness of the disease condition. However, frustration was expressed by the Greek nurses who perceived childhood death as unjust and unfair, whereas the Chinese nurses saw it as the release from suffering and was more accepting. The range of grief responses from the Greek and Chinese nurses were similar to those expressed in the study by Rashotte and her colleagues (1997).

The final finding from this study was that both groups of nurses experienced meaningful reward, mostly pertaining to the care of dying children, either by 'fighting for cure' (critical care nurses) or by 'sharing a close bond and contributing to dignified dying conditions' (oncology nurses) (Papadatou, Martinson and Chung, 2001, p. 411).

The prevalence and triumph of technology in the ICU has created immense moral and ethical dilemmas concerning end-of-life care. An Australian study aimed at exploring the lived experiences of ICU nurses caring for dying patients having their treatment withdrawn or withheld was conducted by Halcomb et al. in 2004. Using Van Manen's (1990) phenomenological framework of conversational interviews, a convenience sample of ten ICU nurses participated in the study. The data generated five themes: (i) comfort and care; (ii) tension and conflict; (iii) do no harm; (iv) nurse-family relationships and (v) invisibility of grief and suffering. The ICU nurses' experiences of providing care for the dying patient having treatment withdrawn or withheld proved to have been accompanied by a significant personal and professional struggle. Not being able to relieve the family and the dying patient's distress, the ICU nurses questioned their nursing practice and its efficacy: '*We detach ourselves very easily but every once in a while you feel that human side to it*' (Halcomb et al., 2004, p. 219).

By contrast, several ICU nurses articulated strong psychosocial issues in response to withdrawing or withholding treatment. One participant expressed that, although she presented a calm-and-collected 'front' in the ICU, the emotional burden dwelled on her at home: *'It's not that it doesn't really affect me that much but in a way it sometimes catches me in my heart. Sometimes we shed a tear but not every time. I'm home already and I'm still thinking about it'* (Halcomb et al., 2004, p. 220). Despite nurses' efforts to provide comfort and care for the dying, the authors highlighted that they were also faced with conflict and tension among their medical colleagues and within themselves.

The study participants recommended improvements in communication between all health-care professionals, and counselling and education about the process of withdrawing or withholding treatment. These recommendations may prove valuable to both ICU nurses and the dying patients' families by improving patient care and reducing the caring burden on ICU nurses.

Caring for patients who are diagnosed as brain dead is an extremely challenging experience for ICU nurses. Pearson, Robertson-Malt, Walsh and Fitzgerald undertook a study in 2001 to identify the feelings and experiences of ICU nurses who had been involved in the nursing care of brain-dead patients prior to organ donation. A phenomenological approach informed by van Manen (1990) was used as the study design. The researchers wanted to obtain descriptions by ICU nurses from different perspectives and therefore an ICU from a metropolitan hospital in South Australia and an ICU from a rural hospital in northern New South Wales were chosen as the study settings. A total of 20 ICU nurses were recruited, ten from each hospital. Data was collected by using a non-structured interview technique and transcribed and analysed according to van Manen's (1990) thematic data analysis.

A total of ten themes were identified in which the primary focus of care was for the donor family. The ICU nurses played a pivotal role in caring for organ donor patients and their families and in the procurement of organs, but their experiences covered a range of conflicting aspects related to the following: (i) 'the apparent ambiguity that accompanies the proclamation of death, over a body which exhibits traditionally accepted signs of life; (ii) the distress of family members who have to confront a sudden catastrophe and comply with requests to equate brain death with 'real' death and (iii) the nurses' own knowledge that the focus of their care relates to an outcome ('saving another life by making organs available for transplant which is rarely witnessed by families involved') (Pearson et al., 2001, p. 138).

As found in Yang and McIlfactrick's study, similar coping strategies were used by the ICU nurses to maintain some sense of equilibrium so that they could continue caring for organ donors and their families. For these ICU nurses, focusing on the eventual positive outcome of saving another life was seen as a coping strategy, and they encouraged the donor family to do the same. A sense of satisfaction was also described by the ICU nurses by 'doing the best they can' for the family and maintaining a caring environment. A caring environment was one that protected the family from unnecessary stress and kept them regularly updated of the situation as it unfolded throughout the organ donation process. Despite this process being emotionally demanding, the ICU nurses felt that it had to be done well and that this was considered as caring for the family.

An area of conflict for this group of ICU nurses related to the ambiguity of a 'death statement:' where 'no hope of recovery' was interpreted to mean 'real' death. Contributions to this ambiguity included the physical appearance of brain-dead patients, the family's presence at the bedside and the ICU nurses' personal attempts to treat brain-dead patients as if they were 'alive and well' (Pearson et al., 2001, p. 138). Such conflicts were not seen as intellectual, but rather as ones of emotion and experience.

Pearson et al. conclude that caring for a patient who has been diagnosed as brain dead and is considered a candidate for organ donation, is a challenging experience for ICU nurses, who search for meaning in each event.

Wilkin and Slevin (2004) conducted a study investigating the nature of caring work in the ICU involving 46 full-time ICU nurses in a large public hospital in the UK. A Heideggerian phenomenological approach was employed and the findings confirmed that caring was an essential function of ICU nursing. The concept of care for the study sample participants was a central element that was wholistic and individualised and included a process of 'therapeutic intervention to meet patients' and relatives' needs' (Wilkin & Slevin, 2004, p. 57). The participants' feelings indicated that a connection had been established with the patients they cared for. This caring behaviour included giving technological support which was integrated into the routine nursing care of ICU patients. Caring for the relatives was considered a component of care for the patient.

This study highlighted that caring for patients in this particular ICU consisted of providing expert physical care as well as humanistic care, but that the use of technology might impinge on the inter-personal aspects of care.

Spiritual care received some attention in a study conducted by Kociszewski (2004). The purpose of this study was to describe ICU nurses' lived experiences of providing spiritual care to critically ill patients and their families. Using a Husserlian phenomenological approach, ten ICU nurses from the New England area in Connecticut in the USA, were interviewed and the data was analysed using Colaizzi's (1978) seven-step method.

The findings of the study supported the concept of wholistic care. However, the provision of spiritual care did not originate from formal education but from personal experiences, mostly around the death of a patient in the ICU. Such tragic situations stimulated ICU nurses to question the meaning and purpose of 'his or her nursing care that developed into a personal philosophy of nursing spiritual care' (Kociszewski, 2004, p. 409). The findings also revealed that spiritual care had little or no religious dominance as had been shown in studies by Emblen and Halstead, 1993; Hall and Lanig, 1993; Taylor, Amenta and Highfield, 1995; Tuck, Pullen and Lynn, 1997 and van Dover and Bacon, 2001.

A study by Badger (2005) was undertaken in an 18-bed medical ICU in a hospital in the north-eastern USA to explore how ICU nurses moved from aggressive life-extending treatment of patients to letting life end (from cure to comfort care). Twenty-four ICU nurses were recruited into the study and a descriptive qualitative research design was used to collect data. Focus group interviews and brief observation (speech, action and non-verbal behaviours) were employed to gather the experiences of the ICU nurses over a six-week period.

The results highlighted the distressing situations for ICU nurses when dealing with young patients dying and the 'flogging' of futile care in elderly patients.

Talking about death was a topic that the ICU nurses barely commented on. For this group of ICU nurses, the sentiment was: *'If you come here and you're uncomfortable with death then you're not going to do well here'* One participant stated: *'I don't know if you can prepare yourself. I think it is just part of the job and comes with working here.'* (Badger, 2005, p. 516).

Some patients' deaths were more stressful for the ICU nurses to deal with. Young patients who were pregnant or who had just given birth were of a concern to this group of ICU nurses. This is aptly illustrated by one participant experiencing the death of a young mother who had given birth earlier in the day: *'I sat in the break room and bawled my eyes out. I kept thinking [that the] baby lost its mom today. They were celebrating and now it's like a horrible tragedy'* (Badger, 2005. p. 517).

Futile care was noted as an area of emotional conflict for the ICU nurses. Understandably, the family did not want their loved one to die and were praying for him/her to live: *'I was praying for him to die. It's hard, it's really hard to do that'* (Badger, 2005. p. 517). Other difficult deaths noted were patients dying alone and families who had signed a 'do-not-resuscitate' order and had then left their loved one to die alone. In both situations, the ICU nurses typically would stay with the patient so that the patient would not have to die alone.

From this study it was interesting to see that there were very few comments by the ICU nurses referring to their personal religious or cultural beliefs as a way of coping with the dying and deaths of patients.

The study concluded that there many factors affecting the transition from cure to comfort-orientated care for this group of ICU nurses. Such factors were the patient's age and the level of discord or agreement among the patient's family members about treatment and medical care decisions. The most important element enabling the ICU nurses to move from cure to comfort-orientated care was reaching a consensus among them, the patients' families and the patients themselves on the medical treatment required.

An area in ICU nursing that has recently received some attention is the moral distress experienced by ICU nurses. Elpern, Covert and Kleinpell define moral distress as a 'psychological dis-equilibrium that occurs when the ethically right course of action is known but cannot be acted upon' (Elpern, Covert & Kleinpell, 2005, p. 523). Moral distress has been associated with job dissatisfaction, burnout and loss of nursing staff from the ICU and the profession (Corley, 1995; Corley, 2002; Corley, Elswick, Gorman & Clor, 2001). A study by Elpern, Covert and Kleinpell (2005) to assess the level of moral distress experienced by 28 ICU nurses in an ICU in Chicago was conducted using an exploratory, descriptive two-part questionnaire.

Part one of the study used Corley’s Moral Distress Scale (MDS) developed in 1995 to measure ICU nurses’ moral distress and to identify moral issues and concerns. The participants indicated on a seven-point Likert Scale (0 = none to 7 = a great extent) the level of moral distress they experienced in 38 clinical situations. Part two of the questionnaire was open-ended and the participants could expand further on other issues of moral distress.

The ICU nurses reported, that overall, they had experienced a moderate level of moral distress (MDS 3.66). Results pertaining to dying and deaths of patients in ICU are shown in Table 7. It is significant to note that out of the top six highest MDS ratings, five were on concerns about dying and deaths of patients in the ICU.

Item	Average MDS rating
Continue to participate in care for hopelessly ill patients who are being sustained on a ventilator when no-one will make a decision to ‘pull the plug’	5.57
Initiate extensive life-saving actions when I think it only prolongs death	5.44
Follow a family’s wishes to continue life support even though it is not in the best interests of the patient	5.41
Provide care that does not relieve the patient’s suffering because the physician fears increasing doses of pain medication will cause death	4.93
Follow the physician’s request not to discuss death with a dying patient who asks about dying	3.56

Table 7. Moral Distress Scale Items Associated with Highest Levels of Moral Distress About Death and Dying (Elpern, Covert & Kleinpell, 2005, p. 526).

The following quotes from the ICU nurses highlight the moral distress that they experienced when caring for the dying and deaths of patients: *‘I often equate my job with keeping dead people alive. On these days, I dread coming to work. It feels like I have created a defence mechanism of just blocking a patient’s death or inevitable death out of my mind’* and possibly the most poignant statement: *‘Death makes me think of someone in my family dying and how I want to die.’*

The authors' conclusions from this research was that moral distress for ICU nurses was intense and frequent, especially when providing aggressive medical and nursing care to patients not expected to survive. Equally important, was that more research and intervention to managing moral distress was required to reduce or prevent post-traumatic stress disorder (PTSD)²⁴ in ICU nurses.

In 2007, Mealer, Shelton, Berg, Rothbaum and Moss set out to determine if ICU nurses were more stressed psychologically compared to their colleagues working in general wards.

Developing control over certain aspects of their practice was also seen by nurses as a strategy for managing their grief. This apparently developed from the professional role of being a nurse and included: (i) establishing boundaries; (ii) withdrawing or distancing themselves and (iii) fulfilling personal death rituals.

A total of 351 general and ICU nurses from three Emory University (Atlanta) affiliated hospitals and 140 ICU nurses from various metropolitan hospitals were surveyed. Symptoms of PTSD were measured against the Post Traumatic Stress Syndrome 10 Questions Inventory (PTSS-10)²⁵ and a self-report scale centred on the Diagnostic and Statistical Manual for PTSD.

The cohort of ICU nurses from the Emory University affiliated hospitals tested positive for symptoms of PTSD (24%) related to their working environment, whereas of the group of general nurses, 14% tested positive for PTSD. Among the ICU nurses from the metropolitan hospitals, 29% reported symptoms of PTSD.

²⁴. Post-traumatic stress disorder (PTSD) is an anxiety disorder that some people develop after seeing or living through an event that threatened or caused serious harm or death. Symptoms include flashbacks or bad dreams, emotional numbness, intense guilt or worry, angry outbursts, feeling 'on edge,' hypervigilance or avoiding thoughts and situations that remind them of the trauma. These symptoms can last at least one month or possibly for years (NIMH, 2009).

²⁵. A total score of greater than 35 is associated with a high probability that the individual meets the diagnostic criteria for PTSD.

The traumatic events related to the type of work that ICU nurses do, is depicted in Table 8.

Post-mortem care (last offices)
Seeing patients die
Combative patients
Involvement with end-of-life care
Verbal abuse from family members
Verbal abuse from physicians
Verbal abuse from other nurses
Open surgical wounds
Massive bleeding
Providing futile care to patients
Performing cardio-pulmonary resuscitation
Stress related to feeling over-extended due to inadequate nurse to patient ratios
Stress related to not being able to save a specific patient

Table 8. List of Traumatic Events Related to Work as an Intensive Care Nurse (Mealer et al., 2007, p. 696).

This study concluded that ICU nurses showed increased prevalence for PTSD symptoms compared with general ward nurses. Recommendations were made to increase awareness of these symptoms and instigate necessary measures to improve ICU nurses' mental health, job satisfaction and the attrition rate.

A Husserlian phenomenological study by Hov, Hedelin and Athlin (2007) was conducted in a nine-bed adult ICU in Norway. The aim of the study was to acquire a deeper understanding of what constituted good nursing care for ICU patients at their end of life. The sample group comprised 14 ICU nurses divided into two groups participating in non-structured group interviews using focus-group methodology inspired by Morgan (1993). The interviews were analysed using Colaizzi's (1978) inductive metho

The study showed that good nursing care was dependant on a number of basic conditions: continuity, knowledge, competence and co-operation. Good nursing care in ICU also included 'clear goals to give life-saving or end-of-life care in a timely and effective manner' (Hov, Hedelin & Athlin, 2007, p. 339). For this sample group, good nursing care also consisted of effective communication skills and the use of their hands. The study also confirmed that ICU nurses are key people in upholding humanity in the ICU environment, especially when patients may be near to dying.

The researchers recommended that ICU nurses receive education in 'touch' and training in 'difficult conversations' with dying patients and their families. Over and above this, the ICU nurses should be competent in managing the technological challenges in the ICU so as not to hinder the execution of wholistic nursing care.

McMillen's small-scale study in an ICU in the north of England explored the perceptions, feelings and experiences of eight ICU nurses relating to end-of-life decision-making (McMillen, 2008). By using grounded theory as a methodology, the most significant of the two themes was that of withdrawal of treatment. The participants felt strongly about getting the timing right, as it affected the patient and relatives as well as the nursing staff. It was considered important for the relatives to be allowed sufficient time to accept what was happening but equally important for the ICU nurse(s) to come to terms with decisions about the withdrawal of treatment. The participants had established caring relationships with the dying patients and their relatives, and became more distressed when withdrawing treatment from a young patient. In this study, the participants felt that when the decision to withdraw treatment was possibly premature, they experienced a sense of having accelerated the patient's death.

Conversely, if the decision to withdraw treatment was delayed, the death was undignified and the process lacked compassion. It was interesting to note that all the ICU nurses described difficulties in caring for patients who had had their treatment withdrawn. McMillen termed these experiences 'emotional labour' (McMillen, 2008, p. 256).

Meadors and Lamson (2008) explored the reality of compassion fatigue as a result of primary or secondary traumatisation in health-care providers working in a children's hospital in eastern Carolina, USA. The interest in the study was generated by the emotionally charged death of a child in the paediatric ward.

Health-care providers working in stressful environments such as the ICU may exhibit symptoms of primary or secondary traumatisation, dependent on three criteria: (i) proximity; (ii) intensity and (iii) duration (Figley, 1989; 1995).

Proximity relates to how close the health-care worker is to the distressing event, intensity is defined by how far-reaching and intense the distressing event is, and duration refers to how long the health-care provider is involved with the distressing event (American Psychiatric Association, 2002).

To better understand the concepts of primary and secondary traumatisation and compassion fatigue, I have inserted a table by Meadors, Lamson and Sira (2010, p. 153).

Term	Definition
Primary traumatisation	The process that can occur from direct contact with a traumatic event (Peebles-Kleiger, 2000).
Secondary traumatisation	Via an indirect exposure, may develop from hearing about a traumatic event or caring for someone who has experienced such an event (Peebles-Kleiger, 2000).
Compassion fatigue	The consequence of working with a significant number of traumatised individuals, in combination with a strong empathic orientation (Figley, 1995) or a formal care-giver's reduced capacity and interest in being empathetic to suffering individuals (Adams, Boscarino & Figley, 2006).

Table 9. Comparative Definition of Terms
(Meadors, Lamson and Sira, 2010, p. 153).

Symptoms experienced with primary traumatisation may include decreased appetite, irritability, increased anxiety and sadness (Meadors & Lamson, 2008, p. 25). These symptoms may actually go unnoticed. Nurses working in neonatal and paediatric ICUs may find that working with a severely burnt child or a child who is physically abused are likely to suffer from primary traumatisation, especially if they have poor coping mechanisms.

Secondary traumatisation occurs when the health-care worker is personally affected by the primary traumatisation of the patient, in this instant, a child and an ICU nurse. The child might share with the ICU nurse his/her experience of being abused or the nurse might be exposed to a child who experienced significant suffering from his/her diagnosis or trauma (Meadors & Lamson, 2008, p. 25). Other symptoms include nightmares and a heightened startle response.

Of the 185 health-care providers in the Meadors and Lamson (2008) study, 56.2% (n = 104) were neonatal ICU nurses and 2.7% (n = 5) were paediatric ICU nurses. The secondary aim of the study was to assess the effectiveness of providing an educational seminar on compassion fatigue to these health-care providers working in the study setting. Meadors and Lamson used a modified version of the Social Readjustment Rating Scale, Index of Clinical Stress and a compassion fatigue measure that they designed. The study participants volunteered to complete the questionnaire before and after the seminar. The educational seminar run after the primary questionnaire proved to be successful in making the participants aware of compassion fatigue and reducing clinical stress. The other finding was that those participants who experienced higher personal stress levels also experienced higher levels of clinical stress and compassion fatigue.

The authors recommended that health-care providers who worked in paediatric and neonatal ICUs be offered a seminar on compassion fatigue and primary and secondary traumatisation. A further recommendation was a work culture that be established that cared about the physical and emotional health of health-care providers, especially in the ICU and paediatric ICU and particularly during the holiday season. This time of the year for these health-care providers proved to be more stressful in their personal lives as well as in the ICU working environment, especially when staff took ill or had to work longer periods without time off.

Using a Heideggerian phenomenological approach, Shorter and Stayt (2009) explored ICU nurses' experiences of grief and their coping mechanisms in an adult ICU in a large teaching hospital in the UK. Eight ICU nurses were interviewed and themes were generated through Colaizzi's (1978) inductive method. The themes that emerged were: (i) the death experience, and (ii) the death thereafter. The ICU nurses felt grief for all the patients they had cared for, however the death experience was less traumatic if they perceived the death to have been a 'good death' (Shorter & Stayt, 2009, pp. 162-163).

For the participants, a 'good death' was one for which they had emotionally prepared and during which they were still able to administer good nursing care. These findings were echoed by Costello (2006) albeit in a ward setting in three hospitals in the UK caring for older people. The ICU nurses in Shorter and Stayt's study exhibited signs of normalising death and described how they dissociated themselves emotionally from dying patients. These actions have been described by both Quint (1967) and

Kübler-Ross (1969) and are discussed in more detail in § [Death education and nursing page 34](#).

Shorter and Stayt's (2009) concluding remarks were that there were many predisposing factors and circumstances that shaped the care of dying patients. Continual exposure to death and dying might lead to occupational stress and subsequent burnout for ICU nurses.

A study was conducted in three Swedish ICUs where nine experienced ICU nurses were recruited to explore their experiences and perceptions of caring for dying people in an ICU. The focus of this study was on 'unaccompanied patients' (death of a patient without the presence of a family member). The proximity of family members and environmental aspects were also looked at (Fridh, Forsberg & Bergbom, 2009). Using conventional content analysis, the main theme derived was that of 'doing one's utmost' in which the ICU nurses endeavoured to provide dignified end-of-life care. This care mainly concentrated on the relationships and interaction with the dying person's relatives. Should the dying person die alone, the ICU nurses saw this as 'tragic,' but their experiences of the dying person left fewer impressions in their memory.

Exploring ICU nurses' perceptions of end-of-life care after multiple interventions for improvement prompted, Hansen, Goodell, Dehaven and Smith (2009) to conduct a study in this area. The authors postulated that caring for dying patients and their families without sufficient death education an adequate practice environment or emotional support could influence ICU nurses' provision of quality end-of-life care.

There were five areas of interest in the ICU nurses' experiences of end-of-life care: (i) knowledge and ability; (ii) work environment; (iii) support for ICU nurses; (iv) support for patients and families and (v) work stress related to specific end-of-life situations. Using a two-phase questionnaire (before and after multiple interventions), 271 ICU nurses from four ICUs (medical, surgical, trauma-neurosurgical and cardiac) in a university medical centre in Oregon, USA were asked to participate in the study. The response rate was 34% in phase 1 and 47% in phase 2. A 5-subscale tool containing 30 items was developed from the literature available. The items were rated on a four-point Likert scale (1 = very good to 4 = poor). A single open-ended question formed part of the tool requesting the ICU nurses' recommendations for building a supportive environment for end-of-life care.

The two most relevant issues identified were the need for better communication between the ICU nurses, physicians and family members and the need for additional death education for ICU nurses, physicians and families. Although not explored further in the study, the lack of spiritual support was a concern for some of the ICU nurses.

The need for death education was different for each ICU nurse's discipline. The medical and trauma-neurosurgical ICU had significantly more deaths than the surgical and cardiac ICUs at this particular institution. Limited exposure to death and dying or fewer years of intensive care nurse training or experience may offer an explanation.

The ICU nurses working in the four ICUs initiated a bereavement programme to support patients' families in the medical ICU, as this unit had the highest number of deaths which was seen as emotional challenging for the ICU nurses. Over time, work stress-related concerns improved in the four ICUs and there appeared to be an increase in self-confidence in providing better end-of-life care (Hansen et al., 2009).

The only study that has explored the experiences of the way ICU nurses understand the dying and death processes of patients in the ICU was undertaken by Sanches and Carvalho in 2009. The study was based on Sanches' 2007 dissertation entitled **'Dealing with death and dying: Being a nurse in an intensive care unit.'** The study was conducted in a teaching hospital in Paraná, Brazil. Using a phenomenological approach, eight ICU nurses were interviewed using a semi-structured questionnaire. The original paper is in Portuguese and the themes that I was able to identify from the short abstract were: (i) futility of treatment hindering the process of death and dying; (ii) difficulty in working with a multi-disciplinary team in ICU; (iii) the relationship to death itself; (iv) the dynamics at work and its implications on the deaths and dying of patients; (v) the relationship with patient's family and (vi) the need for support during the process of death and dying.

From Sanches' dissertation, came recommendations that some attention needed to be paid to curricula in order to demystify the meaning of death, and the fear that patients, families and the multi-disciplinary team experienced. In doing so, sensitivity towards each other might be achieved as well as the realisation that death was a part of life which required understanding in order to cope in an *authentic* way.

The literature thus far has highlighted the increasing stress and conflict that critical care nurses experience in the ICU. In response to this, Crump, Schaffer and Schulte (2010) conducted a study exploring critical care nurses' perceptions of obstacles, supports and knowledge needed in providing quality EOL care. This study was in fact a replication of Beckstrand and Kirchoff's study (2005) in which the authors evaluated the **National Survey of Critical Care Nurses regarding EOL Care** using a questionnaire containing 20 obstacle items, 24 supportive behaviour items, four open-ended questions and 15 demographic questions.

The participants were two critical care nurses from a 446-bed level I mid-western urban trauma centre in the USA. They attended the **ELNEC Critical Care Training Programme** and then returned to their intensive care units to implement educational modules they had learnt. In addition, they conducted a survey to ascertain the knowledge requirements for providing quality EOL care and to identify obstacles and supportive behaviours. The surveys were mailed via internal hospital mail to all 180 critical care nurses (permanent and relief) working in the adult intensive care units. The response rate was 31%. The participants were requested to rate their educational needs using a four-point Likert scale (0 = low to 4 = strongly agree).

Knowledge topic	Mean
Pain management	2.48
Care during last hours of life	2.41
Spiritual care	2.38
Communication with patients	2.34
Symptom management	2.32
Communication with the health team	2.25
Quality EOL care	2.14
Grief/bereavement support	2.14
Communication with families	2.14
Ethical issues	2.00
Cultural aspects	1.95

Table 10. Rank Order of Knowledge Topics
(Crump, Schaffer & Schulte, 2010, p. 299).

From the 29 obstacles to providing EOL care in the ICU, the highest score was that given to family and friends continually calling the critical care nurse rather than the designated family member for an update. Other high scoring obstacles were family issues and nurse-doctor conflict. It was interesting to note that, out of the 29 obstacles, the lack of nursing education and training in various aspects was only ranked 20.

The open-ended questions were about additional obstacles to EOL care. Several concerns were raised by the participants regarding aggressive care. Some of the participants were uncomfortable about having to maintain aggressive care while waiting for a family member to arrive from out of town. Another participant expressed anxiety about having to provide aggressive care when the prognosis of the patient was poor. One participant shared an experience of the family claiming prejudice when aggressive care was not provided. Other obstacles included not having a comfort nursing care plan, having to respond to very emotional families and encountering language barriers.

The supports for providing EOL care specifically in the case of death and dying are described in Table 11.

Supportive behaviour	Rank (out of 29)
Having one family member be the designated contact person for all other family members regarding patient information	1
Having family members accept that the patient is dying	2
Providing a peaceful, dignified bedside scene for the family members once the patient has died	3
Allowing family members adequate time to be alone with the patient after death	5
After the patient's death, having support staff compile, all necessary paperwork for you to be signed by the family before they leave the unit	6
Having family members thank you or in some other way show appreciation for your care of the patient who has died	7
Talking with the patient about their feelings and thoughts about dying	11
Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient	18
Having a support person outside the work setting who will listen to you after the death of your patient	19
Having a fellow nurse put his/her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient	20

Table 11. Supports for Providing EOL Care in Critical Care (Crump, Schaffer & Schulte, 2010, p. 302).

From this study, Crump, Schaffer and Schulte concluded that families and patients must have clear, direct and consistent information to make realistic and appropriate decisions about EOL care. The ability of critical care nurses to deliver quality EOL care is affected by physician issues and requirements for more knowledge, skill and cultural competency.

More recent literature available includes a review of the factors relating to nurses' caring behaviours for dying patients by Prompahakul and Nilminat (2011). The results from the review were grouped in three themes: (i) nurses' personal factors; (ii) technological influencing factors and (iii) environmental factors.

Nurses' personal factors included age, level of education, experience in EOL care and the ICU nurse's self-awareness. Boyd's (2005) concept of self-awareness is based on acknowledging one's own beliefs, and understanding one's feelings and behaviours and how these affect others. Reference to some of the many studies on self-awareness (Jack & Miller, 2008; Jack & Smith, 2007; Rowe, 1999) found that nurses' self-awareness was associated with positive caring behaviours. Drawing attention to the nurses' self-awareness appears to enable them to be less of a victim, thus they are more able to take control of a difficult situation without jeopardising patient care (Bernard, 1992; Jack & Smith, 2007).

The theme of **personal factors** also addressed moral distress. The literature already reviewed thus far highlights that caring for dying patients has certain findings in common. These include role conflict between nurses and physicians, decision-making and withdrawal of treatment. Shared findings may especially include the ICU nurses' experience of guilt and feeling to blame for not living up to their profession of caring, when it becomes futile resulting in a sense of powerlessness, incompetence and avoidance.

The more recent study on death and dying is by Hinderer (2012), who explored the lived experiences of critical care nurses' reactions to death. The study took place in Maryland, USA where six critical care nurses were recruited after meeting the inclusion criteria of having experienced multiple deaths of patients in the ICU. Using a descriptive phenomenological approach, a semi-structured interview was employed in order to generate data. By means of Colaizzi's (1978) method of analysing data, four themes emerged: (i) coping; (ii) personal distress; (iii) emotional disconnect and (iv) inevitable death.

The theme of **coping** revealed that critical care nurses used a variety of strategies to cope with the deaths of their patients. After many years in the ICU and high number of deaths encountered, the critical care nurses coped better than when they were novices (See Benner, 1984), '**Novice to Expert**' on page 41). Some of the participants' anecdotes included: '*The sad thing is they [the deaths] don't bother me as much as they used to. I usually see it as a relief*' and '*The more you experience it, you probably do get hardened*' and '*I think I've gotten more mature about it. I hope I haven't gotten to where [death] doesn't mean anything*' (Hinderer, 2012, p. 254).

Some of the nurses remarked that the patient's family had a major influence on their ability to cope after the patient had died. The consensus was that if the family were able to cope, then so would the critical care nurses. The opposite would also apply.

The critical care nurses identified that support and understanding from co-workers were a key coping mechanisms given before or after the patient's death: *'I think we [nurses] help each other a lot. I can see the newer ones, the younger ones and I can remember acting like that, feeling like that. I think there's camaraderie between nursing staff that helps people deal with [death] because we do deal with it so often'* (Hinderer, 2012, p. 254).

Personal distress was experienced by most of the critical care nurses, especially when they saw the patient suffering and the family and/or patient's inability to see the inevitability of dying and death itself. The critical care nurses found it challenging to provide comfort care to a dying patient, especially in futile cases: *'I think the hardest ones are when you feel like things are being done that are just prolonging suffering'* and *'I feel anger because she should have been treated better. [I was] really frustrated because the system failed her'* (Hinderer, 2012, p. 254).

Deaths that ended the patient's suffering were seen as more positive experiences as opposed to situations resulting in nurses describing death as 'horrible': or when the patient was suffering and/or fighting against dying. One nurse describes her experience of death of a young woman with ovarian cancer: *'She fought every way she could fight to beat it, and it got the better of her. I think that she was scared of dying. It was a terrible death. She wanted to live so bad, she had a little girl, I think she was five'* (Hinderer, 2012, p. 255).

The nurses also experienced death as problematic when the family refused to let go: *'Everyone knows there's not going to be a good outcome. And the family can't face it. Things like that are very difficult for everyone'* (Hinderer, 2012, p. 255).

A major source of stress, (especially anxiety) for these critical care nurses was death itself: *'I don't like anybody to die on me, even if that's what they should be doing. I don't like having to deal with grieving people. I would rather it happened to the other shift. I just don't want to do this'* (Hinderer, 2012, p. 255).

All of the critical nurses stated that it was crucial to provide comfort to the dying, especially pertaining to physical needs such as cleanliness and physical comfort. If there was no further treatment for the patient, the nurses busied themselves around the dying patient's environment, keeping it neat and tidy.

The critical care nurses expressed their ability to distance themselves emotionally from the actual death itself. The theme of **emotional disconnect** arose from the nurses' experiences of regularly dealing with death. Emotional walls were erected or they became hardened to death over time. Such distancing of their personal attachment to patients and families enabled these critical care nurses to 'live with death.' One of the participants describes her experience of being able to switch her emotions 'on' and 'off,' especially when caring simultaneously for two patients – one who was dying and another who was not: *'I think I just have a wall. I mean I like to be sad for the family [of the dying patient], but I can go be happy with my other family. If I have two patients, I'm not going to laugh with the family who has the dying patient, but I can cut that off and go with my other family, and they can tell me something that will make me laugh or smile'* (Hinderer, 2012, p. 255).

Not all deaths affected these critical care nurses equally. If the bond with the patient was short term then the death did not affect them as much. However, all the critical care nurses stated that death could not always be left at work. Emotional responses such as crying were left until they had returned home: *'I definitely have found myself driving home from work and just bawling the whole way home. It's sort of a contained area where you are by yourself, and you can just let it out, and then by the time you get home, you have contained yourself'* (Hinderer, 2012, p. 256).

The last theme of **inevitable death** emerged as a result of the nurses' statements that in order to effectively care for dying patients, it was necessary that they accept that death was natural and inevitable to all living things: *'Over the years I've come to realise that death is a part of life'* and *'I think it [death] can happen to anybody at any time'* (Hinderer, 2012, p. 256). It was also shown that continual exposure to death caused the nurses to confront and reflect on their own lives, especially when it came to dying.

The implications of Hinderer's (2012) study are worth mentioning. Firstly, Hinderer poses the following questions that require further study:

1. Should critical care education include teaching ways of coping with patient death?
2. What are the implications of lack of coping mechanisms related to patient death?
3. How does emotional disconnect alter nurse-patient-family relationships?
4. What are the long-term implications of repeated exposure to death?

Hinderer believes that, from the results of her study, critical care nurses would 'benefit from continuing education on healthy ways to cope with death and the emotions it presents' (Hinderer, 2012, p. 258). Hinderer goes on to propose that continuing education is needed to fill gaps in knowledge of death in all aspects, particularly healthy coping mechanisms. Efforts to educate critical care nurses about patient death, Hinderer believes, may improve patient and family care (Hinderer, 2012).

In my final literature search, an article by Peters, Cant, Payne, O'Connor et al. (2013) performed a review of the literature exploring how death anxiety impacts on nurses' caring for patients at the end of life. Peters and colleagues analysed 15 quantitative studies done between 1990 and 2012 and three key themes were identified: (i) nurses' level of death anxiety; (ii) death anxiety and attitudes towards caring for the dying and (iii) death education was necessary for such emotional work. There were no quantitative studies identified in the review about ICU nurses' anxiety of death and the impact on patient care. The studies concentrated on nurses working in disciplines of hospice and palliative care, oncology, renal, geriatric and in the general medical and surgical wards.

It was interesting to note three definitions of death anxiety and fear of death:

1. Fear of death – Specific and conscious thoughts against death (Wong, Reker, & Gesser, 2004).
2. A negative emotional reaction provoked by the anticipation of a state in which the self does not exist (Tomer & Eliason, 1996).
3. A feeling of dread, apprehension or solicitude when one thinks of the process of dying or ceasing 'to be' (Farley, 2010).

The findings revealed that the level of death anxiety of the nurses working in these specific areas was not high. However, some studies showed 'an inverse association between nurses' attitudes towards death and their attitudes towards caring for dying patients' (Peters et al., 2013). Nurses who were young and inexperienced consistently reported a marked fear of death and increased negative attitudes towards EOLC to patients.

The authors concluded that nurses need to be mindful of their own beliefs and cultures and that a 'worksite death education programme' could reduce death anxiety (Peters et al., 2013).

In summary, the literature reviewed (1971-2014) reveals that ICU nurses' experiences of the dying and deaths of patients in the ICU is both stressful and anxiety provoking. In addition, ICU nurses are unprepared and lack coping skills to deal with death in the ICU and that this may actually disconnect them from both the dying patient and the family. This behaviour may influence the delivery of quality patient care in the last hours of living.

There remains a dearth in information exploring nurses' feelings and their ontological confrontation in coming to terms with their own fear of dying. Equally significant is the lack of death education for ICU nurses and the fact that this teaching and learning strategy often featured as an 'add on' recommendation in the majority of the reviewed studies.

In the following chapter, I discuss and describe the methodology and information unravelling methods used to give the participant sample of ICU nurses a voice to share their experiences of the dying and deaths of patients under their care in the ICU.

CHAPTER FOUR

Methodology and Research Method²⁶

The intention of this study is to understand the experiences of the ICU nurse participants in embodying professional nursing care of and for people who die while under their care in an ICU setting. The nature of the ICU setting and the professional role of the ICU nurse confront the nurse with challenges to his/her *being*. How do such nurses experience the '*possibility of not having any more possibilities*' (BT, pp. 258 - 259. Italics original) both of the patient and themselves § [Death education and nursing on page 34](#).

The Different Approaches to Qualitative Research

I found it useful to draw upon a schematic illustration by Starks and Brown Trinidad (2010, p. 1373) which provides an accessible and useful comparison between often confused approaches to qualitative research which predominate in the nursing literature (see Figure 5).

²⁶ In phenomenological research, methodology and method(s) are separate concepts. Methodology pertains to the philosophical framework and underpinnings that inform the method to be used and method refers to the procedure for carrying out the research.

	Phenomenology	Discourse Analysis	Grounded Theory
HISTORY	European Philosophy	Linguistics/Semiotics	Sociology
PHILOSOPHY	There exists an essential, perceived reality with common features	Knowledge and meaning is produced through interaction with multiple discourses	Theory is discovered by examining concepts grounded in the data
GOAL	Describe the meaning of lived experience of a phenomenon	Understand how people use language to create and enact identities and activities	Develop an explanatory theory of basic processes
METHODOLOGY Formulating a research question Sampling Data collection: Observations Interviewing strategy	“What is the lived experience of [the phenomenon of interest?]”	“What discourses are used and how do they shape identities, activities and relationships?”	“How does the basic social processes of [X] happen in the context of [Y environment?]”
	Those who have experienced the phenomenon of interest	Those situated in one or more of the discourses of interest	Those who have experienced the phenomenon under different conditions
	Observe participants in the context where the phenomenon is experienced	Observe participant in conversation in their natural environment	Observe participants where the basic social process takes place
	Participant describes experience; interviewer probes for detail, clarity	Both engage in dialogue; interviewer probes for intertextual meaning	Participant describes experience; interviewer probes for detail, clarity
ANALYTIC METHODS Decontextualization and recontextualization. Process of coding, sorting, identifying themes and relationships and drawing conclusions Role of analyst's views	Identify descriptions of the phenomenon; cluster into discrete categories; taken together, these describe the 'essence' or core commonality and structure of the experience	Examine how understanding is produced through a close look at the words. Interested in <i>how</i> the story is told, what identities, activities, relationships and shared meaning are created through language	Open, axial and selective coding. Examine concepts across their properties and dimensions, develop an explanatory framework that integrates the concepts into a core category
	Bracket views (if appropriate)	Examine own place in the discourse(s)	Bracket views
AUDIENCE	Clinicians, practitioners and others who need to understand the lived experience of the phenomenon of interest	Policy makers and interventionists who need to understand the discourses in use to craft effective messages	Researchers and practitioners who seek explanatory models upon which to design interventions
PRODUCT	A thematic description of the pre-given 'essences' and structures of lived experiences	Description of language-in-use; identify how different discourses shape new identities, relationship and social goods are negotiated and produced	Generate theory from the range of the participants' experiences

Figure 5. Similarities and Difference of Three Interpretive Approaches with Respect to History, Goal, Philosophy, Methodology, Analytic Method and Product (Starkes, Brown Trinidad, 2010, p. 1373).

It is also important to take cognisance of the fact that there are research questions and problems that phenomenology is not suited to answer.

Van Manen (1990, pp. 21-24) states:

1. *'Phenomenology is not an empirical analytic science.'*

This methodology does not investigate 'empirical facts and scientific generalisations; asking who did what? when? where? how many? to what extent? and under what conditions?' Phenomenology is not inductively empirically derived, but rather phenomenological knowledge is empirically based on experience.

Case study and ethnographic research focus on a group(s), certain circumstances, a location or culture(s) in which the interest is to gain knowledge on 'what goes on there, how these individuals or groups(s) perceive things and how these might differ in time and place from other individuals or groups.' There may be a 'phenomenological quality' to these study approaches as the aim is to inquire about the study participants experiences, however, the results of a case or ethnographic study is to describe precisely a current state of affairs or a particular past or present culture.

It is important to note that phenomenology 'cannot be used to show or prove' and therefore this methodology does not allow for empirical generalisations, law like statements nor for the establishment of functional relationships.' Van Manen emphasises that the only generalisation allowed by phenomenology is 'never generalise about human experience as this makes them of no value.'

2. *'Phenomenology is not mere speculative inquiry in the sense of unworldly reflection.'*

As mentioned previously, phenomenological research at all times starts from lived experience or empirical data. There are western and eastern influences in the philosophy of phenomenology. For example, western influenced phenomenology 'aims at acquiring understandings about concrete lived experience by means of language, whereas, eastern influenced phenomenology may very likely practice other non-script-orientated reflective techniques.'

3. *'Phenomenology is neither mere particularity, nor sheer universality.'*

Merleau-Ponty (1964, p. 92) explains that the 'object of a phenomenological interest is neither eternal and without roots in the present nor a mere event destined to be replaced by another event tomorrow, and consequently deprived of any intrinsic value.' Van Manen simply explains that phenomenology entails in mediating in a

personal way the 'antinomy (a contradiction or paradox) of particularity (being absorbed in concreteness, difference and what is unique) and universality (being absorbed in the essential, in difference that makes a difference').

4. 'Phenomenology does not problem solve.'

Any research question that seeks solutions, procedures, calculative techniques or strategies is complete when the problem is resolved. In phenomenology, questions are *meaning* questions which ask for the *meaning* and significance of certain phenomena. Thus, *meaning* questions cannot be solved and shelved but will always remain an area of conversational interactions of lived life

One methodological approach informed particularly by Heideggerian phenomenology is interpretive phenomenological analysis (IPA). This approach has developed 'as a distinctive approach to conducting qualitative research in psychology offering a theoretical foundation and a detailed procedural guide' to analysis (Brocki & Wearden, 2006, p. 87). Interpretive phenomenological analysis has its origins in fields of inquiry such as phenomenology and symbolic interactionism and the aim is to 'explore in detail the processes through which participants make sense of their own experiences, by looking at the participants' accounts of the processes they have been through and seeking to utilise an assumed existing universal inclination towards self-reflection' (Chapman & Smith, 2002, p. 125).

Husserlian (descriptive) and Heideggerian (interpretive) Phenomenology

While the phenomenology of Edmund Husserl has as its focus a description of the lived world that conceptualises people as detached subjects existing in a world of objects, the phenomenology of Martin Heidegger is based on an existential perspective which considers that an understanding of the person cannot occur in isolation from the person's world (Walters, 1995, p. 792).

Heideggerian Phenomenology

Heidegger's phenomenology holds the existential perspective that a person cannot be understood in isolation from her or his world (Walters, 1995, p. 792). Heidegger claimed that hermeneutics is 'synonymous with the way we interpret the phenomena of our everyday *being-in-the world* (Roberston-Malt, 1999, p. 291). Hermeneutic

phenomenology as a methodology 'respects the capacity of the person for self-knowing and encourages the researcher to reflect on this knowledge' and, 'in doing so, identifies the various motives and attitudes that influence the person's behaviour' (Roberston-Malt, 1999, p. 291).

Utilising hermeneutics as a method 'compliments phenomenology as it assists inquirers in gaining a deeper understanding of the human experience through encouraging particular attention to be paid to the nature and meaning of the language used to describe the experience' (Roberston-Malt, 1999, p. 291).

Hermeneutic analysis guides the interpretation of the written phenomenological texts or narratives of human experience in order to further extricate the meaning of that particular human experience, and for these reasons, hermeneutic phenomenology is both descriptive and interpretive. Van Manen explains that hermeneutic phenomenology tries to be: 'attentive to both terms of its methodology: it is a descriptive (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an interpretive (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena. The implied contradiction may be resolved if one acknowledges that the (phenomenological) 'facts' of lived experience are always already meaningfully (hermeneutically) experienced. Moreover, even the 'facts' of lived experience need to be captured in language (the human science text) and this is inevitably an interpretive process' (van Manen, 1990, p. 180-181).

The heart of the hermeneutic endeavour is to bring the narratives or stories into understanding and seeking a suitable method to achieve this end point is crucial for the success of the research. Geanellos (1998b) reminds the hermeneutic phenomenologist that understanding and interpretation are the primary concerns of hermeneutics. Within these concerns are: '(i) the nature of understanding - what it is and how it comes into being; (ii) textual multiplicity: the many layers of meanings able to be construed from a text; (iii) textual plurality: how interpreters, influenced by pre-understandings, ask questions of and receive answers (interpret) the same text differently and (iv) interpretive accuracy, evaluating interpretations, including criteria by which such interpretations might be judged' (Geanellos, 1998a, p. 154).

Smythe, Ironside, Sims, Swenson and Spence's (2008) views of using Heideggerian hermeneutic phenomenology sums up this methodology:

'What matters is not accuracy in the sense of reliability, or how the researcher came to make certain statements; what matters is what has held the thinking of the researcher and in turn holds the thinking of the reader; what calls, what provokes them to wonder. Any insight gleaned is not about the 'generalised' or 'normalised' person who is in fact, no one, but what shows 'me' how better to understand human experiences' (Smythe et al, 2008, p. 1393).

The goal of using Heideggerian hermeneutic phenomenology is not to produce answers or solutions but rather to entice readers to take 'their own journey, to be exposed to the thinking of the author(s) and to listen for the call on their own thinking' (Smythe et al., 2008, p. 1393).

Heidegger considered it 'necessary to clarify what it means to be human if we are more fully to comprehend thinking and knowing as modes of being human' (Dall'Alba, 2009, p. 35). Dall'Alba explains further that 'if we are fully to understand knowing within various forms of professional practice, we must understand the *being* of those' (Dall'Alba, 2009, p. 35).

Considering all of the above, I thought it appropriate to use Heideggerian hermeneutic phenomenology as it has the potential to open the participant and researcher to a rich and valuable source of learning which may inform the knowledge, action and *being* of an ICU nurse in the *everydayness* of confronting death in the ICU. This in turn may offer insights for curriculum interventions to support ICU nurses in their *lifeworld* of the intensive care unit.

Research Method

My method was informed by van Manen (1990; 1997), both a phenomenologist and educational theorist. Arguing that the 'thrust of phenomenological research remains oriented to asking the question of what is the nature of this phenomenon as an essentially human experience,' van Manen proposes six research stages to structure a project (van Manen, 1990, p. 62). These offer a methodological structure that

promotes 'freedom and initiative in the researcher's involvement with the dynamic process of hermeneutic phenomenological inquiry' (van Manen, 1990, p. 30-31). In brief, van Manen's six stages are:

1. Turning to a phenomenon which seriously interests us and commits us to the world.
2. Investigating experience as we live it, rather than we conceptualise it.
3. Reflecting on the essential themes which characterise the phenomenon.
4. Describing the phenomenon through the art of writing and rewriting.
5. Maintaining a strong and orientated pedagogical relation to the phenomenon, and
6. Balancing the research context by considering parts and wholes.

Using van Manen's six research stages to search for the essence of a lived experience offered opportunities to inquire further about pedagogical issues. Van Manen believes that the reflective awareness of the nature of the phenomenon experienced, allows for transformation or the remaking of ourselves in the 'true sense of *Bildung*' (education). To paraphrase Heidegger, van Manen explains that if the researcher is deeply engaged with the phenomenon, the important question is not 'can we do something with phenomenology, but can phenomenology do something with us?' (van Manen, 1997, p. 45).

Van Manen explains further that phenomenology is itself a 'kind of *Bildung* or *paideia*; it is the curriculum of *being* and *becoming*' (van Manen, 1990, p. 8). The result of phenomenological research for educators is 'a critical pedagogical competence; knowing how to act tactfully in pedagogic situations on the basis of a carefully edified thoughtfulness' (van Manen, 1990, p. 8). Van Manen's later thinking on phenomenology is that all phenomenology is orientated to practice: 'the practice of living' (van Manen, 2007, p. 182). Van Manen refers to this concept as 'a phenomenology of practice,' of which the aims are to 'open up possibilities for creating formative relations between *being* and *acting*' (van Manen, 2007, p. 13).

It is useful to note that hermeneutic phenomenology does not negate the use of a conceptual framework which can be used to focus the inquiry and help make decisions about participants and research questions that need to be addressed. If a framework is used, it should be used to interpret the data or information and explain how the framework was used in the interpretation and in generating findings (Lopez & Willis, 2004, p. 730). In this project, once the lived experience themes have

been identified and described further, Barnett and Coate's (2005) '**The Engaged Curriculum**' framework of 'knowing, acting and *being*' will be utilised to exemplify this concept of a phenomenology of practice and to focus on the implications of a pedagogical intervention specifically aimed at the possible need of introducing thanatology to the Postgraduate Critical Care Nursing curriculum.

Hermeneutic phenomenology is reliant on the self-awareness of the researcher to acknowledge and document their 'pre-understandings (also referred to as prejudices, preconceptions, presuppositions and forestructures)' (Geanellos, 1998a, p. 155). A core philosophical assumption underlying hermeneutic phenomenology is that pre-understandings or expert knowledge on the part of the researcher are valuable guides to inquiry and, in fact, make the inquiry a meaningful undertaking. Gadamer (1976) explains that the *horizon* that is brought to the study by the researcher is influential and calls for reflection.

In keeping with Geanellos' philosophical rigour, I found it useful to document my 'pre-understandings' under the following headings: ontological, epistemological and methodological.

My Ontological Pre-understandings

I had gained significant knowledge of and reflection on the many deaths that I been involved with in a career spanning 25 years of being an ICU nurse. This also allowed me to form close and trusting relationships with the ICU student nurses whom I had been teaching at that time. Therefore, I had a 'lived experience' of the dying and deaths of patients under my care in the ICU as well as of family relationships and multi-cultural issues concerning death and dying.

Of particular importance were my own ontological confrontations with dying and death, having been provisionally diagnosed with a life-threatening disease five years prior to the beginning of the study. My other ontological confrontation with dying and death, were the deaths of two significant people during the initial stages of the study. In both instances I was personally involved with their care and at their last hours of living. The two deaths indirectly forced me to engage with my own mortality and the way(s) that I may die. However, it was the separate deaths of both my parents in the same year that posed the greatest ontological challenge. It was the first time in my life that I had had to grieve for loved ones despite experiencing short and

very limited grief at the deaths of patients under my care.

Journal Entry Friday 25th February 2011.

Today is Dad's funeral. Spent the greater part of the night and early hours writing his eulogy. Not easy as Dad became really cantankerous as he got older. Expectations of me are high. Mom says it is my duty as the eldest daughter to give the eulogy. This will be the third time in less than a year that I have had to speak at a funeral. Hard stuff. Sad stuff. Who will write my eulogy and what will be said?

Journal Entry Thursday 22nd September 2011.

Mom died on my last day at a conference in The Netherlands (17/09/2011). How ironic that I was delivering a paper on the PhD at the Death, Dying and Disposal Conference. Said my goodbyes at the funeral home – private viewing. Never expected my mom to look so dead. She looked like she had been in a concentration camp. This was not my mom. Not the mom I last saw at Dad's funeral. Frail yes, but living. I kiss her forehead ... cold. I see small icicles on her face. Cold from the mortuary. What do you want me to say? All I can think of is the Lord's Prayer. I pray quietly. Regretting being so argumentative at times. What do I do now? No parents. Does that make me an orphan of sorts?

I had to find my own way to grieve and be supportive of my sister and of course myself. For this reason, I felt it important to visit my psychologist Felicity (named with permission) with whom I have a very trusting relationship. Despite the need to care for my well-being, I was about to start my phenomenological conversations with the ICU student nurses. To remain true to the phenomenon of interest, I needed to be clear-headed and emotionally settled to engage with this crucial stage of information collection. This settling down time lasted four-and-a-half months, after which I was eager to start with the phenomenological conversations.

My Epistemological Pre-understandings

My long career as an ICU nurse and later as an ICU nurse educator afforded me many opportunities to gain significant experience and knowledge through the many deaths that I been involved in. This is in keeping with Whitehead's view that knowledge and experience allow readers to 'judge the credibility of the research in relation to intellectual rigour, professional integrity and methodological competence, and the influence on and background of my approach' (Whitehead, 2004, p. 516).

However, I still had much to learn about the cultural aspects of dying and death and how to better prepare ICU student nurses for their future experiences of dying and death in the ICU, as well as in their personal lives.

My Methodological Pre-understandings

I was concerned that I would get too much information from the ICU student nurses' phenomenological conversations and feedback sessions on dying and death in the ICU, and therefore not be able to remain focussed on and true to the research question. My other concern was that of remaining emotionally and even ontologically uninvolved during the ICU student nurses' phenomenological conversations and feedback sessions should they become tearful and emotional. My caring nature as a nurse would be to reach out and provide comfort and support. Krefling warns researchers that they should guard against over-involvement with the participants, as this may lead to the researcher finding it difficult to separate his/her own experience or biases from that of the participants (Krefling, 1991, p. 218).

The credibility and trustworthiness of the researcher in hermeneutical phenomenological research are crucial and the researcher must provide evidence of a decision trail (Whitehead, 2004). In keeping with Whitehead's recommendation, I kept a journal during the course of the study, making entries after each participant's phenomenological conversation and feedback sessions as well as my own thoughts during the formulation of themes. In order for me to capture the essence of the participants' experiences, my thoughts and impressions were captured on the digital audio recorder²⁷ immediately after the phenomenological conversations and feedback sessions. Some of the journal excerpts and reflections have been included in the information gathering section.

It is important that some information about the researcher is included. In my case this would include 20 years of my experiences of death and dying in the ICU both as an ICU nurse and later as an ICU nurse educator.

²⁷. Olympus Digital Voice Recorder DS-50.

Invitation of Participants

There are a number of factors that need to be taken into consideration when determining the selection of participants in phenomenological research.

Sampling selection in qualitative research has a profound effect on the quality of the data. In order to generate rich data²⁸ in qualitative research, Morse argues for the qualitative principle of appropriateness that requires purposeful sampling and a 'good informant' ('one who is articulate, reflective and willing to share with the interviewer') (Morse, 1991, p. 127). Although not exclusively, qualitative research more commonly employs non-probability sampling methods. The intention with non-probability sampling is that it is not usually intended that the findings of a particular study will be generalisable, but will apply only to the specific population under investigation.

Therefore the number of participants is not determined by the need to ensure generalisability, but by a desire to investigate fully the chosen topic and to provide information rich data (Grbich, 1999).

As phenomenology is concerned with the lived experience of an individual, a probability sample would be totally incompatible, because the aim of a probability sample is to seek generalisability (Higginbottom, 2004, p. 16).

Phenomenological studies utilise methods where the participants have a definite knowledge of the phenomenon under investigation, hence purposeful sampling is used.

A crucial point to take into consideration when determining the number of participants in a phenomenological study is that the research question must be obvious and clear in order for the information to be easily obtained from the phenomenological conversations as well as the feedback sessions. Conversely, if the research question is difficult for the participants to engage with, the number of participants will have to be increased.

28. Van Manen (1990) offers some interesting thoughts on the use of the word 'data' in hermeneutical phenomenological research. For van Manen, the word data is misleading as it has overtones of quantitative research approaches. It is more appropriate in phenomenology to speak of 'gathering' or 'collecting' lived experience material, even if it is in different forms

The premise taken by Morse (2000) is that the broader the scope of the research question, the longer it will take to reach saturation.

If the information is rich from the phenomenological conversations and contains minimal dross, then fewer participants will be needed to reach the point of no-further information generation.

Focussing on the research question is paramount to phenomenological information saturation, especially when the research topic is broad in scope. Much more phenomenological information will be needed to reach saturation and this will require more participants, more phenomenological conversations and more information sources. The study may be larger but not necessarily richer (Morse, 2000, p. 3). The study may even be of no value if the level of explanation is shallow and superficial.

Morse is emphatic about the principle of the quality of data in qualitative research in general and the number of interviews per participant, as it determines the amount of usable data (Morse, 2000). If the usable data obtained from each participant is rich (from a number of interviews), then fewer participants are needed. In phenomenological research, each participant may have several phenomenological conversations, thus providing a large amount of information, and therefore fewer participants will be needed.

Participant Sample Size

Having taken all of the above into consideration, I employed a purposeful sampling method of which I personally invited participants who were currently registered for, or had completed the Postgraduate Diploma in Critical Care Nursing (Adult or Child), and who were able to communicate comfortably in English but were also representative of different ethnic groups and religious beliefs or practices.

There is always the likelihood of power relationships when engaging with students past and present, which may impact negatively on the gathering of information and material. In order to minimise this from happening, my use of 'purposeful invitation' of participants was employed, allowing me to choose those that I had a trusting and respectful teacher/student relationship with.

My initial thinking was to invite six participants in order for me to adhere to van Manen's (1990) research stage two's outcome of tying the researcher to the ontological nature of the methodology of the study. The intention of phenomenology as a methodology is to obtain 'full and rich personal accounts from the sample used' and that 'concepts and commonalities are explored across the sample (Hale & Kitas, 2008, p. 91). Hale and Kitas argue 'that true data saturation can never really be achieved' because each individual's experiences are so unique. From the amount and richness of the information obtained from the six participants that addressed the phenomenon under exploration: ICU nurses' lived experiences of the dying and deaths of patients under their care in the ICU, I believed it to be unnecessary to invite further participants for this study.

In total, the time spent on both the phenomenological conversations and participant feedback was 889 minutes and 426 pages of transcriptions. The process of unravelling the ICU nurses' experiences and the emergence of the five themes took almost 24 months²⁹.

The Setting

The sites of the research was at the paediatric ICU at Red Cross War Memorial Children's Hospital in Rondebosch and the ICUs at Groote Schuur Hospital in Observatory, both academic tertiary teaching institutions affiliated to the University of Cape Town.

The conversation setting was determined by the six participants who requested that the same seminar room within the university be used rather than one within the vicinity of the ICU environment. Previous experience has taught me that even when facilitating teaching and learning after a clinical session and giving feedback to the student in an ICU environment, there are many interruptions from various staff members and visitors. This has the potential to jeopardise the study in that essences and developing themes may be lost.

Another obstacle considered was the very real possibility of the emotional state of the participants while sharing their intimate experiences of death and dying with myself. The phenomenological conversations and feedback sessions were approached

²⁹. I have added a participant phenomenological conversation and feedback session schedule (Appendix D on page 289) which illustrates the duration of the phenomenological conversations and feedback sessions.

with sensitivity and there were no requests made for a recess or the conversation(s) to be temporarily suspended.

Before I could have the phenomenological conversations and the follow-up feedback sessions, the following ethical considerations were adhered to.

Ethical Considerations

Clearance from the University of Cape Town's Faculty of Humanities Research Ethics Committee was received prior to the commencement of the study (**Appendix A on page 283**).

In any research which involves human subjects, there must be safeguards for their protection (Holloway & Wheeler, 1996, p. 39). All participant observation, and indeed qualitative interviewing, is covert to some extent.

It is never possible to explain to the research participants exactly what will be done with the material that the researcher is collecting.

This is partly because qualitative research is creative, and what will emerge from the data/information cannot be predicted in advance.

All I could do was to give the best possible account of my intentions at each stage of the research process and to ensure confidentiality and anonymity.

The participants were made aware of the University of Cape Town Code for Research involving human subjects, which sets out the principles relevant between the relationships of the researcher, the research community and its ethos; research subjects and society as a whole³⁰.

A copy of this document was given to each participant.

³⁰ <http://www.uct.ac.za/depts/educate/download/uctcodeforresearchinvolvinghumansubjects.pdf>.

Informed Consent

Holloway and Wheeler emphasise that the participants' autonomy must be respected at all times when making a free, independent and informed choice without any form of coercion (Holloway & Wheeler, 1996, p. 39). The participants chose their own pseudonyms, knowing that this would allow for limited confidentiality only. Signed consent was obtained from the research participants prior to all interviews and feedback sessions and written permission was obtained from the participants to use the information when the study was being written up (**Appendix B on page 284**).

Confidentiality and Anonymity

Anonymity is a controversial issue in qualitative research where the researcher and others can identify the participants, especially when interview guides and focus groups are utilised to generate or validate data or information.

Limited anonymity but strict confidentiality were guaranteed and the participants were informed that they not only had the right to refuse to take part in the study, but that they could withdraw at any time without recrimination or prejudice.

Every attempt was made to ensure that this study represented the experiences described by the participants. In order to protect their identity, a full transcript of an interview has not been included as an example.

All hard-copy transcripts were stored and locked in a drawer in my office and the electronic versions saved on my personal computer which was password protected.

The Phenomenological Conversation

Interviews allow for the development of 'conversational relationships about the *meaning* of an experience' (Maggs-Rapport, 2001, p. 374) and they also allow the researcher to collect narrative material that will augment the understanding of the human phenomenon under investigation.

Smythe et al. offer some useful views on the concept of the phenomenological conversation. It is common to say that we 'conduct' a conversation and in doing

so may become stifled or even silenced to a degree. It is better to say that we 'fall into conversation, or even that we become involved with it' (Smythe et al., 2008, p. 1392). Smythe et al state further that 'to go to an interview with a mind-set of conducting is to freeze the phenomenological spirit' and therefore the interviewing style should not be structured with a 'pre-organised plan.' Yet, neither must it be 'unstructured' where there is no clear purpose of why the researcher(s) are there (Smythe et al., 2008, p. 1392).

I took Smythe and colleagues' views into consideration but had concerns of my own as to how to keep the study participants focussed on the phenomenon under exploration. The ICU nurses participating in the study were purposefully selected in that they were able to talk comfortably and at length about their experiences of the deaths of patients under their care in the ICU. In an attempt to address my concern, I had the research question printed in bold font and placed on the table in front of the participant and myself. I also took the advice of Balls (2009) who recommended that it may be useful to have some questions or prompts to keep the conversation flowing in the right direction, thus enabling relevant information to be generated in order to answer the phenomenon under investigation (**Appendix C on page 288**).

The phenomenological conversation started off with the question:

'Please describe your experiences of the deaths of patients under your care in ICU.'

The Use of Transcribing Equipment

All the participants agreed to the use of the digital audio recorder for the duration of the conversation. Only after the participants had read and understood the purpose of the research and had signed the consent form, was the digital recorder switched on. The phenomenological conversations and feedback sessions required some preparation in advance and the following strategies were employed:

11. The participants were contacted well in advance of the phenomenological conversations and feedback sessions and reminded a few days after the initial notification.
12. Ethical issues and access were considered. This included informed and signed

consent being given prior to the phenomenological conversation and feedback sessions, following an explanation about the nature and purpose of the study and assurance of confidentiality and anonymity.

13. The research setting was spacious and well ventilated to accommodate the participants and the tape-recording equipment.
14. A reflective journal entry was made immediately after the session about unusual, interesting or contradictory ideas as well as gestures, pauses and body language.

Researcher-Participant Relationships

The following characteristics are important for qualitative researchers when conducting any form of research: they should be good listeners, non-judgemental, friendly, open, honest and flexible (Holloway & Wheeler, 1996, p. 8). This required me to adopt an ethical rather than a methodological position regarding the thoughts and words of the participants. I also reassured the participants that there was neither right nor wrong answer. I had asked each participant to allow for 30 minutes for me to explain the purpose of the research project and signing of the consent form. Thereafter, my intention was to engage with the participants for approximately 30 to 40 minutes for however many phenomenological conversations and feedback sessions were required.

Information Generation – Techniques and Strategies

The process of interaction between me and the participants allowed me to discover their *lived-world* by gathering experiential material through the phenomenological conversations and my reflective journal writing.

Journal entries were made immediately after each phenomenological conversation and participant feedback session. Reflective journal writing related to how I felt about the conversation and feedback; what, if any, problems had occurred and my impressions of the process.

The process of eliciting narratives from transcripts was a lonely and challenging exercise and took a considerable amount of time and patience. The transcripts were read many times in order for me to gain some sense of the raw meaning. It was at this stage that initial interpretation was begun, but before I could proceed further, I needed feedback from the ICU nurses to validate their phenomenological

conversations.

Participant feedback or member checking not only enhances the rigour of qualitative research, but can also be a final authenticating stage whereby information, nuances, interpretations and conclusions are returned to the participants for critique and confirmation of the accuracy of their narratives of experiences (Creswell, 1998). It has previously been noted that the researcher cannot be excluded from the research process, particularly in Heideggerian hermeneutic phenomenology, and that the researcher is a fundamental player in the understanding of the *meaning* of the phenomenon of study. It is through participant feedback that *meaning* and co-operative exploration is achieved.

Each of the six ICU nurses was given a hard copy of their narratives to read and comment on. Once this had been done, I engaged with them individually to explain further some of the concepts that I had had difficulty with understanding or trying to do naïve analysis. Having found my own experiences as an ICU nurse dealing with the dying and deaths of patients lonely, I found spiritual release in the process of giving these nurses an opportunity to be heard and taken seriously about their difficulties in dealing with death.

Unravelling of Texts of the ICU Nurses' Lived Experiences

The purpose of information unravelling³¹ is to grasp the essential meaning of a phenomenon. This means reducing an enormous amount of information by sorting into categories and themes through a simultaneous process of analysis and interpretation.

It is important to take cognisance of the fact that there is 'no one single standardised method identified for the methodology of hermeneutical phenomenological inquiry' (Robertson-Malt, 1999, p. 292). Many scholars have designed numerous inductive methods which have guided their research of human experience.

However, there is a common philosophical principle which calls upon the researcher to 'return to the things themselves,' which Taylor is convinced 'both unifies and governs the various methods of hermeneutic phenomenological inquiry' (Taylor,

³¹ 1. Unravel: to undo twisted, knitted or woven threads (Oxford English Dictionary, 2006).

1994, p. 292).

I took van Manen's (1990) six research stages to generate the lived experience themes under the umbrellas of Heidegger's three modes of *being: authentic, inauthentic and undifferentiatedness*.

Van Manen emphasises that although a certain order is inferred in this methodological staging, it does not imply that the researcher must proceed by starting and completing each stage.

During the research process 'one may work at various aspects, intermittently or simultaneously' (van Manen, 1990, p. 34).

1. Turning to the nature of lived experience

Exactly what is lived experience? Dilthey proposes that lived experience is to the soul what breath is to the body: 'just as our body needs to breathe, our soul requires the fulfilment and expansion of its existence in the reverberations of emotional life' (Dilthey, 1985, p. 56). In short, lived experience is the breathing of *meaning*.

Van Manen intimates that lived experience is the 'starting point and end point of phenomenological research' and the aim is to 'transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful' (van Manen, 1990, p. 36). It can therefore be said that lived experience is temporal in structure: it can never be comprehended in its instant disclosure but only reflectively as a past presence.

Having shared the ICU nurses' lived experiences of the dying and deaths of patients under their care in the ICU, I became more convinced that a pedagogical intervention was needed for the future.

The essences of the ICU nurses' lived experiences of death and dying lay within their transcribed narratives. This unravelling of meaning from the phenomenological conversations was an enormously time-consuming task. Taylor insists that the interpretive process be done with a high level of 'mindfulness':

‘It is the responsibility of any researcher doing interpretive work to sift through the gathered information very carefully, so that the essence of its *meaning* can be salvaged. Other details that have no contextual bearing on the main intentions of the research are put to one side. The salvaging of qualitative information is reminiscent of searching for gemstones of a certain type; some gems are of a desired type, others are precious but they are not the type being sought, and some of the other stones are clearly pieces of gravel stones and grit’ (Taylor, 1994, p. 187).

In order to gather the ‘desired type of gemstones’, I colour-coded Heidegger’s three modes of *being* when reading and re-reading the phenomenological conversations. I also added ‘reminders to self’ to help me stay focussed, not only on the phenomenon being explored but also on Heidegger’s philosophy of *Dasein*, *thrownness* and *facticity*, *Sorge* and *mineness*, all concepts of *being-in-the-world* and *lifeworld*.

◆	AUTHENTIC – <i>to be self properly</i> (King, 2001) or owned self (Heidegger, 1927/1996)
◆	INAUTHENTIC – <i>self not properly</i> (King, 2001) or disowned self (Heidegger, 1927/1996)
◆	UNDIFFERENTIATEDNESS – <i>everydayness</i> ; public disclosedness
◆	AUTHENTIC/INAUTHENTIC – I highlighted this in red as I felt that this may be a ‘semi-precious’ gemstone. I decided to view this existential as a state of ‘ denied authenticity ’ (This concept is discussed further in Chapter Seven).
□	OTHER

Reminders to self

- *Dasein* – *being-there*; *being* which understands itself.
- *Thrownness* and *facticity* – absorbed within a relationship with others; *Facticity* describes conditions in which *Dasein* finds itself and which affects its possibilities.
- *Sorge* – *Dasein* becomes engaged with life situations and possibilities.
- *Mineness* – *being-in-the-world* with others.

It was at this stage and at stage two (see below), that interpretation started. I took note of how certain words were used, the tone of voice, hesitations, silences and facial expressions. This was achieved by 'a note to self' at the time of a pertinent part of the participant's story and the recording time on the audio digital recorder was noted. When transcribing the participants stories, my 'notes to self' were checked against the audio digital recorder and relevant nuances were captured in the transcriptions.

Following this, I re-read the transcriptions with and without the highlighted sections and the information that deviated from the explored phenomenon was deleted from the transcribed document.

2. Investigating experience as we live it

Heidegger's thinking of *being-in-the-world* is to be absorbed in a continual mode of endeavouring to understand and bestow *meaning* to our own and others' many *ways-of-being*. This proposition is placed within the context of the bound nature of lived human experience rather than attempting to separate past experience(s) from the present and in doing so disaffecting a fundamental element of human nature.

Being the researcher who had had lived experiences of the dying and deaths of patients under my care in the ICU, tied me to the ontological nature of the phenomenological research. This also enabled me to search for greater *meaning*, enhancing the value of looking for better understanding of the ICU nurses' lived experiences of dying and death in the ICU.

Research stage two is in keeping with Heidegger's phenomenological stance of both *Dasein* and *being-in-the-world*. It was at this juncture that I experienced a break through of sorts. During naïve analysis, it was challenging to grapple with van Manen and Heidegger at the same time. Despite this, and keeping true to the philosophical underpinning of the research study, I started to formulate lived experience themes captured under the three *existentials* of *being* (*authenticity, inauthenticity and undifferentiatedness*), *Dasein* and *being-in-the-world*.

3. Reflecting the essential themes which characterise the experience

I found van Manen's explanation of what essential themes are not very helpful and this guided me in the formulation of lived experience themes. Van Manen proposes that essential themes are **not**:

‘objects or generalisations; metaphorically speaking they are more like knots in the webs of our experience, around which certain lived experiences are spun and thus lived through as meaningful wholes. Themes are the stars that make up the universes of meaning we live through. By the light of these stars we can navigate and explore such universes’ (van Manen, 1990, p. 90).

Unravelling texts of lived experiences by interpreting their meaning is best described as a method of unearthing or disclosing. There is no rigid method or process of formulating a thematic understanding. It is rather a ‘free act of seeing meaning’ (van Manen, 1990, p. 79). Van Manen emphasises that a theme gives control and structure to research and academic writing (van Manen, 1990).

Themes that are phenomenological can be viewed as the scaffolding of experience. In essence, when a phenomenon is analysed, the researcher is attempting to ascertain what themes they can identify and the scaffolding that supports that particular experience.

In staying true to the phenomenon of interest (ICU nurses’ experiences of dying and deaths of patients under their care in the ICU), and adhering to the philosophy of Heidegger, the phenomenological themes were the three existentials of *Dasein* and *being: authenticity, inauthenticity and undifferentiatedness*. This would mean that the lived experience themes would be the main scaffolding or pillars that would support the three existential modes of *being* themes.

Once I had committed myself to utilising the three modes of *being* as the phenomenological theme headings, I worked between two approaches of uncovering *meaning* from the phenomenological conversational texts:

1. The wholistic or sententious approach. In this approach I looked at the text as a whole and followed van Manen’s suggestion to ask myself: ‘What sententious phrase may capture the fundamental meaning or main significance of the text as a whole?’
2. The selective or highlighting approach. By reading and listening to the transcriptions many times and asking myself ‘what statement(s), phrase(s) or story(ies) appear to be crucial or revealing about the phenomenon or experience being described?’

(van Manen, 1990, pp. 92-93). The aim was to hold on to the themes by extracting fitting phrases or by capturing in short statements the foremost thrust of the meaning of the themes, in this case, the lived experience themes.

4. Describing the phenomenon through the art of writing and rewriting

The transcribed conversations became the phenomenological texts upon which the method of hermeneutical analysis was made.

Firstly, the phenomenological conversations were transcribed verbatim and then read with effort on my part to become immersed in the text so that I could identify the embedded and essential (ontic)³² basis of the ICU nurses' lived experiences of the deaths of patients under their care in the ICU.

The lived experience thematic statements were isolated, utilising van Manen's (1990) selective reading methods. These methods required me to listen to or read a phenomenological conversation text several times and ask myself:

'What anecdotal narrative from this particular phenomenological conversational text captures or reveals the phenomenon of ICU nurses' lived experiences of the deaths of patients under their care in the ICU?'

The identified lived experience themes were then revisited with each participating individual ICU nurse, who at this point became co-researchers by validating these lived experience themes.

5. Maintaining a strong and orientated pedagogical relation to the phenomenon

This was perhaps the most vital and rigorous part of the information analysis process. Success of the interpretation was dependent on my being focussed on the research question and the phenomenon being explored. At this stage of analysis the final experiential themes had been 'mined' and the less 'precious' lived experience themes 'sifted,' leaving the real 'desired and precious' lived experience themes.

³². Ontic inquiry is concerned with the things or entities of the world (van Manen, 1990, p. 183).

I made every effort to reflect critically on my choices of the lived experience themes by repeatedly comparing the identified experiential theme (a part of the phenomenological conversational text) with that of the story or experience being shared, and asking myself:

‘Is this interpretation fitting the context of this particular segment of the phenomenological conversational text and also the text as a whole?’

‘Is my interpretation faithful and true to the overall story/experience?’

The identified lived experience themes were then used during the discussion of the interpretation to assist me in selecting the relevant anecdotes from the ICU nurses’ phenomenological stories.

This exemplifies further the essence(s) of the ICU nurses’ lived experiences of the deaths of patients under their care in the ICU. However, it must be noted that the unravelling of the ICU nurses’ narratives are actually a picture in a moment in time and space. Heidegger refers to this as temporality; lived time, and spatiality; lived space (the ICU).

6. Balancing the research context by considering parts and wholes

Common or similar experiences between the six ICU nurses’ phenomenological stories identified five lived experience themes. The analysis and participant feedback was deemed completed when no more new lived experience themes arose.

By adhering to van Manen’s (1990) six research stages to unravel the ICU nurses’ narratives of their experiences of dying and deaths of patients under their care in the ICU five lived experience themes emerged:

- (i) **care**
- (ii) **suffering**
- (iii) **disenfranchisement**
- (iv) **cultural/religious unpreparedness and**
- (v) **living with dying.**

The extrapolated lived experience themes provided the basis for addressing some pedagogical concerns in the Postgraduate Critical Care Nursing curriculum.

Figure 6 illustrates a diagrammatic representation of the phenomenological hermeneutical process for this study of the lived experiences of ICU nurses' caring for the dying and deaths of patients in the ICU.

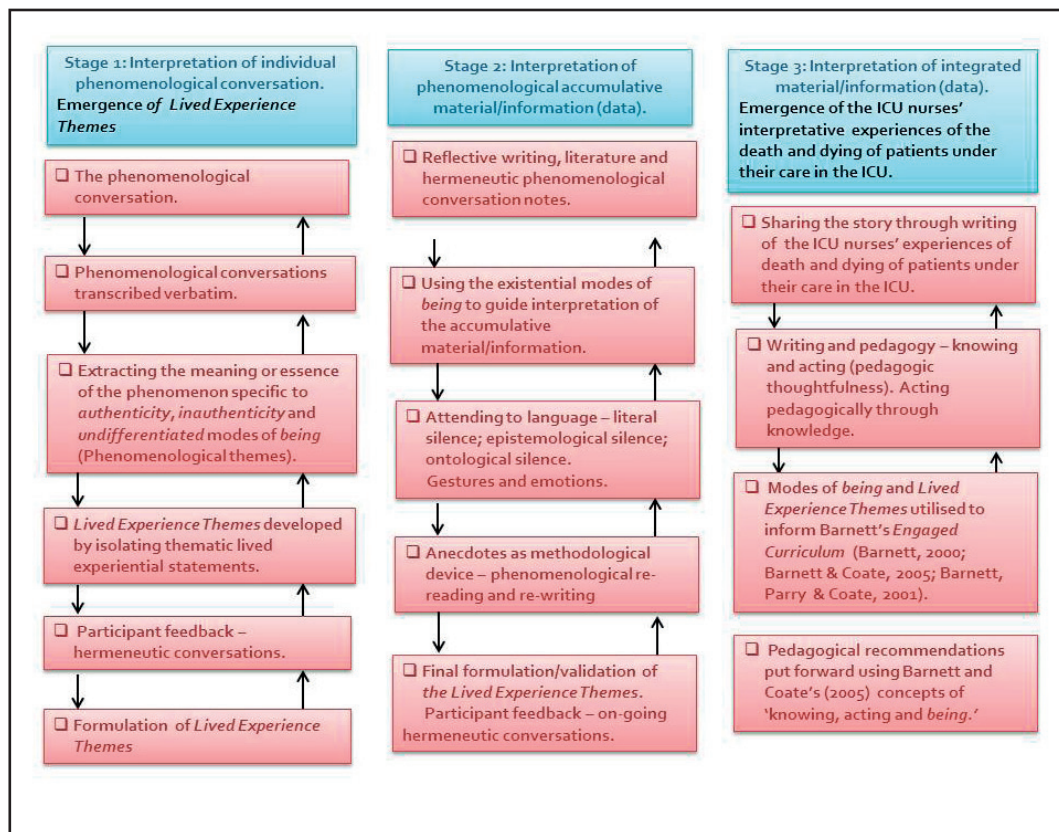


Figure 6. Diagrammatic Representation of the Phenomenological Hermeneutic Process. (C = Curriculum)

As the lived experienced themes were identified, I needed to make sure that there was a process of rigour and precision to the study.

Expressions of Rigour

Within the nursing literature, there is much debate about which criteria are appropriate and explicit to the rigour³³ of phenomenological research (Annells, 1999; Koch, 1994; Koch, 1996; Maggs-Rapport, 2001; Whitehead, 2004). A critical appraisal of rigour in interpretive phenomenological nursing research by de Witt and Ploeg (2006) revealed that the criteria of rigour previously used for generic

33. Rigour is defined as the 'goodness' of qualitative research (Emden & Sandelowski, 1998, p. 206).

application to qualitative research (trustworthiness; auditability and confirmability; credibility and transferability) are not fitting to adequately describe the rigour of hermeneutic phenomenology.

A framework proposed by de Witt and Ploeg (2006) using unique features of interpretive phenomenology is described in Table 12. This framework is largely based on the work of van Manen (1990; 1997) in which he substitutes ‘criteria of rigour’ for ‘expressions of rigour.’

In order for me to be committed academically to the most current expressions of rigour in hermeneutical phenomenological research, I followed deWitt and Ploeg’s (2006) proposed framework as set out in Table 12.

Balanced integration	Related to the articulation of philosophical principles with respect to the topic, the method and the participants’ voices.
Openness	Openness of the study to scrutiny.
Concreteness	Usefulness for practice.
Resonance	Richness, reverberation.
Actualisation	Phenomenological interpretation does not end when a study is finished – future effects of the research findings.

Table 12. The Proposed Framework of Expressions of Rigour
(de Witt & Ploeg, 2006, p. 224).

Having unravelled the information from the participants’ phenomenological conversations and the feedback sessions, I implemented deWitt and Ploeg’s (2006) and van Manen’s (1990; 1997) expressions of hermeneutic phenomenological rigour paying particular attention to the philosophical underpinning of the study.

This is an area of rigour that has previously been a weakness of interpretive phenomenology: the misrepresentation and/or superficial inclusion of philosophy (Crotty, 1996; Draucker, 1999; Paley, 1998).

Adhering to de Witt and Ploeg and van Manen’s concept of expressions of rigour, I have provided examples of balanced intergration, openness, concreteness, resonance and actualisation.

Balanced integration

It is imperative that the researcher include articulation of the basic philosophical underpinnings and its suitability to the research focus, comprehensive intertwining of the philosophical concepts with the research method(s) and findings of and achievement of a balance between the voice of the study participants and the philosophical framework (de Witt & Ploeg, 2006).

An example

Heidegger's *Dasein* means 'to be there, present available, to exist' (Inwood, 1999).

Inshalla is an ICU nurse who is a converted Muslim. She is 39 years old and has 20 years' working experience in the ICU. She has only recently received death education when she completing her Postgraduate Diploma in Critical Care Child Nursing.

'I had a patient who was six months old. The mom was struggling to have babies, then after three miscarriages, she had this little one. The baby was so small, it was a beautiful baby [Smiling]. You know when you have those little 'prems,' when they are so cute and for me, nursing this baby, I thought I'm part of something greater than myself. Because here I am so big and here's this tiny little bundle and I've been doing my utmost to care for this baby, you know. I was sitting and every time I looked at this baby I would think 'hey he's beautiful.' I went to lunch. [Long pause. Thinking back]. When I came back my child was dead. I thought "My God: what did I do wrong?" It cannot be true that this little baby is gone. I really felt like I was losing myself.'

'But that is the time when I go and sit and think about the day. When I sit, and especially when I go and do my Salaah [Muslim prayers that are said five times a day] at night, then before I go and pray, I will always ask Allah: "What did I do wrong today? What could I have done differently?" and if couldn't have done it, then I will always ask Allah for that. Maybe I could have said that at that time, or sometimes I will cry because there is no other way to express yourself, because that is so near to your heart. Like that little baby. I couldn't at night, I couldn't, because my head was feeling heavy and I just cried, and after I cried, I felt much better.' ▶ Inshalla.

This example illustrates two features of balanced integration: namely Heidegger's concept of *being* and *lifeworld*. The philosophical underpinning is clearly evident in the phenomenological conversation of the ICU nurse.

Openness

The notion of openness is also consistent with orientation and being attuned to the phenomenon under exploration, aspects in which the interpretive phenomenological researcher must implement and sustain throughout the study. Such openness is manifested by opening up the study to scrutiny of the various choices made during the interpretive process.

An example

Esther is an Afrikaans³⁴ speaking ICU nurse who is a staunch Protestant. She is 28 years old and has five years' working experience in the ICU. Esther is single and has no children. She has had some, albeit extremely limited death education in her nursing career.

Journal Entry Thursday 25th August 2011.

'I am mindful of Esther and the upcoming phenomenological conversation that is scheduled tomorrow. She is one of the better conversationalists but has been tearful in class when we did the reflective drawing exercise. I know that she will be teary again – death of children still hurts her. I need to be focussed and stay true to the phenomenon of interest and not want to reach out and comfort her. Difficult to suspend one's authenticity as a carer and just watch someone in emotional distress.'

The concepts of balanced integration and openness reflect the research process. The expressions of rigour that remain – concreteness, resonance and actualisation speak to the research outcome.

Concreteness

Van Manen (1997) explains this concept succinctly by simply instructing the researcher to write in such a way that examples are provided to position the reader 'concretely' in the context of the researched phenomenon which will link up with the experiences of their own *lifeworld*.

Van Manen (1997) uses the awkward term 'lived throughness' to describe specific features of interpretive phenomenology that tie readers to a phenomenon of everyday life.

³⁴ Afrikaans is a West Germanic language that has evolved in South Africa, Namibia and, to a lesser extent in Botswana, and Zimbabwe. It originates from 17th century Dutch dialects spoken by the early, mainly Dutch settlers in southern Africa.

An example

Most mothers of young children are concerned when their children experiment with cigarettes and matches [experience in the reader's *lifeworld* if the reader is a mother or parent]. Some parents are punitive in their approach to discouraging such high-risk behaviour, especially in young children [experience in the reader's *lifeworld* if the reader is a mother or parent]. There is the possibility that young children may be injured while experimenting with cigarettes and matches and require hospitalisation in an ICU.

There is also the possibility that the injured child may die [context of the phenomenon]. Thato shares her experience.

Thato is a Xhosa³⁵ ICU nurse who is a Christian. She is 46 years old and has five years' working experience in the ICU. She is married and has three children. She has only recently received some death education in her nursing career during her Postgraduate Diploma in Critical Care Child Nursing.

'These children there were two of them. They were smoking and the mother, I think, she was trying to punish them. But instead of hitting them, she just threw the paraffin and lit them. She is in prison now, but there is another story that she has a psychotic problem. So it's still painful to me, because that child, when he was lying there, he keeps on saying, 'Where is my mom? Can you please call my mom to visit?' 'Mom did come to visit. I'm working day duty, so she had to come with the prison people. I don't think she meant to do that. You know, even if they are going to say, she is alright upstairs, but there is no parent who can do that purposely. There was something that was triggering her to do that and now, with this death, I think her life is going to be miserable forever. She will never forgive herself. I know, because I'm a mother.' ▶ Thato.

Resonance

This expression of rigour incorporates the experiential or effect that the reader has after reading the findings of the study. Van Manen describes this expression of rigour as an epiphany or 'the sudden perception or intuitive grasp of the meaning of something' (van Manen, 1997, p. 364). The synonym 'resonance' is used by van Manen to express depth and *meaning*.

³⁵.The Xhosa people are speakers of one of the Nguni languages living mainly in the south-east part of South Africa.

An example

Another example of resonance is highlighted by one of Phumzile's remarks at a feedback session:

'What you are doing here Nicki is so important, especially to me because there a few people who know about death in our culture. This death thing, [umm] education that you go on about has touched my heart' ▶ Phumzile

Actualisation

The fifth and last expression of rigour in hermeneutical phenomenological research is actualisation.

This expression of rigour focuses on the future possibilities and outcomes of the resonance of the study findings – that is to say, that the phenomenological interpretation does not finish when a study is completed but will carry on being interpreted by readers in the future. The concept of actualisation is discussed later in Chapter Seven.

In summary, van Manen's (1990) six stages were used to unravel the ICU nurses' narratives of their experiences of dying and deaths of patients under their care in the ICU.

Five lived experience themes emerged:

- (i) **care**
- (ii) **suffering**
- (iii) **disenfranchisement**
- (iv) **cultural/religious unpreparedness** and
- (v) **living with dying.**

These lived experience themes will be discussed in the following chapter.

CHAPTER FIVE

The Phenomenological Conversation

In this chapter, I present the lived experience themes that emerged from the unravelling of the phenomenological conversations and aim to give the reader an understanding of and insight into ICU nurses' lived experience of the dying and deaths of patients under their care in the ICU. The ICU nurses' voices are incorporated as anecdotes or stories that allow the reader to 'see' and hence be 'invited' to be reflexive to the *meanings* embedded in the ICU nurses' experiences of death and dying in the ICU.

The formulation of themes have been based on my readings exploring various aspects on suffering, alienation/guilt, bereavement, respect and knowledge of different religions and cultures and the continuous confrontation with dying and death.

Following each theme, I return briefly to describe the theme's relation with Heidegger's concepts of *Sorge*, *Dasein* (*authenticity*), *Angst*, *fallenness*, *Das Man/They* and *thrownness* (*inauthenticity*) and *being-with-death* (*undifferentiatedness*).

I have attempted to follow Rosen's (1986) recommendation that in phenomenological research and writing, the anecdote or story should:

- Compel - a story recruits our willing attention.
- Lead us to reflect – a story tends to encourage reflective search for significance.
- Involve us personally – we tend to search actively for the storyteller's meaning via our own.
- Transform – we may be touched, shaken, moved by a story; it teaches us.
- Measure our interpretive ability – our response to a story is a measure of our deepened ability to make interpretive sense of it (Rosen, 1986, pp. 226-237).

Description of the Lived Experience Themes

Five lived experience themes emerged from the information obtained from the phenomenological conversations and are presented in Figure 7.

Modes of <i>being</i>	ICU nurses' experiences of the deaths of patients under their care in the ICU	Pedagogical theme
Authenticity (to be self properly)	Care (<i>Sorge, Dasein</i>) delivery, quality	Knowing Acting <i>being</i>
Inauthenticity (to be self not properly)	Suffering (<i>Angst, Fallenness</i>) alienation, guilt Disenfranchisement (<i>Das Man, They</i>) bereavement Cultural/Religious Unpreparedness (<i>thrownness</i>) respect, knowledge	Acting <i>being</i> Acting <i>being</i> Knowing Acting <i>being</i>
Undifferentiated (<i>everydayness, being-in-the-world</i>)	Living with Dying (<i>being-with-death</i>) ontological confrontation, death fatigue	Knowing Acting <i>being</i>

Figure 7. The Modes of *being*, Lived Experience and Pedagogical Themes.

Mode of *being* – Authenticity

Lived Experience Theme: **Care** (*Sorge, Dasein*)

Care embodies a primary mode of *being-in-the-world* and is an essential function of nursing which embraces human interaction. Nurse and patient work together in a symbiotic relationship from an ethos of caring, rather than that of curing. The desired outcome of this relationship is to promote growth and development of the individual which would portray nursing as a ‘deeply human activity.’

‘I, like for me, when somebody is dying, I will come to the person, I will speak to him, but in a nice soft tone of voice, without being loud, or, sometimes, when you like if you’re not knowing what’s happening – that’s what I mean: humanly, you come in and you talk.’ ▶ Inshalla.

Phumzile is a Xhosa speaking ICU nurse who holds both Christian and Xhosa traditional beliefs. He is 30 years old and has four years ICU experience. Phumzile is unmarried and has never received death education in his nursing career:

‘I talk to them [paediatric patients] when I’m doing nursing care like washing and feeding. ‘Come on, little soldier, you can do it.’ ▶ Phumzile.

I ask Thato; 'Tell me some of your experiences about deaths of patients in ICU?'

'It depends on how close I am to the patient, because sometimes, the patient you admit you are not too close to. Yes, you do feel a pain, but not like the patient who stayed a bit longer in ICU. The thing that is so painful, is when you look at the family and you look at, sometimes, the age, or you look at the background, because as I get close to the parents, I even know their backgrounds, because they are even willing to share their background with us.' ▶ Thato.

She explains further her relationship with the mother:

[The mother of the dead baby has been married for five years and this is her only child].

'Even if he is a small baby, but because of that and you think of that pain that she's feeling now and she's even thinking "I'm not going to get another child," so she is losing hope and it's so painful, I even to you now, because you were willing to help, you were willing to save this life.' ▶ Thato.

Cindy is an Afrikaans-speaking ICU nurse. She is 36 years old and a Christian. She is married and has two young children. Cindy has never received death education in her nursing career.

Cindy has a spiritual approach to caring when a child is about to die:

'I pray before the child dies. I talk to the soul because after death you are just a body but your soul lives. So you still care. It doesn't stop just because the child is dead. You have the mommy to care about too.' ▶ Cindy.

Caring is a practical activity associated with the perspectives, attitudes and expectations of those doing the caring.

'It's like I want to say "go peacefully" and for me, that is my person - I don't want to feel that, I don't want to feel, you know, sometimes you feel they are thinking, they are fighting something. You don't want to say lose the battle, because you are going to good hands. That is why I'm putting my hand on that person to tell them they are going to hands that will always keep you safe. So then I hold their hand it tightly and it gives me that, that feeling of [pauses, tries to find words to explain] still caring.' ▶ Inshalla.

'And then I also had to work with neonates in ICU. Yes, they were very small, the other thing that also got my attention about it. They are very small. At times, I was, though I was not showing it, but I was a little bit anxious at touching them, because they were very small and with those big wire things around them. So I had a very slow, soft touch which I eventually, I adjusted myself to it.' ▶ Phumzile.

Caring is also a universal phenomenon, but the expression and pattern of it may vary across cultures.

Inshalla explains that with some deaths in the ICU, especially those of children, she carries on caring in her own way for sometimes up to 100 days. She elaborates:

'I was a Christian before I married a Muslim. I've got experience of both Islam and Christianity. Xhosa is what you have learnt or picked up over time as you nursed and there are little bits that I've picked up, but the other two are deep-rooted. You still care, but maybe for longer as a Muslim. In the Muslim religion, it still goes on, the prayers, the Do'as [personal prayer calling to God] that you're under and you have to stay at home. You stay at home, that is the time when you are praying to God to say "open up heaven to receive this person" and as a Muslim, you feel you want to make that difference, that the soul can be gone, the body is gone, but you can still make that difference.

'By praying every day, because for us, when the body is, when you die, you are buried immediately. So there is no time to adjust, there is no time to ask questions, there is no time to say: "we can do this later." It's like everything has to be done now. From the moment you hear of the death, you start praying and we've got certain prayers that we pray and in the Muslim religion, these are quite powerful prayers, because there are certain prayers that you, if you feel you need a question to be answered, like for me, personally, that is my personal experience. If I want to ask God something, there is a special prayer that we pray, but that prayer is prayed when you want to go and sleep and you wake up in the middle of the night - you wake up and you get up on your Mushtaq [prayer mat] and you go and pray and later on God will reveal the answer to you but you still have to pray continuously up to 100 days after that person's death. So for me, it's like you've still got that time to make a difference for that person. Because more prayers can still open up doors for that person, where in Christianity, when people say you are buried, you are finished. There is nothing that still connects you with that person who is dead, but with us, there is still a connection, whether it's three days, or seven days, even 40 days and 100 days, there is still that connection and you start with our burial Do'as [prayers], you will start from day one

until you have reached that point that makes yourself whole.’ ▶ Inshalla.

I probe Inshalla further for clarity, wanting to know if she has prayed for a 100 days for a baby or child that has died under her care. She explains:

‘Yes, not everybody to the 100 days, but some of them, to the 40 days and it’s quite nice, because I have made a difference, I feel part of, I have done something, because sometimes, you ask that question, “Was that enough? Did I do enough?” By that, I got closure. I went to the three days, I went to the seven days and I went to the 40 days. I made the difference.’ ▶ Inshalla.

The art and act of caring is also one of assisting, supporting and enabling caring behaviours including the elements of trust, compassion, nurturing, concern and presence.

Johanna is another Afrikaans-speaking ICU nurse who believes in ‘a God’ but follows no religion per se. She is 25 years old and is married with two children. Johanna cannot recall having had any death education during her nursing career:

‘My husband says I’m too involved with the baby patients. I am a mommy and if my child just died, I would like the nurse to support me.’ ▶ Johanna.

Phumzile shares his experience of a young boy in a paediatric ICU who was ill and required an intravenous line change:

‘So that night when he was bad, I think they were going to insert a line [an intravenous drip] by the doctor in the ICU. Then he crashed and then we were doing CPR [cardio-pulmonary resuscitation] on him and he couldn’t make it. Just before that, I was two beds away from him. So he had called me “Bhuti [isiXhosa for brother], come here.” I say “Ja, [Afrikaans for ‘yes’] what’s happening, boy?” “Please man, stay with me.” I say “I will stay with you, boy. I’m just coming on duty. I’m just busy there, but I’ll come and visit you.” And with him, you could interact with him. He did not want to eat because of the burns but he was fond of drinking because he had lost a lot of fluids. I had my own unique technique; I can say so, because I would bring a male figure to him, in the sense that most in my unit are females. So they [female nursing staff] would try and bring the mother figure to him, when they are trying to make him eat. So I will take a brotherly and also a father figure to him and say “Hey, Bhuti, eat up!” And he would eat. You could see that

response, that “Okay, I’m a young boy and he is a big man.” I had a special relationship with him.’ ▶ Phumzile.

I ask Phumzile how he felt when he saw that the young boy’s condition was deteriorating rapidly:

‘I was a little bit worried. I was sinking and I was praying. I would look at him, whilst I’m busy doing the observations [taking blood pressure and pulse], I’m just talking inside: “Please, please, little boy, man, fight, fight this. You have fought it this far.” [As Phumzile shares his story, his head slowly sinks further down].

Phumzile’s relationship with the ill boy has formed over a month:

‘Yes, more than a month, more than a month. I would talk inside myself and I would say “No man, please, please, fight,” and, at times, when I would talk to him, I would talk to him in a sense that like, trying to uplift his spirit, because every day, he is in bed. I had this connection that I was also fighting in prayers for him, because really, it was, what you can say, it was like a dealing part, because you know, 75 % burns, it’s either you make it, or you don’t make it.’ ▶ Phumzile.

Johanna has had a traumatic experience in her ICU career in which she was caring for a critically ill, elderly patient. Throughout this conversation, Johanna was tearful but insisted on telling her story:

‘An old lady was admitted to the ward for a simple operation. It was supposed to be an in-and-out case but something went wrong in theatre. It was strange because she knew before the time that she was not going to make it. Anyway, she landed in ICU on high doses of adrenaline [a drug given intravenously to stabilise low blood pressure and improve urinary output]. She stayed for days on the ventilator. Nobody had the guts to switch off the ventilator and besides, the family was not ready as they hadn’t made peace. The patient was bloated and the skin was coming off. She was lying in her body fluids. And that smell [grimaces while remembers] filled the ICU. She looked terrible, terrible, terrible lying like this. We [the nurses in the ICU] had a major fight with the doctors, saying it wasn’t humane for her to be lying like this. Basically, she was coming apart [takes a tissue from her pocket]. ▶ Johanna.

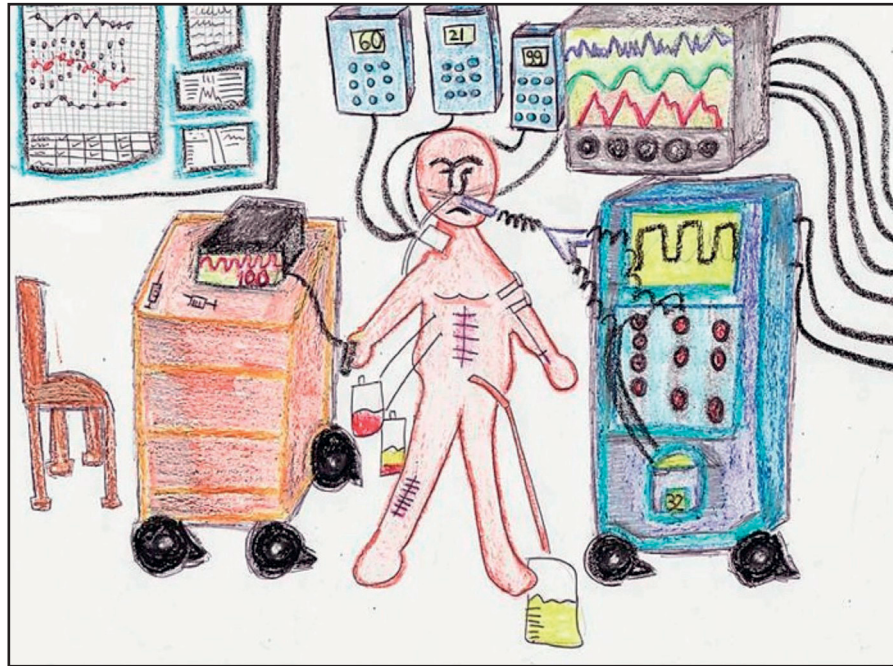
I ask Johanna if she needs a few moments to settle down:

'No, I'm fine, really. I think that we were torturing her, but I'm not sure what her neurological status was but she must have felt something: hectic pain. We just fought with the doctors, it was so frustrating. We all felt hopeless. The family couldn't cope with the smell. You could see it on their faces. It must be terrible. The family said that she [the patient] was always a lady and now they were embarrassed for her because she smelt and looked not at all human. There was even body fluid dripping on the floor. We didn't want to nurse her anymore because her skin was coming off all the time. If I had the power I would have stopped all treatment.' ▶ Johanna.

I ask Johanna if this was a 'good death?'

'BAD' [Emphasis my own. Quick to answer with her voice raised slightly]. *The death like this could have been stopped. They [the doctors] knew post-surgery that she wasn't going to make it. I always, still tell myself: "I should have persisted, tried to get the doctors to stop." But I'm from a small town. When the doctors say, you do. I had no education on how to deal with this.'* ▶ Johanna.

It was interesting to note from the collection of ICU nurses' reflective drawings that caring was most often illustrated as a busy ICU environment filled with technology as portrayed below. In this particular drawing, however, the absence of the nurse is noticeable. The ICU nurse who drew the picture stressed that in order to care for a critically ill patient, it is crucial to have technological competence.



The *authentic* mode of *being* and the lived experience theme of *care (Sorge)* have been captured in the above ICU nurses' stories. It is in *Dasein's authentic* mode (to be self properly), that *Dasein* is aware of what it means to exist in terms of human relationships: in this instance, the *Dasein* of ICU nurses and their relationships with dying or dead patients under their care. It is through *care (Sorge)* that *Dasein* becomes engaged with life situations such as the death and dying of patients in the ICU.

Mode of being – Inauthenticity

Lived Experience Theme - Suffering (Angst, Falleness)

Suffering that accompanies trauma and hardship is often compounded by suffering of a second kind: the loss of community and the sense of connectedness it entails. Initially, suffering alienates the ICU nurse from him/herself and then later, suffering alienates the ICU nurse from others.

Thato conveys her mental image of death which she 'sees' every time a child dies in the paediatric ICU where she works:

'It's an ugly thing. I don't know. Just an ugly animal that you see. Yes, when the person dies, we say: "Okay, may her soul rest in peace." But there is that feeling that there is this ugly thing who pulled this person away from us, because the rude thing doesn't have any mercy, you know, the way he pulls the kids to death. It feels like something grabbing so bad from

in your heart, you know. It's just like this ... another piece of your heart that is just taken off from your heart. That is the pain that is happening. No one understands.' ▶ Thato.

Inshalla remembers a disturbing incident about a traumatic death of a child:

'I will never forget, it still feels like yesterday. I had a child who came in. He was in a motor vehicle accident, a MVA. It was a child of two years old and the child was not with his parents when the accident happened. He was playing with other kids and it was also not his fault and why I'm bringing that up, for me it was: "But this was not this child's fault. Why is he dying? Why is he dead? He was just at the wrong time, like for me, at the wrong place at the wrong time!" And I thought: "How could God let this happen to this little boy? He still hadn't lived life, he still had his life ahead of him, but why did it happen to him?" The taxi drove through the yard and knocked the child and crushed the child against the wall and you know why I was thinking about that, why so severely, man? Why was it that he had to be crushed like that? Why did he have to die so violently?' ▶ Inshalla.

Cindy has also experienced guilt and suffering. Her sense of humour may be seen as a coping mechanism in this instance:

'The child was really ill. I was looking after another patient and the ventilator alarm and monitor alarm were going off. I couldn't leave my patient to answer it. When I did go, the patient's intestines had broken through the sutures. I felt really guilty because maybe I should have answered the alarm quicker. Then I became angry because the older, more experienced ICU nurses knew that this might happen. Don't laugh, but I couldn't eat tomato sauce for a long time [giggles]. All that blood. Yucky. So messy.' ▶ Cindy.

During my second round of phenomenological conversations with Phumzile, I ask him how he copes with the different types of death that he has experienced, both in the adult and paediatric ICU. He paints a picture in one instance of himself as a failure:

'I had another feeling of, maybe I let him down. If only maybe I could have done the chest compressions much harder.' ▶ Phumzile.

I ask Phumzile how he felt doing chest compressions on a patient whose chest is burnt, emphasising that it can be traumatic and messy:

'Mmm.' [agreeing]. ▶ Phumzile.

I probe further and ask if doing chest compressions on a burnt patient impeded effective CPR:

'Um ... [Head to one side – thinking]. You know, with him, as I was busy doing the chest compressions, I felt this hope, I had this hope. "No man, patient, come, come back, come back!" And as I was busy doing the chest compressions, I was looking in his eyes, like: "Come back, boy, man, come back." And I felt he was going to come back, but he didn't make it. After that, I went to the toilet, stayed for some time. Wanted to be alone.' ▶ Phumzile.

The ICU nurse's suffering may cause their friends, families and acquaintances discomfort, because visible suffering tears away the sociable appearance of self. This may further alienate and isolate the ICU nurse:

'Well, my girlfriend is also doing nursing and we do get to share what is happening at work, but with him, with this little boy, I did share it and I told her, like, I was very sad and that the boy has died and at least, with her, she can listen, she can listen. I would say with her there is a more understanding thought of what I'm going through. So, she is the person who I'm always sharing those sad moments with at home. And with my other family, because I'm currently staying with my brother and my sister, I don't talk much with them about my work things. And at home, also, we don't have small children, but when I'm meeting with my other siblings and related family, when there is a young child, I always have that, that feeling of sadness and wanting to go to my own home.' ▶ Phumzile.

Phumzile explains why he is so sad and wants to go home:

'I would see the other children playing and remember his name: Aphiwe.' ▶ Phumzile.

What does Aphiwe mean, I ask?:

'Aphiwe is like: "We have received a gift." ▶ Phumzile.

Johanna has experienced another traumatic event in the ICU which has had a profound effect on her personal life:

'You know that the child is going to die. You gave your best, but it was not good enough. You look hard, but I go behind the curtains and cry with the mom. It means a lot to the mommies. You look hard because you don't know what to say, what to do. You want to say

'bye' but can't. It can make you sick. While I was in labour with my last child, I heard my baby's little heart beat drop. I was so scared that she was going to die because it was a traumatic labour. I don't want any more kids. Imagine my baby dying?' ▶ Johanna.

Pain and suffering, despite not meaning the same, are, however, related and have commonalities. Each of the ICU nurses expressed their pain, suffering and uneasiness in the following stories:

'If you don't deal with stuff, then you are not going to go down that lane again, because it hurts and, I mean, who wants to hurt themselves continuously? I think, I think a lot of the time people suffer, or children suffer, whereas we actually know that this child is not going to make it and then we just prolong it and prolong it and prolong it and that I hate. But then again, it's like, a lot of people have this thing that, yes, you have to give them an honest try but you actually know that, you know this child is not going to make it and it's sort of, I think, sometimes, it's stupid, what we do.' ▶ Esther.

'That child, she said to herself: "I am dying." But she prepared herself and that also prepared you to know that you, you try to not show her any emotions. But still, you feel that sadness, because you cannot erase that sadness when it comes to death. You feel it, but you try to be strong, because you see this strong face, the strong image that that child portrays. Then you think: "Okay, I must also be strong." So you will hide your feelings to the best of your abilities at that moment, because that child is now putting himself on the path towards dying. So I must help him, put him on that path, you know, help by talking, asking. If he asks a question, then I will just politely answer the question: And if it's about: if there is a God; like the one child asked me: "Is there a God?" I asked her: "What do you think?" She said: "There is a God, because I'm going to Him now." So saying these words, it is a sudden shock for you. "Oh, my God, this child is now, is she reasoning with God? Is she talking to God? What is she trying to say to me?" So that is for me, it's a feeling that you cannot explain, but you feel it inside you. What do you say at that moment?' ▶ Inshalla.

'I pray for a patient to die. I physically pray for that patient to die. I was pregnant and had two deaths that day and was preparing the cot for the next patient. I told the registrar that I was not looking after this one because all my patients were dying. This one was also going to die. He asked me: "How do I know?" I just knew. I got this feeling. Anyway, he insisted that I take the patient. The child was there for only five minutes and the child died. I started swearing and crying and shouted to everyone not to ask me to do anything. I went to the toilet to cry. The following week, my last week of working before I went on

maternity leave, I went into premature labour by one month. ▶ Cindy.

I ask Cindy if the stress of three patients dying may have caused her to go into early labour:

'I think so.' ▶ Cindy.

Thato shares her stories with me:

'Nicki, it's very painful. It's very painful to see a patient dying if you are looking after the patient. Our feeling is to resolve pain, but not with death. Yes, there is that belief of when they die, they don't have pain anymore, but it is not what we want as health workers. We like to see healing. So it's so painful.' ▶ Thato.

Thato describes her pain further:

'It's painful in such a way that, how can I put it? [Pauses, while thinking]. There is a pain whereby you can put something on you, then you pinch yourself. But this one is a pain that is in deep, deep inside, in the heart, you know. There are people who say they just empathise, they don't sympathise. I think it's the pain that goes with the sympathy whereby you feel that: "I wish I could do something, or I wish I could have saved, or like you even feel that your heart is like, it's pumping so fast, you know, and you don't know this person because he is not too close to you. He's just your patient, but there is that feeling whereby you even lose your mind: "Okay, I did put this, I have to do this." But that thing is just in your mind: "Oh, my God, I don't know what happened now. Where did it go wrong? What did we do wrong? Why has this happened only with us? During the day, this didn't happen, but now we're just coming on [night] duty and all of a sudden at half-past eight, the child died. Is it us?" You know, so it's that pain whereby you sometimes even blame yourself. You are putting the blame on yourself, because you think, maybe it's because of me. But it's not because of you, it's just from the pain whereby you collect all these things like I didn't give enough as I'm supposed to give. So that is the pain that I used to feel.' ▶ Thato.

My phenomenological conversation with Thato elicited many references to her pain and suffering. It was during the reading and re-reading process that my phenomenological conversation became almost like a debriefing session for Thato.

'As a result, I even had to call her [the grandmother of the ill child] about the situation. So now the death of this child, to me, it was painful. It was painful, because we had to switch off the machines, and that switching off, I had to be involved in the explanation of this to the family. You know us as Blacks, there are things that are so sensitive to explain to the family. And the grandmother said: "What do you mean, Sister, by switching off the machines?" I said: "To switch off the machines, you know, the child has been supported by the machines for breathing and everything. So now you're going to switch that machine off, because now the child is not going to make it anymore." "Do you mean now, you are going to kill this child?" "We are not killing the child." "But what are you doing?" "No, it's just to take that machine off that is keeping this child alive." I couldn't explain it at this level because I was still new. I can't explain this thoroughly, because it is my first death in ICU. I still feel painful for this because if I can't accept it in myself, how can I force another person to accept it?'

Thato takes this opportunity to share more of her experiences:

'It is enough, because through those laparotomies [an exploratory operation of the abdomen] they had to cut and cut and cut until the bowel was too short and now, the child could not survive with no bowel. Now I do understand it, but then I couldn't understand it. So that is why it is still painful to me and I'll never forget that, to take the child away from the mother and let the mother watch when we switch off the machines. The mother had been with her child for months in hospital. It wasn't a short time, and now we are breaking that bond between them, you see, and in all that, yes, we switched the machine off, we switched off all IV's [drips] and the thing was: "Okay, we keep this morphine." I know morphine is a respiratory depressant. To me, really, I still felt: "Are we killing this child now, because we know what his morphine is doing", I had to cry.' ▶ Thato.

One of the stories that Thato shares is the death of her mother. At one stage, this story started to dominate the phenomenological conversation which started drifting away from the phenomenon being explored: 'ICU nurses' experiences of the deaths of patients under their care in the ICU.' The use of the phenomenological conversation prompts **(Appendix C see page 288)** proved to be very helpful in getting Thato focussed back on the question at hand.

Phumzile, although wanting to be strong as a male figure, also experienced pain and suffering:

'Well, for me, as a male, I, there is only once that I've shed a tear in the unit, with that child, the Muslim boy that I was busy with doing CPR. I shed a tear that day. I went to the storeroom and I shed a tear, with Palela [a colleague], and I was, I was drained, ja [Afrikaans word for 'yes']. And recently, there was another parent, also in the unit, the child had been there for long, I think since the child was born. In those cases, I will move away and not come closer because I feel like if I'm going to come closer, then I would'

[Trying to find the word: looks down at his hands]. ▶ Phumzile.

I prompt ... 'Let your emotions go?'

'I will, yes, I will feel more pain with that parent. I'll feel more pain, so if I'm a little bit away, then I won't feel more pain, but I will be just having an understanding, but if I'm much closer to that patient and that parent, then I'll feel more pain.' ▶ Phumzile.

From the ICU nurses' experiences of suffering, it appears that they have identified their own *meaning* of being a patient in the ICU. Suffering may bring an individual nearer to their own existence (*Dasein*) because it breaks down walls and allows them to consider other possibilities of *being*. The ICU nurses needed to articulate what it is that they had learnt from their experiences of death and dying in the ICU was not an intellectual articulation but rather an *existential* reality.

For the release from suffering and from the alienation of self, communication is central. Reich (1989) has identified three phases of suffering: (i) the mute phase: the sufferer is unable to express emotions (this is the phase when loss of autonomy is likely to occur); (ii) the expressive phase: the sufferer seeks language and gestures to express suffering and (iii) the final phase: the sufferer discovers a voice with which to express suffering (Reich, 1989, pp. 83-108).

Sharing one's experiences of suffering in an expressive way serves three purposes. Firstly, it allows the sufferer to gain distance from the trauma by talking and taking ownership of the event. Secondly, it is hoped that the story told will allow the listener(s) to offer some affirmation that the suffering is justified. The third purpose is an interpretive one, in that the sufferer often expresses him or herself through a

higher being or religion, with the intention of being liberated.

An example of mute suffering is Phumzile's experience of literally watching a child take his last breath:

'I felt, you know, when they say, it's like a knife going through your heart? "Well it is. Watching the child being alert and looking at life going out. I mean, yes, I have seen a lot of adults dying and I have seen also the other children dying, but with that child, when that child was being taken off from the ventilator and the child was in the mother's arms, as they were taking the tubes out, they prayed in Arabic and I was also there, just looking, at the breath, man, you know, when a breath of a child, I don't know whether it is just me, but when you have this connection of touching a child, the skin of a child, it's so unique and just looking now, at this, this life going out.' ▶ Phumzile.

Phumzile elaborates no further. I allow him a few moments before returning to the conversation. He appears a little subdued after having shared his experience.

Expressive suffering is often shown through crying and the desire to be heard. A form of expressive suffering is often expressed through a story.

During my phenomenological conversation with Esther, she begins to cry as she reveals her own spiritual views of her own death:

'Well, to me, it is that if I should die, then I will not continue living on this earth, but I know that I will go to heaven and be with Jesus Christ, because He's my Saviour and He closed the gap between me and the Father. So I will go there and' [Nervous laugh, becomes teary]. ▶ Esther.

I ask Esther if she is alright and if she would like to suspend the conversation for a few moments. She is reluctant to do so and accepts a tissue from me to dry away her tears:

'Yes, no, I'm fine. So to me, it's not something that I fear. It's actually something that, well, with my walk with Him is that I am starting to know that, that is something that is actually amazing and that it's something that I'm actually looking forward to because there would be no more pain, no more sorrow when that happens.' ▶ Esther.

Earlier on in the phenomenological conversation, Esther is very expressive about her views should she be admitted to the ICU:

'Please, I don't want to be in ICU forever, because it sucks.' ▶ Esther.

Inshalla also is very vocal about her possibly dying in the ICU:

*'This is my wish if I must die. **No nurse around me** [emphasis my own]. Just my family and my friends around me. No tubes. I don't want to be connected.'* ▶ Inshalla

The loss of the 'voice of suffering' may predispose the individual to a state of alienation where the major challenges would be to move away from this and enter into a renewal of connectedness but on a higher level than would have been probable before the suffering. Alienation must not be viewed as the absence of connection, but rather as a state of 'negative connectedness' with one's self, others or even the spiritual realm of *being*.

Inshalla's story is an example of 'negative disconnectedness':

'The one thing that I remember, it was the little boy who was severely burnt. He used to say: "Bring me a photo of myself." And I always wanted to know why and he said that he just wants to see himself before he dies. Then I thought, seeing yourself before you die; is it because you've got bandages on or you feel you don't know yourself, or what? He said to me: "Sister, you know why? Because there is God." And I said to him: "Why, is that God? You, your photo?" He said to me "Yes." And I still wonder, you know, that wondering in me, like people say: "We are all the image of God." So I still have that question in myself. "Is that the message that I got? Is God in all of us?" I don't know. I feel far away from my God when that happens. You know, you're asking all these sorts of questions and still, I mean, I don't want to be. Sometimes I stay away from asking all these questions. I don't want to be faced with that, but that stuck in my mind when he died, and he died after we gave him that photo.' ▶ Inshalla.

Returning to Heidegger where he explains that alienation hides *Dasein's* possibilities and therefore one does not exist in an *authentic* manner. This may manifest alienated *Dasein* in the following ways:

1. The 'despised self' (*Dasein*) – a discrepancy between the individual's preferred self and the perceived actual self.
2. The 'disguised self' (*Dasein*) – a false consciousness that is out of touch with one's feelings.
3. The 'detached self' (*Dasein*) – a disjunction between activity and effect (Heideggerian term is *fallenness*).

Fromm (1976) sums up this alienated and *inauthentic Dasein* as not seeing *Dasein* as being the centre of one's world (Heideggerian term is *disclosedness*) and, in this mode of *being*, not being the *authentic* self in one's involvement with others.

Some of the study participants' anecdotes support these concepts of *Dasein's inauthentic* self:

'Within sixty minutes, the child is dead. You know, you are so stunned that you don't know if you are coming or going. You just see that, it's like everything around is white. That is what I saw. Everything around me was just white.' ▶ Inshalla.

I ask Inshalla to explain the colour and meaning of 'white.'

'White, I was just thinking: "I'm not seeing anything." Not black, in the sense that everything doesn't you can't see through it. But everything is just clear, it's clear, but I cannot see through it. That is how I felt at that moment. I couldn't see beyond this part here. Everything was white around me, but I couldn't see through that. I was so stunned. I was just there and I couldn't face anybody around me and I could feel it in myself "that I'm actually lost now." And that is how I felt.' ▶ Inshalla.

Phumzile explains like this:

'But as a nurse, you are working with people, so your feelings at that specific time when someone is dying, your feelings are not important at that time when someone is dying. You need to, you need to chest [be brave] it out for that person, you need to chest it out for that family. But at the end, you yourself, you are a human being. So we need to, we need

to be prepared as a nurse, how to handle death.' ▶ Phumzile.

Thato is quite explicit:

'That death thing is just with me forever... of which it's killing me, you know.' ▶ Thato.

The lived experience theme of suffering highlights that the ICU nurse is a vulnerable, imperfect and mortal being who is compassionate in her care towards patients but is incapable or ill-equipped to be compassionate towards herself. The ICU nurse's uncompassion towards self has a negative outcome of feeling alone. Heidegger (1962) describes this as *existential* loneliness which is a natural part of life (*everydayness*, the *undifferentiated* mode of *being*) and may emanate from instances of an individual's own ontological confrontation with death.

Mode of being – Inauthenticity

Lived Experience Theme - Disenfranchisement (Das Man, They)

To disenfranchise an individual is to take away their acceptable right to something or someone. Doka (2002) explains the concept of disenfranchised grief at the death of someone as something that cannot be openly acknowledged, socially sanctioned or publically mourned. In this instance, the ICU nurse has set norms, as stipulated by SANC Scope of Practice, in which there is no such thing as grieving rules or policies. There is no compassionate leave if a patient that one has nursed for a considerable amount of time dies, unlike normal job communities, where a legitimate right to grieve the loss of someone is acknowledged. Therefore it appears that nursing is not regarded as a normal job community where grieving is socially recognised and sanctioned.

The stories that follow are all examples of being disenfranchised of grief:

'When I started nursing, I was told not to cry. It's unprofessional. If I can't cry, my tongue swells up and I can't breathe or talk. Well, the death of this child, I tried very hard not to cry and because of this I had to leave the unit and went to my room in the nursing home, packed my bags and went to my home out of Cape Town. I said: "I'm never coming back." I was sick in bed for two days because of that death. All because you are not allowed to cry.' ▶ Cindy.

Cindy speaks to me about some of her personal issues:

'I have my own stuff and other things in my history that could be triggered by crying at the bedside. So I never know when I'm going to hit that point and not be able to do my job if I let go and break down. I can have tears on my face but if I feel that low point is going to trigger those things, I hold and stand back. I don't want to be out of control when I have a job to do.' ▶ Cindy.

I ask Thato who feels for her when she is feeling for and consoling the family:

'To be honest with you, I think no-one. Really, I think no-one, because as soon as I have this death now, within no time, I had to admit another child, you know.' ▶ Thato.

I ask Thato if she ever gets the chance to say goodbye to a patient that she has cared for, who dies:

'Not even once.' ▶ Thato.

I encourage Thato to tell me if she has had closure on patients who have been special to her. I share my experiences of special long-term ventilated patients and how best I tried to assist the family while having Theatre and Trauma Unit phoning for a bed and you never getting to say goodbye to my patients.

'Nicki, it's almost, it's like the bed is still warm.' [Thato pauses for a moment, looks down at her hands, fidgets with her wedding ring].

'To be honest with you, it's not easy in ICU to say good-bye to the patient. I had another experience. I was still new at the time. I had a death. It was, I think, around about 2. Then, while I was still busy trying to sort out this patient, cleaning the patient and taking the patient to the Bereavement Room [laying out room], C2 phoned, they needed the bed. The patient was very sick on that side. We had to just take that body to the Bereavement Room and give the body to the nurses. You see, to me, it's like I'm throwing the body there. I don't have any time again with that patient. I am preparing the space for this one that is coming. I admitted that patient and we had resuscitation. Now there is another body that is still waiting for me as a Sister, and this one, who also died.' ▶ Thato.

I question Esther about whether she withdraws from patients if they are dying or have died:

'Yes, there are nurses that when they come on duty, you're like a machine. You are a machine. You just do what you do and I think it's very bad, because then you don't, then you don't look after the patient wholistically, and that, that could actually do more harm to a patient than good.' ▶ Esther.

I ask Esther whether what she basically does is monitoring vital signs and cancelling the alarms: task orientated activities. Esther nods in agreement:

'Ja, [Afrikaans for 'yes'] that's the word, 'task-orientated.' ▶ Esther.

I ask – 'no connection with the patient or family?'

'No connection with patient or family.' [In agreement]. ▶ Esther.

I keep on probing: 'Then to lunch, then off duty. There is no connection whatsoever?'

'Nicki, you just go there and you do what you have to do and you go to tea when you have to go, when it's time.' [Sounding a little irritable with the probing]. ▶ Esther.

I pursue with the same line of questioning feeling as though I may bring Esther to tears:

'There is no connection whatsoever.' ▶ Esther.

We sit silently watching each other:

'That's how it sounds, very much like somebody who has post-traumatic stress.' ▶ Esther.

Following this phenomenological conversation with Esther, I wrote up a journal entry.

Journal Entry Tuesday 23rd August 2011.

I am feeling a little uncomfortable, if that is the correct word. I have always had a good relationship with Esther, but today she was a little irritable with the probing questions. She is an excellent nurse and cares very much for the children and families in the ICU but I

can't help wondering if she was ashamed of almost being caught in the act of not truly caring. I am sure that it seldom happens and maybe she is just a bit burnt-out with this death and dying stuff. I certainly am at the moment. I must make an effort to go to Mass this Sunday. Need some spiritual comfort.

These stories from the ICU nurses are some examples of disenfranchised grief. But, however, disenfranchised grief, can also be viewed as 'empathetic failure' or more subtly; empathic distancing (Neimeyer & Jordan, 2002), in which the source of grief is the failure to empathise with the bereaved, in this case the ICU nurse. It is a failure to take cognisance of their suffering and pain and consequently becomes destructive.

Esther shares her story about empathic failure:

'When the family experiences torment, that's bad to me, because I know that the death shouldn't be like that. To me, death is not, it shouldn't be traumatic. It shouldn't, well, initially, it would be a shock if it's something that, like a car accident, or something like that. I mean, that's very unexpected. But my thing is, we all should be at the place where, where we could make peace with the fact that that person has passed away and yes, I am sad about it, because I will miss that person, but it's not like, I don't know where that person is. I don't know where they are going. That shouldn't be and that's why it's so, so bad to me, when people are so like, like that – anxious... that's not good. No-one understands about this sadness.' ▶ Esther.

Thato also has experienced empathetic failure:

'Nicki, sometimes when I get in my room, I do cry, really, I do cry, because as I said, I think, I used to think what we could have done better than this, and I said: "But no one can stand in the way of God's Will." If it's my time, I can even die here on my bed while I am still alone like this. So let me just accept this the way it happened. Maybe it was the time, maybe God wanted it to happen like this, maybe God wanted me to experience this. I have chosen this career to be a nurse. I didn't know that I'm going to go through all these things. So maybe God is trying to open my eyes to the career that I've chosen and is trying to make me stronger. I do too much thinking. I feel that it's not only the dying patients that I'm nursing. There are also patients who are surviving. So why must I stress like this and it's not that it's 90 percent that is dying. I think it's 90 percent or 80 percent that are surviving and it's only maybe percent or 10 percent that are dying. So why can't I feel nice and know that really, sometimes I do a good job. Sometimes I don't want to be an

ICU nurse. ▶ Thato.

From the stories thus far, it appears that the ICU nurses in this study have endured grief and compassion fatigue.

Mode of being – Inauthenticity

Lived Experience Theme - Cultural/Religious Unpreparedness (thrownness)

The lived experience theme of cultural/religious unpreparedness emerged from two of the phenomenological conversation prompts:

1. Have you ever received any death education about how you may be able to handle deaths of patients in the ICU?
2. What do you know about other cultures and death?

'Death and dying. I think death is a topic that you cannot have enough knowledge about, because every death is a different experience and you feel different every time. Sometimes it is a lifetime experience you will never forget. Other cultures and death. The only cultures that I know is my own culture [Islam] and a little bit about the Xhosa culture and then about the Christian culture. I don't always know how to care for them after the patients die.' ▶ Inshalla.

I enquire if Inshalla has ever received any death education:

'No, I have not, except for my course when I did the Critical Care Course that I did with you. I learnt the most, like, how to express yourself. That was a good thing, because we were able to talk, and learn how to relate to death. That was for me a good experience. And to get everybody's point of view, culture, diversities about death. That was interesting, because sometimes, in nursing, you generalise. Nursing is just nursing. But it's so diverse, because every person feels things differently, but sometimes you as the nurse, you generalise everything. It's just death, but for something else, that is not just death. It's a totally different experience.' ▶ Inshalla.

I ask Esther what she knows about death and dying in other cultures:

'Very little [Soft laugh]. Very little [Almost sarcastically. Laughs a little louder]. Well, like with people who work with you, I think you are, we are fortunate in the fact that we have

different cultures in our unit. So if you don't understand something, you can easily just go to the one next to you and say to them: "Please, can you sort out this family." Because you have no insight to what it is. Like the Xhosa people. I actually don't have any idea of how they view death. It's actually bad.' ▶ Esther.

Esther elaborates further on post-mortem care (last offices):

'You're still respectful in a professional way, but there are little things that you are not supposed to do, or you're supposed to do, or areas that you are not supposed to touch and that kind of thing. But we do, as professionals, still carry on dignified, human care.' ▶ Esther.

I pose the same questions to Phumzile:

'I don't even remember receiving that [death education], being taught at the college. The first time was with you in class.' ▶ Phumzile.

I ask Phumzile if there should be death education in the Postgraduate Critical Care Nursing curriculum:

'A lot, yes, a lot, because, as I'm saying, when I wanted to go to ICU, it was a turning point and I had to rearrange my view of children, because children were not so responsive in ICU. It's either, they are ventilated and sedated. So I had also to rearrange my thinking and grow with it. Growing was through experience. It was just through personal experience in ICU. So I think, yes, yes, I agree with that, that we need to be prepared. We need to be prepared about cultures and death.' ▶ Phumzile.

Phumzile is a little concerned about talking of death because of his cultural beliefs:

'Just the thought of dying, it's, to me it's taboo and to my community, Xhosa, it's a taboo. Talking about death, thinking about death, it's a taboo.' ▶ Phumzile.

I ask why talking about death is a taboo in the Xhosa culture:

'Because I believe that what you say with your mouth and what you think with your head can happen. I believe so, and in most of my community we believe so. And someone else is going to say: "We believe in witchcraft." Witchcraft exists with us Blacks, black magic does exist, so I believe that for you to be a witch, you don't need to be there and dress like

a witch and do things. I believe that witchcraft is how you think and what you say. So me, by thinking about death and talking about death, it's taboo, I shouldn't be even thinking of such a thing. I shouldn't even be talking about such a thing.' ▶ Phumzile.

I indicated to Phumzile that we should not be having this conversation. I suggest to him that, as an ICU nurse from the Xhosa culture, talking about death may be taboo but it is also about education and science:

'Yes, yes, yes, yes, as a scientific background for a nurse, I think I'm there, because if you're going to work with people, we are dealing with live people here, we're not dealing with machines. We are dealing with humans. So we need to get prepared and it's really necessary for nursing. And consulting all the ethnic groups that's one thing that has been missing and someone like you has now thought about it.' ▶ Phumzile.

Johanna has a particularly personal and spiritual approach to children dying in the ICU:

'I'm a Christian and don't know much about other religions and cultures. I believe that a child's soul goes straight back to God. They don't go through purgatory or whatever. I'm at peace. There is a peaceful transition for them and they are not scared. I touch the forehead and say goodbye. But don't ask me about Muslim deaths, or Jewish, and I know nothing about Black cultures and the ritual things.' ▶ Johanna.

Cindy explains how she feels when performing last offices (post-mortem care):

'I pray when I'm laying out.' ▶ Cindy.

I ask Cindy why?:

'So that God will take good care of them and be with the family. I don't know what else to do. I pray in English even for the Black babies.' ▶ Cindy.

Thato is next to answer the questions about death education and knowledge of other cultures:

'Only with your course did I get death education. I did the Critically Ill Child Diploma. That is why I say, I am at a better level than the level I was before. So now there was

that experience after my post-grad diploma qualification and it's much better. I try by all means to see that, okay, this patient has died and there is nothing I can do about this. I must look after myself, because that patient is dead. I did learn that it's better sometimes to empathise than to sympathise, because by sympathising, really, that thing is just with me forever of it's killing me, you know. So I've learnt a lot.' ▶ Thato.

To be honest, I'm not, I'm not clear about other cultures. In Cape Town there are lots of Muslims. I didn't meet a Muslim who can explain to me exactly what they are doing and why they are doing it.' ▶ Thato.

The ICU nurses' stories reveal that there is a need for death education, especially the cultural and religious aspects of death and dying, with an added educational need for good clinical practice: post-mortem care or care of the dead body.

Mode of being – Undifferentiated

Lived Experience Theme - Living with dying (being-with-death)

The most commanding ontological confrontation occurs when facing the inevitability of one's own demise. For ICU nurses, this is a daily occurrence.

Koestenbaum (1976) in his book, **'Is There an Answer to Death?'** searches for positive consequences of ontological confrontation of death by giving greater *meaning* to life. He argues that one's expectations of death shows who one truly is. The same can be said of ICU nurses caring for patients who are dying or have died in the ICU.

Koestenbaum posits ten consequences of one's anticipation of death. The following have relevance to ICU nursing:

I. By recognising death, the individual is on the way to becoming decisive. The following anecdotes support this:

'It's like I want to say to you: "Go peacefully," and for me that is my goodbye. Not to lose the battle, because you are going to good hands.' ▶ Inshalla.

Esther has been vocal about not wanting to die in the ICU.

'Please, I don't want to be in ICU forever, because it sucks.' ▶ Esther.

2. By remembering death, the individual concentrates on essentials.

'I have an in-grown nail on my toe. It's for the third year now. When I think of going to theatre and lying on that bed and getting sedation, the thought of dying is great, so I keep on wearing these open shoes, because I'm scared of going in for this toe. So if I may die in ICU, if it can be possible that all my family will be there, you know. I know it's not going to be easy and it's not going to be nice for them, but the first thing is my family.' ▶ Thato.

Thato expresses her stance on some of the essentials of her life that may occupy her mind on her death bed:

'So, the first thing that I think of is my children. If I die, are they going to be able to stand on their own? What are they going to go through after my death? Okay, am I dying now?'" Really, all of these things that I'm talking about now they have just come into my mind. But if I die, what is going to happen about my body? Okay, my body they are going to bury, what is going to happen exactly if I die? Let me just not think about this, this is the devil that is hurrying me.'" And that, you know. So, I'm scared.' ▶ Thato.

Johanna has a more 'live in the present' approach in her own ontological stance towards her own death:

'You're an ICU nurse. You know you are going to die sometime. You should be used to death. But before being an ICU nurse, I am a person, a wife, a mother, I have my dogs, my house and my friends.' ▶ Johanna.

Cindy tells her story about remembering the deaths of children in the ICU:

'I re-lived the deaths. But my brother said that I'm used to death now because I don't cry as much anymore. I've put mental blocks in my head to cope and forget. My family remembers me coming home and crying, but I don't anymore. So they think I'm used to it. I'm not in tune with it [death] anymore.' ▶ Cindy.

Another of Koestenbaum's ten consequences of the ontological confrontation with death is that, by recognising death, the individual will become honest and gain strength.

Esther illustrates her spiritual strength:

'So to me it's not something like: "Oh, my word, I don't know where I am going." To me, it's cool. I know where I'm going.' ▶ Esther.

2. The thought of death makes the individual more willing to assume a total plan for life or even for death.

Thato wants to be treated with respect should she find herself dying in the ICU:

'With respect. I may feel better if they make me more comfortable. If I can be in that comfortable place and comfortable bed and everything is clean and in order, that's okay, now I'm leaving. I want to die in a clean environment. Your soul goes to heaven cleaner and quicker as opposed to somebody who dies with blood and guts everywhere and everything is untidy.' ▶ Thato.

Johanna is explicit about not wanting to die in the ICU:

'I never thought that I would be nursing death. Please God, don't do this to me. Sometimes we nurse patients in ICU to death.' ▶ Johanna.

From a phenomenological and *existential* perspective, by reflecting on the possibilities of dying in the ICU, the ICU nurses in this study may have experienced some sense of gaining *meaning* and release from the dread of death.

The themes generated from the participants' lived experiences of the dying and deaths of patients under their care in ICU are discussed in the next chapter highlighting commonalities and differences found in my study to that of the nursing literature that has been reviewed.

CHAPTER SIX

Unravelling and Description of the Themes

Introduction

In this chapter, the themes generated from the participants' lived experiences of the dying and deaths of patients under their care in ICU are discussed in relation to the reviewed nursing literature highlighting commonalities and differences.

Ely, Anzul, Friedman, Garner et al. (1991, p. 179) propose that 'doing qualitative research is by nature a reflective and recursive process' and therefore this chapter, in part, becomes a reflection on the research process as well as the self. I will deliberate on some of the issues and paradoxes that have emerged from the study and discuss how these relate to the literature.

I have again inserted Figure 7 which illustrates the modes of *being*, lived experience and pedagogical themes, as an invitation to the reader to engage with me in the phenomenological conversation.

Modes of <i>being</i>	ICU nurses' experiences of the deaths of patients under their care in the ICU	Pedagogical theme
Authenticity (to be self properly)	Care (<i>Sorge, Dasein</i>) delivery, quality	Knowing Acting <i>being</i>
Inauthenticity (to be self not properly)	Suffering (<i>Angst, Fallenness</i>) alienation, guilt	Acting <i>being</i>
	Disenfranchisement (<i>Das Man, They</i>) bereavement	Acting <i>being</i>
	Cultural/Religious Unpreparedness (<i>thrownness</i>) respect, knowledge	Knowing Acting <i>being</i>
Undifferentiated (<i>everydayness, being-in-the-world</i>)	Living with Dying (<i>being-with-death</i>) ontological confrontation, death fatigue	Knowing Acting <i>being</i>

Figure 7. The Modes of *being*, Lived Experience and Pedagogical Themes

The unravelling of the ICU nurses' stories also required of me to work with Barnett's (2007) concept of *authenticity*, as I needed to keep to a pedagogical focus. This is discussed more fully in Chapter Seven.

Barnett's eight 'planks' in achieving *authenticity* can also be applied to me as teacher and researcher which is discussed more fully on page 188. There were many occasions after my parents' deaths that I wanted to abandon the study because it became too painful and intense. I found myself surrounded by death books, death literature, nurses' suffering and my own ontological confrontations around the study topic. However, I knew that the ICU students' narratives, their voices, had to be heard and given *authenticity* and *meaning*. It is for this reason that all quotes from the nurses in the review of the nursing literature and from the ICU nurses in the study were allocated a blue colour to emphasise what was being said and hopefully, be heard.

In keeping with point seven of the eight planks of *authenticity* (in the presence of *authentic* claims, we are in the presence of the four ethical qualities of integrity, courage, determination and sincerity), I believed in myself and also in my past and present students, validating that their experiences of the deaths of patients under their care in the ICU was worthwhile and influential towards future teaching and learning about death, however uncomfortable it was at times.

Voice

In this study the voices that can be 'heard' came from both the ICU nurses' narratives as well as from me. Barnett maintains that no two voices are the same and it is through voice that 'one becomes oneself uniquely' and 'the self places itself out in the world' (Barnett, 2007, p. 90). Furthermore, voice is a mode of communication; it implies a reaching out to the world; it looks for an audience and wills itself to have an impact. There was a willingness by the ICU nurses to give voice to their experiences of the deaths of patients under their care in the ICU.

In this study, there are two voices:

1. The voices that were first heard, but do not form part of the study were the distinctive and inimitable 'voice' in the reflective drawings in which the ICU nurses authentically placed themselves in the world of death and dying in the ICU (*Undifferentiatedness, everydayness, being-in-the-world*).

2. My voice as student, teacher and researcher.

Barnett (2007) suggests that the voices be named: the **'pedagogical voice'** (the student inserts him/herself and makes his/her presence felt) and the **'educational voice'** (the student becomes him/herself). In seeing the two voices in this way, the pedagogical voice is 'realised through autonomy and the educational voice is realised through *authenticity*' (Barnett, 2007, p. 92).

The Pedagogical Voice

Barnett believes that the pedagogical voice is autonomous but at times can be coerced and half-hearted. This is often the case when a student feels compelled to contribute to a class discussion or group work and hence raises the question if the voice that the teacher is hearing is *authentic*. In the case of my study, this was very true. Initially there was reluctance among the ICU nurses to engage with death and dying, the main reason being 'it's a taboo subject' or 'it is bad luck.' I was sensitively determined to hear the pedagogical voice of the ICU students and had to come up with a teaching and learning strategy to achieve this, even if in part. This prompted the possibility of getting the ICU students to draw or voice themselves on paper on certain topics of death and dying. This tactic was viewed with much suspicion and some disbelief as drawing was seen as 'child-like.' This teaching and learning strategy 'sparked' the phenomenon of interest and I entered into a compassionate drive to attend to the educational needs for the ICU students.

The Educational Voice

Prior to this study, this 'child-like' strategy brought the educational voice out at full volume. Initially, the 'utterances' as Barnett refers to them, were depicted as small and bland drawings of themselves in an array of death and dying situations in the ICU. In many of the drawings, the ICU nurses saw themselves (and the dying patients) as small and colourless individuals whereas the doctors were portrayed as large figures, drawn in bold colours.

Although not part of this study, the educational voice is *authentic* and, as the ICU students engaged more fully in their drawings, they began to depict themselves as larger individuals, often identifying themselves with stethoscopes and as providing comfort to families and other grieving individuals. The educational voice, in this instance, was given space, time and, most importantly, was heard.



Barnett (2007), in his book **'A Will to Learn'**, discusses **'being a student'** in detail and also has a section on **'being a teacher.'** The section of his book on being a student had relevance to me in two ways. Firstly, I identified myself as a doctoral student and therefore had my own pedagogical and educational voice that needed to be heard. Secondly, I had to form my own voice in a university faculty that was entrenched in the provision of a 'better investment in medical students' and a largely trusted, and traditional curriculum. It was for this reason that I changed faculties to study, in an attempt to form my own voice as a student and a teacher. I had my own intellectual, curricular and pedagogical challenges to encounter and respond to.

Throughout a nursing career of 35 years, I had never received any form of death education. Therefore in my epistemological voice; I had only my own interpretations and interventions regarding the topic of death and dying in the ICU to offer. I found myself alone, with no teacher other than my supervisor (not a nurse) to affirm my *being* as a student of death and dying. In the faculty where I was registered as a doctoral student, I was known as 'the death nurse.' As the study progressed, I started to see my title as 'the death nurse' as one of affirmation and significance.

My ontological voice (my *being*) was easier to recognise as I had experienced the deaths of friends, beloved pets and, most significantly, my parents. Being a student and a teacher of death and dying, I was able to engage with the ICU student nurses' experiences of the deaths of patients under their care in the ICU. I had to agree

with Barnett's (2007) stance that the epistemological and ontological voices are 'intertwined', but it is the ontological voice which has the upper hand. When I commenced the study, I did not for a moment consider that both my parents would die, let alone within such a short period of time (six months) of each another. I had a voice which was silent in my grieving, but audible and clear when I re-engaged with the study and the ICU students. During this perplexing time, I started to acknowledge my self-worth as a student, a teacher and a person. My self-worth was also recognised by fellow doctoral students, close friends and, of course my supervisor. This instilled a **'will to learn'** and **'a will to endure'** through many challenges and obstacles in the study. In doing so, my epistemological voice became stronger and more articulate even in moments of quiet introspection.

I believe, that by acknowledging and taking cognisance of my two voices, allowed me to be more fully engaged in the unravelling of the ICU nurses experiences of the dying and deaths of patients under their care in the ICU.

Mode of being – Authenticity

Lived Experience Theme - Care (Sorge, Dasein)

In *Dasein's authentic mode* (to be self properly), *Dasein* is aware of what it means to exist in terms of human relationships. Krasner (1996) elaborates that an *authentic* relationship involves responding to the presence of other *Dasein* and, that through *care (Sorge)*, that *Dasein* becomes engaged with life situations and other possibilities for being § Heidegger and *Dasein* on page 18.

Gaut (1983, p. 314) considered the meanings given to the word 'caring' in both lay and scholastic terms. The notion of caring involves three major attributes:

1. Attention to or concern for another.
2. Responsibility for or providing for another.
3. Regard and fondness for or attachment to another.

Gaut (1983, p. 316) concluded that caring is a word that is vague and ambiguous, with a family of meanings that shift according to the context of the situation. Caring is a practical activity associated with the perspectives, attitudes and expectations of those doing the caring.

Human caring has always been acknowledged as a fundamental attribute in a nurse

and has been studied since Leininger brought caring to the forefront in nursing literature in the 1980s. The literature to date offers two dimensions of caring in nursing. The first is a definitional approach (Watson, 1979; Leininger, 1981) and the second focuses on the *meaning* and intuitive values of *care* as a concept (Benner, 1984; Benner & Wrubel, 1989). The definitional approach utilises lists and taxonomies in order to enlarge our understanding of the phenomenon. Watson (1985) created a list of ten ‘carative’ factors and Leininger (1981) developed a taxonomy of ‘caring constructs.’ This knowledge contributes to our understanding of professional care.

The Definitional Approach of Care

Watson’s Theory of Caring

The structure for the science of caring is built upon the following ten ‘carative’ factors:

1. The formation of a humanistic-altruistic system of values.
2. The instilling of faith and hope.
3. The cultivation of sensitivity to one’s self and to others.
4. The development of a helping, trusting relationship.
5. The promotion and acceptance of the expression of positive and negative feelings.
6. The systematic use of the scientific problem-solving method for decision-making.
7. The promotion of interpersonal teaching and learning.
8. The provision of a supportive, protective and/or corrective, mental, physical, socio-cultural and spiritual environment.
9. Assistance with the gratification of human needs.
10. The allowance for existential phenomenological forces.

Watson views caring as the most valuable attribute nursing has to offer to humanity, yet caring has, over time, received less emphasis than other aspects of the practice of nursing in that:

‘The human care role [in nursing] is threatened by increased medical technology, bureaucratic-managerial and institutional constraints in a nuclear-age society’ (Watson, 1988, p. 33).

Watson sees the nurse as scientist, scholar, clinician, humanitarian and moral agent

and she has high expectations of the capacity and knowledge of nurses to be skilled in all these areas (Watson, 1988, p. 54). Nurse and patient work together in a symbiotic relationship within an ethos of caring, rather than one of curing. The outcome of this approach suggests the promotion of growth and development of the individual, and nursing is portrayed as a 'deeply human activity' (Watson, 1979, p. 7). This approach relies on a relationship of inter-dependence between the nurse and the patient, and rests on the assumption that patients are always able to express themselves.

Although Watson acknowledges the importance of fundamental needs such as nutrition, elimination and ventilation, she pays little attention in her writings to the patho-physiological and technical aspects of caring that predominate in the speciality of intensive care nursing (Watson, 1985, pp. 28-39). This may suggest that working in the ICU, where nursing includes technical skills, attention to the biophysical needs of the patient may have little 'caring' value because of the difficulty in forming an interpersonal relationship or in getting to know the patient.

Watson's theory (1988, pp. 28-29) emphasises the subjective experience for both the nurse and the patient, and promotes personal growth and self - actualisation for both parties. This may suggest that nursing in a technical, highly specialised environment such as an intensive care unit and attending to the biophysical needs of patients may have little caring value when the interpersonal relationship cannot be fully realised by knowing the patient.

Meaning and Intuitive Values of Care

Benner and Wrubel

Benner (1984), and later Benner and Wrubel (1989), attempted to unravel the different meanings of care through hermeneutic interpretation of 'narratives.' Clarke and Wheeler (1992, p. 284) suggest that although such interpretations contribute a great deal to the study of the phenomenon of caring they offer an American perspective and can be criticised for being too analogous. Benner and Wrubel (1989, p. 368) describe caring as 'a basic way of *being-in-the-world*.' Not all people are caring and perhaps Benner and Wrubel (1989) are pointing to a deeper sense of care, a sense of care which is appropriately described as ontological care (Edwards, 2001, p. 168). It is a form of care which all humans, by definition, must have instilled in them, a kind of care which features in the very make-up and constitution of all human persons (Edwards, 2001, p. 168).

Leininger's Theory of Trans-cultural Care

Leininger (1988a, p. 5) views caring as a universal phenomenon, but the expression and pattern of it may vary across cultures. Her model has been used predominantly to generate a theory. However, Leininger intended its use for both theory and practice.

For nurses to provide therapeutic nursing care using Leininger's theory, they should have knowledge of the caring values, beliefs and practices of their patients. Again, as with Watson's theory (1979; 1988), implicit within this statement is the belief that the patient is articulate and expressive and that the nurse is skilled in understanding the meanings given by the patient. If extrapolated to patients who are mechanically ventilated in the ICU, caring is determined by the meanings and assumptions given by the nurse.

Leininger's (1988b, p. 45) definition of professional caring, that is, taking responsibility and providing for, fits into Gaut's (1983) dimensions of caring. These supportive, assisting and facilitative acts towards patients are learnt within the culture of the health-care system (Beeby, 2000, p. 78).

Leininger (1988a, p. 7) believes that, by ascertaining the cultural influences on caring, a nurse can begin to provide 'meaningful' care for the patient. Both Watson and Leininger value the humanistic sciences. From this perspective, caring, a fundamental part of nursing has therapeutic benefit that is distinct from but complementary to that of curing (Beeby, 2000, p. 79). Leininger's (1985) classification of caring describes many important factors that are also important in ICU practice, namely assisting, supporting and enabling caring behaviours that include the elements of trust, compassion, nurturing, concern and presence.

Summary of Caring in Nursing Relevant to the Study

Watson's (1988) theory of caring, although organised and inter-disciplinary, may have limitations, as it can be perceived possibly as a guideline only as a result of minimal empirical data. This is in contrast to Benner and Wrubel's (1989) theory. In addition, Watson theorises about care/caring in a very matter-of-fact manner even though she claims to be taking a phenomenological approach.

Benner and Wrubel (1989) offer an abundance of empirical data and a much finer phenomenological approach, but lack the organised structure that Watson provides.

Leininger's (1988) theory of trans-cultural care seems to have sufficient data, giving anthropological and ethnographic perspectives based on the credence that recognition of cultural variety play a significant role in the understanding and practice of caring.

Each of the above theories of care in nursing deal with different meanings and concepts, but there is consensus that the notion of *care/caring* should be central to the core of nursing based on Heidegger's phenomenological approach. However, the more immediate requirement for nursing practice, as posited by Leininger, is that 'care is critical and is a unifying domain and focus for nursing care knowledge' (Matsuoka, 2007, p. 47).

From the ICU nurses' narratives, it is clear that their *care/caring* for the dying patient or the death of a patient incorporates the concepts of Benner and Wrubel, (Benner, 1984; Benner & Wrubel, 1989), Watson, (1985; 1988) and Leininger (1984) and therefore *authentic* patient care and *authenticity* of self were reflected. Leininger's (1984) classification of caring points to important aspects that are also relevant to ICU nursing and were revealed in the ICU nurses' phenomenological conversations. These are: (i) assisting; (ii) supporting and (iii) enabling caring behaviours, including the elements of compassion, trust, nurturing, concern and presence.

The Lived Experience Theme of 'Care' and its Relation to the available Nursing Literature

Having established that the ICU nurses in this study had aligned their *authentic* care and caring for the dying and deaths of patients under their care in the ICU with the older and more established nursing theories on care and caring, I now look at how the findings on care compare with the available literature on the concept as laid out in Chapter Three (pages 34 – 84).

McClement and Degner's (1995) study set out to identify expert nursing behaviours in care of the dying adult in the ICU (pages 39 – 44) using Quint's (1967) theoretical concept of how nurses learn to care for the dying and the Dreyfus' Model of Skill Acquisition (1980).

The findings of McClement and Degner's study generated six categories which were similar to the experiences of palliative care nurses and nurse educators in a study done by Degner, Gow and Thompson in 1991. The six categories were: (i) responding during the death scene; (ii) responding to the family; (iii) responding to anger; (iv) responding to colleagues; (v) providing comfort and (vi) enhancing personal growth.

In McClement and Degner's study, the category of responding to the family which the authors identified as a caring behaviour entailed the family's need for information pertaining to patients who may not survive. From the ICU nurses' phenomenological conversations, it was clear that the ICU nurses were connected to both the patient and the family and that the response to the family was on more of an emotional and supportive level.

Cindy (page 138) states:

'That God will take good care of them and be with the family.'

Phumzile (page 131) shares his support for the family:

'You need to, you need to chest [be brave] it out for that person, you need to chest it out for that family.'

Even though Esther (page 137) has little knowledge about the cultural aspect of death and dying for the Xhosas, she asks for help from a colleague as the family cannot understand her because she does not speak isi-Xhosa:

'Please, can you sort out this family?'

The concluding remark from McClement and Degner's (1995) study was that ICU nurses and other care-givers needed to risk being involved with dying patients and their families despite concerns about what to say or do. In my study, this was revealed through the ICU nurses' phenomenological conversations where it is very apparent that the ICU nurses' caring behaviours embrace human interaction and included the elements of compassion, nurturing and presence.

Isaak and Paterson (1996) explored critical care nurses' lived experiences of unsuccessful resuscitation (pages 45 – 47) and three themes emerged: (i) knowing

what to expect; (ii) the after-math and (iii) care of significant others.

In Isaak and Paterson's study, care of significant others included the provision of information and emotional support, and the accessing of suitable resources. In their study, the critical care nurses expressed that they were better able to care compassionately if they understood the significance of the patient's death on the family. Even though the ICU nurses in my study may not have understood or accepted the way of or reason for the death of a patient under their care (especially the deaths of children), the empathy and determination to provide and deliver quality care were neither decreased nor withdrawn.

Inshalla still carries on caring, sometimes for up to 40 days after a death of a patient:

'You still care maybe, for longer as a Muslim.'

Cindy remains caring towards both the dead child and the mother:

'I pray before the child dies. I talk to the soul because after death you are just a body but your soul lives. So you still care. It doesn't stop just because the child is dead. You have the mommy to care about too.'

Esther demonstrates her caring when laying out a dead patient, even though she has received minimal death education on the cultural and religious aspects of death and dying:

'You're still respectful in a professional way, but there are little things that you are not supposed to do, or you're supposed to do, or areas that you are not supposed to touch and that kind of thing, but we do, as professionals, still carry on with dignified, human care.'

A study by Bush and Barr (1997) used a phenomenological approach to formulate the fundamental structure of caring as a lived experience of ICU nurses (page 48). The findings proved that caring originated from the nurses' feelings and knowledge which allowed them to perform competent and appropriate actions that contributed to the care of the patient and the family. Bush and Barr's findings verified that caring is a relational process as depicted in Figure 8 below.

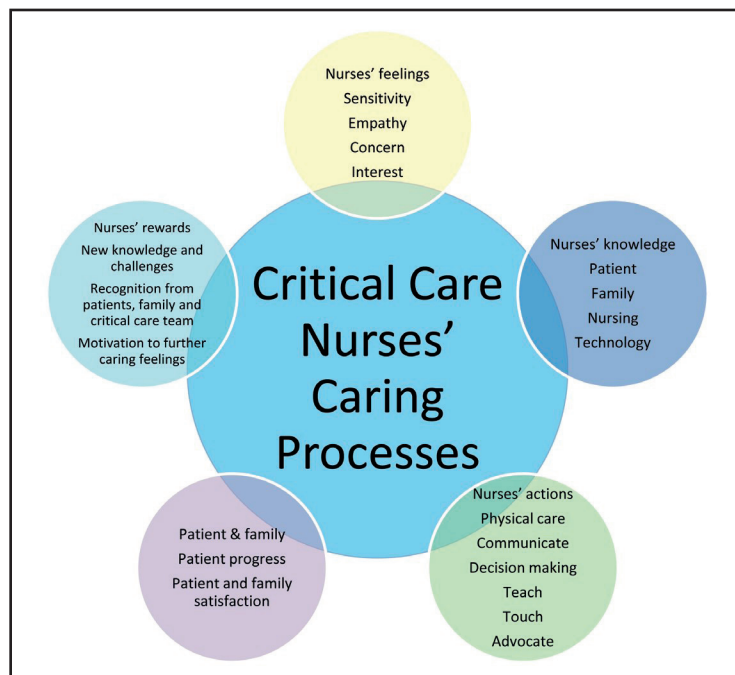


Figure 8. Critical Care Nurses' Caring Processes (Bush & Barr, 1997, p. 391).

Bush and Barr's study did not set out to explore ICU nurses' caring behaviours when caring for the dying or deaths of patients, but it is noticeable that the caring behaviours of the ICU nurses in my study align with the critical care nurses' caring behaviours as identified by Bush and Barr (1997).

Wilkin and Slevin (2004) investigated the meaning of caring work in the ICU using a Heideggerian phenomenological approach. The ICU nurses in this study indicated that a connection had been established with the patients they cared for. This caring behaviour included giving technological support that was already integrated into the routine nursing care of ICU patients. Caring for the relatives was also considered as a component of care for the patient.

My study findings have clearly alluded to the caring and connected relationships that the ICU nurses have with the dying or dead patient and their family. This is particularly noticeable in Phumzile and his caring of babies and infants:

'I had a special relationship with him. I had this connection that I was also fighting in prayers for him. I don't know whether it is just me, but when you have this connection of touching a child, the skin of a child, it's so unique, and just looking now at this, this life going out.'

Wilkin and Slevin (2004) also highlighted that caring for patients in that particular ICU consisted of providing expert physical and humanistic care, but that the use of technology may impinge on the interpersonal aspects of care.

The reflective drawing on page 122, points to the fact that ICU nurses view technological competence as being able to care for critically ill patients. Technology represents a significant component of the *lifeworld* of the ICU. Ihde's (1993) philosophical stance on technology proposes that technology can concurrently magnify and diminish the human-ness in the world. This is in keeping with Heidegger's '**Question Concerning Technology**' (1953), in which he writes that technology is a supreme danger to understanding *being* and that human beings will become additional resources to be effectively and efficiently ordered.

From the ICU nurses' phenomenological conversations, it was apparent that the presence of technology did not hinder or interfere with the delivery of quality nursing care to patients who were dying or had died in the ICU.

Hov, Hedelin and Athlin (2007) aimed to acquire a deeper understanding of what good nursing care entailed for ICU patients on the edge of life (page 71). The study revealed that good nursing care was dependant on a number of basic conditions: continuity, knowledge, competence and co-operation. In my study, the ICU nurses included good communication skills and the use of their hands as necessities for good nursing care. Phumzile shares his experience about caring for neonates:

'They are very small. At times, I was, though I was not showing it, but I was a little bit anxious about touching them, because they were very small with those big wire things around them. So I had a very slow, soft touch which I eventually, adjusted myself to.'

The issue of ICU nurses requiring good communication skills in order for them to be able to care, as described by Hov, Hedelin and Athlin, does have some relevance to my study. Johanna was caring for a patient who, as a result of extreme oedema, had body fluid dripping on the floor (page 121). Johanna was extremely frustrated about the futile outcome for this patient under her care and had even had an altercation with the doctors that they were inhumane. During her phenomenological conversation, Johanna is visibly distraught:

'The death like this could have been stopped. They [the doctors] knew post-surgery that she wasn't going to make it. I always, still, tell myself 'I should have persisted, tried to get the doctors to stop.' But I'm from a small town. When the doctors say ... you do. I had no education how to deal with this.'

Hov, Hedelin and Athlin (2007) recommend that ICU nurses receive education in 'touch' and training in 'difficult conversations' with dying patients and their families. Intensive care nurses' needs for effective and appropriate communication skills when caring for the dying and their families in the ICU may require a special set of communication skills in this instance. This will be discussed later when I propose some pedagogical interventions in death education aimed specifically at the types of needs expressed by the six ICU nurses in my study.

Summary of Caring in Critical Care Nursing

Having reviewed the nursing literature of caring in the ICU, Rushton (1991) sums up caring challenges and obstacles that ICU nurses have to overcome in order for them to deliver quality nursing care in an environment which is often dehumanising: '(i) inconsistent philosophies about patient care delivery and decision-making; (ii) personal and professional value conflicts; (iii) poor communication patterns; (iv) unresolved ethical dilemmas; (v) increased technology; (vi) shortages of human and material resources; (vii) inadequate support systems; (viii) lack of professional skill; (ix) inadequate administration support, and (x) the physical design of the unit environment' (Rushton, 1991, pp. 238-240).

Taking Rushton's (1991) challenges and obstacles as identified above together with the concepts of caring for dying patients in the ICU (Bush & Barr, 1997; Hov et al., 2007; Isaak & Paterson, 1996; McClement & Degner, 1995; Wilkin & Slevin, 2007), there appears to be a consistency in behaviour of ICU nurses remaining caring when patients are dying or have died, despite many difficulties. Although not captured in the nursing literature review chapter because it does not address any aspect of the research phenomenon – **ICU nurses' lived experiences of the deaths of patients under their care in the ICU**, - Beeby's (2000) study of nine staff nurses working in an ICU and a Coronary Care Unit (CCU) has significant similarities and compares most closely with my study. Beeby's theme clusters of **'being there', 'being close', 'respecting the person', 'having feelings**

for the patient’, ‘involving the family’, ‘being supportive and having experience and expertise’ - are all incorporated in the mode of *being* theme of *authenticity* and the lived experience theme of care. Beeby’s use of *being* also has relevance to the philosophy of Heidegger.

Notwithstanding the lack of death education in the Postgraduate Critical Care Nursing curriculum, the ICU nurses in this study appear to remain caring in their profession and as individuals in their families and communities. This is *authenticity* in its truest sense; to be *self properly* as a *caring* ICU nurse.

Mode of being – Inauthenticity

Lived Experience Theme – Suffering (Angst, Fallenness)

I remind the reader of Heidegger’s concept of the second mode of *being*: *inauthenticity*. In this mode, *Dasein* struggles with the present, which he calls *falling* or *fallenness* (*Verfallen*), and a consequence of *fallenness* may result in *Dasein* becoming absorbed in its world and losing sight of its *being* (see page 25).

The word ‘suffering’, although used in daily conversation, remains a term that is difficult to define.

The conceptualisation of suffering in conjunction with physical pain has received attention for many years (Cassell, 1991; Gadow, 1991; Koskoff, 1977). The Online Oxford Dictionary (2011) defines suffering as ‘the state of undergoing stress, pain or hardship.’ Several authors have endeavoured to define suffering in order to provide reasons and principles to differentiate the religious perspectives from those of physical pain (Cassell, 1994; Hauerwas, 1979; Younger, 1995). Cassell’s broad definition of suffering does offer some clarity:

‘Suffering is a specific state of severe distress induced by the loss of integrity, intactness, cohesiveness, or wholeness of the person, or by a threat that the person believes may dissolve his integrity’ (Cassell, 1994, p. 1899).

Irrespective of ‘suffering being an actual or perceived threat’, Younger (1995, p. 55) believes that suffering alienates one from others. ‘Suffering removes an individual’s central purpose’ and an individual without a central purpose is unable to identify

with others and as a result withdraws from others, relationships and even the human community. A consequence of alienation of the self is a loss of autonomy and, should the individual be able to voice the suffering and understand the suffering, the sufferer may 'discover that change is possible and can regain autonomy' (Younger, 1995, p. 55).

Suffering by critical care nurses regarding EOL and DNR decision-making received some interest in 2000. Anecdotally at that time, it was believed that critical care nurses experienced emotions identified with suffering. However, there was very little information on how these critical care nurses dealt with their suffering and the long-term and unrelieved consequences of such suffering.

It is interesting to note that the ICU nurses in my study did not refer to 'suffering' but instead used the words 'pain' and 'painful' to describe their distress and anxiety.

Spencer (1994) conducted a study exploring how ICU nurses dealt with their own grief when a patient died in the ICU (see page 37). The findings revealed that the majority of the ICU nurses experienced feeling of sadness, anger, shock and relief. This was also found in my study.

Esther describes her sadness:

'I am sad about it, because I will miss that person, but it's not like, I don't know where that person is. I don't know where they are going. That shouldn't be and that's why it's so, so bad to me, when people are so like, like that anxious, that's not good. No one understands about this sadness.'

Inshalla has a protracted sadness, even after 40 days:

'But still, you feel that sadness, because you cannot erase that sadness when it comes to death.'

In Spencer's study there was found to be some support offered to the ICU nurse. This was mostly given by their peer group and in the form of informal discussions. Spencer pointed out that there was a full-time nurse counsellor in the study setting but, in line with the literature, nurses do not like to admit that they are unable to deal with their feelings (Casey, 1991; Charnock, 1985; Slater, 1988). The ICU nurses in Spencer's study were reluctant to utilise this resource, as they felt that

the counsellor was not experienced enough. The ICU nurses in my study did not receive any support, debriefing or counselling nor were there any resources for them to do so.

Spencer also mentions that the majority of the study participants had received little or no training in how to deal with their emotions when a patient died in the ICU. This is in keeping with the findings of my study.

Returning to the available literature, there is a dearth of information in the domain of emotional and organisational support for ICU nurses and other health-care professionals working in the ICU environment (Clarke, Curtis, Luce et al., 2003). The need for formal debriefing sessions, particularly after life-support measures had been withdrawn, has been highlighted by Jones and Fitzgerald (1998). Intensive care unit meetings focusing on counselling after a patient had died seldom or never occur (Puntillo, Benner, Drought et al., 2001).

Guilt is a common emotion expressed by ICU nurses. Isaak and Paterson (1996) found in their study exploring ICU nurses' experiences of unsuccessful resuscitation that grief, loss, guilt, anger and regret were experienced. Some of the ICU nurses' emotions were triggered a considerable time after the event and were attributed to their connectedness to the patient and/or family.

Thato was particularly close to a patient and the mother:

'The thing that is most painful, is when you look at the family and you look at, sometimes, the age, or you look at the background, because as I get close to the parents, I even know their backgrounds.'

Johanna expresses some guilt:

'You know that the child is going to die. You gave your best but it was not good enough.'

Thato describes her pain:

'So that is why it is still painful to me and I'll never forget that, to take the child away from the mother and let the mother watch when we switch off the machines.'

Phumzile is distressed after a failed resuscitation of a child with extensive burns:

'I had another feeling of, maybe I let him down. If only maybe I could have done the chest compressions much harder.'

Rashotte, Fothergill-Bourbonnais and Chamberlain (1997) explored the grief that paediatric nurses experience when children die (see page 48). The sub-theme of **hurting** emerged under the theme of **grief reactions**. A participant's quote from their study:

'It left me with a really bad pain. I felt so rotten. It tore me apart for a couple of weeks' demonstrates a similar hurt to that felt by Thato:

'It feels like something grabbing so bad from in your heart, you know. It's just like this, another piece of your heart that is just taken off from your heart. That is the pain that is happening. No one understands.'

The emotion of sadness and sorrow was expressed by the paediatric nurses in Rashotte and colleagues' study and again was as a result of the nurses' involvement with and attachment to the child and/or family. This is in keeping with the findings of my study and has already been discussed under the lived experience theme of *care*.

Other variations of hurting were dependant on the context of the child's death. These included accountability, emptiness, powerlessness and vulnerability. From Johanna's phenomenological conversation where she shares her experience of a patient in multiple organ failure and tissue fluid is dripping onto the floor:

'The death like this could have been stopped. They [the doctors] knew post- surgery that she wasn't going to make it. I always, still, ask myself 'I should have persisted, tried to get the doctors to stop.' But I'm from a small town. When the doctors say ... you do. I had no education how to deal with this.'

Johanna's story has similarities with a participant's quote from Rashotte et al.'s study:

'Should I have spoken up five hours earlier and been more aggressive and said 'enough is enough? Stop this ridiculousness. Do you see what we are doing? Do you see what we

are perpetuating here?’ Then I feel anger. I feel frustrated. I feel self-recrimination from the fact that you didn’t speak up.’

In Rashotte et al’s study, the findings are congruent with Isaak and Paterson (1996) and my study that the relationship and connectedness between the ICU nurse and patient and/or family are in correlation with the intensity and duration of their grief.

Continuing with Rashotte et al’s study, a theme of **dissonance** emerged which was an irrefutable factor in affecting the intensity, type and duration of the nurses’ grief reactions. In Rashotte et al’s study, dissonance referred to the ‘clashing of co-existing beliefs, values or expectations within themselves or others when the reality of the child’s death contradicted their expectations about death and dying processes’ (Rashotte et al., 1997, p. 379). Factors that impacted on the nurses’ grief were their beliefs about the ideal death for a child, what ICU nursing is and what their professional responsibilities were. Senseless deaths of children were harder to accept. Inshalla expresses similar feelings:

‘But this was not this child’s fault. Why is he dying? Why is he dead? He was just at the wrong time, like for me, at the wrong place at the wrong time and I thought: “How could God let this happen to this little boy? He still hadn’t lived life, he still had his life ahead of him, but why did it happen to him?” The taxi drove through the yard and knocked the child and crushed the child against the wall and you know why I was thinking about that? Why so severely, man? Why was it that he had to be crushed like that? Why did he have to die so violently?’

One participant in Rashotte et al’s study describes how a child should die (see page 50). The use of words such as ‘peaceful,’ ‘comfortable,’ ‘cuddling’ and ‘nice’ are used to describe the scenario for an acceptable death of a child. Similar words and scenario settings were also found in my study.

Inshalla’s scenario is a spiritual one:

‘It’s like I want to say to you, “Go peacefully” and for me that is my goodbye. Not to lose the battle, because you are going to good hands. That is why I’m putting my hand on that person. You are going to hands that will always keep you safe.’

A coping mechanism used by Rashotte et al’s study participants was that of self-

expression which had a private and public domain. For these nurses, presenting at conferences, writing in journals and being involved in death and dying projects helped them with their grief and in understanding the death and dying processes. In contrast, for the six ICU nurses in my study, the phenomenological conversations were their first opportunity to share their experiences of deaths of patients under their care in the ICU. In keeping with the findings of Rashotte et al. the nurses talked to colleagues, friends and family, although reluctantly as they did not want to upset anyone. Phumzile's experience is an apt example:

'Well, my girlfriend is also doing nursing and we do get to share what is happening at work, but with him, with this little boy, I did share it and I told her like I was very sad and that the boy has died and at least, with her, she can listen, she can listen. I would say with her there is a more understanding thought of what I'm going through. So she is the person that I'm always sharing those sad moments at home. With my other family, because I'm currently staying with my brother and my sister, I don't talk much with them about my work things.'

The theme of **self-nurturance** in Rashotte et al.'s study describes how the participants engaged in various activities to nurture themselves and to re-establish a sense of stability in their grief. Some of the participants bought something for themselves or took part in exercise and gardening activities. Thato is the only participant in my study who mentions that she needs to take care of herself. She does not elaborate further on how she intends to do this:

'This patient has died and there is nothing I can do about this. I must look after myself.'

The final theme from Rashotte et al.'s study was that of **self-reflection** and it emerged from the nurses still being haunted by certain deaths. Rashotte et al. viewed this finding as an affirmation of the caring nature of the nurses; it formed a significant component of their experiential learning. This was also found in my study. Thato describes her images of deaths of children that she has witnessed:

'But there is that feeling that there is this ugly thing that pulled this person away from us, because the rude thing doesn't have any mercy, you know, the way he pulls the kids to death.'

Esther states that it is necessary to deal with the deaths of children:

'If you don't deal with stuff, then you are not going to go down that lane again, because it hurts and I mean, who wants to hurt themselves continuously?'

Rashotte, Fothergill-Bourbonnais and Chamberlain's (1997) study concludes that more research is needed into the experiential learning processes when paediatric ICU nurses experience multiple and accumulative deaths. In addition, further research is required that examines strategies and interventions to enhance education and support for the grief experienced by nurses in general.

Jezuit (2000) conducted a study to gain further insight into the phenomena of emotional distress of critical care nurses with EOL and DNR decision-making (see page 56). The ICU nurses were asked to describe situations and circumstances which caused them emotional suffering. One of the participants in Jezuit's study described how she felt she might be causing the patient's death after adjusting a narcotic infusion prior to the withdrawal of life-support:

'I am concerned that I am causing their death. I have to actually tell myself that I am providing comfort to a patient rather than killing them.'

This has a remarkable similarity to Thato's experience when taking a child off a ventilator after further treatment was deemed futile:

'I know morphine is a respiratory depressant. To me, really, I still felt "Are we killing this child now, because we know what this morphine is doing?" I had to cry.'

Another area of suffering identified was that of conflict, especially between physicians, other critical care nurses and family members. This is consistent with other studies done (Crump, Schaffer & Schulte, 2010; Rushton, 1991; Rushton, 1992). The story of Johanna and her altercation about inhumane treatment of a patient in multi-organ failure also points to this type of suffering.

Jezuit concludes that there still is no universal definition of suffering and that further research is needed to explore the type of suffering endured by critical care nurses. However, it is evident that the descriptions in the study of suffering experienced by critical care nurses caring for critically ill and dying patients can be viewed as a form of suffering which is unique. It is recommended that further research is needed to

explore if the suffering experienced by critical care nurses is related to the critical care environment, the discipline of critical care nursing or the dying and deaths of patients.

In 2001, Yang and McIlfatrick undertook a study exploring ICU nurses' experiences of caring for dying patients in Taiwan (see page 59). The themes of **grief reaction** and **feelings of sadness** were a predominate finding. In Yang and McIlfatrick's study, some of the ICU nurses reverted to crying, both privately and with families, when patients had died. This was also a finding in the Isaak and Paterson (1996) study. From my phenomenological conversations, I found that Thato, Johanna, Esther and Cindy expressed their suffering in crying, and of significance is that Thato, Johanna and Esther also expressed visible distress during their phenomenological conversations with me.

Another form of suffering identified by Yang and McIlfatrick was that of dealing with the patient's family's grief and bereavement. This is also consistent with my finding, as Inshalla explains:

'When the family experiences torment, that's bad for me, because I know that the death shouldn't be like that.'

Yang and McIlfatrick (2001) point out that it is important to acknowledge that ICU nurses face dying and death on a daily basis and this alone cannot prepare them for these types of events. Educational programmes are needed that are tailored to address the suffering experienced by ICU nurses.

Elpern, Covert and Kleinpell (2005) explored moral distress experienced by ICU nurses, as this phenomenon has been associated with job dissatisfaction, burnout and attrition of nurses from the ICU (see page 68). Using a Moral Distress Scale (MDS), the highest ratings were concerns about dying and the deaths of patients in the ICU. In the Elpern et al.'s study, one participant states:

'I often equate my job with keeping dead people alive. On these days, I dread coming to work.'

This statement resonates with Johanna's experience:

'I never thought that I would be nursing death. Please, God, don't do this to me. Sometimes we nurse patients in the ICU to death.'

The conclusion from the Elpern et al. study was that moral distress for ICU nurses is an intense and frequent occurrence, especially in situations of caring for patients who were unlikely to survive. A recommendation was that further research was needed to address the potential for ICU nurses to develop PTSD.

Mealer and colleagues set out a few years later in 2007, to determine if ICU nurses were more stressed psychologically compared with their colleagues working in the general wards (Table 8 on page 71 highlights the traumatic events that ICU nurses frequently experience). The findings showed that ICU nurses had an increased prevalence for PTSD symptoms compared with the general ward nurses. In the phenomenological conversations, Esther tells the story of how she disconnects herself from a dying child and the family. This is her coping mechanism which involves becoming very task-orientated. This coping behaviour is well described by Corr, Doka and Kastenbaum (1999) on page 197. I ask Esther if she likens this disconnectedness to a form of post-traumatic stress. Her answer is:

'That's how it sounds: very much like somebody who has post-traumatic stress.'

Mealer et al. concluded that ICU nurses had a higher risk of developing PTSD symptoms compared with general ward nurses. Recommendations included an increased awareness of identifying PTSD symptoms and implementing necessary measures to improve the mental health of ICU nurses.

The most current study by Hinderer (2012), who set out to explore the lived experiences of critical care nurses through their reactions to death, identified that personal distress was experienced by most of the critical care nurses, especially when they saw the patient and family suffering. This finding was also evident in my study. Thato tells of her personal distress in caring for a patient who is dying in the presence of family:

'Nicki, it's very painful. It's very painful to see a patient dying if you are looking after the patient. Our feeling is to resolve pain, but not with death, but yes, there is that belief of when they die, they don't have pain anymore, but it is not what we want as health workers. We like to see healing. So it's so painful.'

Hinderer also highlighted a major source of stress for the critical nurses as being death itself. The participants expressed their anxiety about patients dying on their shift and having to deal with grieving people. Phumzile's experience of being with a dying child and the family emphasises his emotional distress:

'I felt, you know, when they say, it's like a knife going through your heart, well it is. Watching the child being alert and looking at life going out. I mean, yes, I have seen a lot of adults dying and I have seen also the other children dying, but with that child, when that child was being taken off from the ventilator and the child was in the mother's arms, as they were taking the tubes out, they prayed in Arabic and I was also there, just looking, at the breath, man, you know, the breath of a child. I don't know whether it is just me, but when you have this connection of touching a child, the skin of a child, it's so unique and just looking now, at this, this life going out.'

In summary, the literature and the lived experience theme of suffering highlights that ICU nurses experience emotional distress when caring for patients who are dying or have died. The findings of my study have similarities with those of other studies in that the ICU nurses suffer emotionally with the families and other caregivers involved in the dying and death processes. However, there are two important issues that need to be brought to the reader's attention. From the nursing literature reviewed (pages 33-82), the ICU nurses in my study did not distance or disconnect themselves from the patient or family, and secondly, the delivery of nursing care was not interrupted or withdrawn even in cases of futility.

Mode of being – Inauthenticity

Lived Experience Theme – Disenfranchisement (Das Man, They)

Having discussed the lived experience theme of suffering and reviewed the nursing literature, I have found it evident that ICU nurses' experiences of suffering have a significant relationship with grief. At times, the grief of ICU nurses is invisible, avoided or even silenced (Halcomb et al., 2004; Papadatou, Martinson & Chung, 2001; Rashotte et al., 1997). In these instances, where ICU nurses' grief is silenced or perceived as invisible, they become **disenfranchised** and are **denied** a sense of *authenticity* to be caring professionals and caring to self (*Dasein*). In my study, disenfranchised grief was a significant finding and has not been identified or discussed in any of the literature that I have reviewed.

To disenfranchise an individual is to take away an acceptable right to something or someone. Doka (2002) explains the concept of disenfranchised grief as the death of someone that cannot be openly acknowledged, socially sanctioned or publically mourned. The ICU nurse experiences a death but can neither share the circumstances of the event nor receive support, as, on most occasions, there are very few or no resources available. In these situations, the ICU nurse alienates him/herself from others within the profession and from their families and communities, thereby disenfranchising their grief.

Corr (2002) expands the concepts of disenfranchised grief and bereavement. Firstly, grief reactions and expressions can be disenfranchised when some individuals insist that it is inappropriate for the bereaved to experience emotions and physical and psychological effects and behaviours. Cindy's experience is a good example of a disenfranchised grief reaction:

'When I started nursing, I was told not to cry. It's unprofessional. If I can't cry, my tongue swells up and I can't breathe or talk. Well, this death of a child, I tried very hard not to cry and because of this I had to leave the unit and went to my room in the nursing home.'

Secondly, mourning can be disenfranchised when the significance of rituals in response to loss is disregarded or the bereaved are discouraged from attending or participating in them (Attig, 2004, p. 200). Intensive care nurses seldom, if ever, have the opportunity to attend the funeral or the memorial service of a patient who has died under their care in the ICU. In my nursing career, I have only attended one funeral of a patient who died in the ICU that I worked in. The patient had been in the Isolation ICU for over a year and was seen as part of 'our ICU family.' The ICU staff, including other nurses, as well as domestic workers and friends attended the funeral to say their goodbyes and to be with the family. It is very seldom that ICU nurses have the opportunity or privilege to say goodbye to patients who have died. For most ICU nurses, there is no closure, only a brief moment to recollect ourselves and prepare for the next ill patient requiring our care and expertise.

Thato is very vocal about her experience of not having had any time with a child that had just died and having to prepare for another admission:

'Nicki, It's almost, it's like the bed is still warm.'

She states further in our phenomenological conversation:

'To be honest with you, it's not easy in ICU to say goodbye to the patient. We had to just take that body to the Bereavement Room [laying-out room] and give the body to the nurses. You see, to me, it's like I'm throwing the body there. I don't have any time again with that patient. I am preparing the space for the one who is coming.'

Attig is insistent that 'disenfranchisement of grief is a serious social failure' (Attig, 2004, p. 200). His opinion echoes that of Neimeyer and Jordan (2002) who state that disenfranchised grief can also be viewed as empathetic failure in which the source of grief is the failure to empathise with the bereaved: the ICU nurse. The failure is to not take cognisance of the ICU nurses' suffering and pain and that consequently becomes destructive. Johanna explains:

'My husband says I'm too involved with the baby patients. I am a mommy and if my child had just died, I would like the nurse to support me.'

Phumzile has a similar story:

'I don't talk much with them about my work things, and at home also, we don't have small children, but when I'm meeting with my siblings and their related families, if there is a young child at home, I would always have that, that feeling of sadness and wanting to go to my own home.'

Taking disenfranchised grief further, Attig is of the opinion that there is a sort of political failure which includes abuse of power and neglect. Politics can be understood as the 'distribution of power in relationships' and abuses of power 'often result from misuse of authority.' In addition, Attig states that authority (as expertise) 'derives from a differential in knowledge between persons' and 'abuse is possible when some pretend to know or understand more than others when they do not' (Attig, 2004, p. 201). Taking this thinking into consideration, it can be construed that the South African Nursing Council (SANC), which has set norms as stipulated by the SANC Scope of Practice (in which there is no such thing as 'grieving rules or policies'), can be interpreted as some element of political failure. Often the rules and regulations are made by nurses in managerial positions who are much older or have little or no experience in death and dying of patients.

Death is inevitable and unavoidable and will cause bereavement and grief to all individuals at some time in their lives. This is especially true for an ICU nurse who may have up to three deaths on one shift (usually an eight-or-12 hour day). Attig argues that there is suffering that individuals impose on themselves that can be eliminated or at least minimised. This is an issue that ICU nurses and ICU nurse educators should take note of, as this can be seen as a form of neglect, by the self and the profession because we're failing to use our power of restraint in such instances. Taking Attig's stance that we are culpable for imposing such grief on ourselves and that this issue needs to be addressed, there is clearly motivation to include self-bereavement care as a pedagogical intervention into nursing curricula.

Lastly, Attig explains his views of disenfranchisement as an ethical failure. The concept of respect to Attig is in 'understanding and appreciating a person's vulnerability and potential for suffering' and 'requires acting respectfully in accord with these understandings.' In fact it requires acting or *comporting* ourselves in a constructive manner: (i) 'in ways that acknowledge and reflect genuine concern and comfort in response to suffering and hurt' and (ii) 'in ways that actively support thriving or a return to it' (Attig, 2004, p. 204). In short, disenfranchisement of grief is extremely disrespectful on all counts.

If I take Attig's view of disenfranchisement of grief as an ethical failure literally: despite the fact that the concept of death and dying for ICU nurses has been an area of interest of mine for many years (see page 3), I have also failed as it has taken me almost seven years to address this issue, on behalf of the ICU nurses and myself.

I agree with Attig that the misunderstanding or lack of knowledge of ICU nurses' grief in effect compounds the loss and hurt they endure. This lack of understanding reinforces feelings of powerlessness, hopelessness, guilt and even shame for ICU nurses. In my study findings, the ICU nurses are denied, isolated and abandoned in their grief and sorrow when experiencing the deaths of patients under their care in the ICU.

This conversation about ICU nurses' disenfranchisement of their grief would not be complete without returning to Heidegger's mode of *inauthenticity* (see page 20). An ICU nurses' *everydayness* (*undifferentiated mode of being*) of working in a technological environment (*thrownness*) includes the reality of experiencing death. His/her *Dasein* conforms to fit the expectations of the *They* or *das Man* (SANC and society) when

a patient dies in the ICU and the ICU nurse is disenfranchised of his/her grief. Such disenfranchisement of grief (*fleeing*) in the face of death alienates and denies ICU nurses from their potential for *being* (*authentically*) and, as a consequence, their *being-toward-death* causes *Angst* and guilt.

In *Dasein's* authentic mode, *Dasein* takes responsibility for *Dasein's* own *being*. However, *das Man* takes away *Dasein's* responsibility and unburdens *Dasein* by taking away possibilities to exist *authentically*. By not acknowledging ICU nurses' suffering and disenfranchisement, we deny them the possibility to exist *authentically*. This *denied authenticity* may have negative consequences for *Dasein's* self-care and care of others.

Dasein may become a despised self where a discrepancy exists between *Dasein's* preferred self and perceived self. *Dasein* may even *comport* itself with a false consciousness (disguised self) which is out of touch with its *being*, or *Dasein* may be detached in a state of *fallenness* and have a negative effect on activity and emotions. These many alienated faces of *Dasein* may cause ICU nurses to be seen as *standing-reserve* (*gestell*) or a resource rather than *Dasein*. This *enframing* is an *inauthentic being-in-the-world*.

Doka eloquently states that 'our goal, regardless of cost, must be to enfranchise the disenfranchised' (Doka, 1999, p. 39). In an attempt to re-instate *Dasein's* possibilities for *being-in-the-world* as an ICU nurse that is *authentic* (enfranchise), there is a need to address the ICU nurses' care of self when they are bereaved as a result of their experiences of the deaths of patients under their care in the ICU.

Mode of being – Inauthenticity

Lived Experience Theme – Cultural/Religious Unpreparedness (thrownness)

Leininger (1988a, p. 5), a nurse theorist, views caring as a universal phenomenon, but the expression and pattern of it may vary across cultures. Leininger posits that for nurses to provide therapeutic nursing care they should have knowledge of the caring values, beliefs and practices of their patients. This is an important pedagogical consideration when designing a curriculum in a country such as South Africa that has 11 official languages as well as a vast array of cultural groups.

In reviewing the nursing literature specific to death and dying with regard to religion and culture, there were only two studies that mentioned culture and then only an aspect of it.

The first is Papadatou, Martinson and Chung's (2001) project of a comparative trans-cultural study of oncology and critical care nurses' experiences of caring for dying children in Athens and Hong Kong. The findings revealed that, irrespective of the discipline of nursing or the cultural background of the nurses, the deaths of children deeply affected them. The nurses' stress levels were elevated as a result of feeling helpless to relieve the physical suffering of the dying children and the emotional and spiritual distress experienced by the children and their families.

Crump, Schaffer and Schulte (2010) conducted a study exploring critical care nurses' perceptions of obstacles, support and knowledge needed in providing quality EOL care. This study was in fact a replication of Beckstrand and Kirchoff's study (2005) in which the authors conducted a **'National Survey of Critical Care Nurses regarding EOL Care.'** The participants were two critical care nurses who attended the **ELNEC Critical Care Training Programme** and then returned to the intensive care units where they had previously worked to implement the educational modules they had learnt. The topic of cultural aspects came last on the list of knowledge topics.

One of the conclusions from the Crump et al.'s (2010) study was that the ability of critical care nurses to deliver quality EOL care was affected by issues with physicians and that more knowledge, skill and competency in matters of a cultural nature are required. No pedagogical intervention was offered.

The only pedagogical intervention or strategy seemingly being provided currently is offered by the University of Washington School of Nursing and the Massachusetts Institute of Health Professions. They have a **'Tool-Kit for Nursing Excellence at End-of-Life Transition' (TNEEL)**. This initiative consists of an innovative package of electronic tools distributed to American nurse educators and researchers in academic and clinical settings. It takes the form of a web-based self-study course. Even here, only one topic addresses cultural concerns at end-of-life.

The lived experience theme of cultural/religious unpreparedness arose out of one of the set of phenomenological conversational prompts and confirmed by the ICU

nurses' reflective and class discussions prior to the study. I realised from these that the ICU nurses were culturally and religiously ill-equipped to provide wholistic care to dying patients and their families. At times they were distressed that they had little knowledge of other cultures and religions when it came to the dying and death processes. Inshalla shares her concerns:

'Death and dying. I think death is a topic that you cannot have enough knowledge about. Other cultures and death, the only culture that I know is my own culture [Islam] and a little bit about the Xhosa culture and then about the Christian culture. I don't always know how to care for them after the patients die.'

Esther explains:

'Like the Xhosa people. I actually don't have any idea of how they view death. It's actually bad.'

Phumzile is emphatic that there should be death education addressing cultural issues:

'So I think, yes, yes, I agree with that, that we need to be prepared. We need to be prepared about cultures and death.'

Thato also lacks knowledge about other cultures and religions:

'To be honest, I'm not clear about other cultures. In Cape Town there are lots of Muslims. I haven't met a Muslim who can explain to me exactly what they do and why they are doing it.'

Other issues that caused some concern for the ICU nurses were the care of the dead and performing last offices: Esther describes her uneasiness:

'You're still respectful in a professional way, but there are little things that you are not supposed to do, or you're supposed to do, or areas that you are not supposed to touch and that kind of thing.'

On the other hand, Cindy is a little more at peace when laying out a dead child:

'I pray when I'm laying out.'

On questioning Cindy why, she elaborates:

'That God will take good care of them and be with the family. I don't know what else to do. I pray in English even for the black babies.'

One of my teaching and learning strategies prior to the study (the study participants included), was to set the ICU nurses two activities:

1. They were asked to draw a picture of any death that had had a profound effect on them.
2. They were then asked to draw a picture of a significant death that they had experienced in the ICU.

Once their drawings were complete (I set aside 30 minutes for each), each ICU nurse had to explain their drawing to the class. I did this because, most, if not all the Black cultures, irrespective of their traditional beliefs and westernised influences, view the subject of death as taboo. It is considered bad luck for the individual and family, as well as their community, to talk about any aspect of death and dying. I felt that it was a sensitive and educationally sound teaching and learning strategy to have the ICU nurses and I engage in this unpleasant and disturbing exercise.

Phumzile was a little uncomfortable and concerned about participating in the drawing exercise and sharing his experiences verbally:

'Because I believe that what you say with your mouth and what you think with your head can happen. I believe so and in most of my community, we believe, so and someone else is going to say: "We believe in witchcraft, witchcraft exists with us blacks, black magic does exist." So I believe that for you to be a witch, you don't need to be there and dress like a witch and do things. I believe that witchcraft is how you think and what you say. So me, by thinking about death and talking about death, it's taboo, I shouldn't be even thinking of such a thing. I shouldn't even be talking about such a thing.'

During the course of the teaching session, and the phenomenological conversation, Phumzile became more receptive about discussing and sharing his views and fears of death and dying:

'Yes, from a scientific background as a nurse, I think I'm there, because if you're going to work with people, we are dealing with live people here, we're not dealing with machines. We

are dealing with humans. So we need to get prepared and it's really necessary for nursing. Consulting all the ethnic groups, that's one thing that has been missing and someone like you has now thought about it.'

Johanna also has little knowledge of other cultures and religions:

'I'm a Christian and don't know much about other religions and cultures. I believe that a child's soul goes straight back to God. They don't go through purgatory or whatever. I'm at peace. There is a peaceful transition for them and they are not scared. I touch the forehead and say goodbye. But don't ask me about Muslim or Jewish deaths and I know nothing about Black cultures and the ritual things.'

The ICU nurses' phenomenological conversations and the stories reflected in their drawings clearly demonstrate that there is especially a need for death education from a cultural and religious perspective with additional education in good clinical practice in the post-mortem care of the body within the appropriate cultural and religious parameters.

Mode of being – Undifferentiated

Lived Experience Theme – Living with Dying (being-with-death)

The most demanding ontological confrontation for ICU nurses occurs when they face the inevitability of their own demise. Again, I used a phenomenological conversation prompt to address the ICU nurses' view on death and how they would like to die.

Koestenbaum (1976) searches for positive consequences of ontological confrontation with death by bringing greater *meaning* to life. He argues that the expectation of death shows who one truly is. The same can be said of ICU nurses caring for patients who are dying or have died in the ICU. The narratives of the ICU nurses in my study (see page 130 for review) showed that they were adamant that they did not want to die in the ICU. Esther sums up her view laconically:

'Please, I don't want to be in ICU forever, because it sucks.'

Thato wants to be in a more caring environment should she die in ICU:

'With respect. I may feel better if they make me more comfortable. If I can be in that

comfortable place and a comfortable bed and everything is clean and is in order, that's okay, now I'm leaving. I want to die in a clean environment. Your soul goes to heaven cleaner and quicker as opposed to somebody who dies with blood and guts and everything is untidy.'

Although not well articulated, I had the impression that the ICU nurses in my study were suffering from or had experienced some form of **'death fatigue.'** The concept of burnout for critical care nurses has received considerable attention in the last two decades. The classic signs are emotional exhaustion, depersonalisation, detachment and feelings of ineffectiveness in the work place (Bakker, Le Blanc & Schaufeli, 2005; Bühler & Land, 2003; Lederer, Kinzl, Traweger, Dosch & Sumann, 2008). If McFeeley states that burnout is 'so pervasive in the ICU that it almost has become part of the background noise' (McFeeley, 2007, p. 37), then surely the same can be said about nurses who regularly experience the death and dying of patients in the ICU?

There is no empirical evidence to support this, but I am of the opinion that, as a result of the intensity of compassion given to dying patients in the ICU with little hope of a positive outcome, the very likelihood of developing compassion fatigue and hence death fatigue too, is realised. Cindy is exhausted from caring for dying children:

'I re-live the death. My brother said that I'm used to death because I don't cry as much anymore. I've put mental blocks in my head to cope and forget. My family remembers me coming home and crying but I don't anymore. So they think I'm used to it. I'm not in tune with it [death] anymore.'

Death fatigue may also result from the amount of time and compassion that families need when a loved one is dying or has died. Thato has on many occasions developed a close relationship with the parents and family:

'The one thing that is so painful, is when you look at the family and you look at, sometimes, the age, or you look at the background.'

Cindy does not stop showing her compassion:

'It doesn't stop just because the child is dead. You have the mommy to care about too.'

When ICU nurses are not supported by members of the multi-disciplinary ICU

team and especially nurse managers when patients die, feelings of ineffectiveness are compounded, exacerbating death fatigue. Esther takes on a 'task-orientated mode' in dealing with children who are dying, as she receives no support from any of her colleagues or other health-care professionals:

'You just do what you do and I think it's very bad, because then you don't, then you don't look after the patient wholistically and that, that could actually do more harm to a patient than good.'

The literature highlights that the nurse manager of an ICU plays an important role in preventing burn-out (viz death fatigue) in critical care nurses (Leiter & Maslach, 2009; Sawatzky, 1996; Stayt, 2007). Coles (2010) recommends that one way in which nurse managers can improve their supportive role to ICU nurses is by staying out of their offices as much as possible and being involved in a daily-walk about report back with the nurse in charge of the ICU. In my study, no mention was made of any supportive measure from any health-care professional other than a colleague who was with them at the time of the death or from a family member. Coles (2010) goes on to endorse the education of both ICU nurses and nurse managers in recognising moral distress and being able to deal with it.

Brosche (2007) proposes that a grief team be available around the clock, composed of chaplains and nurses with special training, is a cost-effective way to meet the need for emotional support among ICU nurses. This is undoubtedly a First World view of the health needs of ICU nurses. In South Africa, the nurse-to-patient ratio in the ICU is often one nurse to three patients. The scarcity of clinically expert nurses is a reality in South Africa and the proposition of a grief team is at best idealistic.

Hernandez, a registered nurse, states that 'before we can care for others, we must first care for ourselves' (Hernandez, 2009, p. 130). I think Huggard's words best sum up the possibility of ICU nurses experiencing death fatigue: 'in caring for the carers, the challenge for health-care organisations lies in developing respect and care for their employees in the same way they require their employees to care for patients' (Huggard, 2003, p. 162).

There have been some pedagogical interventions (AACN, 2000; ELNEC, 2001) that have addressed curricular content on death education, and some hospitals and nursing faculties have introduced informal short courses and seminars which,

however, by and large have no structured format or design. More recently, Kavanaugh, Andreoni, Wilkie et al. (2009) developed a blended course on dying, loss and grief. This integration of face-to-face classroom contact and on-line learning addressed the social, cultural and psychological aspects of EOL care for the Advanced Practice Palliative Care Nurse (APPCN) at the University of Illinois at the Chicago College of Nursing. In an attempt to reach a larger number of APPCNs, a major portion of the content was offered on-line and consisted of four modules:

1. Personal and professional narratives of dying, loss and grief.
2. The dying trajectory and near-death experiences.
3. Grief and conceptual dimensions.
4. Healing in individuals and families.

However, my concern remains that that there is an overwhelming need for the improvement of **self-care** of ICU nurses. This improvement must take place in a structured fashion with the student (ICU nurse) in the forefront, attending to his/her *authentic being* and personal development.

In summary, the review of the nursing literature with regard to death education (thanatology) has highlighted the fact that there is a lack of death education for ICU nurses (Allchin, 2006; Ferrell et al., 2000).

The chapter that follows brings together the concept of Heidegger's *being*, nursing and education. In this chapter, the topic of nursing and death education will be discussed and a pedagogical intervention of incorporating thanatology or death education into UCT's Postgraduate Diploma in Critical Care Nursing curriculum will be proposed as a way of facilitating this transformation of *being* of ICU nurses.

CHAPTER SEVEN

Phenomenology and Pedagogy

Introduction

This chapter draws together the insights from the phenomenological conversations and the analysis of these, and considers a pedagogical response that may serve to address the emergent need for preparing future critical care nurses to manage the deaths of patients under their care in ICU.

Heidegger and Education

A central purpose of education, according to Heidegger, is transformation of the self. This transformation of the self can be achieved by interrogating and challenging assumptions about our world and ourselves that have previously been taken for granted (Dall’Alba, 2009, p. 37). Heidegger points out that transformation of self can be achieved by “*removing human beings from the region where they first encounter things and transferring and accustoming them to another realm where beings appear*” (BT, p. 167. Italics original). Thomson agrees with Heidegger and emphasises that the purpose of self-transformation is ‘to bring us full circle back to ourselves, first by turning us away from the world in which we are most immediately immersed, then by turning us back to this world in a more reflexive way’ (Thomson, 2001, p. 254).

Ontological Education and Heidegger and Plato’s Allegory of the Cave (see Appendix F for a synopsis)

Thomson (2001) describes Heidegger’s pursuit to find the ‘essence of education’ by returning to *Plato’s Allegory of the Cave* in which Heidegger writes of in his book **‘Plato’s Teaching on Truth’ (PTT)** (*Platons Lehre von der Wahrheit*, 1940/1998). Heidegger explains that the essence of *paideia* (Greek for education or instruction), does not consist:

‘in merely pouring knowledge into the unprepared soul as if it were a container held out empty and waiting. On the contrary, real education lays hold of the soul itself and transforms it in its entirety by first leading us to the place of our essential *being* and accustoming us to it’ (PTT, p. 167. Italics original).

Echoing Plato, Heidegger positions his view of the essence of *paideia* to oppose two notions of education. Firstly, Heidegger cautions against a ‘false interpretation’ in that we cannot accept education as the dissemination of information; ‘the filling of the psyche with knowledge’ or training’ (Thomson, 2001, p. 254). Thus in **‘Being and Time’** we are *thrown* beings, always ready, moulded by traditions and cultures and so we cannot be empty vessels or clean slates waiting to be filled. Heidegger contests this ‘false interpretation of education’ and emphasises that ‘real or genuine education’ (*echte Bildung*), is the essence of *paideia* or ‘truth’ and draws on The Allegory of the Cave to illustrate the essence of education, the *paideia*, the truth.

In **‘Plato’s Teaching on Truth’**, Heidegger reinforces his concept of ‘real education’ which ‘actually takes hold of the soul itself and transforms it in its entirety by firstly leading us to the place of our essential *being* and accustoming (*eingewöhnt*) us to it’ (PTT, p. 168). This transformative journey of education leads us back to ourselves, to the place we *are* (the *Da* of our *Sein*) and teaches us to ‘ *dwell*’ (*wohnen*) ‘*there*’ and in the process, be transformed. For Heidegger, ‘*paideia*’ means the turning around of the ‘whole human being in the sense of displacing them out of the region of immediate encountering and accustoming them to another realm in which things appear’ (PTT, p. 167).

Heidegger recalls Plato’s allegory and puts forward how the ontological education he advocates can surpass *enframing* (standing-reserve). The prisoner; (the ICU nurse):

1. Begins in captivity within the cave: The ICU nurse is prisoner to her ontological confrontation with death.
2. The prisoner escapes the chains and turns around to discover the fire and objects responsible for the shadows on the wall previously taken as reality; the ICU nurse shares her experiences of the dying and deaths of patients under her care in ICU and is freed from *Dasein’s Angst* of her ontological confrontation with death which was formerly accepted albeit reluctantly as part of her *being* as an ICU nurse.

3. The prisoner climbs from the cave into the light of the world, coming to comprehend what he sees is made possible by the rays of the sun; the ICU nurse, through a pedagogical offering of death education is enlightened and that it is possible to understand and confront the dying and deaths of patients under her care in ICU.
4. The prisoner finally returns to the cave and tries to free the other prisoners who vehemently resist their now potential 'liberator.' The ICU nurse returns to the ICU, a liberated *authentic Dasein* and attempts to unshackle others who resist or who are not enabled to ontologically challenge the dying and deaths of patients under their care in ICU.

In this illustrious scenario, Heidegger advocates that this is the pedagogy³⁶ of ontological education.

The four different dwelling places of the prisoner, communicate the four sequential stages whereby 'ontological education breaks students' bondage to the technical mode of revealing, freeing them to understand what-is differently' (Thomson, 2001, p. 257). Heidegger explains that the educator plays a pivotal role in facilitating students' passage between each of the four stages. Ontological freedom is attained when entities reveal themselves in 'their full phenomenological richness' (Thomson, 2001, p. 258).

Thus, for example, when the *everydayness* of death and dying of critically ill patients in the ICU appears in a new light for ICU nurses, a way may be opened for other ways of *being* for them. A curriculum³⁷ strategy of incorporating thanatology or death education into the Postgraduate Diploma in Critical Care Nursing curriculum may be a way of facilitating this transformation of *being* of ICU nurses: 'first by turning [them] away from the world in which [they] are most immediately immersed, then by turning [them] back to this world in a more reflexive way' (Thomson 2001, p. 254). To make this possible, the curriculum needs to be responsive to the different modes of *being-in-a-world* of change and complexity.

Added to this is the responsibility of academics to nurture students' *being* and address pedagogical issues that should arise.

³⁶ Barnett views pedagogy as 'the set of principles upon which teachers can assist students in moving effectively and efficiently from a relative state of ignorance to a state of well-found knowing' (Barnett, 2009, p. 432).

³⁷ A curriculum in higher education is a pedagogic vehicle for effecting changes in human beings through particular kinds of encounters with knowledge (Barnett, 2009, p. 429).

'In other words, we are calling for educational approaches that engage the whole person: what they know, how they act, and who they are' (Dall'Alba & Barnacle, 2007, p. 689). A major pedagogical challenge within this remains how to respond to the needs of ICU nurses whose culture precludes discussion about death.

Curriculum design is often developed from previous 'experience of education particularly our understanding of our discipline and our personal, cultural and political values' (Toohey, 1999, p. 44).

The professional role of nurses also requires them to act within specified codes of conduct and within the Nursing Act № 33 of 2005. It appears that critical care nurse academics who are involved in curriculum design have not taken into consideration the concept of different philosophical approaches or ideologies.

Equally important is that the same critical care nursing academics have had little or no educational preparation around this concept. With this in mind, it may be useful to revise the five identified approaches to curriculum design:

1. Traditional or discipline-based.
2. Performance or systems-based.
3. Cognitive.
4. Personal relevance/experiential.
5. Socially critical.

(Eisner, 1994; Kemmis, Cole & Suggett, 1983; Posner, 1995).

Nursing curricula in general incorporate approaches one to four, of which the personal experiential broaches specifically to the ICU nurses' experiences of death and dying in the ICU. Such actual experiences are invaluable in informing curriculum design, content and assessment. Taking cognisance of my own failings as a critical care nurse academic involved in curriculum design and evaluation, the socially critical approach may be an area that requires some attention.

Toohey defines this approach as one which 'seeks to develop a critical consciousness in students that they become aware of the present ills of our society and are motivated to alleviate them' (Toohey, 1999, p. 62). This 'critical consciousness' should also apply to educators, irrespective of what discipline they are involved in.

Higher educational philosopher Ronald Barnett is insistent that the ontological dimension of curriculum design has not featured prominently in debates in higher education until recently when much interest has been paid to the ontological nature of the problems faced (Barnett, 2000a; Barnett, 2004; Barnett & Coate, 2005; Dall’Alba, 2005). Arguing that there ‘is a need for an ontological turn in teaching within higher education’ (Barnett, 2004; Barnett & Coate, 2005), Barnett asserts that ‘instead of knowing the world, *being-in-the-world* has to take primary place in the conceptualisations that inform university teaching’ (Barnett, 2005, p. 795).

To do this, Barnett insists that pedagogies are required that promote the formation of human *being* and *lifeworld* becoming. Such pedagogies could allow space for *meanings* to come from within and offer a chance of recovering the self. Barnett describes this process of recovery of self as ‘looking back to that which was suppressed but also looking forward to a new realisation of human being’ (Barnett, 2000c, p. 419).

Human *being* also poses challenging questions, to both students and educators: ‘Who are we? How are we to know the world? How are we to live with the world and with each other?’ (Barnett, 2009, p. 433). These questions Barnett refers to ‘as coming-to-know’ the world and claims that ‘coming-to-know the world is uplifting and is the process of knowing that brings forward personally worthwhile attributes’ (Barnett, 2009, p. 433). The process of ‘coming-to-know’ requires certain dispositions and qualities. Barnett views dispositions as:

- A will to learn
 - A will to engage
 - A preparedness to listen
 - A preparedness to explore
 - A willingness to hold oneself open to experiences
 - A determination to keep going forward
- (Barnett, 2007, p. 102).

As human beings get to know the world, various qualities become apparent that characterises the individual. These may be:

- Integrity
- Carefulness
- Courage
- Resilience
- Self-discipline
- Restraint
- Respect for others
- Openness

(Barnett, 2007, p. 102).

In brief, dispositions enable *being* and qualities provide character. The students' dispositions and qualities and their will to learn enable them to acquire the necessary knowledge and skills. It can thus be construed that epistemology (knowledge) and ontology (*being* and *becoming*) are 'irreducible to each but are interlinked' (Barnett, 2009, p. 437). This curriculum concept Barnett and Coate refer to as the 'engaged curriculum' (Barnett & Coate, 2005).

The Engaged Curriculum

Barnett believes that:

'A curriculum for supercomplexity is an educational project at once embracing the domains of being, knowing and action; a project of ontology, epistemology and praxis. Otherwise, the resources for coping with and continuing to prosper under conditions of supercomplexity are likely to be lacking' Barnett, 2000b, p. 263).

Barnett advocates that curriculum design in higher education should integrate the dimensions of the epistemology (knowing), praxis (action) and ontology (self-identity or *being*) (Barnett, 2000b, p. 258).

Together with Parry and Coate, Barnett suggests that the domains of knowing, acting and *being* may offer a framework by which to ‘understand and communicate different patterns of curricula across disciplines and courses’ (Barnett & Coate, 2005, p. 70; Barnett, Parry & Coate, 2001). For this study, the domains of knowing, acting and *being* will be used as a basic structure by which to describe and, if necessary, respond to deficiencies and omissions in the current Postgraduate Critical Care Nursing curriculum. Barnett et al. illustrate the engaged curriculum concept by using schemata but warn those, involved in curriculum design that any ‘diagrammatic representation may lend itself to an interpretation of a fixed or static frame of reference’. With this in mind, it is advisable to be reminded that ‘curricular change is dynamic and fluid’ (Barnett & Coate, 2005, p. 71).

Barnett and Coate also propose that curricula have distinctive but integrated components and different weightings of each domain that can be represented in a diagrammatic form as in Figure 9.

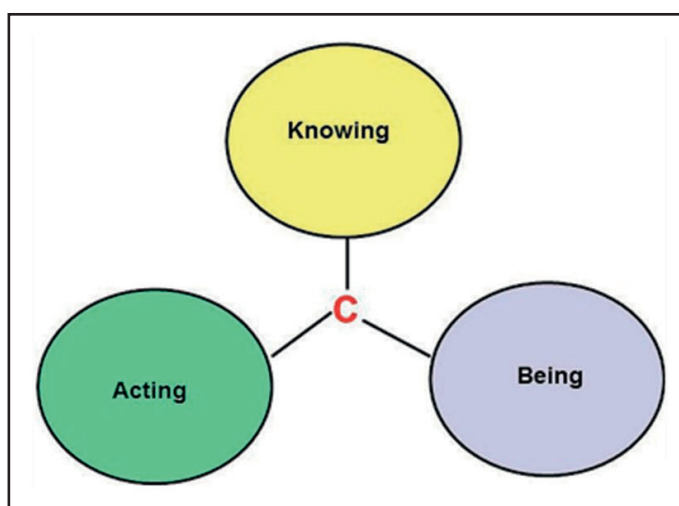


Figure 9. General Schema (C = Curriculum).

(Barnett & Coate, 2005; Barnett, Parry & Coate, 2001).

For example, Barnett and Coate represent a schema the for an engaged curriculum in sciences and technologies as in Figure 10.

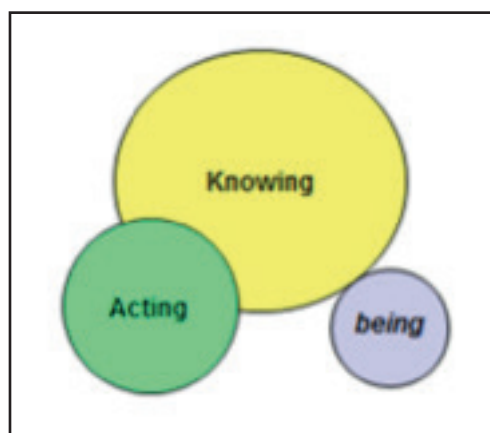


Figure 10. Schema for Sciences and Technologies (Barnett & Coate, 2005, p. 75).

Barnett and Coate advocate that the three domains represented by the three circles of knowing, acting and *being* should be of equal size. Each domain should play an important part and engaged to some extent but not coinciding. Should there be a total overlap, it would imply that the 'student's self are framed almost entirely by the rules of the discipline' (Barnett & Coate, 2005, p. 148). In other words, the student just becomes a pharmacist or engineer enclosed in the existing standards of the discipline.

The Domain of Knowing

Knowledge remains one of the fundamental structures within curricula and has often been the most important consideration in curriculum change or design. Barnett stresses that knowledge has the 'power to transform lives' and in doing so one becomes 'capable of shaping, changing and even leading society' (Barnett & Coate, 2005, p. 81).

The knowledge domain³⁸ is not a fixed and static entity which can simply be incorporated into curricula. It is a domain that is contested and under perpetual transformation and shift, one of which is a performative shift.

³⁸The knowledge domain refers to those components of a curriculum that are based on discipline specific competencies and those aspects of teaching and learning that develop subject specialist – ICU nurses for example (Barnett, 2001, p. 438).

Barnett refers to this shift as a 'repackaging of the knowledge domain into more efficient modes of curricular delivery' together with an 'emphasis on knowledge with a use value driven by responses to the needs of the labour market' (Barnett & Coate, 2005, p. 91).

Another shift in the knowledge domain of curriculum change is to move away from propositional knowledge towards an experimental knowing through real world encounters that allow the student to be at the forefront of problem-solving situations: 'the skills of knowing' (Barnett & Coate, 2005). This knowing is more concerned with the capability to manipulate knowledge by 'knowing situations.' Should ICU student nurses not have the 'knowing skills,' their experience of death and dying of patients in the ICU may be one of extreme anguish and suffering.

A curriculum which stipulates that students know a subject area or specialty (performative) ought to be integrated with ways of *being* and acting. If the domains of *being* and acting are not integrated, a fragmented or performative experience may be encountered with little or no engagement with knowledge. For this reason, the 'relationship between the dimensions of knowing, acting and *being* are key' to Barnett and Coate's thinking on curricula change (Barnett & Coate, 2005, p. 93). This educational philosophy offers a curriculum approach in which the domains of knowing, acting and *being* of an ICU nurse caring for patients who are dying or have died in ICU can be integrated into a Postgraduate Critical Care Nursing curriculum.

The Domain of Acting

Barnett's domain of acting is about 'doing' and requires practical skills and competence. It is often part of a student's educational requirements, especially in subject areas such as nursing, engineering and chemistry.

To understand the clinical competencies in the discipline of nursing, Benner offers a diagrammatic viewpoint of the six stages of clinical competence (see page 41).

Some skills may be transferable across subject areas (such as medicine and nursing) or they may be necessary for employment. Profession-based skills, transferable skills and employment-related skills pose challenges for curriculum design.

Within the confines of ICU nursing, the task of 'acting' or 'action' when patients are dying or have died is extremely restricted. Patients do not die at a specific time or in a certain way. It is impossible to set up a real-life scenario how to teach, act and behave in a situation where a patient is dying or has died in the ICU. For some, the inexperienced and novice ICU students, the experience of being in an ICU is overwhelming. Hay and Oken view this as similar to the impressions of a member of the public or even a family member entering an ICU:

'A lay person entering an intensive care unit (ICU) is at once bombarded with an array of sensory stimuli, some emotionally neutral but many highly charged. Initially the greatest impact comes from the machinery: flashing lights, buzzing and beeping monitors, gurgling suction pumps and whooshing respirators. Critically ill and battered human beings are hooked up to these machines. Simultaneously, doctors and nurses are rushing saving lives. The atmosphere is not unlike that of the tension- charged strategic war bunker. One can hear moaning, screaming and the last gasps of human life. Sights of blood, vomitus and excreta, exposed genitalia mutilated wasting bodies, and unconscious and helpless people assault the sensibilities' (Hay & Oken, 1972, p. 110).

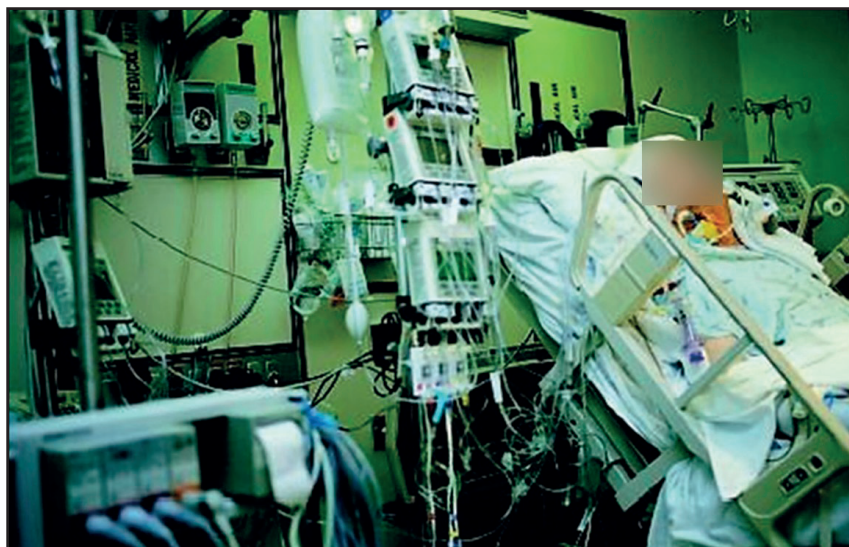


Image 5. 'A Typical Scenario in the ICU'

Taking Hay and Oken's vivid description of an ICU, it is inconceivable to simulate a scenario with dying patients to teach ICU student nurses about dying and death in a classroom or clinical skills laboratory. The popular but teaching method regarding medical students' acquisition of some clinical skills: 'see one, do one, teach one' has no place in any curriculum.

Fragmentation of a curriculum with little or no integration of the three dimensions may result in the action domain becoming performative in nature. This has been highlighted in the nursing literature as well as in a number of 'task-based' models of dying (Attig, 1991; 1996; Corr, 1992; Corr & Doka, 1994; Corr, Doka and Kastenbaum, 1999; Worden, 1991). Intensive care nursing students may still provide *authentic* patient care, even if it is performative. But recalling Van Hooft's (1996) position on caring as an 'ontological structure of human existence,' of which the two forms are: (i) caring about oneself and (ii) caring about others, the former may be forfeited and the ICU student nurse has no option other than to experience *inauthentic* care of him/herself.

The Domain of being

Heidegger maintains that in order to understand thinking and knowing as modes of being human, it is important to explain what it means to be human. Dall'Alba explains further that 'if we are fully to understand knowing within various forms of professional practice, we must understand the *being* of those who know' (Dall'Alba, 2009, p. 35).

For Barnett, 'a student is a human being, has *being* as a human being' (Barnett 2007, p. 28). In this case, the *being* of an ICU student is the way the ICU student is in the world of intensive care nursing: *being-there* or *Dasein*. No-one can feel the student's feelings, attitudes or values about death and dying. The student's experience of death and dying belong, to his/her, or as Heidegger refers to a *mineness* and as such makes up his/her *being*.

The ICU student nurse's experiences of death and dying may cause him or her to come into a different relationship with his/her self, regarding his/her life and mortality. In this scenario, ICU student nurses can be seen as a pedagogical *being* whose *being* is tied up with one another.

Taking Barnett's pedagogical *being* further, it is through all modes of knowing, that the student's *being* is given over to a new relationship with the world (Barnett, 2007).

It has been highlighted in the nursing literature that ICU nurses experience a great deal of stress when patients in their care are dying, or finally do die. Whether ICU nurses are seasoned or super-experienced (*ready-to-hand*) or are ICU student nurses who are educationally (and emotionally) unprepared to deal with death and dying (*present-at-hand*), the stress (*Angst*) is liable to shatter their *being*. From an educational perspective, Heidegger welcomes *Angst* as he sees it as a potentially enlightening event (Watts, 2001). Ontological *Angst* is an essential mode of *being* and hence is essential for knowing. It is through anxiety, that the ICU student nurse may emerge into a more caring and *authentic* mode of *being*.

Authenticity

Barnett is insistent that a higher education that 'does not call, does not insist on *authenticity* in the student is no higher education' (Barnett, 2007, p. 40). For Barnett, *authenticity* is the key concept in higher education that is seldom if ever evoked. Further questions that arise:

- Can *authenticity* ever be attained?
- What would it meant to attain it?

Barnett describes 'eight planks' in his concept of *authenticity* with a pedagogical setting in mind (Barnett, 2007, p. 51):

1. The *authentic* student is one who takes 'hold' of her educational experiences in her own way and utilises the available resources (epistemological, practical and psychological) and makes something of them. The reflective drawings done by the ICU students of death and dying in the ICU are examples of this 'taking hold' and engaging with their own ontological confrontation with dying and death. This 'taking hold' was also present when religious and cultural aspects were openly discussed and shared, even if some of the ICU students viewed this as being taboo and forbidden.

2. *Authenticity* announces itself not necessarily in originality, but in creativity: the student breaks free. Other than the reflective drawings, the ICU students were asked to write their own obituary. Although this does not form part of the study, it was interesting to note that most of the ICU students considered themselves to be caring individuals, but found the exercise difficult to do as they had to engage and reflect on what their life had been.
3. In order for point two to take place, the student places herself in such a position as to be 'disencumbered'³⁹ by other voices and messages, which is not to say that she ignores them, but rather to the contrary.
4. *Authenticity* is never fully achieved by most. But rather it is a matter of the extent to which it is realised. In being *authentic*, one leaps into the unknown and *authentic care* takes place when the nurse 'leaps ahead,' not to take the patient's care away but to give it back *authentically* and, in doing so, the patient is helping to *care* for his *being*.
5. One measure of *authenticity* is the presence of the student in a state of commitment to her offerings, be they in writing or in action.
6. In being committed to her utterances or actions, the student infuses herself into them: both knowing and practices have an ontological substrate.
7. In the presence of *authentic* claims, we are in the presence of the four ethical qualities of integrity, courage, determination and sincerity.
8. While there are often outward signs of *authenticity* (in words or actions), *authenticity* has an inward quality: the student is committed not just to her words or actions but to herself.

If there is no self, then there is no *authenticity*. Returning to Heidegger, the *authentic* self is the self which has taken charge of its *Dasein* and not the *They-self* (*Das Man*). When *Dasein* or *being* discloses the world in its own way it opens its *authentic being*.

³⁹. Heidegger uses a similar term: 'disburdened' but uses it the opposite way to that in which Barnett uses. Rather Barnett uses 'disencumbered' to refer to the way in which the *They* enlightens *being*. In other words, to a situation of *inauthentic being* (Barnett, 2007, p. 44).

However, as pointed out previously, *authenticity* is not easily attained. *Dasein* is inclined to flee from its *authentic* self and instinctively hide behind the accepted view of others (Kübler-Ross, 1969; Quint, 1967). This pedagogical environment for ICU student nurses may unwittingly abet *inauthenticity* especially when patients are dying or have died in the ICU.

In summary, *being* should be explored and seen as a fundamental concept in a Postgraduate Critical Care Nursing curriculum which attempts to address ICU student nurses' experiences of death and dying in the ICU. It is through *being* that ICU student nurses reject or accept their own involvement in the dying or deaths of patients in the ICU and so make, even in part, these *authentic* experiences their own.

The three domains of knowing, acting and *being* have been explained in detail and are useful to provide a structure to design curricula or pedagogical interventions around professions, courses or other curricula. Barnett, Parry and Coate are emphatic that:

1. The weight of each of the three domains varies across curricula.
2. The domains may be integrated or held separate.
3. Patterns of curricular change are dominated by epistemological differences in the knowledge fields.

(Barnett, Parry & Coate, 2001, p. 439).

I will later discuss in this chapter, using Barnett and Coate's (2005) schema, the concept of thanatology and how this may offer a pedagogical and an ontological response for ICU nurses who experience the dying and deaths of patients under their care in the ICU.

The Status of the Postgraduate Diploma in Critical Care Nursing Curriculum in 2009

In 2009, I became increasingly more concerned that I was unable to engage with the ICU students about the dying and deaths of patients in the ICU, particularly in children. This was due to the content of a course – ***'Impact of the Critical Care Environment'*** that needed to be covered in eight classroom sessions of three hours each in the first semester. The ICU students also had time-on-task activities to be done outside of the classroom in order to complete the requirements of the course. I have added an Appendix of the course descriptors as it appeared in the

UCT Faculty of Health Sciences Handbook in 2009 (**Appendix E on page 290**).

A schema which reflected anecdotal comments made by ICU nurses' experiences of dying and the deaths of patients under their care in ICU in 2009, may be represented in Figure 11.

The highly technological environment of the ICU creates an enormous distance between the interaction of *being* and caring (as represented by the action domain) for both the ICU nurse and the patient in their last hours of living.

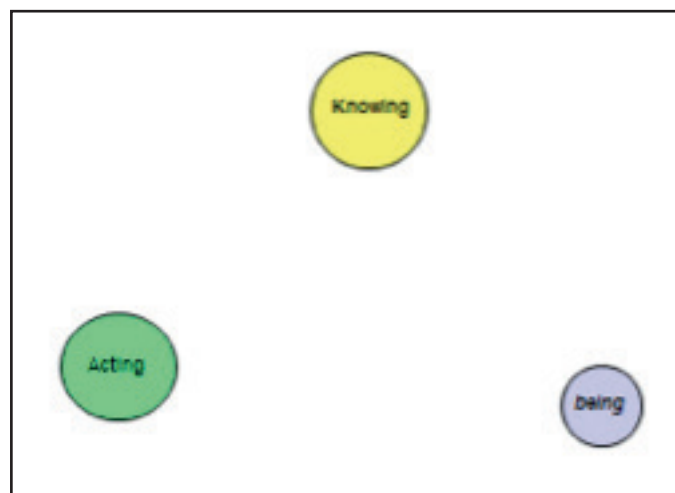


Figure 11. Anecdotal Schema Representing ICU Nurses' Experiences of Death and Dying of Patients Under Their Care in the ICU in 2009.

Within the context of this so-called anecdotal schema, the following drawings done by ICU nursing students would appear to support this diagrammatic representation. I remind the reader that the ICU students drawings are not part of data collection or analysis but rather a 'voice' to their distress experienced by the dying and deaths of patients under their care in the ICU.

The Domain of Knowing



'This is a daily occurrence death of babies. I have never been taught how to cope or say goodbye. I have so much documentation to get through. The next admission must come urgently. I don't know what to do.'

The Domain of Acting



'Enough is enough doctor. We can't keep on going forever. Let her go please.'

The Domain of being



'The pink cloud is because it is peaceful and death is expected.

All pain and suffering is gone when death comes. I have often been in this situation and feel safe in myself when death is expected.'

Between 2010 and 2012, I made an independent decision to incorporate more teaching and learning of the dying and deaths of patients in ICU, but had to find time and space to teach the other topics that formed part of the course requirements. This I did by adding the 'deficit' of the course content to the course **'Nursing the Critically Ill Adult'** which ran throughout the academic year. In addition to class attendance, the ICU students were also required to accumulate 960 clinical practice hours in order for them to be registerable with the SANC. The clinical requirements are stipulated by SANC and apply to all postgraduate nursing diplomas which have a clinical speciality.

At the end of 2011 and early in 2012, all South African tertiary institutions were required to align their qualifications with the prescriptions of the Higher Education Qualifications Sub-framework (HEQS-F) which is also part of the National Qualifications Framework (NQF). Each qualification has an exit level outcome that relates to the skills that may be expected of candidates who have completed a qualification or course at the HEQS-F level. Every qualification also has a minimum number of NQF level credits at that HEQS-F level. One credit is equivalent to 10

notional hours. The Postgraduate Diploma in Critical Care Nursing 2009 (General and Child) had 135 credits. This required the Division of Nursing and Midwifery at UCT to re-curriculate and re-structure all of the Postgraduate Diplomas in Nursing. This was completed at the end of 2012 and approved by the HEQS-F. The newly aligned Postgraduate Diplomas in Nursing (Clinical and Non-clinical) were implemented in 2013.

Pedagogical Offerings

With this opportunity of re-curriculating and re-structuring, I was able to incorporate a significant amount of teaching and learning of the dying and deaths of patients in the ICU. However, it was only after the unravelling of the ICU students' lived experiences of the dying and deaths of patients under their care in the ICU that I am able to propose some 'pedagogical offerings' (Barnett, 2007, pp, 133-134) to the educational and ontological needs of the six participants in the study.

Agreeing with Barnett, an *ontological turn* appears to be an issue that requires closer attention in curriculum design in higher education:

'If curricula are to provide the kinds of experiences that are likely to sponsor the kinds of subjectivities called for by a world of instability, knowledge and practical dimensions are necessary claimants for our attention but they cannot be sufficient. A world of uncertainty poses challenges not just of knowing and of right action, but also, and more fundamentally, on us as human beings in the world' (Barnett & Coate, 2005, p. 108).

Barnett is emphatic that the academic community at all levels and across all disciplines take the matter of curriculum seriously and that the student's *being* has to come first. Barnett repeatedly reminds us that '*being* is what matters' (Barnett & Coate, 2005, p. 145) and without *being* given attention in curriculum design, the others 'can never get off the ground' (Barnett, 2005, p. 149). Such a curriculum calls for teaching that is likely to 'engage, to connect, to lift, to enthuse and even to inspire:' 'a pedagogy for engagement' (Barnett & Coate, 2005, p. 148).

A pedagogical offering as represented in Figure 12, may help address the ICU nurses' 'denied authenticity' and in doing so, empower themselves to take care of self and their *being* when caring for patients who are dying or have died under their care in ICU. Taking Barnett and Coate's thinking regarding a need for an *ontological turn* in Higher Education, I have used their schema of knowing, acting and *being* to organise my pedagogical offerings which I intend to implement in 2015. I may only be able to implement some of my proposed pedagogical offerings due to the time and content restraints of incorporating other topics of ICU nursing that is required for the Postgraduate Diploma in Critical Care Nursing.

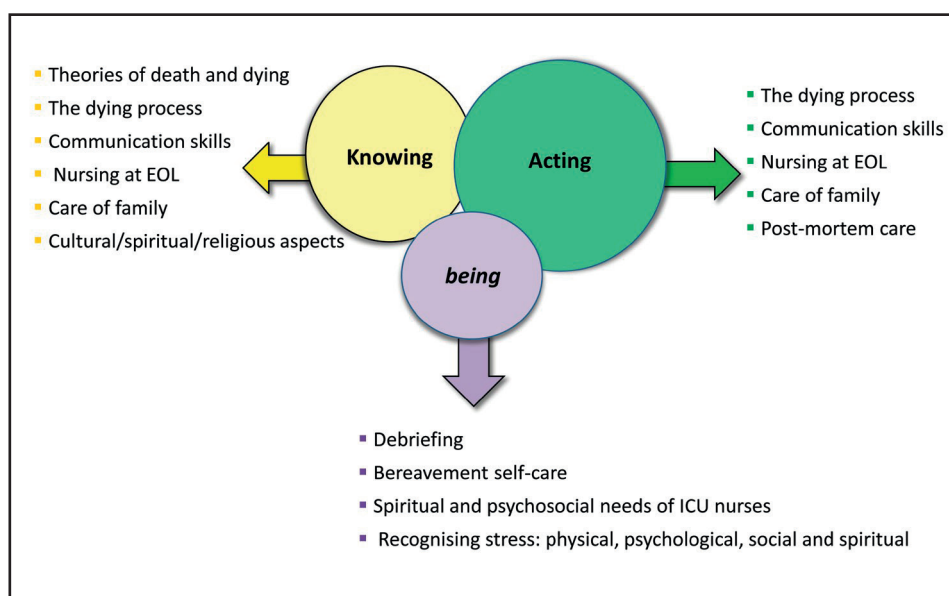


Figure 12. Proposed Pedagogical Offerings for Death Education for ICU Nurses

Before describing my pedagogical offerings further, the concept of thanatology deserves some attention. I will firstly explain to the reader the discipline of thanatology and then propose some pedagogical offerings using Barnett and Coate's (2005) schema of knowing, acting and *being*.

The Field of Thanatology

Death has been examined in a wide variety of disciplines, including art and literature, dating as far back as the 13th century. A protégé of Louis Pasteur, Elie Metchnikoff urged his colleagues to establish two new fields of study with the focus on aging – gerontology; and death - thanatology (Metchnikoff, 1903). Even though the two fields of study were significant, as was the prestige of Metchnikoff himself, few scientists

took up the challenge. Park (1912), an American physician, also made an appeal for a study to be done in these areas but was similarly ignored.

Thanatology only emerged as a field of scholarly interest following the Nazi genocide and nuclear infernos of World War II. Herman Feifel (1915-2003), an American psychologist, is internationally recognised as a pioneering figure in the study of death and dying (Wass, 2004). Feifel's research efforts helped break the prevailing taboo that discouraged the scientific study of death and dying. Feifel became increasingly dissatisfied with psychology's neglect of the *existential* richness of life, including the everyday matters of death and dying (Feifel, 1959; Feifel, 1977; Feifel, 1982). A major consequence was his eventual focus on what has since become known as the field of thanatology.

The foundation of thanatology, Feifel emphasised, is 'reflected in the goals of death education which stress both acquisition of knowledge and development of self-understanding and clarification of values, meanings and attitudes toward death' (Wass, 2004, p. 290). The field of thanatology has an extensive and notable history of disciplinary and inter-disciplinary scholarship (Schim, Briller, Thurston & Meert, 2007).

The publication of Feifel's pioneering book in 1959, '**The Meaning of Death**', drew attention to a broad spectrum of issues relating to death, dying and bereavement (Corr, Doka & Kastenbaum, 1999). Within the last 15 years, significant developments in theory and research in thanatology have contributed to and challenged understandings of processes and experiences of bereavement. Some examples include a moving away from viewing grief as a series of stages (Corr & Doka, 1994; Worden, 1991), the proposal of new models of mourning (Rando, 1993; Stroebe & Schut, 1995) and the reaffirmation by Prend (1997) of the possibility of personal growth even in the midst of experiences of death and dying.

Thanatology and Scholarship

Courses on death and dying are mostly attributed to the work of Robert Kastenbaum. In 1969, a colleague of Kastenbaum, Dan Leviton, established the Centre for Death Education (now the Centre for Death Education and Bioethics, University of Wisconsin). In 1970, '**Omega: The Journal of Death and Dying**,' the first professional journal in this field, was established by Kastenbaum. Hannelore Wass in

1977 founded the journal **‘Death Education’** which was later renamed **‘Death Studies.’** This journal is considered to be the leading and most comprehensive one of its kind in thanatological research.

As the field developed, death education courses became popular offerings in colleges and universities, albeit primarily in the USA and Canada. Staying with the same universities, weighted heavily, credit-bearing courses as part of a Master’s Degree (concentrating on care of the dying and bereaved) and individualised programmes in death-related studies at undergraduate level are offered. Under the auspices of The Thanatology Association, the Association of Death Education and Counselling (ADEC, 2010) offers a number of web-based courses on death education, bereavement and counselling.

Pedagogical Offerings – (These are intertwined with knowing, acting and being of the ‘The Engaged Curriculum’).

Overview of the Theories of Death and Dying

The Context of Awareness Theory

In 1965, the sociologists Glaser and Strauss published their book **‘Awareness of Dying’** identifying four stages described as ‘awareness contexts’ or patterns of ‘interaction and interpersonal communication between dying people, their family members and professional care providers’ (Corr, Doka & Kastenbaum, 1999). Each awareness context is structured around the dying person, the need to know or not to know the truth about his/her diagnosis and prognosis, the willingness of family and professional care providers to share the facts in question. Glaser and Strauss (1965) underscored a central point of their awareness contexts: dying is characteristically: an experience lived out in social contexts, of which a key feature is the involvement of more than one person in the process of death and dying.

Dying Trajectories

Using material from their previous work, **‘Awareness of Dying’**, Glaser and Strauss published **‘Time for Dying’** in 1968. They hypothesised that there is a relationship between the phases of dying and four ‘death expectations’ or trajectories. These trajectories are: (i) certain death at a known time; (ii) certain death at an unknown time; (iii) uncertain death but a known time when the certainty will be

established and (iv) uncertain death and an unknown time when the question will be resolved (Copp, 1998, p. 385). Glaser and Strauss also proposed that a person's dying trajectory involved two important elements: **time** and **shape**. Any of the four dying trajectories may vary in duration and form. For example, a person may die quickly, slowly or they may reach a plateau. Dying persons' trajectories may also move upwards or downwards in relation to their condition. At times, the dying person may show some improvement or may even relapse before finally plummeting downwards and succumbing to death. Should an expected death trajectory change, tension and conflict may arise between the patient, the family and the medical and nursing staff.

Stage Theory of Dying

An important development in the literature on death and dying is that of coping with dying. The most widely known is the work of Dr Elisabeth Kübler-Ross (1969) in her book '**On Death and Dying.**' Her approach was to postulate five stages in the response to awareness of impending death: denial, anger, bargaining, depression and acceptance (See Figure 13).

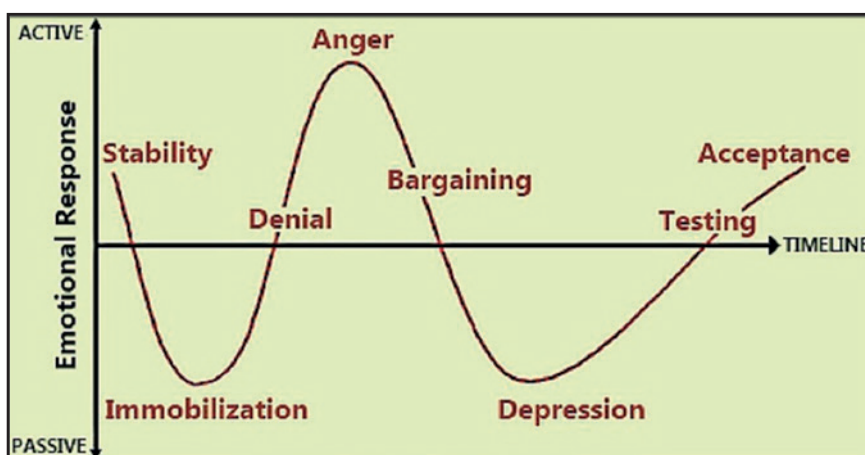


Figure 13. Kübler-Ross' Five Stages (1969).

Kübler-Ross described the stages in various ways as 'reactions' or 'responses,' as 'defence' mechanisms and as 'coping' strategies. She also suggested that a dying person and the significant other(s) who were coping with dying, could jump from stage to stage and that various stages could at times exist side by side. The central feature of this theoretical framework is the emphasis placed by Kübler-Ross on the dying person's response(s) to what is happening.

This prompted Corr (1993) to propose three lessons to be drawn from Kübler-Ross' work: (i) dying persons are still alive and may have important issues they need or want to deal with; (ii) care-givers and significant others cannot be expected to administer effective care unless they listen actively to dying people and establish with them the priorities that oversee such care and (iii) there is a great deal that all human beings can learn from dying individuals and others coping with dying about their own mortality and their responses to imminent death.

Kübler-Ross' (1969) stage-based theory resonated with the spirit of the time 'in its rejection of a dehumanising technology and the affirmation of a natural death' (Corr, Doka & Kastenbaum, 1999, p. 246). Her five-stage theory remains popular among the public and in many areas of professional education (Coolican, Stark, Doka & Corr, 1994; Corr, 1992), although it has been strongly criticised (Feigenberg, 1980; Kastenbaum, 1998; Pattison, 1977; Weisman, 1977). Weisman (1977) was of the opinion that the five stages were at best approximations and, at worst, obstacles to individualisation, and Pattison noted that 'staging dying may oversimplify coping processes and suppress individuality in coping' (Pattison, 1977, p. 304).

Kavanaugh (1972) uses Kübler-Ross' five stages of grief and describes seven emotional and behavioural responses in the coping process based on his research of bereaved family members. Kavanaugh eloquently states: 'These seven stages do not subscribe to the logic of the head as much as in the irrational tugs of the heart, but to the logic of need and permission' (Kavanaugh, 1972, p. 123).

At this point, it must be emphasised that grieving ICU nurses are not exempt from such coping behaviours when patients under their care die in the ICU.

Kavanaugh's Seven Coping Behaviours (1972)
Shock and denial
Disorganisation
Volatile reactions
Guilt
Loss and loneliness
Relief
Re-establishment

Table 13. Kavanaugh's Behaviours and Feelings as Part of the Coping Process
(Kavanaugh 1972, in Brosche 2003, p. 174).

The first response of **shock** and **denial** allows those who are grieving a safe but transitory space in which they can work through the different stages of loss. This stage may be hastened if the environment and people support systems are available.

The second stage of **disorganisation** is where the grieving ones feel that they are isolated and out of touch with the on-going of normal life; *everydayness*. This may be experienced as 'timelessness, motionless and helplessness' (Brosche, 2003, p. 176). It is at this stage that the grieving need to talk in order to regain their thinking abilities that have confused their minds resulting in unwanted thoughts and unaccustomed and frightening feelings. A dependable friend or support system is crucial at this time to assure the grieving that life and living is worthwhile despite them being unable to focus on this issue.

Volatile reactions that resonate with the unfathomable pain experienced (emotionally and spiritually), constitute the third stage. Kavanaugh explains that behind these volatile emotions 'are the more primary feelings of helplessness, hurt and frustration.' The natural reaction is to deny and bury these feelings out of a 'sense of shame' (Kavanaugh, 1972, p. 113). Consequently these feelings simmer inside of the griever and impede any potential growth through mourning. Other harmful effects may manifest themselves through headaches and gastro-intestinal complaints. Kavanaugh (1972) brings attention to the importance of 'permissive listening' in which the griever is permitted to voice his/her feelings of rage and resentment without judgement. For those who are listening, it is essential to take note that the grievers' feelings are real and belong to them and that they are neither good nor bad. The fourth stage is **guilt**. It is at this stage that the bereaved want

another opportunity to prevent or defer the death and time to wipe away any personal neglect or failure (Leming & Dickenson, 1985). This guilt stage may result in low self-esteem and depression.

Loss and loneliness make up stage five and it is this stage that is the most afflicting. The griever experiences extremes of sadness, depression and self-pity and frequently keeps busy and self-occupied in order to lessen or deaden the pain. Kavanaugh (1972) strongly advises the importance of encouraging the individual to grieve because denying the grieving process to the end comes at a greater cost of increased pain over time.

The sixth stage is **relief** and often causes confusion for the griever as it reflects the need to move on. In order to regain normalcy, relief must be acknowledged in order to avert any form of guilt.

Lastly, stage seven is **re-establishment** which is a slow and time-consuming process. At this stage, a new life is possible in which the individual now sees opportunities to move forward towards the end.

Brosche (2003) has used Kavanaugh's (1972) seven stages of coping behaviours, and has designed a **Grief Care Plan** specifically for the nurse. The objective is to assist in recognising the nurse's emotions in facing dying and death and his/her coping mechanisms (if any). The Grief Care Plan is a tool to break down barriers and encourage open communication and collaboration about grief that nurses have experienced.

The Living-dying Interval/phase Theory of Dying

Glaser and Strauss' works, '**Awareness of Dying**' (1965) and '**Time for Dying**' (1968), prompted Pattison from his work, '**The Experiences of Dying**', (1977) to put forth the 'living-dying interval' model for understanding the process of dying as shown in Figures 14 and 15.

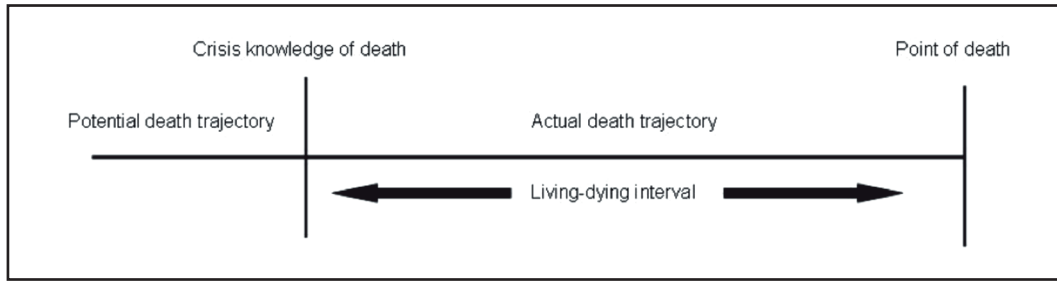


Figure 14. The Living-Dying Trajectory from 'The Experiences of Dying' by Pattison (1977) in Copp (1995, p. 384).

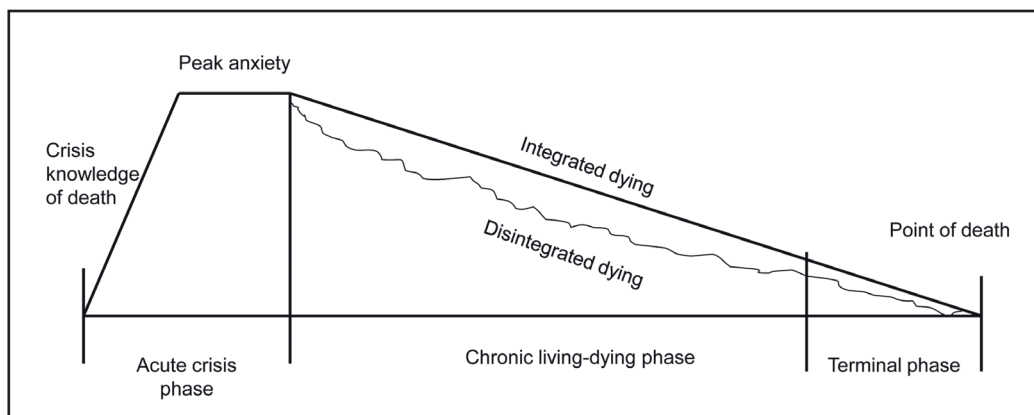


Figure 15. Phases of Dying from 'The Experiences of Dying' by Pattison (1977) in Copp (1995, p. 386).

Pattison proposed that we project a 'trajectory' of our lives and argued that this trajectory changes in crisis situations such as the awareness of death. The 'living-dying interval' commences at the 'crisis of the knowledge of death' and ends at the 'point of death.' In between these two intervals are three clinical phases of the 'living-dying interval': (i) the acute phase; (ii) the chronic-living-dying phase and (iii) the terminal phase. Pattison put forward that when patients first face the knowledge of death, the first task of the care-giver(s) is to act appropriately to the reactions of the patient in order to provide calm and comfort.

Returning to Kübler-Ross' theory (1969), it is not unusual for care-givers to use psychological defence mechanisms such as denial, anger and bargaining. As believed by Pattison, reducing anxiety by providing emotional support and attending to reality issues are more likely to help the dying person to express appropriate responses to his/her 'living-dying'.

The second phase is to respond to the various ways that the dying person adapts to the 'chronic living-dying phase' and the third task is to facilitate the dying person to move into the 'terminal phase.' The 'terminal phase' is often not clear-cut but is perceived to start when the dying person begins to withdraw from the outside world (Lieberman, 1965; Norton, 1963).

Pattison's (1977) 'living-dying interval' model appears to originate from a combination of psycho-dynamic and humanistic frameworks. This is in contrast to other theories as Pattison takes into consideration the need for incorporating dying in relation to the rate, feelings and reactions of the dying person. Pattison's model proposes an assumption that after the 'acute crisis phase', dying may take on either an 'integrated' or 'disintegrated' form. This process may depend on how the original crisis phase is managed. However, Copp (1995) is of the opinion that Pattison's model may have overlooked the likelihood that both the 'integrated' and 'disintegrated dying' may occur, at different times.

In addition, Copp believes that the process of dying is not always a downward trend as many dying people may 'plateau' and then rapidly go into the 'terminal phase' as illustrated in Figure 16.

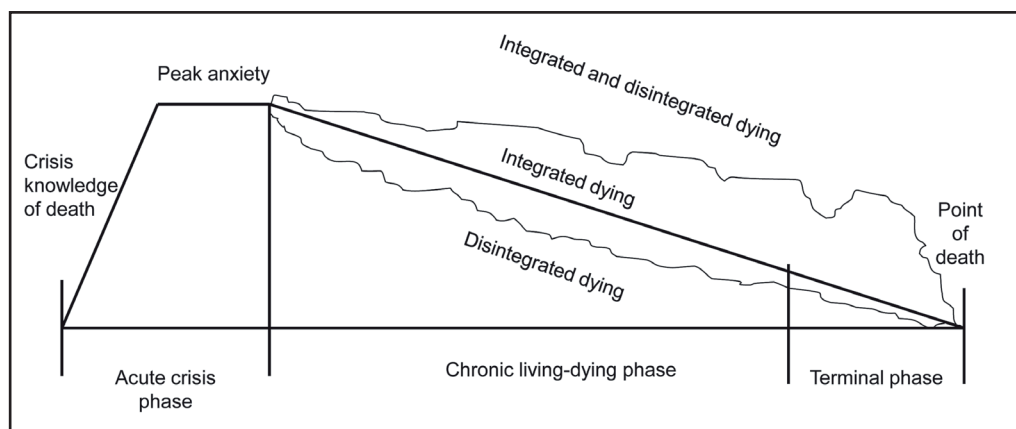


Figure 16. Integrated and Disintegrated Dying with Plateaus and Declines at Different Times in Copp

(1995, p. 386).

The 1980s saw a number of the earlier works on the concept of coping and bereavement being researched further but approached from an interventionist perspective. During this period, bereavement studies focused on grief work which took into account developmental theories that the bereaved needed to be engaged in 'tasks' of grieving if they were to succeed in adjusting to their bereavement (Worden, 1991). The concept of 'tasks' had been raised in Pattison's (1977) work on the 'living-dying interval' model.

Expounding on Pattison's thinking, Kalish (1979) in **'Death, Dying and Transcending'**, argued that the 'tasks' which dying persons have to confront may evoke both 'coping' and 'action' responses from the dying person(s). These responses may take the form of addressing financial concerns, drawing-up of a will and dealing with family relationships.

A Task-based Approach to Coping with Dying

Taking over from Kalish's (1979) notion of 'tasks of the dying person,' Corr (1992) and later Doka (1993) highlighted ways in which dying people and others cope with impending death. Both Corr and Doka found 'task-based' approaches to be of value in gaining an understanding of the issues that people face as they tried to cope with their own impending death or with the impending death of a significant other.

Corr (1992) identified four dimensions of 'task-work' that needed to be included in a wholistic approach to coping with dying: physical, psychological, social and spiritual. Physical tasks include for example, bodily needs and minimal patient discomfort; psychological tasks emphasise autonomy and quality in living; social tasks involve interpersonal relationships with particular individuals and social groups; and spiritual tasks centre on meaningfulness and hope. Corr (1992) wanted to make clear that the 'task-based' model functioned from the perspective of individuals and their coping tasks as 'there is no single right way in which to cope with dying, although there may be better, worse and even unacceptable modes of coping from the standpoint of each of those involved' (Corr, 1992, p. 83).

This is consistent with other 'task-based' models of mourning after a death (Attig, 1991; Attig, 1996; Corr & Doka, 1994; Worden, 1991). Corr, Doka and Kastenbaum

(1999) point out that the 'task-based' theory is open to criticism as it expresses a cultural bias toward work and achievement and that there is a possibility that care-givers and researchers might assume or even pressure dying persons to regard their final phase of life as a series of coping tasks.

Corr (1992) also emphasised that dying not only concerns the dying individual but also affects family, friends and care-givers who are drawn into the dying and death experience. The greatest impact is that on the care-givers because coping with death and dying involves being mindful of the challenges and the events together with the efforts to deal with them. The 'task-based' approach to coping with dying can only be successful if it meets the following criteria: it should contribute to improved understanding, empowerment, participation and guidance regarding all the individuals coping with dying. Corr argued that the 'task-based approach to coping with dying model' fulfils these criteria (Corr, 1992).

Body and Self

Copp's (1996) study which has been discussed previously inspired Copp to give some attention to the 'body.' From the interviews with patients whose death was imminent, the nurses referred to the 'body' as a separate entity from the 'self'. Copp refers to this concept as a 'body-person split' which the nurses used as an indicator to assess the patient's 'readiness to die' (Copp, 1996, p. 388). The 'readiness to die' concept was characterised by four modes as illustrated in Figure 17.

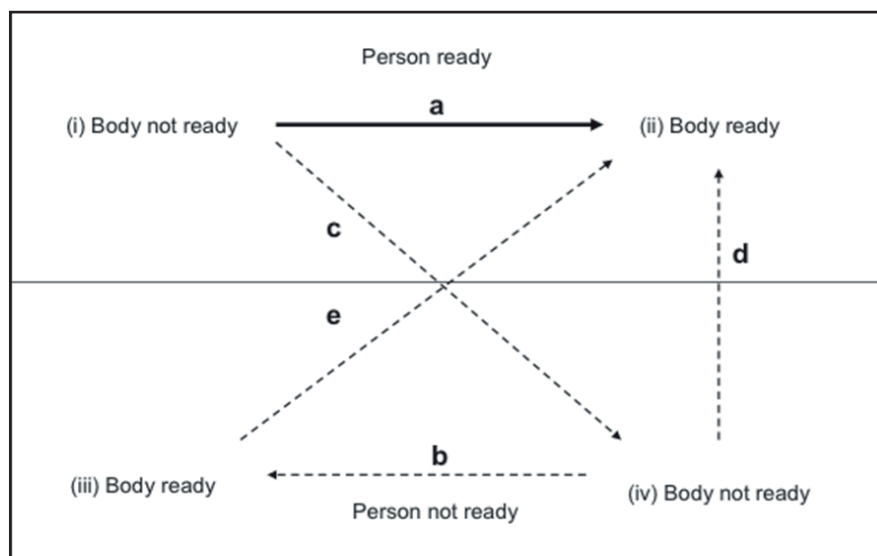


Figure 17. Readiness to Die Conceptual Map. Copp (1995, p. 386).

[Bold solid arrow shows observed transition and dashed arrows show potential transitions].

These modes are defined by the shape, duration, expressions and manner of dying. Copp explains that a dying person may exist in one mode at a time, but may change between modes depending on the physical condition of the dying person's body as well as on the dying person's acceptance of the certainty of death. In Copp's study, transitions to other modes were not evident but Copp stated that it was theoretically conceivable that such transitions could take place.

The impact of death and dying on the nurses in Copp's (1995) study received attention only from the nurse-patient perspective. An important issue that was not pursued was how nurses dealt with their emotions following the deaths of patients whom they had cared for.

The death bed scene in which the dying person, family and care-givers are provided with an opportunity for interaction, has received limited attention in the literature. Previously, the deathbed scene was often regarded to be the most significant and decisive moment of life (Ariès, 1981; Taylor, 1651/1971). Medical technology, bureaucratic hospital systems and intensive care interventions have removed the deathbed scene as portrayed in Image 6.



Image 6. Typical Death Bed Scene in the ICU.

More recently, hospice has endeavoured to bring back the value of the death bed scene as portrayed in Image 7.



Image 7. Death Bed Scene in a Hospice Setting.

In a study by Kastenbaum and Normand (1990) looking at how dying persons, family and care-givers interpret and control the death bed scene, it was found that in imagining one's own death bed scene, there was a strong inclination to visualise a peaceful story book ending. Such an ending to life appeared peaceful as neither pain nor physical symptoms were evident.

Some lessons to be learnt from this selected literature review on dying and coping with dying are summarised below by Corr, Doka and Kastenbaum (1999, pp. 254-256).

Awareness of and Communication about Dying

- Every death is unique to the dying person and all experiences of dying occur within particular social contexts.
- Awareness of dying is characteristically complex, multi-dimensional and changing in its forms.
- As a result, the key question is not whether the dying person is aware that they are dying, but when that awareness is shared and with whom.
- Sharing awareness of dying may take place in verbal and non-verbal ways and may involve literal or symbolic forms of communication.
- The nature of the interpersonal communications and other interactions between

those are implicated in a specific awareness context or particular social context will affect how dying is experienced by all concerned.

Coping with Dying

- A key variable in dying is how individuals cope with their experiences.
- Dying people who are coping with dying are alive; they are not yet dead.
- Individuals who are coping with dying include dying people, members of their families and significant others and their care providers (who may include family members and who may be both professionals and non-professionals).
- Social interactions help to shape challenges encountered by those who are coping with dying; social support – its nature and its availability or lack thereof – may assist or hinder individuals in coping with dying.
- Effective care for individuals who are coping with dying requires careful attention and active listening to those individuals. Such careful attention to those who are coping with dying has much to teach others about coping with living and human mortality. Coping with dying is a matter of individual and social efforts to manage as well as one can, the losses and challenges faced during dying. The concept of ‘tasks’ or ‘task-work’ may represent one useful way of focusing on efforts involved in coping with dying. It is important to approach coping with dying in a wholistic way.

These theories of death and dying have made a significant contribution to health-care professionals’ clinical practice by enabling them to take into account some fundamental issues regarding death and dying. More importantly, the theories provide a means to re-examine attitudes and behaviours of health-care professionals towards dying patients and their families. However, there are a number of limitations concerning the current theories of death and dying.

Other than Copp (1998), none of the theoretical approaches consider the dying person’s physical state (Corr, 1992; Glaser & Strauss, 1965; Kübler- Ross, 1969; Pattison, 1977). The authors refer to the dying person’s body as an abode and consequently a symbolic construction is visualised. Copp (1998) maintains that the physical entity of any dying patient should be part of any comprehensive theory of dying.

Another limitation is that the perspectives of the dying person’s own values

are frequently unaccounted for. This oversight provides for a limited essential understanding of the dying person's individual way of dying.

It must also be noted that there are other models of grief and dying which may be useful:

- Disease or illness models (Lindemann, 1944).
- Biological models (Haig, 1990).
- Attachment theory models (Bowlby, 1980; Gaylin & Person, 1988).
- Psychosocial and cognitive models (Parkes, 1988).
- Crisis and coping models (Kaplan, 1964).

More recently, Coombs, Addington-Hall and Long-Sutecall (2012) undertook a study (2008-2009) to identify the challenges for health-care professionals working in ICU when moving from a recovery trajectory to an end of life trajectory. The study took place in two ICUs at a large university-affiliated hospital in the UK. Using a single semi-structured interview involving 13 medical staff and 13 nurses associated with 17 patient deaths whose treatment had been withdrawn, data was collected by audio-recordings and transcribed verbatim.

The findings of the study revealed that patients who demised in ICU tended to follow a three-stage end of life trajectory as shown in Figure 18.

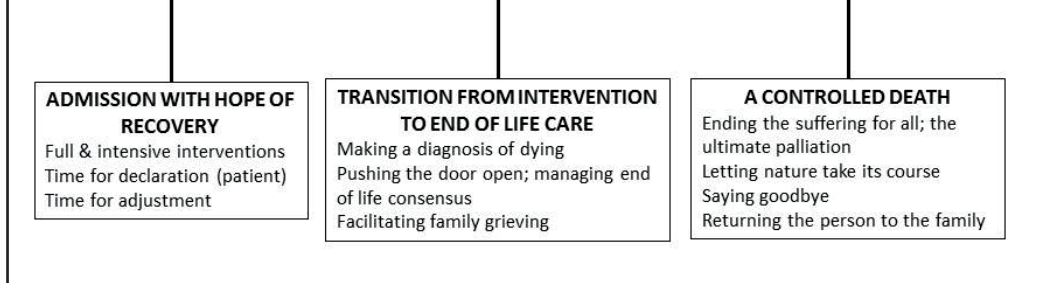


Figure 18. End of Life Trajectory in Intensive Care: Key Stages and Themes (Coombs, Addington-Hall & Long-Suthehall, 2012, p. 522).

The most problematic for the participants was the transition from intervention to end of life care with a significant potential for conflict between nurses and doctors and other medical teams.

Coombs et al. conclude that a policy on end of life care highlights the significance of end of life care for all patients irrespective of the setting. The findings also demonstrate that in the ICU, the need should be to centre on the transition from a curative intervention to end of life care rather than end of life care itself in order that effective and judicious decision-making prioritises the care of patients who die in ICU.

Death and Dying in Contemporary Society – Attitudes and Rituals

Illich (1990), in his book entitled **‘Limits to Medicine’**, claims that the dominant picture of death in a particular society is determined by the concept of health. This concept is ‘shaped by institutional structures, deep-seated myths and the social character that predominates at the time’ (O’Gorman, 1998, p. 1128). Throughout history these westernised changes have affected different professional groups, individuals and families. Illich (1990) has developed a theory that stating this view of health, death and dying evolved over a period of 500 years in five distinct stages. At the time of Illich’s theory development, a sixth stage was becoming part of the concept: **death in intensive care**. See Figure 19 (stage six) for Illich’s (1990) stages of development of current attitudes to death and dying.

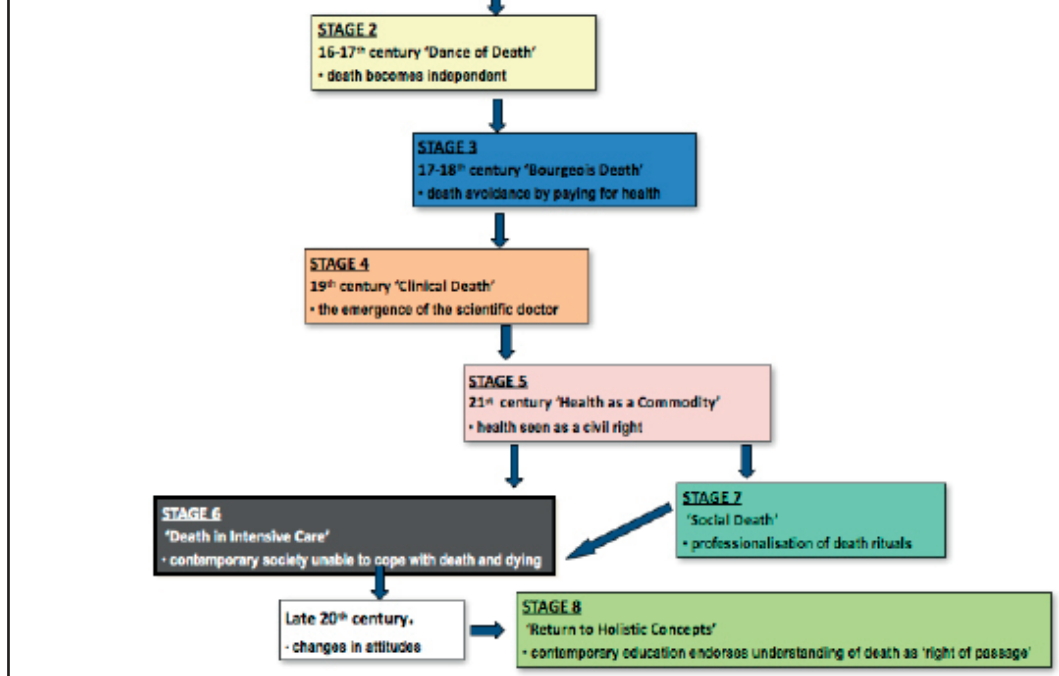


Figure 19. Stages in Development of Current Attitudes to Death and Dying (Illich 1990 in O’Gorman 1998, p. 1128).

For Illich, stage six is a gravely ill patient in an ICU who is protected from dying by technology and at the same time ‘defeated by the victory of medicalisation over society’ in which the patient is ‘no longer able to set the scene for his own death’ (O’Gorman, 1998, p. 1130). In addition, the health-care professionals who have taken control over life and death cannot agree amongst themselves what constitutes death (Sweeting & Gilhooly, 1992). Moreover, Pietroni (1991) notes that medical doctors and nurses consider themselves to have failed when a patient dies. Kübler-Ross (1969) asserts that when health-care professionals identified when a patient was dying, they withdrew from the patient’s bedside as they were unable to cope with the dying process within themselves. Consequently, care was impaired and support of the patient and family was minimised.

Illich’s (1990) stages reveal that contemporary society has compromised health by being unable to engage with death. Cultures which preserve and maintain traditional rituals and practices appear to be more able to overcome the fear of death. Contemporary attitudes to death and dying remain unsatisfactory and civil society has become almost dissociated with the meaning of life. O’Gorman, emphasises that ‘the proliferation of thanatology research and literature proves this misgiving amongst professionals responsible for death education (O’Gorman, 1998, p. 1133).

Prior to the 20th century, death was a common phenomenon. Many people died of terminal illness, fewer reached old age and the rate of infant mortality was very high (Draper, 1991; Ham, 1994). However, through advances in medical knowledge and the development of public health systems, Ham (1994) believes that man has achieved

an average of 36.7 years of extra life. Whatever the validation is for an increased lifespan, Barley (1995), Helgeland (1985) and Illich (1990) advocate that as a result of our preoccupation with health and living, any meaningful acceptance or preparation for death has been stifled. To avert mentioning death, even in conversation, death is referred to by intricate euphemisms such as ‘passed away’ or ‘departed from this life’ (Wahl, 1959).

Illich’s stage seven – ‘social’ death warrants some discussion as it has some relevancy to death and dying in the ICU. Dying in an ICU, the rituals of death and dying are unable to be realised or observed as a result of them being ‘professionalised’ (O’Gorman, 1998). A patient dying in an ICU may be socially dead before being biologically dead. This is illustrated by Sweeting and Gilhooly’s (1992) differences between ‘primitive’ societies and those of western cultures (see Figures 20 and 21).

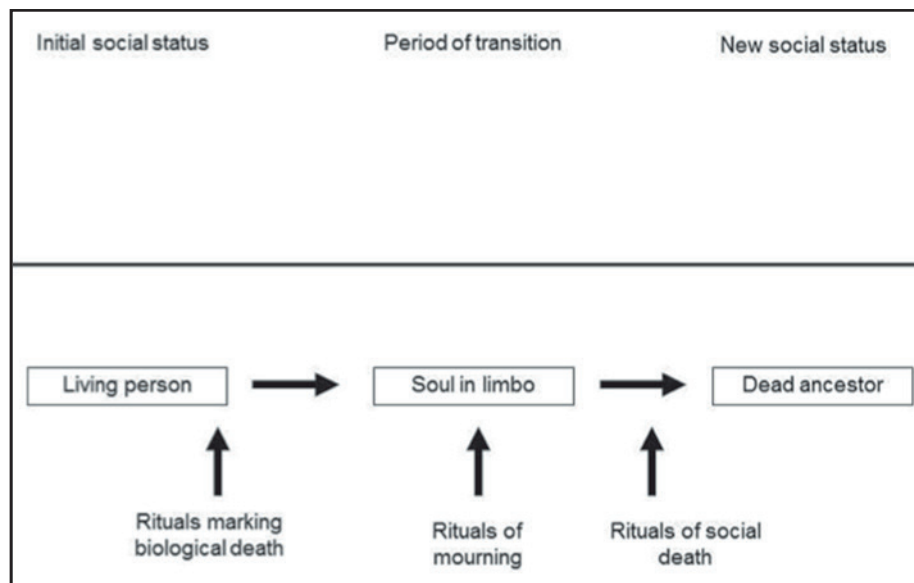


Figure 20. Stages in the Process of Social Death in ‘Primitive’ Societies.’ Sweeting and Gilhooly (1992) from O’Gorman (1998, p. 1128).

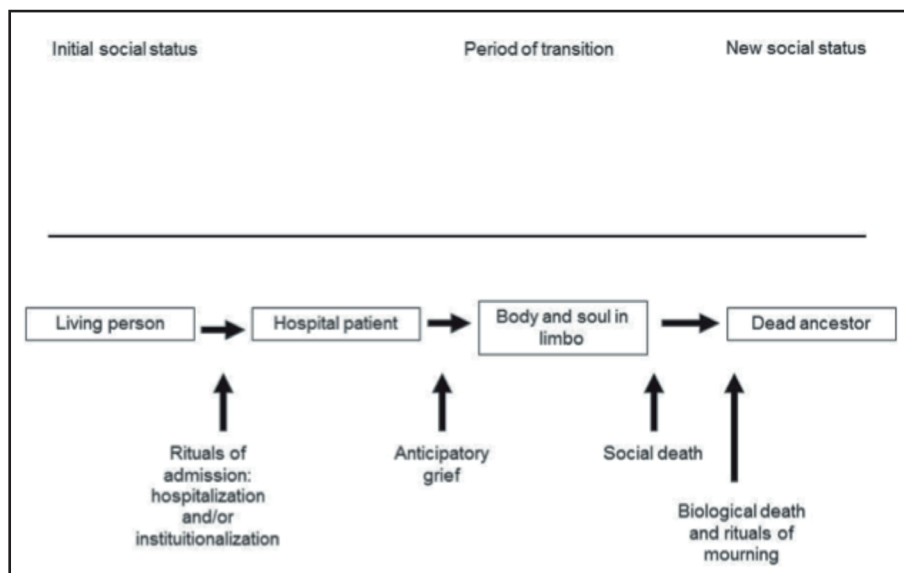


Figure 21. Stages in the Process of Social Death in 'Modern Western Societies.' Sweeting and Gilhooly (1992) from O'Gorman (1998, p. 1128).

The comparison as shown above demonstrates that traditional rituals in westernised societies have been curtailed and as a result the expression of grief is denied.

In summary, it appears from these models that contemporary society has endangered health practices by being unable to discuss and engage with death. Such fears of death and unresolved grief can manifest as anxiety, depression and even physical harm. Traditional rituals that have been maintained by certain cultures are able to overcome and accept death and in doing so enrich their lives and their communities.

From the literature thus far, there is a realisation that attitudes and the lack of death education towards dying and death are unsatisfactory. The expanding area of thanatology proves this short-coming, especially amongst health-care professionals who are responsible for death education.

My personal belief is that before ICU nurses can help dying patients in the ICU, as well as their families, it is imperative for them to confront their fear of death and examine the traditions of other cultures. In doing so, a better understanding of dying patients and their families' fears and beliefs can be achieved. Such strategies may enhance the quality of nursing care of dying patients and provide or at least facilitate a good death (*amicus mortis*) in the ICU.

Religious and Cultural Diversity in Dying and Deaths of Patients in the ICU

It is important to acknowledge cultural and religious diversity when caring for dying patients in the ICU. Intensive care nurses may experience difficulties in understanding the dying patient's needs when their religious and cultural backgrounds are different to those of the patient. This is an important concept that ICU nurse educators need to consider when addressing death education as part of the ICU nursing curriculum.

The literature is disappointingly limited on the viewpoints of the world's major religions and different denominations within those religions, regarding end-of-life decisions in ICUs especially, regarding those that pertain particularly to withholding and withdrawing life-sustaining treatment and to brain death. Not all religions specifically address these issues, so the review cannot be fully comprehensive (Bülow, Sprung, Reinhart, Prayag et al., 2008).

Christian Perspective

The term Christian encompasses many different groups ranging from Roman Catholics and Jehovah's Witnesses to Lutherans and Mormons. The literature review will concentrate on the major religions' and religious groups' perspectives on death and dying in the ICU.

Roman Catholic Perspective

The Catholics' attitude towards the futility of life-support was officially expressed in 1995 by Pope John Paul II in his **'Evangelium Vitae'** (1995). This was later summarised in a shorter version in **'Catechismus Catholicae Ecclesiae'** (1997) in which the Catholic Church supported the withholding and withdrawing of futile therapy if the expected outcome was one that would endanger or worsen the outcome for the dying patient. **'The Declaration on Euthanasia'** issued in 1980 allowed for the alleviation of pain in dying patients, even though there was the real possibility that this strategy would shorten the life of the dying.

However, to many Catholics there is some special meaning in not alleviating pain when

dying, as it holds an ideation of Christ's suffering on the cross. Active euthanasia⁴⁰ is forbidden and, instead, palliative care is to be initiated.

Withdrawal of therapy was instituted in Pope John Paul's case but, shortly before he died, he was against withdrawing artificial nutritional support of patients who were believed to be brain damaged or were not expected to survive. His thinking on this particular issue has provoked much debate around bio-ethical dilemmas and the rights to basic human needs.

Care after death

Routine last offices⁴¹ are performed. Burial is the preferred option for bestowing of the body but there are no objections to cremation. A traditional Catholic ritual in Irish communities is to show the body before the funeral procession. There is no objection to organ donation.

The Anglican tradition holds, as with many Catholic doctrines, that should an infant die unbaptised, the rite of baptism can be performed by a priest soon after death.

Protestant Perspective

The Protestant traditions are more amenable to the vast array of life-sustaining medical and technological therapies and accepts that if there is no positive outcome or hope of recovery, withdrawal of therapy is an appropriate action to take (Pauls & Hutchinson, 2002).

It is worth taking note of the diversity within Protestantism, in that the Evangelical Lutheran Church in Germany has developed advance directives for end-of-life options but disallows active euthanasia, also referred to as 'physician-assisted suicide' (May, 2003). This is in contrast to the reformed traditions, as seen in the Netherlands, in which active euthanasia is permitted under very strict guidelines.

Jehovah's Witnesses

The main aim for Jehovah's witnesses is to live their lives according to the **Old**

⁴⁰. The word euthanasia comes from the Greek for 'good death'. The Greek Orthodox Church defines good death as a 'peaceful death with dignity and without pain'. The current international meaning of 'active euthanasia' is perceived as 'mercy killing' (Bilow, Sprung, Reinhart, Prayag et al, 2008, p. 425). Euthanasia may be active, passive, voluntary, involuntary, physician-assisted, suicide or assisted suicide.

⁴¹. Last offices, also referred to as post-mortem care, takes place after the deceased is certified as dead. The nurse removes any secretions or excretions from the face and rectal areas. A bath may be required if the patient should be excessively soiled by blood, vomitus or faeces. All tubing is removed and the body covered with a sheet so that the head and arms are visible. The family are invited to see the deceased prior to being placed into a shroud and identified by a label or tag.

and New Testament. Jehovah is the Supreme Being and Jesus is the Son of God who was formerly in a pre-human state as the Archangel Michael (Rutty, 2005). Just prior to World War I, the Heavenly Kingdom resulted in the invisible enthronement of Christ as King.

The future, for Jehovah's Witnesses, is the Battle of Armageddon where Jesus, under Jehovah's wrath, will perform retribution on all other religions of the world. This cleansing would create God's Kingdom on Earth for one thousand years. Jehovah's Witnesses believe that Satan controls the world. Followers will not run for public office, vote or join the military or police force.

Care after death

Last offices are carried out but no last rites are implemented. Cremation and burial are acceptable with no formal funeral service. Organ donation and post-mortems or autopsies are discouraged but may be considered according to the individual's conscience. All organs and tissue must be thoroughly drained of blood prior to transplantation, as blood represents life and must be treated with respect. There are followers who do not permit blood to be stored or re-used. Orthodox Jehovah's Witnesses do not allow equal opportunity for men and women and hence the authority in the family tends to be held in men.

Greek Orthodox Perspective

The perspective of death for the Greek Orthodox Church is that death is not only a biological event but a mystery with a sacred, spiritual component and a great blessing. With regards to end-of-life decisions, the church rejects any death resulting from human decisions as being an insult to God and any medical intervention that does not contribute to the prolonging of life is condemned (Hatzinikolaou, 2003). The Holy Synod of the Church of Greece Bioethics Committee (2007) stipulates that: (i) medication to alleviate pain is permitted but must be administered in doses that do not hasten or assist death; (ii) withholding or withdrawing of any form of nutritional support is not allowed, even if there is no prospect of recovery and (iii) organ transplantation is allowed if the donor or the family have agreed knowingly and voluntarily. However, the Greek law states that 'non-refusal' of the relatives is interpreted as consent of the donor (Bülow, Sprung, Reinhart, Prayag et al., 2008).

Jewish Perspective

The Jewish faith consists of three branches: Reformed, Conservative and Orthodox, of which the Orthodox Jews are the most religious.

Halacha or the Jewish legal system, which was developed from the Bible (**Tanach**) and the **Talmud**, does not allow the hastening of death, even if the patient is terminally ill (Ravitsky, 2005; Steinberg & Sprung, 2006).

However, there is no compulsion to prolong pain and suffering in the dying or to keep the dying alive. Halacha allows for the withholding of life-sustaining therapies, provided that it is relevant to the dying process, but the withdrawal of life-sustaining therapies when it is an on-going form of treatment, is forbidden (Ravitsky, 2005; Steinberg & Sprung, 2006). Physician-assisted suicide or active euthanasia is prohibited, even if it is the request of the dying patient. Steinberg and Sprung (2006) point out that a new Israeli law attempts to seek a balance between the sanctity of life and the principles of autonomy. The law prohibits the withdrawal of any life-sustaining therapies but allows withholding further treatment should it be an intermittent life-sustaining measure and only if this action is in keeping with the patient's request. This may include mechanical ventilation (respirator), surgery, dialysis or chemotherapy.

Withdrawal of mechanical ventilation, food and fluids is forbidden, as these life-sustaining therapies are viewed as a continuous form of treatment. However, such a decision may result in prolonging suffering and hence Israeli law and Halacha have allowed for the changing of mechanical ventilatory support from a continuous form to an intermittent form of treatment. This is done by connecting the ventilator to a timing device and in doing so this intervention is seen as an intermittent form of treatment. The patient's death according to their wishes is seen as morally acceptable because the aim is achieved by omission rather than by commission (Ravitsky, 2005; Steinberg & Sprung, 2006). This concept may be useful for health professionals such as ICU nurses who may have psychological problems in fulfilling the patient's wishes in the dying process.

The Jewish definition of death is when spontaneous breathing ceases. The Halacha permits organ transplantation only if strict medical criteria are met to verify total and irreversible cessation of breathing. There are some Halachic authorities, especially the ultra-orthodox Jews, which insist on the cessation of heart action as well as breathing before organ donation may be considered.

Care after death

Minimal handling of the body is essential as there is a significant relation to the ritual cleansing and clothing of the body which must be carried out by the same gender to that of the deceased. This is important for all health-care providers to acknowledge. Ideally, the eyes and mouth of the deceased should be closed by a child, relative or devoted friend, preferably in this order.

The body is then covered with a sheet, labelled and the Jewish undertaker and the synagogue notified. Between the time of death and burial of the body, the body is seen as vulnerable and unable to watch over itself and therefore is closely guarded. Only when the body has 'come home' to its final resting place within the grave, is it seen as safe (Rutty, 2005, p. 525). As it is a humiliation to the deceased not to be buried, the burial should ideally take place within 24 hours, unless it is the Sabbath. Cremation is not an option as it is seen as an unnatural way of treating a human body.

An autopsy examination is disapproved of and therefore is not permitted by Jewish law unless required by civil law. The belief concerning autopsies originates from the Jewish belief that all humans are created in God's image and no form of mutilation is allowed so that the body can be buried as a whole person.

Islamic Perspective

The **Qur'an** (the holy book of the Muslim faith), the **Shariah** (Islamic Law) and the **Sunna** (Islamic Law based on the Prophet Muhammad's words and acts) form the basis of Islamic bioethics (Daar & Khitam, 2001). Muslims believe that everything possible must be done to prevent premature death, although life-sustaining therapies can be withheld or withdrawn in the terminally ill provided that the physician(s) are certain about the inevitability of death. The hastening of death is not permitted and is based on the Islamic principle of **la dararwa la dirar** - no harm and no harassment (Ebrahim, 2000). It is unlawful to discontinue any form of nutrition because such withdrawal would in effect starve the patient to death. In cases where treatment is deemed futile, the decision to withdraw therapy is seen as allowing death to take its natural course provided, that there has been a collective consensus with the family and health-care professionals.

The retrieval of organs for transplantation following brain death is accepted by most Islamic countries. The Qur'an takes a firm stance regarding the alleviation of pain – 'Allah does not tax any soul beyond that which he can bear' and pain and suffering is not a punishment but rather a **kaffarah** (expiation) for one's sins (Ebrahim, 2000). Providing pain relief or sedation is permitted even if death is hastened (double effect), as long as death was not the intention of the physician (Sachedina, 2005). Euthanasia is never allowed as it is Allah's prerogative to bestow life and cause death.

Care after death

Should the family not be available, then last offices may be performed by health-care personnel with minimal handling while always using disposable gloves. Neither washing of the body nor cutting of hair or nails is permitted by health-care personnel. A white sheet is spread over the body making sure that the whole body is covered.

Practising Muslims wash the body with soap and water a minimum of three times and then the body is wrapped in a specific way. Three pieces of white cotton cloth (**kafan**) and a scent or perfume is used. The eyes are then closed and the lower jaw strapped to the head to prevent gaping of the mouth. The body is laid out straight and the head is turned towards the right shoulder so that the body can be buried with the face looking towards Mecca. Cremation is not an option as Muslims believe in resurrection. Burial takes place within 24 hours and delays cause much anguish for the relatives. Should an autopsy be required, ceremonial preparations in caring for the body will only begin after the autopsy (Rutty, 2005).

Hindu Perspective

Diverse interpretations, opinions and actions around death are possible with regard to the Hindu religion as there is no single central authority to oversee legal and ethical issues that arise in the ICU arena (Mani, 2006).

The Hindus believe in a duty-based rather than rights-based approach to ethical decision making. Death is perceived as the passage to a new life. However, untimely death is deeply grieved over as it is the way that the person dies that is important for the Hindus. Good deaths are considered by old age, proper good-byes and the settlement of all family and financial obligations. A bad death may be violent, premature or considered to have occurred in the wrong place such as in the home or the Ganges River and is usually accompanied by excrement, vomit and horrible

facial expressions (Firth, 2005). Dying in the ICU appears to fall into the category of a bad death.

The Do-Not-Resuscitate (DNR)⁴² order by and large acceptable to the Hindus because death should be peaceful and mechanical life-sustaining support is viewed as being of no value.

Organ transplantation is permitted. However, in India this is extremely limited. In some Hindu traditions, suicide is viewed as a form of spiritual purification, especially among the terminally ill.

By ensuring that the dying person is not exposed to their own faeces, vomit or urine, a good death is realised (Firth, 2005).

Care after death

Consultation of the relatives is required before the body is washed by non-Hindus. Washing of the body is part of the funeral rites.

Non-Hindus may not wash the body but are permitted to close the eyes, straighten the limbs and wrap the body in a plain sheet with no patterns or religious insignia. This can only be done when wearing disposable gloves.

Hindu family members wash the body and wrap it in a piece of new cloth. Removal of sacred beads or other forms of body adornment is not allowed. Cremation is advocated, as the soul is reincarnated. In India, the eldest son lights the funeral pyre. In westernised countries he watches the coffin pass into the crematorium furnace to ensure that the deceased has a favourable rebirth. On the third day following the cremation, the ashes are thrown into a river if possible, the Ganges.

Organ donation and autopsies are not opposed but are not popular. As in the Muslim religion, preparation of the body begins after the autopsy.

Traditional Xhosa/Zulu Perspective

⁴² DNR (Do-Not-Resuscitate) order. This states that CPR (cardio-pulmonary resuscitation) is not to be initiated if breathing ceases or the heart stops beating. The order may be written by the person's doctor after discussing the issue beforehand with the person (if possible) or his/her proxy or family. The acronym of DNR has evolved to include DNAR – do not attempt resuscitation; AND – allow natural death and in nursing homes and long-care facilities; DNH – do not hospitalise.

The traditional Xhosa and Zulu tribes are traditionally venerate ancestor believers but today many of the Xhosa and Zulu speaking people in South Africa are Christians as a result of their early contact with missionaries from Europe in the mid-19th century.

Death for the traditional Xhosa and Zulu is not perceived as the end of life but rather as a physical detachment from other human beings. Their strong belief in the **ancestors** is associated with the life hereafter (Mndende, 1997). Mcetywa (1991) illustrates this traditional view of death by using words or phrases from the Mpondo people who originate in the Transkei:

- **Utshonile** (has disappeared) and also in less-used **Utshabile**
- **Akasekho** (not present)
- **Usishiyile** (has left us)
- **Uhambile** (has gone)
- **Ukusweleka** (that which is scarce)

The death of a traditional Xhosa or Zulu person means to join the ancestral world to become a guardian of the living and an intermediary between the spiritual and physical worlds (Mndende, 1997). This concept is extremely important for health-care professionals who may be involved in the dying process so that the necessary conditions are provided or adapted to facilitate the transition. The conditions and facilities make it almost impossible to respect such traditions should a Xhosa or Zulu person be dying in an ICU.

Mndende (1997) conducted informal interviews in Khayelitsha (an area in Cape Town inhabited predominately by Black people) with the **amagoduka** (those who come to urban areas to work but return home intermittently to rural areas) about where they most preferred to die. The respondents indicated that hospitals would be avoided if at all possible and cited three reasons: (i) a hospital is not a home; (ii) the wishes of the dying person are not easily taken into account and (iii) the traditional approach to treating the dead is difficult to respect (Mndende, 1997, p. 796).

The Xhosa and Zulu view hospitals as foreign structures and therefore are not conducive to preparing for death. A person is born in an **endlinenkulu** (main hut) and the soul should ideally depart from the world from the same place. Another difficulty that is encountered is that the body should be buried near the **inkaba**

(kraal or cattle pen) which is complicated to arrange from a hospital.

Intensive care therapies, especially mechanical ventilatory support, are seen as undesirable and pointless interference in the process of dying naturally. A concerning consequence is that such a death results in traumatic memories for the family and community. Equally important for the family is their presence at the bedside or home as it is believed that blessings are bestowed upon them from the dying person.

Care after death

There is a dearth of information in the literature concerning this aspect of death and dying amongst the Xhosa and Zulu populations. Most information was obtained via email correspondence with Dr Sibusiso Madonde, a senior lecturer in the Department of African Religious Studies at the University of Cape Town

The body is washed by women who have passed child-bearing age in the belief that younger women may become infertile, which is not viewed favourably by their clans. Because death seldom happens in the home, the undertakers do most of the preparation of the body and arrangements for the funeral.

Traditional Zulu and Xhosa people view autopsies as suspicious, as it is important that the dead are buried whole.

Mndende (1997) writes that the Zulu and Xhosa also believe that body parts are removed at autopsies and used for research or even for *muti*⁴³ and witchcraft by traditional healers or witch-doctors. This reaffirms this group's desire often to avoid hospitals when dying.

It is the head (chief) of the tribe that decides if organ donation is permitted. More often than not, organ donation is declined because the journey to the ancestral world is thought to be broken for the dead person missing an organ(s).

Although no literature is available, Dr Madonde reports on a unique South African phenomenon known as 'the politics of dying.' The social standing of the dying person determines how they will be buried. In contemporary society, affluent families tend to have large, lavish funerals.

⁴³ Muti is a term used for traditional medicine in southern Africa. The word is derived from isi-Zulu meaning tree. Muti may also be applied in different formulations used in traditional dispensaries by traditional healers or witch-doctors (Richter, 2003).

Now the poor also try to give their dead relatives the same type of funeral. To a large extent, this has become possible as a result of the proliferation of insurance companies offering funeral cover targeted at the Black population. It is quite common in the townships and rural areas to have burial societies or clubs – **Omasingwabisane** or **imibutho**. Membership of these societies and clubs contribute a fee every month to ensure that when a death occurs, there will be no financial ruin after the requisite burial ceremony.

Lack of familiarity with or knowledge of religions and death rituals may be perceived as disrespectful, and subsequently can be damaging for the dying or deceased patient and the family.

Health professionals may be seen as strangers or outsiders, rather than as a valued person in whom the dying patient and family can have trust and confidence. It is through knowledge and experience of the dying and deaths of people that empathy and compassion will succeed in earning the gratitude of families (Rutty, 2005).

Care of the Dying Patient

When a patient is dying in the ICU, the ICU nurse has only one chance to allow for a good death and if done well, there may be significant personal and family growth. However, if done poorly, the 'closure' or 'finale' of death for the patient and family may be incomplete and bereavement can possibly be prolonged and traumatic.

It is a time that allows an opportunity for the patient and family to build upon final memories, attend to any unfinished business and of course to say goodbye. Should the patient be conscious, semi-conscious or even comatosed, the role of the ICU nurse is to provide care to the patient and family and to maintain the identity and dignity of the dying. This requires of her to explore ways of involving families in patient care and this contribution can provide a sense of a final gift.

In the final hours of living, there are absolute necessities that need to be adhered to. Firstly, the family requires education about the dying process and that the time of death is unpredictable. Secondly, the interdisciplinary team should endeavour to assist the family as much as possible to avoid physical psychological exhaustion.

Signs and Symptoms of Impending Death

Identifying the key signs and symptoms of dying is an important clinical skill. These are:

- Rapidly increasing weakness and fatigue.
- Difficulty in swallowing with a loss of the gag reflex. This results in pooling of oro-pharyngeal secretions causing a gurgling sound known as the 'death rattle.'
- Decreasing level of consciousness which may cause delirium and agitation.
- The patient may have apnoeic (cessation of breathing) spells.
- Evident cardiovascular changes – slowing of the pulse rate and electrocardiogram (ECG) abnormalities – extra heart beats (ectopics); lethal arrhythmias (ventricular fibrillation or flutter) and even asystole (no heart beat).

The Phases of Dying

There are three phases of dying as shown in Table 15.

PHASE ONE Preparation	PHASE TWO Symptom Management	PHASE THREE At the Time of Death
<ul style="list-style-type: none"> • Focus on the patient and family • Educate the family and/or significant other on the last hours process to alleviate fear • Increase involvement in patient care as much as possible • Get contact details of family and/or significant other – home, work, cell, neighbour • Discuss death certificate process • Family education – there may be different agenda of family, children, religious customs and beliefs, DNR orders • If patient dying of a brain injury or non-malignant illness, consider bringing up the topic of organ donation • If possible and appropriate, children and pets to have a short farewell visit • Discuss the will, power of attorney • Care of orphans/guardianship • Funeral plan 	<ul style="list-style-type: none"> • Pressure care and positioning. Elevate head slightly. Use of flat boards/ draw sheet to aid turning. This prevents tearing of the skin • Skin care. Keep patient clean and pleasant smelling as there may be physical contact from the family and significant other. Gentle massaging of extremities. Provision of special mattress • Mouth care. Keep mouth clean – use of mouthwash helpful but dilute as can be abrasive. The family/significant other may want to kiss the patient. Clean and moisten dentures or remove if drowsy • Relieve pain and anxiety. Literature suggests that pain rarely increases in the last hours. May need to reduce or change Morphine • Continue nutrition and hydration – human right not to ‘starve to death.’ Reassure the family/significant other that this is not so. Moisten conjunctivae (artificial tears), nostrils and lips (lip lotion, petroleum jelly) • Remove accumulating secretions by positioning patient on his/her side • Gentle oro-pharyngeal suction or use ‘finger swab’ to dab out secretions • Consider medication to dry out secretions • Oxygen rarely needed • Incontinence of urine/faeces cleaned up immediately • May require use of urinary catheter as diapers/nappies cause creases and require securing and therefore effects skin integrity • Terminal sedation. May be required if signs of pain and suffering. Requires discussion with family/significant other 	<ul style="list-style-type: none"> • Counsel family/significant other not to be alarmed • Advise and encourage family/significant other to be with the deceased • At an appropriate time, discuss the death certificate and ‘what happens now?’ • This is an opportunity for the ICU nurse and other members of the interdisciplinary team to say goodbye

Table 15. Phases of Dying. Modified and Adapted from Anderson (2000).

I have adapted and modified an End-of-Life Care Plan for the dying patient to facilitate learning for the six participants in the study. This care plan includes components from the Liverpool Care Pathway in Ellershaw and Ward (2003, p. 32) and the American Association of Colleges of Nursing Competencies Necessary for Nurses to Provide High-Quality Care to Patients and Families during the Transition at the End of Life in Brenner (2002, p. 12).

COMFORT CARE	<ul style="list-style-type: none"> ✓ Promote the provision of quality comfort care to the dying as an active, desirable and important skill. ✓ Assess (i) current medication and discontinue 'non-essentials'; (ii) continue with medication for pain, agitation, nausea and vomiting; (iii) withdraw antibiotics, stop blood test and x-rays and (iv) maintain good basic nursing care – pressure and mouth care, fresh/clean linen. ✓ Apply knowledge gained from palliative care research to end of life education and care.
PSYCHOLOGICAL CARE	<ul style="list-style-type: none"> ✓ Have the ability communicate in the language of the patient and/or family. May need an interpreter.
SOCIAL CARE	<ul style="list-style-type: none"> ✓ Recognise one's own attitudes, feelings, values and expectations about death and the dying person's cultural and spiritual diversity existing in beliefs and customs. ✓ Identify barriers and facilitators to patient's and care-givers' effective use of resources. ✓ General practitioner or 'Family Doctor' notified of patient's condition. ✓ If appropriate, the patient's place of employment notified.
SPIRITUAL CARE	<ul style="list-style-type: none"> ✓ Religious, cultural and spiritual concerns discussed with family. ✓ The probability of performing traditional and cultural rituals in the ICU. ✓ Early contact with religious personnel – prayers for the dying/ last rites/ anointing of the dead. The patient may even be required to be baptised.
FAMILY CARE	<ul style="list-style-type: none"> ✓ Communicate effectively and compassionately with the patient (if conscious), family and other members of the ICU team about EoLC. ✓ Assist the family, colleagues and one's self to cope with suffering, grief, loss and bereavement at end of life. ✓ Demonstrate respect for the patient's (and family's) views and wishes during end of life.
ETHICAL & LEGAL CARE	<ul style="list-style-type: none"> ✓ Understand the implementation and consequences of issues related to resuscitation, with-holding and with-drawing treatment, foreshortening life and futility. ✓ Be aware of medico-legal issues.
PREPARATION TO DIE	<ul style="list-style-type: none"> ✓ Respect Advanced Directives, Living Wills, DNR, Organ Donation. ✓ Involvement of family with post-mortem care. ✓ ICU nurses' knowledge of post-mortem care of various religious groups. ✓ Observance of rituals and traditions.

Table 16. End of Life Care for the Dying Patient in ICU.

Providing dignified comfort care of the dying in the last days of living can be achieved and it is possible to have scenarios as depicted in the images below. Such scenarios have been in place for centuries and despite greath advances in health care and life sustaining technology, we should strive for the well-being of the patient, their families and ourselves.



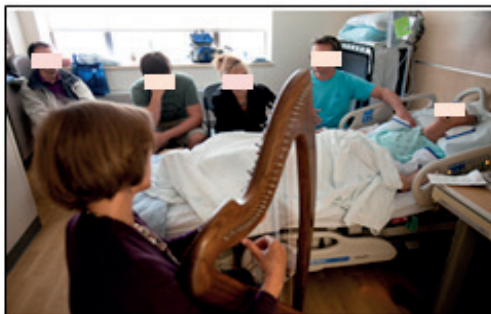
Napoleon Bonaparte's Deathbed Scene.
St Helena. 1821



Leonardo da Vinci's Deathbed 1818



From a Book of Hours made ca.1440 for the Duchess of Guelders: the dying man is flanked by a seated priest, administering the last rites; beside him a nun or the widow, praying for his soul. Women on the other side appear to be caregivers and assist with the last rites. Beyond, the physician examines urine, and the heir waits to come into his inheritance.



Playing Peaceful Music in the Last Hours of Living

Saying Farewell to other Friends



In this chapter, I have discussed Heidegger's thinking of phenomenology and education and have used Barnett and Coate's schema to organise my pedagogical themes into pedagogical offerings of death education for the six study participants.

In the final chapter, I will reflect upon my phenomenological journey and put forward recommendations for nursing practice and research as well as further pedagogical offerings in the field of thanatology and ICU nursing.

CHAPTER EIGHT

Reflection on the Phenomenological Journey

Introduction

In the final chapter of the study, I will reflect on the epistemological and ontological obstacles that had to be attended to in order for me to be focussed on the phenomenon under exploration: **'ICU nurses' experiences of death in the ICU and the implications for postgraduate nursing pedagogy.'**

In addition, I will put forward my thoughts and recommendations on pedagogy, death education and the possibilities for further research.

My Phenomenological Journey

I begin by returning to Heidegger (1996) and his thinking that phenomenology is 'as-lived,' that is to say, 'who one is as researcher is fundamental to the thinking of research, for thinking does not happen as a mechanistic process divorced from *being-in-the-world*' (Smythe et al., 2008, p. 1390). Thinking, for Smythe and colleagues is:

'lived, breathed, dreamt, felt, run-with, laughed and cried. It arises from all that has come before in one's life, both the remembered and that which is known without knowing' (Smythe et al., 2008, p. 1390).

My intention was to draw the reader into thinking and, in doing so, wanting to know more about the phenomenon of ICU nurses' lived experiences of the deaths of patients under their care in the ICU. The researcher as human, according to Heidegger, is always in the midst of a situation which is continuously in flux, and thus:

'In life doing this research this way with these people at this time and place in this mood with these possibilities does not always fit with pre-thought ideas of order or process' (Harman, 2007, p. 28).

Concurring with Heidegger (1996), I struggled with the lack of structure in doing phenomenological research, wrestled with language and had to face ontological challenges that were unforeseen. I understood that my *being* could not be learnt from instruction and that one must, live the experience, which I believed I had done through the many encounters of death and dying in my nursing career. Heidegger uses the Greek word *aletheia* to define truth as ‘unconcealment, drawing something forgotten into visibility’ (Harman, 2007, p. 92). My *aletheia*, as it were, were the deaths of my parents in which I was forced to engage first-hand with death in a very personal way. Heidegger (1996) alleged that there were numerous ways of *being-in-the-world* but the most significant way was being aware of one’s own *being* or *Dasein*. I entered into an inquiring mode by questioning my own *being* and *authenticity*. I began journal writing again to lift the curtain of silence brought on by grief and angst.

My responsibility as a researcher of phenomenology was to listen to the ICU nurses in a way that strived to understand the *meaning* of what was said and to reciprocate with thinking that was provocative and engaging. In a letter to Elisabeth Blochmann⁴⁴ in 1919, Heidegger talked of ‘graced moments’ as experiences in ‘which we feel ourselves belonging immediately to the direction in which we live’ (Crowe, 2006, p. 30). I would like to believe that such ‘graced moments’ have taken place to whoever reads this study, and opened up the world of ICU nurses’ experiences of the deaths of patients under their care in the ICU.

My Nursing Journey

Reviewing the literature and finding limited discussion of death education for ICU nurses, it proved challenging to offer the reader as much insight into death and dying in the ICU as I wanted to invite and provoke thinking. I was ambivalent about what information and material to omit and what to include. Therefore, it may appear from Chapter Three that there is a substantial amount of information about death and dying in the ICU. This is not the case.

It is perhaps only Hinderer’s study (2012) that bears the most similarities to mine. It was encouraging that the findings of Hinderer’s study were published almost two years after my first completion of phenomenological conversations and the beginning of my naïve unravelling of the ICU nurses’ narratives. As a researcher, I believed

⁴⁴. German scholar of education and philosopher (1892 - 1972).

myself as uncontaminated and clean in that I had not been influenced or subjected to self-interrogation on how to conduct the phenomenological conversations. Despite methodological discrepancies in Hinderer's study, such as the use of a phenomenological pilot study and a lack of a philosophical underpinning, some results concurred with mine.

The themes that emerged in Hinderer's study – (i) coping; (ii) personal distress; (iii) emotional disconnectedness and (iv) inevitable death all highlighted that experiencing the deaths of patients in the ICU was a stressful event. Hinderer has raised similar questions to my own:

3. Should critical care education include teaching on ways of coping with patient death?
4. What are the implications of lack of coping mechanisms related to patient death?
5. What are the long term implications of repeated exposure to death?
(Hinderer, 2012, p. 258).

In her study, Hinderer has not offered any pedagogical interventions or offerings addressing her concerns regarding critical care nurses' reactions to patient death.

My Educational Journey

One of my greatest challenges in using Martin Heidegger's concept of phenomenology was his use of language. Heidegger's opus, **'Being and Time'** (1927/1996), was originally written in German. Although, eventually translated into English, much of the translation is cause for considerable confusion for any scholar reading Heidegger. In **'Poetry, Language and Thought'** (1971), Heidegger maintains that 'man acts as though he were the shaper and master of language, while in fact language remains the master of man' (Heidegger, 1971, p. 146). This did not alleviate my concern about my ability to understand Heidegger's philosophy, even at a superficial level. I set about gaining insight into Heidegger by reading the 'basics', accessing on-line resources and blogspots which I found most useful as these had been written simply and succinctly.

My next educational hurdle was the writing. As a professional nurse my academic home was in the Faculty of Health Sciences, and my writing style was scientific and

factual. I was advised to join the Writer's Circle – a group of academics and doctoral students who share their writing experiences in order for me to better prepare myself under the auspices of the Faculty of Humanities, for the writing of the proposal and later the study. This proved invaluable and I made headway in many aspects of the study, feeling somewhat relieved when I read a section from Crotty's book, **'Phenomenology and Nursing Research,'** where Crotty notes that 'Heidegger apologised for his awkwardness and inelegance of expression' (Crotty, 1996, p. 166).

Barnett and Coate's contribution to the study was considerable in that the concepts of **voice** and *authenticity* were integrated to the voices played by the ICU nurses and by me both as researcher and individual. The vehicle of voice allowed the ICU nurses' narratives to be heard and hence invited and provoked others to think and engage. In my opinion, this is what Barnett and Coate may have intended when they wrote **'Engaging the Curriculum in Higher Education'** (2005). Barnett and Coate offer two metaphors for the term 'engagement.' Firstly they suggest that engagement is 'one of cogs meshing – engaging with each other' and secondly, on a more personal level that 'individuals are engaged with each other such that there is a mutuality and long-term interconnectedness of an emotional character' (Barnett & Coate, 2005, p. 123).

Pedagogical Offerings

The field of thanatology has over the past three decades, been transformed and become a more acceptable topic of conversation and debate. However, health-care professionals continue to face many challenges because of medical advancements that keep patients alive for longer. One of the challenges for health-care professionals is to stay abreast of the knowledge base of thanatology specific to their areas of practice (Wogrin, 2007). The International Work Group on Death and Dying and Bereavement (IWGDDDB) states:

'that when providing end-of-life and bereavement care, all professional care-givers need to possess in-depth knowledge, experience and skills in order to be able to attend to a wide variety of specific and often complicated circumstances' (IWGDDDB, 2006, p. 650).

Such requirements would include interpersonal skills, clinical knowledge, technical proficiency, and personal and professional experience. The IWGDDB emphasises that health-care professionals are responsible for educating themselves regarding care for the dying and their families.

Noppe claims that the 'teaching of death and dying has always demanded a certain degree of creativity from instructors' (Noppe, 2007, p. 333). The most noteworthy pedagogical change in thanatology courses has been the accessibility of on-line material and forms of assessment. This pedagogical intervention may have some value, especially for nurse educators who are still very much novices in the discipline of death education, however this teaching strategy may prove extremely limited for ICU nurses' unique experiences of death and dying of patients under their care in the ICU.

The need to understand the influence of culture and race on the dying process has received more extensive attention among death educators (Schim et al., 2003). This issue, especially from a South African multi-cultural perspective, involves examining how culture, religion, spirituality and diversity influence the social aspect of dying processes together with moral and ethical issues at the end of life. This topic was highlighted by the lived experience theme dealing with the 'cultural and religious unpreparedness' of the ICU nurses in the study. For critical care nurse educators, learning how death education is taught in other countries (or other ICUs) can lead to a cross-pollination of ideas in the teaching and learning of multi-cultural issues surrounding death and dying.

Thanatology is beginning to be included in palliative care nursing curricula and even in some ICU nursing curricula. However, such instances remain few and far between.

I have proposed using Barnett and Coate's (2005) framework of knowing, acting and *being* as the structure for a pedagogical offering to meet the need for death education in a Postgraduate Critical Care Nursing curriculum.

Taking into consideration the ICU nurses' experiences of the deaths of patients under their care in the ICU, I have incorporated skills, knowledge and competencies that I think are necessary for these nurses to deliver quality care in the last days/ hours of their patients' lives. Equally as important, I believe that this pedagogical offering will attend to the ICU nurses' care of self and address their *denied authenticity*,

thus enfranchising them to be caring *authentic* ICU nurses.

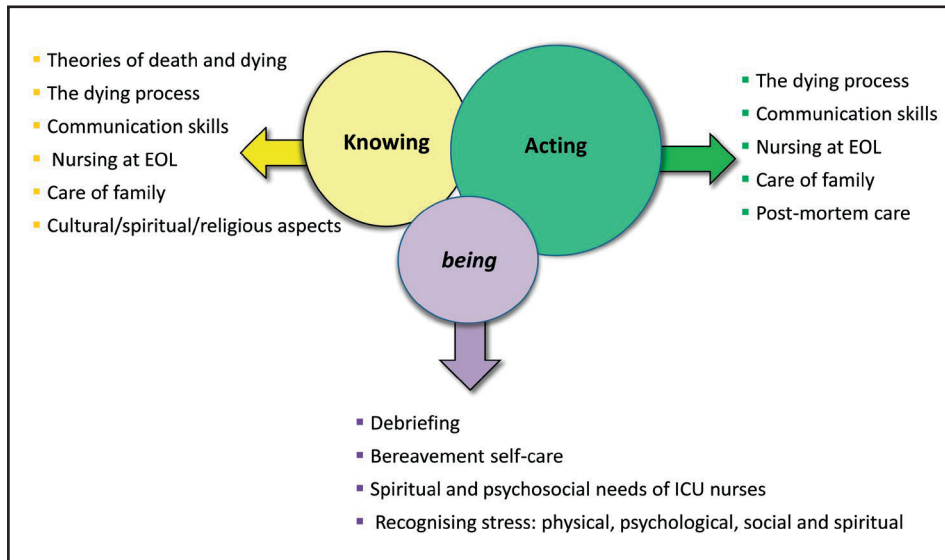


Figure 12. Proposed Pedagogical Offerings for Death Education for ICU Nurses

The schema of knowing, acting and *being*, provides an opportunity for students to engage in ‘three dimensions – those of knowledge, action in the world and the self’ (Barnett & Coate, 2005, p. 124). Another possibility for engagement from Barnett and Coate’s schema is the one of self- engagement on the part of the student. Self or personal engagement, from Barnett and Coate’s perspective, points to the student’s self-becoming and even self-transformation. In this form of engagement, Barnett and Coate emphasise that the student is ‘energised to will herself forward, even at the price of emotional risk’ and ‘lays out her vulnerabilities in voyaging herself’ (Barnett & Coate, 2005, p. 126).

Expressing this point differently is the concept of voice which can be conveyed through each of the three domains of knowing, acting and *being*. In this study, the ICU nurse’s epistemological voice, their practice voice and an ontological voice through their own self and *being*, were heard and taken note of. Therefore a curriculum not only engages the student but also enables and inspires the student to engage him/herself.

Barnett and Coate advocate that for a curriculum to engage, ‘personal and collective energy of *authentic* effort is necessary’ and therefore it ‘follows that curricula for engagement entail pedagogies for engagement’ (Barnett & Coate, 2005, p. 128). They maintain that if curricula are to maintain a deliberate envisioning and progression

of educational experiences, it is through pedagogies and teaching methods as well as the pedagogical relationships between teacher and student and even student and student, that the efficacy of the curriculum is realised.

In this study, although not addressing curriculum change but rather a pedagogical offering through introducing death education into a Postgraduate Critical Care Nursing curriculum, I believe that there has been engagement between the ICU students and me and, to a larger extent, between student and student and student and self (through reflective drawings of death and dying and group discussions thereof).

This study has allowed me to recognise that teaching and learning about the ICU nurses' experiences of the deaths of patients under their care in the ICU, has, to a point, produced knowledge and skills. It enabled the ICU nurses to begin dealing with their ontological insecurity and lack of confidence during the death and dying of their patients. Referring back to Barnett (2004; 2005), *being-in-the-world* instead of knowledge-of- the-world must be the primary objective for teachers to nurture life-long learners in higher education. Life-long learning about death and dying, for both student and teacher, implies ongoing existence in the *being* mode, with the purpose is eliciting thinking of and search for *authentic meaning* and, in doing so, producing and increasing knowledge.

Limitations

It would be limiting to assume that phenomenological research could or should realise a pre-defined end. This is not the case; the study is modestly 'on its way.' Thinking will never be complete; it will always be in a state of *situatedness*. Many layers, to be peeled back and unravelled, wherein lie many possibilities for further thinking and *meaning*.

The ICU nurses in this study entered into a personal and, at times, grieving dialogue with me. This phenomenological journey allowed the ICU nurses to express and identify their suffering. My objective was to articulate their stories in their own language, that was both sincere and *meaningful*.

I was not out to prove or disprove or provide unassailable evidence but instead to encourage thinking about the ICU nurses' lived experiences of the deaths of patients

under their care in the ICU and how to better prepare them for this event. Thus, the thinking was my own interpretation of coming to understand which is always and already drawn from all my experiences of death and dying. I knew full well that the insights I could offer were at best provocative, encouraging others to think on and wonder further about the ICU nurses' experiences of death and dying.

My intention was not to provide answers, as that would shut down thinking, but rather to invite readers to take their own journey with the ICU nurses and myself, be exposed to the thinking of others and listen for the invitation to do their own thinking. Each person reading the study will go away with their own thoughts, some epistemological but mostly, I believe, on their ontological existence and the inevitability of their own deaths.

Barnett and Coate's schema provides a pedagogical language in which to understand the ICU nurses understanding and ontological difficulties of their experiences of patients dying and or who have died in the ICU. Using Barnett and Coate's (2005) schema of knowing, acting and *being* may not be an appropriate educational framework for teaching and learning in larger curricular projects. However, the three circles lended itself to a skeleton on which to organise the pedagogical themes so that I could identify pedagogical offerings for the six participants in the study. However, the study is merely a brush stroke of the importance for the inclusion of death education for ICU nurses.

Implications for Pedagogy and ICU Nursing

As a researcher, educator and individual who has experienced death and dying on many levels, I believe that this study has given me the agency and credentials to put forward a pedagogical offering to address the need for death education in a Postgraduate Critical Care Nursing curriculum. However, I cannot do this on my own. Intensive care nurses must be actively involved and committed to pedagogical offerings that address their suffering and bereavement as a result of patients dying under their care. In other words, ICU nurses and nurse educators need to address the state of *denied authenticity*. Nurse educators are required to continue examining further the nature of ICU nurses' suffering and explore the moral and ethical implications of how their suffering affects patient care and care of self. If nurse educators ignore the need for or fail to advocate a pedagogical offering for inclusion of death education in the curriculum, skilled and committed nurses might be lost to

the caring profession, especially in the specialist field of ICU nursing.

Next Steps

This study offers opportunities for further research exploring other aspects of ICU nurses experiences of the dying and deaths of patients in the ICU. My thinking on 'death fatigue' deserves attention as this has the potential for burn-out and PTSD.

Although the students reflective drawings of dying and death was not part of data collection or analysis in this study, the nurses stories from their drawings has potential for other pedagogical offerings that may enable ICU nurses to better understand other aspects of dying and death including their own ontological confrontation with death.

The concept of *denied authenticity* which may have serious consequences for the delivery of quality nursing care to patients who are dying or have died in ICU also warrants the need for further research (See End of Life Care Plan on page 225). Returning to Heidegger, *Dasein* is inclined to flee from its *authentic* self and instinctively hide behind the accepted view of others (Kübler-Ross, 1969; Quint, 1967). This pedagogical environment for ICU student nurses may unwittingly abet *inauthenticity* especially when patients are dying or have died in the ICU.

The study may open up opportunities for designing and implementing a credit based course or module for continuing professional education. The course would be open to any individual interested in death education such as social workers, clergy, psychologists and other health-care professionals.

In conclusion, the ICU nurses in this study remain dedicated to the delivery of quality nursing care, concentrating mainly on the physical and emotional aspects of comfort care. Intensive care nurses are the ones at the bedside/cot when patients are dying or have died, yet at times they feel that the care they provide is inadequate. This may be due to a reluctance to engage in a conversation about death and dying and about their own lack of self-care. In order for them to initiate self-care, they need to be empowered to care about themselves.

Reich sums up the importance of sharing stories and the positive outcomes that may result:

‘To tell a child a story is an act of maternal care, the tradition of which has been passed along for centuries. To recognise that the sufferer searches for a story and to assist him or her with “that which he would do unaided” is an act of care, the essence of nursing. The suffering person needs to articulate and re-formulate his or her own story as a way out of suffering isolation’ (Reich, 1987, p. 117).

This thesis is a phenomenological story of ICU nurses’ experiences of the deaths of patients under their care in the ICU. It is an attempt to provoke thinking of and give *meaning* to their lived experiences and, in doing so, consider options of addressing their *denied authenticity* and the possibilities of improving self-care and their care of patients in the last days of living.

My Final Journal Entry Prior to Submission – Friday 23rd August 2013.

I think about death a lot. Mine especially, lately. Throughout my life, I have been involved with death in many different guises and in many different ways. I have looked into the eyes of patients and friends who have asked me to help them die, who have told me how scared they are, who are in agony, who are not ready, who are starting to see that white light beckoning. And I have kissed the foreheads of those at peace, who fear nothing, who look forward to living again in another world: a world of no pain and no disfigurement, a world filled with comforting sounds, not the clatter of life support.

I have watched and heard that last breath. I have waited to hear that one more gasp at life that gives on-lookers, loved ones and nurses false hope. I have turned off ventilators and waited patiently for the ECG trace to slow and flatten out. I have felt like the grim reaper when organs are needed for patients fortunate enough to receive another chance at life. I have been impatient with doctors taking their time in filling out death certificates, delaying death and cultural rituals, watching family and elders pace the corridors of the ICU. No place to grieve.

I have seen cold bodies in the mortuary. I have held stillborns, warm from their mother’s

protective womb. I have heard the voice of grief, that eerie howl, wolf-like, echoing, drowning out the noise in the ICU. My grief is swallowed and put on hold. My heart beats fast, but it beats. I'm alive.

These are the times from which I have learnt the most. These are the times that continue to haunt me, and will do forever.

As I learn, I am acutely aware that this learning does not help those who have already died under my care or make their family's grief any easier. I hope however, that the voice I am giving to my students will make a difference in the future. I pray to be an authentic caring ICU nurse.

Who we love and how we love are brought into sharp relief when that one, single moment comes for us to be faced with and finally parted by death. How we die, is the same as of how we have loved and were loved in life. The most important job I have now is to make sure that dying is done well and valued as much as life itself.

Final word count (content only) – 72 028.

The Rime of the Ancient Intensivist

**Twelve weeks ago, when life was more
Than vitals, fluids, and suctioning chores,
A man turned sick, and tried to die:
The unfortunate Timothy Linger.**

**In a modern age, with modern skill
And tools to fix the critically ill,
He was intubated and ventilated;
Catheterized and phlebotomized.**

**He was kept alive, though his brain was dead;
“Well, not quite dead,” the experts said.
Still, hope seemed grim, and chances weak
That he would ever live to speak.**

**His loving family would not hear
Of words or sounds of death and fear.
They hoped that soon their Dad would wake:
The docs would see their big mistake.**

**So days passed by, but not disease;
The tube became a tracheotomy.
His lines were changed, and blood transfused;
But Linger’s health was not improved.**

**Unconscious, swollen, on a vent
Bleeding through his tracheal stent;
The doctors sought to end his suffering,
And asked the family’s word and blessing.**

**“Quality of life, what do you mean?
He looks quite happy on that machine.
If he leaves this unit he will die,
But he’ll get well if you’ll just try.”**

**“No, no,” the doctors said, “You’re wrong,
His mind and body have long gone.
We can make him live, that’s true,
But bring him back we cannot do.”**

**The family told them, “Keep on going.”
His heart kept beating, toenails growing;
And Mr. Linger stayed alive,
Though now and then would try to die.**

**He’d cough up blood, his heart would slow,
He’d look like he was going to go;
But then the nurse would bag or suction,
Again his lungs would start to function.**

**And so he’d live another day
To bleed and cough and waste away.
The family, they were not impressed,
And wanted Dad to get the best.**

**Weeks more passed, he would not die.
Indeed, it seemed he could not die.
Until one day he rose to say,
“My life is going to end today.”**

**Now in the calm of early morning
He clogged his airway without warning;
His saturation dropped quite low,
His beating heart began to slow.**

**His nurse now ran beside the bed.
She cried, “Call Respiratory,” and dropped his head.
With shaking hands and beads of sweat
She tried to bag but couldn’t vent.**

**Then Respiratory came and shoved her away.
He twisted the bag and pulled and strained,
To no avail; the time seemed nigh
For Mr. Linger to finally die.**

**But even as Death's hand squeezed the grip
And Linger's pressure started to slip,
Dr. Griffin stormed upon the scene;
His face of stone, his eyes a gleam.**

**He glanced at his watch, it read five to eight,
"Not on my shift!" he was heard to state,
"After all, what would the family think?"
But Linger's pressure continued to sink.**

**Then Griffin leapt to the top of the bed,
Grabbed a laryngoscope and pulled back the head.
The respiratory tech ripped out the trach,
And blood spouted out; Linger started to shake.**

**"Get him paralyzed now!" Griffin said with a growl,
And looked in the mouth, but Linger spewed foul Vomitus
forth into Griffin's eyes. "Get an 8,"
Griffin cried, "I'll save this airway before it's too late!"**

**As Linger lurched up with agonal gasps
Griffin looked again, "This 8 tube won't pass!
Get me a 7, I won't let him win!"
But Linger's heart had begun to give in.**

**And now Linger's body started to stiffen,
His spirit stepped out and laughed at Griffin.
Incensed, Griffin snatched the 7 tube and pushed It deep
inside Linger's dark, gurgling mush.**

**Now the tech bagged the tube, the chest started to move;
The pallor of his skin began to improve.
The crowd fell silent as the blood pressure climbed
And day broke for Linger, one more time.**

**Griffin wiped his face, and spat on his hands,
“I wouldn’t have done that for any other man;
But what would his family have thought of me,
If I had merely let things be?”**

**Linger’s spirit said nothing as it went back inside,
His heartbeat and oxygen started to rise.
His 7200 joined him at last,
And things were as nothing different had passed.**

**And so Mr. Linger continues to live
Despite his futile attempts to give
Himself a way out; he cannot die.
Protected he is, should he even try.**

**For the University Medical ICU
Is the best in the world, they pull them all through.
Should the hospital fall from a shattering quake,
Mr. Linger will remain: alive, not awake.**

David Ryon, MD (1995).

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IMAGE REFERENCES

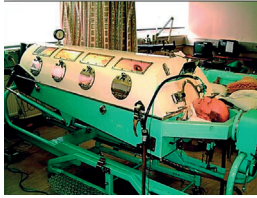


Image 1. The Iron Lung.

<http://news.bbc.co.uk/2/hi/health/3182096.stm>



Image 2. Evolution of Intensive Care Units.

<http://www.thegalleryofheroes.com/florence-nightingale/>



Image 2. Evolution of Intensive Care Units.

http://www.discoveriesinmedicine.com/images/mdis_0000_0002_0_img0092.jpg



Image 2. Evolution of Intensive Care Units.

<http://media.baylorhealth.com/photos/bcec/2464/bcec2464-0de8-6e1c-efe2-72004c6a9ff3-480x320.jpg>



Image 2. Evolution of Intensive Care Units.

http://farm5.static.flickr.com/4069/4316609896_6dc2f52955.jpg

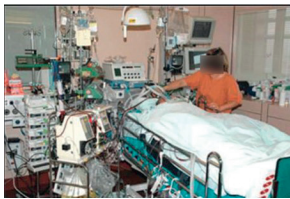


Image 2. Evolution of Intensive Care Units.

<http://wwwtheseareafewofmyfavouritethings.blogspot.com/>

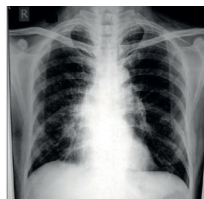


Image 3. Concepts of *Gestell*.

<http://openi.nlm.nih.gov>

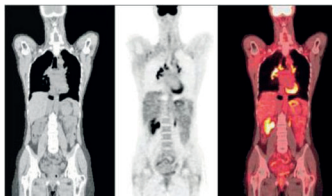


Image 3. Concepts of *Gestell*.

<http://upmc.com>



Image 3. Concepts of Gestell.

<http://ambulancetechnicianstudy.co.uk>



Image 3. Concepts of Gestell.

<http://hipswift.cmbi.ru.nl>

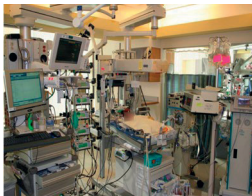


Image 4. The Dominance of Technology in ICU.

http://vectorblog.org/wp-content/uploads/2013/03/ICU_monitors1-1024x768.png

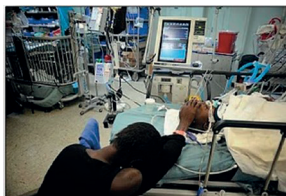


Image 5. Typical Death Bed Scene in ICU.

http://projecthopeinthefield.blogspot.com/2010/02/life-and-death-in-icu_05.html



Image 6. Death Bed Scene in a Hospice Setting.

<http://www.obit-mag.com/articles/off-the-backs-of-the-dying>

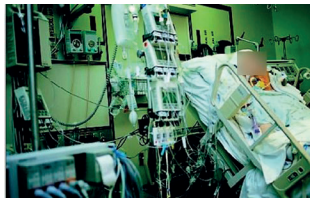


Image 7. 'A Typical Scenario in the ICU.'

<http://vanandlisa.blogspot.com/2010/07/one-moment-more.html>



Peaceful Death.

http://www.napoleonguide.com/pixs_napdeathscene.htm



Peaceful Death.

http://www.artres.com/C.aspx?VP3=ViewBox_VPage&VBID=2UN365QQ0MI7&IT=ZoomImageTemplate01_VForm&IID=2UNTWAIUQQ77&PN=37&CT=Search&SF=0



Peaceful Death.

<http://users.trytel.com/~tristan/towns/florilegium/popdth05.html>



Peaceful Death.

<http://newnurseblog.com/2011/09/08/death-in-the-icu/>



Peaceful Death.

<http://www.nydailynews.com/news/national/faithful-dog-rusty-bids-final-farewell-dying-young-owner-article-1.1556534>



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22 April 2010

TO WHOM IT MAY CONCERN

**Research ethical clearance: Nicola Fouché FCHNIC001, PhD
study: Implications for a Postgraduate Nursing Curriculum of
Intensive Care Nurses' Understanding of Death in the Intensive
Care Unit**

This letter confirms that Nicola (Nicki) Fouché has applied for ethical clearance as regards research involving human subjects for her proposed PhD research, as titled above, and her proposed research has been approved on behalf of the Research Ethics Committee of the Faculty of Humanities.

Ms Fouché has made a detailed joint written statement (dated 30/11/2009), co-signed by her supervisor, Dr Kevin Williams, where she has adequately and satisfactorily addressed all the relevant ethical concerns pertaining to her research, to the satisfaction of the School of Education, acting on behalf of the Humanities Faculty Research Ethics Committee. This approval was a prior condition for her successful registration as a PhD student with the School of Education in the Humanities Faculty. The signed joint statement has been filed as a record that the ethical concerns of her research have been appropriately addressed and approved within Humanities Faculty structures.

Sincerely,

Mastin Prinsloo, Research Ethics Portfolio, School of Education



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**CONSENT FOR PHENOMENOLOGICAL CONVERSATIONS
AND FEEDBACK SESSIONS**

Dear

Thank you for agreeing to participate in this research project concerned with gaining an understanding of Intensive Care Nursing students' experiences of the death of patients in Intensive Care (ICU).

What is the objective of this research project?

This study seeks to establish the need for, and importance of, a deliberate attending to the preparation of ICU nursing students for their care for themselves and of people who die whilst in ICUs. Part of the provision of a caring environment should include caring for the nurse him or herself. The lack of death education, also known as thanatology, in the current Postgraduate Critical Care Nursing Curriculum at the University of Cape Town has been made apparent from comments made by current and past students in this programme through their module evaluations. By incorporating thanatology into the Postgraduate Critical Care Nursing Curriculum at the University of Cape Town, it is hoped that ICU nursing students will experience the phenomenon of death and dying of patients in ICU differently. This project may also offer an opportunity for addressing the well-‘Being’ and the well-‘being’ (to use Heideggerian terms) of the ICU nursing student. Lastly, the ideal outcome from using Barnett’s concept of an Engaged Curriculum, will be that of quality care for all; the patient, their families and the ICU nurse.

What will participation in a conversation involve?

Your participation in the study will initially involve conversations lasting approximately 45 minutes and undertaken by myself. Once the first phenomenological conversation has been transcribed, an appointment will be set up for a feedback session. Once the feedback session has been assessed, a second phenomenological conversation will take place. Again, thereafter, there will be another feedback session. However, as the project progresses, there may be a need for further phenomenological conversations

Confidentiality of responses

The confidentiality principle guiding the research is that the conversations and feedback sessions will be anonymised as far as possible. Your conversations will be assigned a participant pseudonym of your choice to ensure confidentiality. Participant anonymity will be protected at all times with the proviso that the researcher will know your name and will be the only person with access to both your name and your chosen participant pseudonym. Signed consent will be obtained from you prior to all conversations and feedback sessions and written permission will be required from you to use the information when the study is being written up. You may withdraw at any stage of the study without recrimination or prejudice.

All 'raw' information from the conversations will be kept in safe keeping in a locked cabinet. Once transcriptions have been made and finalised, any electronic recordings made will be encrypted and stored on CD or USB Flash Drive. Original digital recordings will be erased. No raw information containing identifying information or otherwise will be made available to any person other than the researcher named in this document.

Respect for colleagues and students

You are respectfully requested to avoid reference to students or to other members of staff within either the Faculty or the University, by name.

Right to withdrawal

You have the right to request to withdraw from this project at any time during the research process. Should you choose to do this, please indicate this request in

writing (including the use of email) to myself (Nicki.Fouche@uct.ac.za). Once this request has been received, any information gathered from you will be omitted from the information record and destroyed

Attestation of agreement and confidentiality

I, Nicki (Nicola) Fouché (researcher) undertake that all information obtained as a result of these conversations will be treated in such a way that the right to confidentiality of the provider of that information will be respected.

Signed: _____

Date: _____

I, _____ (research participant) do hereby acknowledge that I have been informed of the nature, method and purpose of this research project, and have given my informed consent to participating in the project provided that my confidentiality is observed according to the procedures outlined above. I give permission for conversation transcripts and drawings, with my identity concealed, to be used for the purposes of this research project.

Signed: _____

Preferred Participant Pseudonym: _____



Centre for Higher Education Development
Higher & Adult Education Studies & Development Unit

Hlanganani Building Level 7
36 North Lane Private Bag Rondebosch 7701
Tel: (021) 650-3490 – Fax: (021) 650-5045

CONVERSATION №:

PSEUDONYM:

DATE:

The Phenomenological Conversation

Please describe your experiences of deaths of patients in ICU.

The Phenomenological Conversation Prompts

1. Have there been any specific incidents, events or situations that stand out for you?
2. How do you personally cope with deaths of patients in ICU?
3. Have you ever received any death education about how patients may die in ICU?
4. Have you ever received any death education about how you may be able to handle deaths of patients in ICU?
5. What do you know about other cultures and death?
6. What does death mean to you?
7. Are you afraid to die?
8. If you had to die in ICU, how would you like to die and what resources/personnel would you like to have?

APPENDIX D

Participant	Phenomenological Conversation # 1	Participant Feedback	Phenomenological Conversation # 2	Participant Feedback	Reflective Conversation	Information and Material Gathering
Phumzile	05/09/2011 Duration: 50:15 17 pages of transcription 6013 words	26/09/2011 Duration: 20:44 12 pages of transcription 3099 words	18/11/2011 Duration: 34:29 13 pages of transcription 4136 words	18/01/2012 Duration: 22:21 12 pages of transcription 3277 words	22/02/2012 Duration: 15:56 10 pages of transcription 2745 words	Total: 143 minutes 64 pages of transcription 19 270 words
Thato	22/07/2011 Duration: 58:38 23 pages of transcription 8882 words	19/08/2011 Duration: 40:15 16 pages of transcription 6296 words	15/11/2011 Duration: 29:03 15 pages of transcription 5001 words	02/12/2011 Duration: 25:42 13 pages of transcription 5678 words	22/02/2012 Duration: 13:59 11 pages of transcription 2862 words	Total: 167 minutes 78 pages of transcription 28 719 words

Participant	Phenomenological Conversation # 1	Participant Feedback	Phenomenological Conversation # 2	Participant Feedback
Inshalla	20/07/2011 Duration: 37:50 14 pages of transcription 5869 words	17/08/2011 Duration: 42:00 17 pages of transcription 6301 words	18/11/2011 Duration: 21:58 12 pages of transcription 2993 words	09/12/2011 Duration: 23:03 12 pages of transcription 3177 words
Esther	26/08/2011 Duration: 27:40 13 pages of transcription 4331 words	07/10/2011 Duration: 35:50 14 pages of transcription 5869 words	09/11/2011 Duration: 28:44 15 pages of transcription 5901 words	22/11/2011 Duration: 31:42 14 pages of transcription 5899 words
Johanna	23/01/2012 Duration: 44:06 19 pages of transcription 6459 words	17/02/2012 Duration: 30:09 17 pages of transcription 5002 words	01/03/2012 Duration: 22:47 12 pages of transcription 3800 words	13/03/2012 Duration: 16:33 11 pages of transcription 2997 words
Cindy	23/01/2012 Duration: 22:08 12 pages of transcription 3782 words	17/02/2012 Duration: 17:04 12 pages of transcription 3003 words	01/03/2012 Duration: 33:49 14 pages of transcription 6629 words	13/03/2012 Duration: 20:56 12 pages of transcription 3254 words
SUMMARY				
Total duration with participants: 889 minutes				
Total number of pages of transcribed text: 426				
Total word count of all texts 147 252				

APPENDIX E

AHS4053G

Course convenor: Ms U Kyriacos.

Course outline: This course is aimed at the acquisition of knowledge (terms, concepts, and principles), skills and attitudes related to ophthalmic nursing practice in secondary and tertiary care settings. The intention is the development of clear understanding of the reasons for every action and the progressive development of professional and skilful practice. Main concepts include peri-operative, pre-operative, intra-operative and post-operative nursing care with integrated learning of the biosciences.

Assessment: Formative assessment contributes 40% of the final mark. The summative assessment contributes 60% of the final mark. Details of the formative assessment are given to the student at the beginning of the module. The summative assessment is externally moderated.

AHS4053H PRACTICE-BASED LEARNING

Course convenor: Ms U Kyriacos.

Course outline: This course is aimed at the acquisition of knowledge, skills and attitudes required to perform ophthalmic nursing skills in primary, secondary and tertiary care settings.

Tutorials: A total of 24 hours throughout the year.

Fieldwork: A total of 250 supervised hours at various health delivery services throughout the year.

Assessment: Formative assessment contributes 40% of the final mark. The summative assessment contributes 60% of the final mark. Details of the formative assessment are given to the student at the beginning of the module. The summative assessment is externally moderated.

AHS4054F IMPACT OF THE CRITICAL CARE ENVIRONMENT

Course convenor: Ms N A Fouché.

Course outline: This course is divided into the following sections: Effects of the economic environment on patient care and the implication for nursing practice; effects of sensory alterations, including stressors for patients and staff, sensory overload and deprivation, sleep and rest disturbances in the critical care unit; the dying process and death; immobility in critically ill adults, including pain management, wound healing and altered body image; communication, communication channels, communication barriers and interventions that improve communication; effects of occupational hazards, including infection, chemical and radiation hazards, noise and chemical dependency; legal and ethical aspects e.g. euthanasia, withdrawal of therapy, 'do not

This includes issues related to reproductive health.

Assessment: Formative assessment contributes 40% of the final mark. The summative assessment contributes 60% of the final mark. Details of the formative assessment are given to the student at the beginning of the module. The summative assessment is externally moderated.

AHS4060S FINANCIAL MANAGEMENT IN THE HEALTH SERVICES

Course convenor: Assoc Prof S E Duma.

Course outline: This course aims to empower the student at clinical or managerial level essential financial management skills in order to meet the challenges of the ever-shrinking health service budget. It focuses on budgeting and budget plans, and cost containment as applied to public or private health and nursing service. Different types of budget and budget proposals are analysed. The student is assisted in planning, implementing and evaluating cost-effective financial resource management.

Assessment: Formative assessment contributes 40% of the final mark. The summative assessment contributes 60% of the final mark. Details of the formative assessment are given to the student at the beginning of the module. The summative assessment is externally moderated.

AHS4061H CRITICAL CARE CHILD NURSING PRACTICE

Course convenor: To be announced.

Co-requisite: AHS4063H.

Course outline: This course runs concurrently with AHS4063H Nursing the Critically Ill Child and includes guided clinical learning experiences and the development of critical care nursing skills. The aim is to develop clinical judgement and to equip the critical care nurse to practice independently in a variety of settings.

Fieldwork: Students are allocated to various health and critical care settings for children.

Assessment: Formative assessment contributes 50% of the final mark. The summative assessment contributes 50% of the final mark. Details of the formative assessment are given to the student at the beginning of the module. The summative assessment is externally moderated.

AHS4063H NURSING THE CRITICALLY ILL CHILD

Course convenor: To be announced.

Co-requisite: AHS4061H.

APPENDIX F

the critical care nurse. The course also explores the effects of the economic environment on patient care and the implication for nursing practice; effects of sensory alterations, including stressors for patients and staff, sensory overload and deprivation, sleep and rest disturbances in the critical care unit; **the dying process and death**; immobility in critically ill adults, including pain management, wound healing and altered body image; communication and interventions that improve communication; effects of occupational hazards and legal and ethical aspects of practice.

DP requirements: (a) Two-thirds of contact time; (b) all of the time on task activities, assignments and clinical learning activities prescribed per course; and (c) a minimum of 50% of hours of clinical learning activities to be completed prior to the summative clinical examination in October/November of the year of examination.

Assessment: Continuous coursework assessment contributes 40% towards the final mark. The final summative assessment contributes 60% towards the final mark and the pass mark is 50%.

Understanding the Allegory of the Cave

Humans are Prisoners in a Cave

According to Plato's allegory of the cave, the way we perceive things around us and the way we lead our lives, is actually not the "truth." We human beings are leading ignorant, incomplete lives, following the paths, rules, norms, ethics, set by the previous generations, without questioning them. Plato brings up this plight of humans by depicting them as prisoners in a cave. These prisoners are sitting facing a wall, tied in chains, with a fire between them and the wall, which makes shadows on the wall. The prisoners mistakenly think that these shadows on the walls are the "reality," because that is what the fellow prisoners or the ones before them conveyed.

Questioner Escapes to Explore the "Truth"

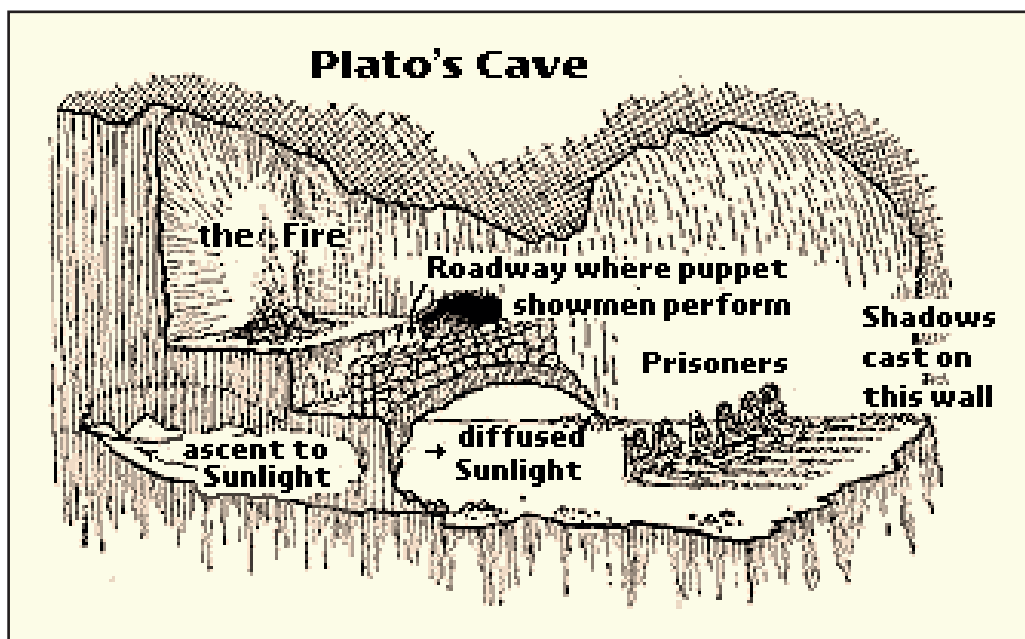
Generations come and generations go and the prisoners lead the same unaware and ignorant lives in the dark caves, until one of the prisoners starts questioning. This prisoner breaks the chains that bind him and in order to know the real truth, escapes the caves into the unknown world. In the outside world, this questioner faces lots of challenges as he is not used to the sunlight, to the presence of nature and all its elements around him. The questioner, in spite of these obstacles, starts exploring this new world to seek reality. He treads on a lonely, unknown path to discover the truth, but does not give up his questioning spirit.

Philosopher Returns to Guide

At some point, this questioner, thinks of going back to the caves to tell the other prisoners about the reality. To tell them that there is a beautiful world out there, waiting for them, and that there is more to life than just the cave and its "imaginary reality" as depicted by the shadows. When the questioner, now a philosopher, shares this new found knowledge with the other captives of the cave, he is met with disbelief. People think of him as a pariah who should be removed from the society, to preserve its belief systems. People are averse to any kind of change, which the philosopher tries to bring about with his knowledge of the real truth, as they have become used to and dependent on the norms and ethics, handed over to them by their predecessors.

Through this, one can conclude that most of the human beings would rather live a comfortable, happy and familiar life, than a life full of challenges and pain, which would ultimately lead them to the “larger truths of life.” Most human beings are contented with the “consensus reality,” which is the reality i.e. the reality agreed by all, even if it is as imaginary and as unreal as the shadows on the walls of the cave. Humans are contented that they have the security of a family, of a society, of religion around them. However, according to Plato, there will come one questioner, one philosopher, from time to time, who will critically look at himself and the world around him, who will wonder why things are the way they are and then will make his own decisions regarding how things should be.

<http://www.silviaminguzzi.com/mfa/aesthetics-the-allegory-of-the-cave-in-plato-and-the-matrix/>



Great Dialogues of Plato. Signet Classics. 1999. New York, Warmingtton and Rouse.

STUDENT DRAWINGS

This is a collection of drawings done in class by the ICU nursing students' of their experiences of death and dying in ICU.

I have included these drawings to highlight the need for a study in this area.

Cultural/ritual experiences



Rituals in Kenya – Masai Tribe.

“The Masai fear death – when it does happen – women especially do not come to terms with it.

The community comes to help the bereaved. The body comes from the mortuary and stays overnight in the house guarded by the elders.

The following day is the burial, all family members view the body – women included. The body is cleansed. Milk cream is placed on the traditional chair with some green leaves and the family puts the milk cream on the head of the dead person. The body is then taken and buried in the middle of the cow-shed. For the head of the family it symbolises that he is still taking care of his cows even if he is dead since the Masai see cows as a sign of wealth.”



Rituals in Zambia – Tonga Tribe.

“When a husband/wife dies, the brother or sister of the deceased has to have sexual relations with the surviving spouse. This happens five days after the burial where the surviving spouse and brother or sister-in-law are put in a hut and made to have sex in the presence of two elderly people. But this is being discouraged now with HIV/AIDS.”



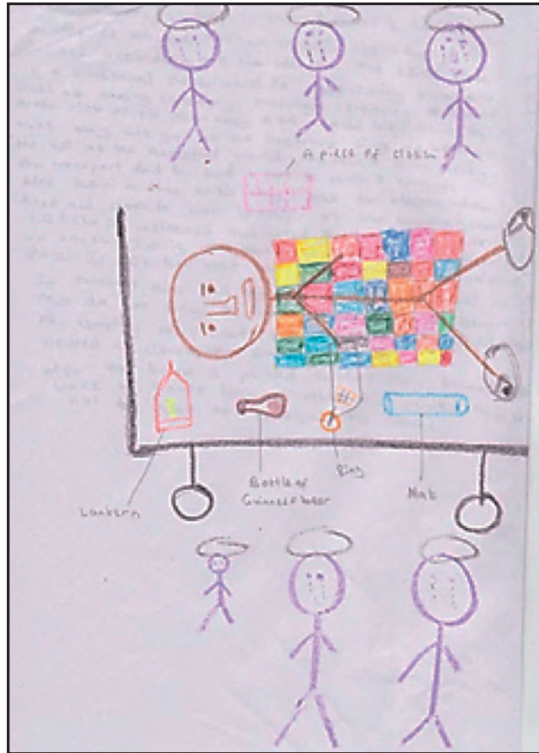
The Ebola Epidemic in Uganda.

“It was the Ebola epidemic in Uganda where everyone was in great fear of the disease and many doctors and nurses died.

Nursing care was difficult as there were little resources. The Medical Superintendent of the hospital contracted the disease and was admitted to a single room and all the available resources/care were given to him. He died and was properly shrouded.

Another patient just outside the room where the Medical Superintendent was also died. He did not receive any care and was still bleeding. He was just covered up with a piece of plastic.

This man should have been cared for and his death left us with a big shock. We were also angry.”



The Kente Cloth – Ashanti Culture in Ghana.

“When a person dies in the Ashanti culture, it depends on the person’s wealth how the deceased is dressed.

The Kente cloth is a traditional cloth which is used during occasions such as a naming ceremony, marriages and death of the wealthy.

We believe in the ancestral world. So money is given for transport, food in case he/she is hungry, a lantern to shine the way and a mat for sleeping with a cloth to cover him/herself.

At the ancestral world they are welcomed and asked questions about how good or bad they have been. If they were bad, they are beaten and if they are good they are rewarded a place.

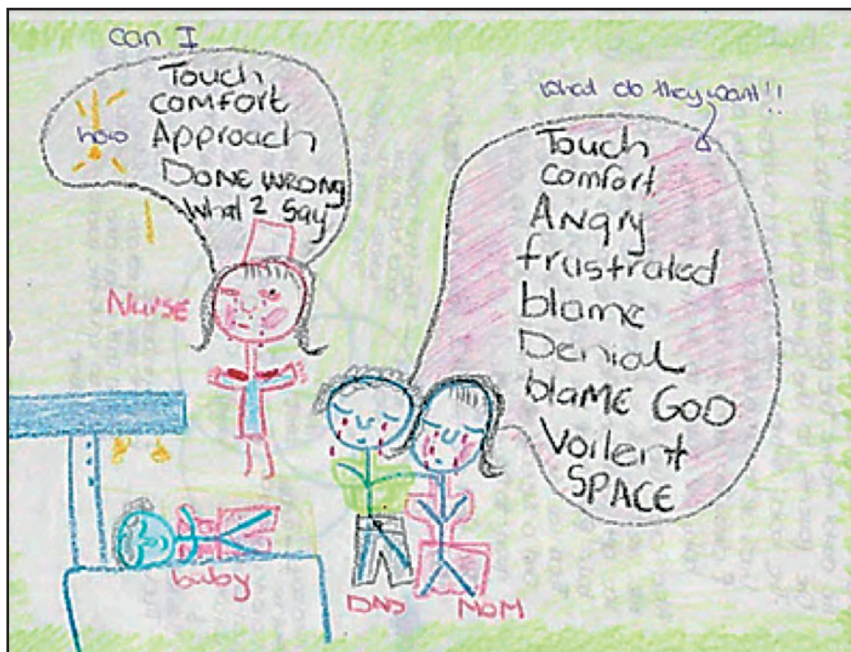
If someone dies an unnatural death, like if they die in hospital, the body is taken straight away to the cemetery to prevent further deaths or bad luck.

Also the house is painted so that they can recognise the house if they come back.”



A Kenyan nurse's perspective of death.

"When a child dies ... Africa cries ... and black rain pours down."



ICU Experiences



A paediatric nurse's experience of the death of a premature baby in the Neonatal ICU.

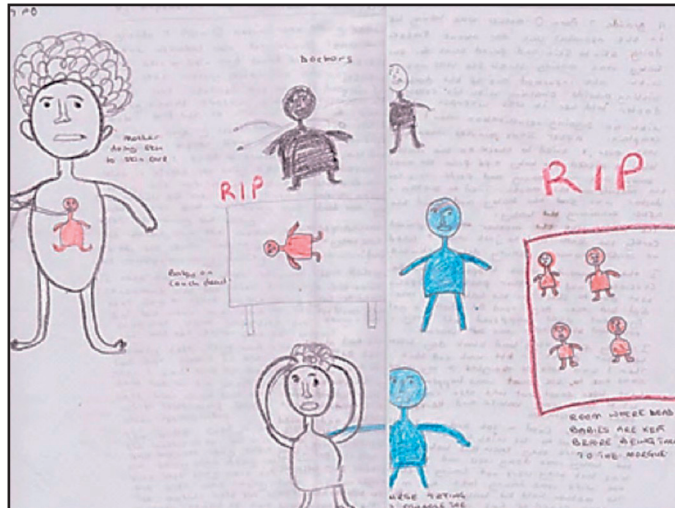
"A pre-term baby was admitted with necrotising enterocolitis⁴⁵ and was also HIV positive. Surgery was done but nothing further could be done for the baby.

The father did not know that the baby was HIV positive. Eventually the baby died. The father was very sad and was still looking at the other babies in the unit – he was asking why are the other babies alive and his is not.

The baby was then pushed to the mortuary on this big trolley.

I was very sad for the father because maybe the mother is taking anti- retrovirals and the husband is not. That is cruel and inhumane to do this to someone you love and trust.

⁴⁵. Necrotising enterocolitis (NEC) is a condition primarily affecting low birth weight or preterm infants. It is probably caused from lack of oxygen leading to infection and gangrene of the bowel.



A neonatal nurse from Ghana and her experience a death of a premature baby in the Neonatal ICU.

“This mother had had seven miscarriages and now had a preterm baby who she was caring for skin-to-skin. She noticed that her baby was not moving well.

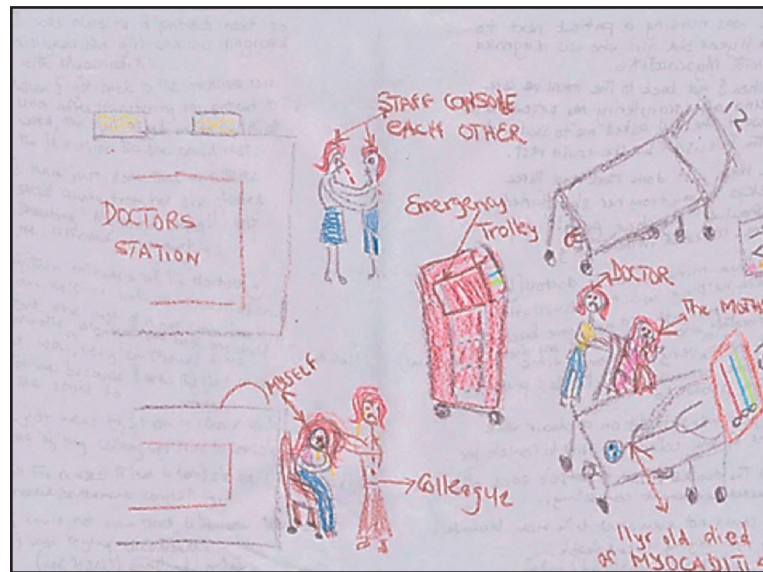
The mother told one of the doctors who was sitting outside the unit chatting and said that the baby was just having hiccoughs. I had overheard the conversation but was busy with a resus. When the resus was over, I went to check on the mother and baby. When I picked up the baby from the mother, I noticed that the baby was not moving and that the feed was coming out of the nose. I suctioned and called a doctor over who told me and the mother that the baby was dead.

The doctor who said that the baby had hiccoughs certified the death and wrote in the notes ‘called to see baby with no cardiopulmonary activity. Baby clinically dead.’

I documented what had happened and the next day the consultant read the nursing notes and the doctor was warned,

I felt really bad that day because we already had four deaths and this was the fifth one. I had lots of thoughts in my mind like ‘what if I had found the time to see what was happening and the baby could have been saved.’ But I was really busy with a resus and did not want to lose more babies and therefore concentrated on the resus.

The mother cried a lot. I left her to grieve until the baby was sent to the mortuary’.



A paediatric nurse's experience of the death of an 11 year old girl in the Paediatric ICU.

I was nursing and 11 year old girl with myocarditis⁴⁶.

I was transferring a patient from the ICU and when I got back, the little girl asked me to switch the TV on so that she could rest.

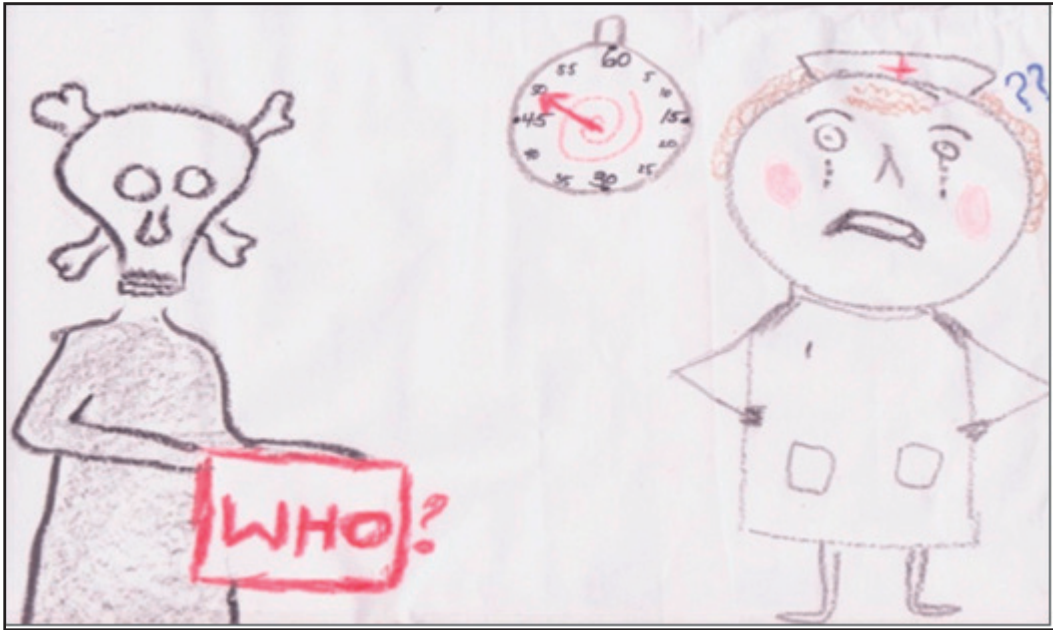
I had just moved away from her bed when she screamed "my chest pain. Help me." She arrested soon after that.

Within minutes all the doctors were helping with the resus, but she did not come back.

Her mother was hysterical and shouting "come back my child."

It was a very emotional time for me as I was the last one that she had spoken to. I sat on the chair while one of my colleagues consoled me. I could not even speak to the mom because I was crying uncontrollably.

⁴⁶. Inflammation of the myocardium as a result of a viral infection or rheumatic fever.



'You come on duty and think who will die today?

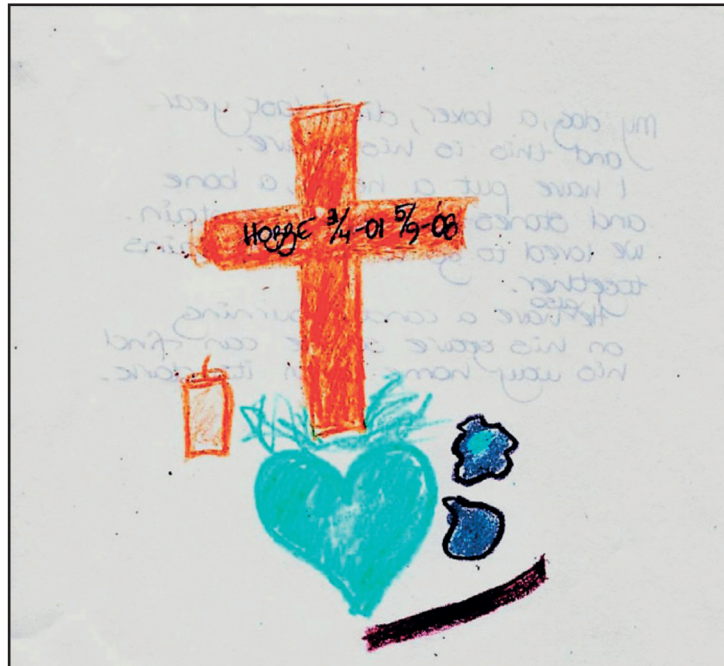
Whose turn is it? I'm just so tired.'

Swedish ICU nurses' experiences of death and dying.

Seminar Jönköping University in Sweden and Ersta Sköndal University College,
Stockholm – sabbatical October 2009.



“We (Muslims) don’t cry because then the soul can’t pass to the other side. Even if my family were victims of ethnic cleansing in Bosnia.”



“My dog died last year.

This is his grave. I have put a heart, a bone and stones from the mountain. We loved to go to the mountains together.

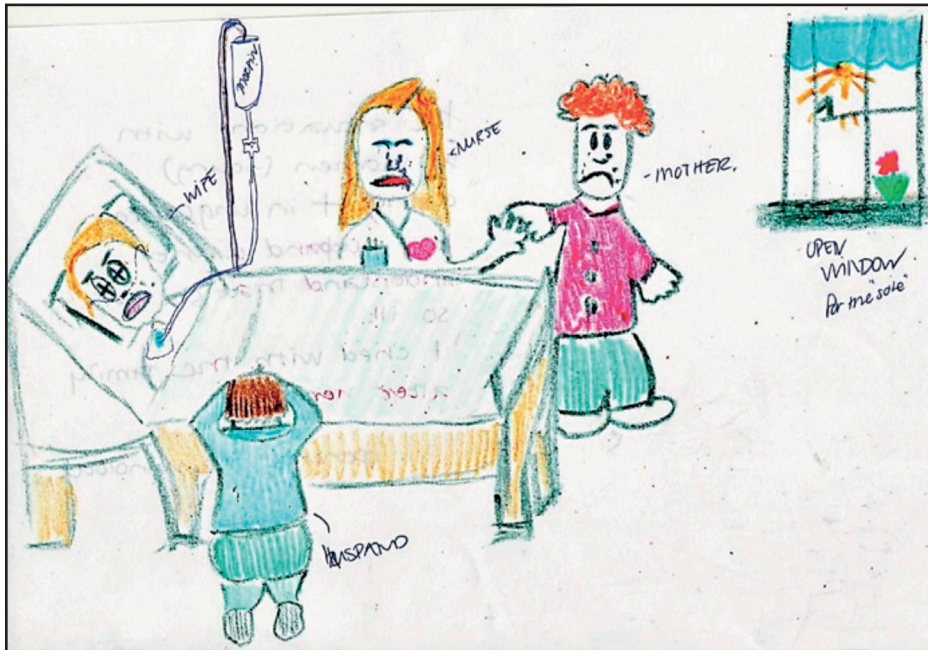
We also have a candle burning on his grave so that he can find his way home when it is dark.”



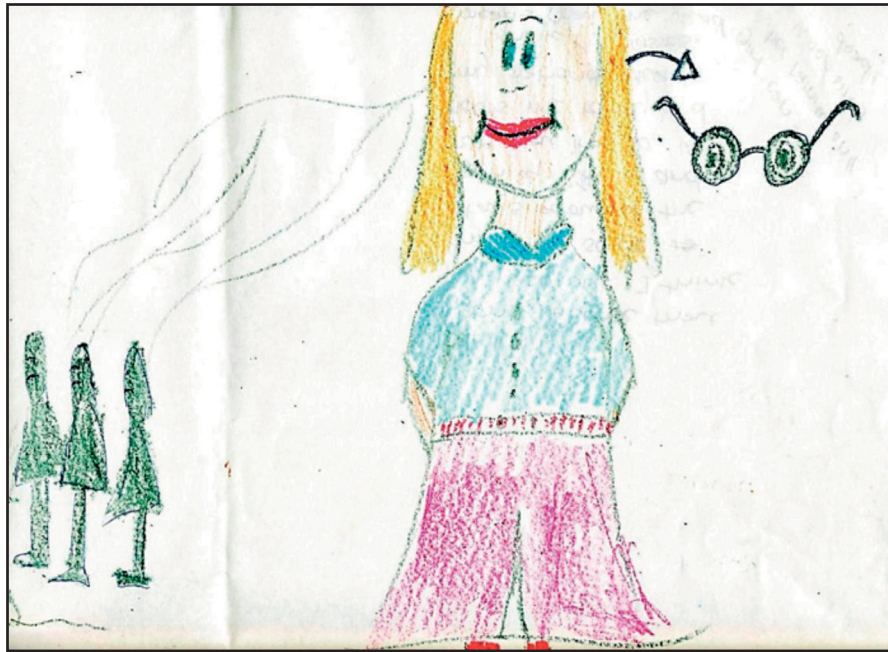
Window is open so that the soul can go out.

“My Mom died eight years ago in a hospice. It’s my brother, his baby, our father and our dog. We had a nurse looking after her. My Mom loved purple.”





“A young woman dying with lung cancer. Her husband did not realise that she was so ill. I cried with the family after her death ... opened the window.”



“I don’t believe that you just die. I think that the soul stays around the family. I hope that this is so. It helps me cope when my patients die. I think the glasses means that the dead girl can see her family still.”

USEFUL RESOURCES

- **Association for Death Education and Counselling.**

www.adec.org

The Association for Death Education and Counselling envisions a world in which dying, death, and bereavement are recognized as fundamental and significant aspects of the human experience. Therefore, the Association, ever committed to being on the forefront of thanatology (the study of death and dying), will provide a home for professionals from diverse backgrounds to advance the body of knowledge and to promote practical applications of research and theory.

- **The End-of-Life Nursing Education Consortium (ELNEC).**

www.aacn.nche.edu/elneec

The ELNEC project is a national education initiative to improve palliative care. The project provides undergraduate and graduate nursing faculty, CE providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in palliative care so they can teach this essential information to nursing students and practicing nurses. ELNEC-Core content is divided into eight modules: Nursing Care at the End of Life; Pain Management; Symptom Management; Ethical/Legal Issues; Cultural Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement; and Preparation for and Care at the Time of Death.

- **Toolkit for Nurturing Excellence at End-of-Life Transition (TNEEL).**

www.uic.edu/tneel.asp

TNEEL is an innovative, easy-to-access, teacher/learner-friendly package of electronic tools for palliative care education. TNEEL includes topics such as:

- Comfort goals and preferences
- Assessment and management of pain and other symptoms
- Signs and symptoms of approaching death
- Decision-making at the end of life
- Communications and relationships supporting patient and family-centered care at the end-of-life transition
- Grief, loss, and bereavement

- Hope and well being
- Complementary comfort therapies
- Spiritual and psychosocial needs
- Impact of dying (epidemiology, economics, service delivery systems, and resource utilisation at end of life)
- Cultural, ethical, legal and quality of life concerns at this life-stage. The content is organised as a teaching portfolio including:
- Student learning objectives
- Myths (misconceptions and assumptions)
- Definitions (verbal and image/sounds)
- Pre-assessment items (attitudes and belief questionnaires for self-reflection)
- Teaching materials (lecture outline; PowerPoint slides [1000 slides])
- Speaker notes and tips for each slide; audio (184 clips), video (56 clips), graphical exemplars for the content; photos of patients, family, health team members
- Action videos and sounds to demonstrate effective and ineffective communication techniques
- Conflict resolution, collaboration between nurses and other team members
- Case studies; images and sounds to demonstrate anatomy, physiology, and pathophysiology concepts;
- Case studies (written, narrated, movie clips) for problem based learning; standardised patient scenarios

- **Best Endings.**

www.bestendings.com

Dying and death can be hard to think about and even harder to talk about. But if you become too ill or too injured to direct your own care at the end of life, someone else makes those decisions for you. Best Endings is a safe place to learn at your own pace about medical interventions, and to think through what's important to you.

- **Deaths and Mortality.**

www.cdc.gov/nchs/faststats/death.htm

This website includes death and mortality statistics provided by the Centers for Disease Control and Prevention. The statistics are reliable, regularly updated and include figures dating back to 2002.

- **Centre for Thanatology Research & Education.**

www.thanatology.org

CTRE is a non-profit niche publisher and resource centre specializing in thanatological concerns. Their 'Death & Dying Studies' sub-page includes a list of recommended thanatology texts that are updated quarterly. As well, their FAQ section provides a list of North American schools offering thanatology degree programs.

- **Medline Plus – End of Life Issues.**

www.nlm.nih.gov/medlineplus/endoflifeissues.html

Medline plus is a service of the National Library of Medicine. Of particular importance are the 'Research' and 'Reference Shelf' sections which provide students with resources fit for use in essays or academic papers.

- **Growth House.Inc.**

www.growthhouse.org

This is a portal site for life-threatening illnesses and end-of-life care. It contains a powerful search engine which allows for very precise and targeted searching. There are also a variety of e-books available through this website.

- **The National Hospice and Palliative Care Organization (NHPCO).**

www.nhpco.org

The National Hospice and Palliative Care Organization was founded in 1978 as the National Hospice Organization. The organization changed its name in February 2000 to include palliative care. Many hospice care programs added palliative care to their names to reflect the range of care and services they provide, as hospice care and palliative care share the same core values and philosophies. Defined by the World Health Organization in 1990, palliative care seeks to address not only physical pain, but also emotional, social, and spiritual

pain to achieve the best possible quality of life for patients and their families. Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. To better serve individuals who have advanced illness or are terminally ill and their families, many hospice programs encourage access to care earlier in the illness or disease process. Health care professionals who specialize in hospice and palliative care work closely with staff and volunteers to address all the symptoms of illness, with the aim of promoting comfort and dignity.

- **Organ Donor Foundation of South Africa.**

www.odf.org.za

- **Encyclopaedia of Death and Dying.**

www.deathreference.com

- **Five Wishes.**

www.agingwithdignity.org/5wishes.html

Five Wishes is an easy to use legal document written in everyday language that lets adults of all ages plan how they want to be cared for in case they become seriously ill. It is America's most popular living will with more than 18 million copies in circulation.

Five Wishes helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. It is unique among all other living will and health agent forms because it speaks to all a person's needs: medical, personal, emotional and spiritual. Five Wishes also helps structure discussions with your family and physician.