ICU NURSES IN KWAZULU-NATAL: LIVED EXPERIENCE OF END-OF-LIFE DECISIONS

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DECLARATION

I, Cheryl Carter, declare that this dissertation entitled ***"ICU nurses in KwaZulu-Natal: lived experience of end-of-life decision making"*** is my own work. I have not submitted this work or part thereof for a degree at any other university. All the sources used or quoted from have been acknowledged by means of complete reference.

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DEDICATION

This dissertation is dedicated to my parents and all ICU nurses wherever you are.

To my parents, without your continual love and support I would never have been able to succeed. Thank you from the bottom of my heart.

To all ICU nurses' keep the faith and know that someone does care.

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ABSTRACT

Aim. To describe and interpret the experiences of ICU nurses' when dealing with withdrawing and withholding treatment associated with the Do Not Resuscitate/Allow Natural Death order.

Background. End-of-life decisions are frequently made based on the principle of medical futility resulting in therapy being withdrawn or withheld. Nursing staff end up dealing with the aftermath of such decisions. When conflict exists between medical and nursing staff regarding these decisions, it results in moral distress. When referring to this DNR process there has been a proposed change to the terminology be used from Do Not Resuscitate to Allow Natural Death (AND).

Methodology. Heideggerain's phenomenological approach was used during the research process. Data was obtained through interviewing seven ICU trained professional nurses. Data was analysed using Tesch's analysis process to identify meaningful segments and develop categories, themes and sub-themes.

Findings. The DNR process was frequently described as traumatic by participants, especially when dealing with the dying patient's family. Participants described feelings of empathy towards patients and their families, especially if there was something with which the participants could identify. The importance of cultural practices and permitting death rituals was revealed. Participants described the need to be involved in the end-of-life decision-making process, and the importance of being part of communications with the patient's family. Barriers to communicating with the patient's family were described in

terms of reservations and the social standing of nurses. How participants accept DNR decisions is dependent on timing and the level of experience, while their willingness to be actively involved in withdrawing therapy was dependent on how involved they had been in the decision-making process and experience level. The main source of emotional support was described as the shared experience, with formal support systems being viewed with distrust. Coping strategies emerged as talking about experiences, rationalisation/understanding and suppression and detachment. Mixed opinions were expressed regarding the use of AND when referring to the DNR process with participants either viewing this as just a change in words, or a positive focus on what would be done rather than what would not be done for the patient.

Recommendations. Recommendations have been suggested for both educators and employers regarding equipping and supporting nurses faced with death and dying. A collaborative approach to decision making needs to be taken when considering end-of-life issues to ensure effective communication, and to decrease moral distress on the part of ICU nurses. The use of the term AND when discussing end-of-life issues requires further exploration.

TABLE OF CONTENTS **PAGE**

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND……1

1.2 PROBLEM STATEMENT…….6

1.3 PURPOSE OF STUDY……...7

1.4 RESEARCH OBJECTIVES……7

1.5 RESEARCH QUESTIONS…….7

1.6 OPERATIONAL DEFINITIONS……...8

1.7 SIGNIFICANCE OF STUDY…….9

1.8 CONCLUSION……..10

CHAPTER 2: RESEARCH METHODOLOGY

2.1 INTRODUCTION……..12

2.2 PHILOSOPHICAL FRAMEWORK……..12

i) Descriptive phenomenology ……...13

ii) Interpretive phenomenology……14

iii) Analytical phenomenology……..15

2.3 RESEARCH APPROACH……..15

2.3.1 Background……...17

2.3.2 Pre-understanding…….17

2.3.3 Co-constitution…….18

2.3.4 Interpretation……19

2.3.5 Hermeneutic circle……19

2.4 SETTING……..20

2.5 PARTICIPANTS……..21

2.6 DATA COLLECTION…….22

2.7 TRUSTWORTHINESS…….25

2.7.1 Credibility……..25

i) Prolonged engagement and persistent observation……....25

ii) Triangulation……..26

iii) Member checking……...27

2.7.2 Dependability…….27

2.7.3 Confirmability……....27

2.7.4 Transferability……....28

2.8 DATA MANAGEMENT……28

2.9 DATA ANALYSIS…….29

2.10 ETHICAL ISSUES…….....31

i) Independent review……..31

ii) Informed consent…….32

iii) Respect for recruited participants……32

iv) Favourable risk-benefit ratio……33

v) Scientific validity…….33

vi) Fair selection of study participants……..33

vii) Social value……..33

2.11 CONCLUSION……34

CHAPTER 3: LITERATURE REVIEW

3.1 INTRODUCTION……...35

3.2 DEATH AND DYING…….36

3.2.1 Death in society……....36

3.2.2 Dying in ICU……38

3.3 THE DNR ORDER: WITHDRAWING AND WITHHOLDING THERAPY……40

3.3.1 The DNR order…….40

3.3.2 The DNR decision-making process……..…….....43

3.3.3 Communication as part of the DNR process…….…….……..44

3.3.4 Allow Natural Death vs. Do Not Resuscitate…….…….....47

3.4 THE EMOTIONAL IMPACT OF DEATH ON THE ICU NURSE……...48

3.4.1 Grief and moral distress…….…..…….....48

3.4.2 A "Good Death"…..…….....52

3.5 SUPPORT SYSTEMS FOR ICU NURSES…….53

3.5.1 Informal support……...53

3.5.2 Formal support……..53

3.6 CONCLUSION…….54

CHAPTER 4: PRESENTATION OF THE RESULTS OF THE STUDY

4.1 INTRODUCTION…….……...55

4.2 RESEARCH FINDINGS……..55

4.2.1 PARTICIPANTS' PROFILES…….……56

4.2.2 RESEARCH FINDINGS ACCORDING TO CATEGORIES, THEMES AND SUB-THEMES…….....57

4.2.2.1 CATEGORY 1: THE IMPACT OF DEATH AND DYING ON THE ICU NURSE…….59

4.2.2.1.1 Theme 1: Dealing with the Family……..59

i) Sub-theme 1.1: Grief……60

ii) Sub-theme 1.2: Empathy……...61

iii) Sub-theme 1.3: Being human vs. professionalism…..……..63

iv) Sub-theme 1.4: No family available…….……..……..64

4.2.2.1.2 Theme 2: Cultural clash…….....65

i) Sub-theme 2.1: Cultural practices and death rituals…….65

4.2.2.2 CATEGORY 2: COMMUNICATION IN THE DNR DECISION……..….67

4.2.2.2.1 Theme 1: Making the decision…….…..67

i) Sub-theme 1.1: Our opinion should count…….…..67

ii) Sub-theme 1.2: Medical decision…….……71

iii) Sub-theme 1.3: Breaking the news……...72

iv) Sub-theme 1.4: Taking the brunt……..75

4.2.2.2.2 THEME 2: BARRIERS TO COMMUNICATION…….……..76

i) Sub-theme 2.1: Reservations and blame……..76

ii) Sub-theme 2.2: More receptive to doctors……..……77

4.2.2.3 CATEGORY 3: ACCEPTING THE DNR ORDER…….78

4.2.2.3.1 Theme 1: Timing……78

4.2.2.3.2 Theme 2: Experience vs. inexperience……...81

4.2.2.3.3 Theme 3: Conflict in carrying out the order……...83

4.2.2.4 CATEGORY 4: SUPPORT SYSTEMS AND COPING STRATEGIES…..85

4.2.2.4.1 Theme 1: Informal support…….……86

i) Sub-theme 1.1: Shared experiences……..86

ii) Sub-theme 1.2: Family and friends……..89

iii) Sub-theme 1.3: Medical colleagues…….91

4.2.2.4.2 Theme 2: Formal support……..…...92

i) Sub-theme 2.1: Nobody cares about us……92

4.2.2.4.3 Theme 3: Coping strategies……93

i) Sub-theme 3.1: Talking about the experience……..94

ii) Sub-theme 3.2: Rationalisation/understanding…….94

iii) Sub-theme 3.3: Suppression and detachment……95

4.2.2.5 CATEGORY 5: NAMING THE DNR PROCESS……..97

4.2.2.5.1 Theme 1: Just words…….97

4.2.2.5.2 Theme 2: More human vs. don't help them…….....98

4.3 CONCLUSION……..…….…….....98

CHAPTER 5: DISCUSSION OF THE MAJOR FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

5.1 INTRODUCTION……99

5.2 THE IMPACT OF DEATH AND DYING ON THE ICU NURSE…….....100

5.2.1 Dealing with the family……..…100

5.2.1.1 Grief……100

5.2.1.2 Empathy……..101

5.2.1.3 Being human vs. professionalism……...102

5.2.1.4 No family available…….....103

5.2.2 Culture clash……104

5.2.2.1 Cultural practices and death rituals……...……..104

5.3 COMMUNICATION IN THE DNR PROCESS……...105

5.3.1 Making the decision……...106

5.3.1.1 Our opinion should count…….....106

5.3.1.2 Medical decision……109

5.3.1.3 Breaking the news…….…….....111

5.3.1.4 Taking the brunt…….……112

5.3.2 Barriers to communication…….……113

5.3.2.1 Reservations and blame…….……..113

5.3.2.2 More receptive to doctors……114

5.4 ACCEPTING THE DECISION…….....115

5.4.1 Timing……...……..115

5.4.2 Experience vs. inexperience……..……..…116

5.4.3 Conflict in carrying out the order……....117

5.5 SUPPORT SYSTEMS AND COPING STRATEGIES…….....118

5.5.1 Informal support……..118

5.5.1.1 Shared experiences……..118

5.5.1.2 Family and friends…….…..119

5.5.1.3 Medical colleagues……..120

5.5.2 Formal support……....121

5.5.2.1 Nobody cares about us……....121

5.5.3 Coping strategies……...……..121

5.5.3.1 Talking about the experience……...121

5.5.3.2 Rationalisation/understanding……...…….....122

5.5.3.3 Suppression and detachment……..…....122

5.6 NAMING THE DNR PROCESS……..…….124

5.7 CONCLUSIONS OF THE STUDY……...125

5.8 RECOMMENDATIONS……126

5.8.1 The Impact of death and dying on the ICU nurse…….....127

5.8.2 Communication in the DNR decision…….....128

5.8.3 Accepting the DNR order……130

5.8.4 Support systems and coping strategies……130

5.8.5 Recommendations for future research…….131

5.9 LIMITATIONS..……..……...……131

5.10 CONCLUSION…….....132

LIST OF REFERENCES……..133

LIST OF ANNEXURES **PAGE**

ANNEXURE A: PARTICIPANT INTERVIEW GUIDE……....138

ANNEXURE B: ETHICAL CLEARANCE FROM UNIVERSITY OF KWAZULU-NATAL HUMANITIES AND SOCIAL SCIENCE ETHICS COMMITTEE ……..139

ANNEXURE C: HOSPITAL LETTER OF SUOPPORT FOR STUDY AND REQUEST FOR DEPARTMENT OF HEALTH APPROVAL…….140

ANNEXURE D: KWAZULU-NATAL DEPARTMENT OF HEALTH APPROVAL FOR STUDY…….……....141

ANNEXURE E: PARTICIPANT INFORMATION SHEET AND INFORMED CONSENT……142

ANNEXURE F: SAMPLE OF IN-DEPTH INTERVIEW WITH PARTICIPANT…144

ANNEXURE G: EXCERPTS FROM RESEARCHERS REFLECTIVE JOURNAL.165

LIST OF TABLES **PAGE**

TABLE 2.1: PARTICIPANT INCLUSION EXCLUSION CRITERIA……21

TABLE 4.1: PARTICIPANT DEMOGRAPHICS…….56

TABLE 4.2: CATEGORIES, THEMES AND SUB-THEMES…….58

LIST OF FIGURES

FIGURE 2.1: DIAGRAMATIC INTERPRETATION OF THE HERMENEUTIC CIRCLE……20

LIST OF ABBREVIATIONS

ICU Intensive Care Unit

DNR Do Not Resuscitate

AND Allow Natural Death

CPR Cardiopulmonary Resuscitation

EAP Employee Assistance Programme

CHAPTER 1:

INTRODUCTION

1.1 BACKGROUND

Intensive Care Units (ICU) are places where science and technology reign supreme, extending life beyond what nature would consider the normal life-span of the human being. The development of sophisticated life sustaining therapies has resulted in life being prolonged where it was not previously possible (McDermid and Bagshaw, 2009). However, ICU mortality rates, despite these advances in medicine and technology have remained at approximately 20%, and may be as high as 40% in some sub-groups (Knaus, et al. 1986, quoted in Langley and Schmollgruber, 2006). It has been estimated that 90% of deaths in ICU occur after the decision to limit therapy (Truog, Cist, Bracket, Burns and Curley, 2001).

The ICU staff face many ethical dilemmas, not least of them the end-of-life issue which Thelan (2005) describes as the most frequently experienced ethical problem encountered in clinical practice. End-of-life decision-making in the ICU is particularly difficult where the goal is seen to be the sustaining of life (Chang, Huang and Lin, 2010). Thus instituting the withdrawal or withholding of treatment in the ICU creates moral dilemmas for doctors and morale distress for ICU nurses (Oberle and Hughes, 2001).

When considering end-of-life decisions in the ICU, the ethical principles of autonomy, beneficence and non-malefience apply. Autonomy is perhaps one of the

most important ethical principles applied when decisions are made regarding the health of the individual. This principle implies the right of the individual to determine his/her own destiny, including making decisions about refusing and agreeing to treatment relating to the individual's own health, or in this instance his/her death.

In the setting of the ICU, the patient is frequently unable to make autonomous decisions due to the nature of his/her disease process, level of consciousness, etc. In developed countries such as the USA and the United Kingdom, decisions regarding end-of-life issues in the ICU are made in consultation with family or surrogate decision-makers taking into account the desires of the patient 60-80% of the time (Thelan, 2005; Chang, Huang and Lin, 2010). When applying the principles of beneficence and non-maleficence, the best interests of the patient remain paramount, and result in balancing therapies that, if continued, will benefit the patient versus continuing ineffective therapies that may cause distress and discomfort to the patient and inevitably prolong death (Vincent, 2005).

In addition to the previously described principles, the principle of what Savory and Marco (2009) describe as "stewardship of resources" is also applied when making end-of-life decisions. ICU services internationally, for different reasons, are exceeded by the demand for them, resulting in patients being accepted into the ICU or denied access to the ICU based on perceived benefits or physicians rationing ICU access at the bedside (McDermid and Bagshaw, 2009). These authors go on to

describe the ICU challenge of being able to provide "limited and expensive therapy for patients who will most likely benefit, whilst at the same time avoiding prolonged treatment in those patients who will not." (pp. 2).

In the South African context, the ICU is a scarce resource, with only 23% of public hospitals having ICU facilities (Bhagwangee and Scribante, 2007). Even in those hospitals that have these facilities available, they are often limited due to staff and resources shortages. Thus this scarce resource is placed under increasing pressure which is compounded by the increased severity of illness due to delays in treatment at many levels (Hodgson, 2006). The ICU thus needs to be reserved for those patients who will benefit from its service. This results in intensivists making decisions that maximize the utility of the resources. Doctors therefore rely on their expertise and professional and ethical knowledge (Langley and Schmollgruber, 2006) to make these decisions, taking into account the best interests of the patient.

In this context, providing ICU therapy for the dying patient would prevent maximal use of this scarce resource, and potentially prevent the service being utilised by a patient with a chance of survival (Hodgson, 2006). Thus the provision of futile care is one of the criteria used when making decisions regarding end-of-life issues in the ICU. Hodgson (2006, pp.73) defines futility in the ICU, as "the withdrawal of therapy in patients who are failing to respond to intensive interventions". This withdrawal or withholding of treatment in the ICU is commonly referred to as the Do Not Resuscitate (DNR) order. The implication of this order is dependent on the

individual patient, and may range from no further escalation of treatment, withholding treatment such as ventilation or inotropic support to the withdrawal of those same treatments. The frequent outcome of such a decision is the death of the patient (Ferrand, Robert, Ingrand and Lemaine, 2001).

Furthermore, the term DNR has negative connotations as it focuses on what will not be done rather than on what care will be provided (Pantilat, 2009; Wittmann-Price and Celia, 2010). Current discussions are aimed at finding a term that is potentially psychologically more acceptable. To this end the term Allow Natural Death (AND) has been proposed as an alternative (Knox and Vereb, 2005; Wittmann-Price and Celia, 2010). This change in terminology is meant to humanise the process of end-of-life decision-making and assist healthcare workers when communicating with patients and family members.

Although these decisions are most frequently made by the consultant in charge of the unit, after consultation with the family where possible, it is the nursing staff that are left to deal with the family, providing support, explanations and comfort (Thiabault-Prevost, Jensen and Hodgins, 2000; Oberle and Hughes, 2001). Furthermore, nurses may in fact disagree with the decision, as they may believe that treatment may have been stopped too soon, or continued for too long, or in fact that they have to act against their conscience (Oberle and Hughes, 2001).

Dealing with the family of the ICU patient once a DNR order has been executed can be particularly stressful, even when extensive consultation has occurred with

family members. Families frequently fail to differentiate between technological support to maintain body functions and those which save a life (Kaufmann, 1998). Indeed, it is the nurse who intimately and actively deals with the consequences of the DNR order i.e. the death of the patient. Nurses experience moral distress when faced with the dying patient, and express fears about prolonging death and causing suffering by inflicting pain during procedures on dying patients as part of the treatment (Dracup and Bryan-Brown, 2005).

South Africa is a diverse country with many diverse cultures and religions, and may thus reflect differing attitudes etc. to those expressed in the literature. Several South African studies were reviewed on the quality of death in the ICU and end-of-life issues in the ICU (Fouché, 2006; Langley and Schmollgrubber, 2006). These highlighted the nurses' priorities when managing death in the ICU and the ethical issues surrounding end-of-life issues, or outlined the decision-making process used prior to a DNR/AND order (Hodgson, 2006). A South African study exploring the influence that violent death has on emergency room nurses was also reviewed (Brysiewicz, 2002). Although this study did not involve ICU nurses, the experiences of the emergency nurse when dealing with death appear to have relevance to the ICU context.

The attitudes that are prevalent in South African society today will obviously impact on the way nurses, working in the ICU experience death and dying in relation to the DNR/AND order. Little is known about how nurses working in South African ICUs experience the DNR process, what coping strategies are

utilised, what support is available, or indeed how they perceive the proposed change in terminology when discussing the DNR order. This study seeks to explore these issues.

1.2. PROBLEM STATEMENT

The Intensive Care Unit is an environment of technology and science. In this context, expectations exist in both healthcare professionals and the general public with regards to saving lives However, ICU mortality rates have remained at approximately 20%, and may be as high as 40% in some sub-groups (Knaus, et al. !986, as cited in Langley and Schmollgruber 2006, pp. 58). In fact, internationally, up to 90% of deaths occur in the ICU as a result of decisions to withdraw or withhold treatment (Truog, et al., 2001). It is the ICU nurse who deals with the end result of these decisions. These decisions and their aftermath cause emotional and moral distress to ICU nurses (Thiabault-Prevost, Jensen and Hodgins, 2000; Oberle and Hughes, 2001). Hay and Oken (1972) identify that the quality of care patients receive and their outcomes rely on the people providing the care, i.e. the nurses. These authors go on to explain that this care is a product of the nurses psychological state as much as technical expertise, yet compare the psychological burdens that nurses endure in the ICU to those experienced by soldiers in an elite combat group. If this description is fact, then provision of psychological support to nurses working in the ICU should be paramount, yet Shorter and Stayt (2009) reveal that nurses, in principle agree that formal support would be a “good idea”, however they do not access these services even when they are available.

1.3. PURPOSE OF STUDY

To describe and interpret the experiences of nurses working in a public sector Intensive Care Unit (ICU), when dealing with withdrawing or withholding of treatment associated with the Do Not Resuscitate Order/Allow Natural Death order.

1.4. RESEARCH OBJECTIVES

- To describe and interpret the experiences and of ICU nurses when dealing with the Do Not Resuscitate/Allow Natural Death order
- To describe and interpret of psychosocial support and coping strategies among ICU nurses when dealing with the Do Not Resuscitate/Allow Natural Death order
- To establish the preference for the terminology used to describe the Do Not Resuscitate/Allow Natural Death process

1.5. RESEARCH QUESTIONS

- What are the experiences of ICU nurses when dealing with Do Not Resuscitate/Allow Natural Death orders?
- What are the psychosocial support experiences and coping strategies utilised among ICU nurses when dealing with Do Not Resuscitate/Allow Natural Death orders?
- What are the preferences for the terminology used to describe the Do Not Resuscitate/Allow Natural Death process?

1.6. OPERATIONAL DEFINITIONS

- End-of-life-decisions – In the context of this study, this refers specifically to the Do Not Resuscitate order which precedes withdrawing or withholding treatment in the context of the Intensive Care Unit.
- Do Not Resuscitate (DNR) – Traditionally, the DNR order states that CPR (cardio pulmonary resuscitation) is not to be initiated if breathing stops or the heart stops beating. However, in the context of this study the DNR order is defined as the decision taken by the ICU consultant, after discussion with the multidisciplinary team and the patient's family, where applicable, when further treatment is deemed futile. It incorporates either withdrawing or withholding treatment.
- Withholding treatment – Treatment is maintained at the level it was when the decision was taken, but is not to be increased further, i.e. no further escalation of treatment which could include maintenance of ventilation settings with no increase of levels of support; no addition of inotropic support if the patient becomes hypotensive, etc. Analgesia and sedation are maintained, and all nursing care is rendered as usual.
- Withdrawing treatment – Life-sustaining treatment is to be withdrawn as ordered, e.g. decreasing or removal of ventilator support, inotropic support, etc. Analgesia and sedation are maintained, and all nursing care is rendered as usual.
- ICU trained nursing staff – Registered nurses who have completed an additional qualification in the field of Critical Care Nursing Science, e.g. Diploma;

Master's level; according to Regulation R212 of the South African Nursing Council.

1.7. SIGNIFICANCE OF STUDY

The literature contains a plethora of research regarding death and dying, especially in the realms of palliative medicine. In recent years, interest in the experience of death and dying in the ICU has gained momentum, with studies being conducted which focus on the quality of death in the ICU for the patients and family, as well as the nursing staff. Several studies have been conducted in first world countries regarding ICU nurses when dealing with death, using both a quantitative and qualitative approach (Thibault-Prevost, Jensen and Hodgins, 2000; Halcomb, Daly, Jackson and Davidson, 2004; Giles and Moule, 2004; McMillen, 2008). These studies provide information regarding the experiences of nurses in first world countries, where the ICU patient population in general consists of the older patient with a chronic disease process, and a culture that encourages family participation in end-of-life decision-making. South African ICUs, on the other hand, serve a generally younger population group with trauma and acute disease processes frequently being the reason for admission to the ICU. At the same time, the diverse cultures and educational extremes, as well as the severe lack of resources results in a different milieu in which the ICU nurse practices and experiences end-of-life decision-making.

This research thus hopes to discover information regarding the relationship between the DNR order and the nurses' experiences of dying in the ICU, and to provide insight and understanding of the phenomena in the South African context. It is

hoped this may assist in the development of support and coping strategies for nurses working in the ICU environment when dealing with death and dying, and inform institutions and curriculum development for critical care students regarding these issues.

1.8 CONCLUSION

This chapter outlined the background to the study and identified problems that it is hoped will be explored. The research purpose, objectives and questions, operational definitions and the significance of the study were also elaborated on.

Subsequent chapters will address the following topics: -

- Chapter 2 – describes the methodology utilised in the study. The philosophical framework of the phenomenologists is explained, and the hermeneutic approach that is applied during the study is expanded upon. This chapter includes descriptions of the setting, selection of participants, data collection, data analysis and ethical issues.
- Chapter 3 – reviews the literature relating to the topic under study and includes views on death and dying in society, as well as the ICU, the DNR process, the emotional impact DNR orders have on the ICU nurse, and the support systems and coping strategies employed in the ICU.
- Chapter 4 – provides the findings of the study and identifies the themes and sub-themes that emerged. These themes and sub-themes are discussed under the following categories: the impact of death and dying on the ICU nurse;

communication in DNR decisions; accepting the DNR order; support systems and coping strategies and the naming of the DNR process.

- Chapter 5 - discusses the summary of the major findings and conclusions regarding the study. The chapter incorporates the limitations of the study and provides the recommendations for addressing the issues highlighted, as well as recommendations for further research.

CHAPTER 2:

RESEARCH METHODOLOGY

2.1 INTRODUCTION

This chapter outlines the approach taken during the research process conducted to gain understanding and provide meaning to the lived experience of ICU nurses when dealing with end-of-life issues pertaining to the DNR order. The chapter describes the philosophical framework which informed the research approach, and the application in terms of the setting, data collection and analysis.

2.2 PHILOSOPHICAL FRAMEWORK

This research explores the lived experience of ICU nurses and therefore the philosophical approach of the phenomenologists was chosen. According to Polit and Beck (2008, p.64) phenomenology has its roots in both psychology and philosophy and focuses on the human lived experiences. It is understanding the lived experience that makes phenomenology a philosophy and a method (Creswell 2009, p.13). Creswell (2009, p.13) goes on to describe the method as a process involving prolonged engagement with a small group of participants which enables patterns and relationships of meaning to emerge.

According to van Manen (1990, cited in Lowes and Prowse, 2001, p. 475) one of the defining characteristics of phenomenology is when the researcher "turns to a phenomenon that interests them and commits them to the world".

It can thus be said that the purpose of phenomenology is to describe experiences as they are lived and experienced by those living them (Burns and Grove, 2005, p.55). These experiences will include the perceptions, thoughts, memories, emotions and social activities involved in the experience. Primary data for phenomenological studies is generated from conversations or interviews which are then reflected on using experiential accounts, literature and one's own experience (van Manen, 1990, cited in Tashallori and Teddlie, 2003, p.192).

Traditionally, three methods of phenomenology are described:

i. Descriptive (Transcendental) (Eidetic) phenomenology which is based on the works of Husserl (1835 -1938). Husserl believed that phenomena cannot be explained by causal relationships, but rather occur when there is a person to experience that phenomenon, and that the phenomenon needs to be described within the context in which it occurs (Burns and Grove, 2001, p. 56). In other words, Husserl's phenomenology describes the experiences of the individual/groups as they are lived and the meaning that this experience has for them. In order for researchers to truly describe these experiences, Husserl believed that it is essential for the researcher to bracket, or put aside any preconceptions s/he may have regarding the phenomena under study (Ray, in Morse, 1994, p.121). Thus the researcher transcends his/her natural attitude and suspends individual beliefs regarding his/her experiences related to the phenomena (Lowe and Prowse, 2001).

Husserl, according to Lowe and Prowse, describes this process as "standing outside the research process".

Thus descriptive phenomenology asks, "What do we know as persons?" with the emphasis being on descriptions of the human experience (Polit and Beck, 2008, p.228). This study proposes to examine the experiences of the participants, going beyond the scope of Husserl's approach by interpreting these experiences and therefore this approach was not considered appropriate.

ii. Interpretative (Hermeneutics) phenomenology is based on the works of Heidegger (1889 – 1976). Hermeneutics can be described as ontological self-interpretation and deals with the interpretation of the meaning of an experience which is determined by the context in which it is experienced

iii. (Cohen and Omery, in Morse, 1994, p.148). Heidegger believed that people are shaped by the world in which they live, i.e. their situation/culture, and that the world of each person is different, and that each person's concerns are qualitatively different and can only be understood in the context in which that person lives (Burns and Grove, 2001, p.55). Unlike Husserl, Heidegger believed that bracketing is not possible. He believed that, as the researcher or questioner was "already present in the world", this gave them the ability to understand the phenomena under study and thus provide meaning (Ray, in Morse, 1994, p.120). According to Lowe and Prowse,

(2001, p.474) Heideggerian phenomenologists are of the belief that "all knowledge originates from people who are already in the world and seeking to understand people who are already in the world". Thus it can be seen that interpretative phenomenology asks, "What is being?" with the emphasis on interpreting and understanding, not just on describing the human experience (Polit and Beck, 2008, p.253). This approach therefore meets the needs of this study in providing a means by which to interpret the phenomena under study.

iii. Analytical phenomenology which is guided by the Dutch school of thought and is a combination of both Descriptive and Interpretative phenomenology.

2.3 RESEARCH APPROACH

The philosophy of Heidegger, i.e. hermeneutics phenomenology supports the objectives of the research, namely to describe and interpret the lived experiences of ICU nurses and thus this approach was taken during the research process.

Gadamer (cited in Koch, 1995, p.830) describes the hermeneutics process as "not to develop a procedure of understanding, but to clarify the conditions in which understanding takes place". Heideggerian phenomenology takes an ontological approach asking the question, "What does it mean to be a person?" This approach believes that a person exists by "being-in-the-world". This philosophy proposes that the individual's personal context, i.e. social history and traditions will be

integrated into how they experience the world and provides meaning to their experiences. Papathanassoglou and Patiraki (2003) propose that human beings share a background familiarity that allows them to have a shared collective, as well as individual interpretation of the world. Furthermore, Ray (in Morse, 1994, p.122) explains how Hermeneutics provides a rich understanding of the human condition which is based on social-historical reality.

Taking into account the unique history and circumstances of the target unit, the research approach thus provided the means by which the experiences of the nursing staff, working in the target unit, could be described and interpreted, and thus given a meaning which is unique to their context.

As previously mentioned, unlike Husserl, Heidegger does not support the process of bracketing preconceptions, but rather embraces these preconceptions in providing meaning to a phenomenon. This concept is referred to as the historicality of understanding which, together with the hermeneutic circle, form the two essential components of Heidegger's' phenomenology (Koch, 1995). This author outlines the essential processes used to understand the previously mentioned concepts of historicality of understanding and the hermeneutic circle. These processes are background, pre-understandings, co-constitution and interpretation. Thus in keeping with Heideggerian phenomenology these principles were applied during data collection as outlined below.

2.3.1 Background

Koch (1995) proposes that the background of an individual provides his/her history and is instilled from birth and influences the way s/he views the world. It can thus be said that individuals are self-interpreting beings, and that they use language as a means of revealing and interpreting their own existence (Papathanassoglou and Patiraki, 2003). In the context of this study, participants were asked questions relating to their demographics in terms of age, level of training and ICU experience as it was felt these factors would potentially assist the researcher in applying meaning to their experience of DNR decisions, taking into account their "background".

2.3.2 Pre-understanding

Koch (1995, p.831) interprets Heidegger's term "pre-understanding" as describing the language and practices that are "in the world before we understand". Koch goes on to describe pre-understanding as the process of being-in-the-world. Thus it can be assumed that how the individual experiences this process of being-in-the-world will influence their understanding of the phenomena under study, providing meaning in the context. Mak and Elwyn (2003, p.396) use Gadamer's expansion on Heidegger's hermeneutics to demonstrate how pre-understanding does not constitute a bias, but rather is used as a "pre-condition to the truth". They further explain how the researcher's past experiences, perspectives, as well as their expectations of what will be revealed enhance the research process during analysis.

In the context of this study, the researcher's knowledge and experience of working in the ICU environment, i.e. being in the world of the ICU, enhanced the understanding and interpretation of the experiences of the participants of the study, who are also in the world of the ICU. It was this pre-understanding that enhanced the data collection process, as the participants were comfortable discussing this potentially sensitive issue with someone they felt would understand, and had insight into their expressed experiences; thus they potentially revealed information that they would not have divulged under different circumstances. This was particularly true of those participants who had formed a previous working relationship with the researcher in which cases, a trusting relationship built on shared experiences existed.

2.3.3 Co-constitution

Koch (1995, p. 831) describes co-constitution as the "philosophical assumption of indissoluble unity" of the person and their world. The author explains that this implies that the individual constructs the world from his/her own experiences and background, and that it is therefore impossible to separate the individual from his/her world. It can thus be said that the individual exists in a world within a specific context based on experiences and thus they co-constitute with each other. In the context of the ICU, it can thus be assumed that common meanings will exist.

During the interview process, the data was collected through an exchange based on an opening question and a series of linked questions. This interaction results in

each response being influenced by the preceding response (Lowes and Prowse, 2001). Thus these authors describe how the interview is co-created by the researcher and participants, and this will be reflected in the data collected.

2.3.4 Interpretation

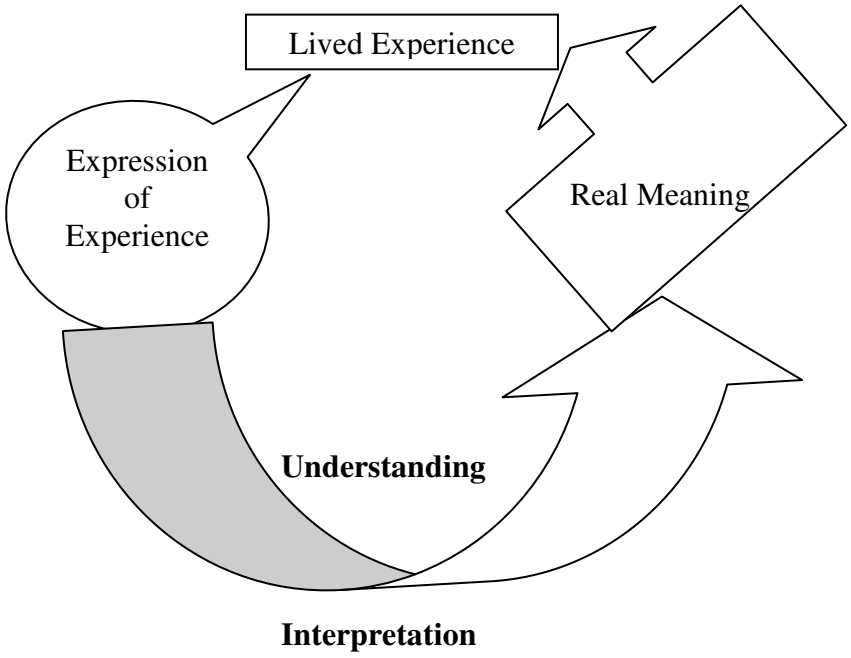
According to Koch, (1995) Heidegger described a situation where nothing exists without reference to the background understanding, and thus everything needs to be interpreted by taking into account that background understanding. It can thus be said that we are able to understand based on our own reference to the world. In the research process this implies that the researcher brings his/her own beliefs and values into the research process, and will thus influence the interpretation of the generated data (Lowes and Prowse, 2001). These authors further state and support, the views put forward by Drew (1989) stating that the researcher's "interest and emotional investment" in the study add significance to the study, not only on the part of the researcher, "but in the wider context, for society, of which the researcher is a representative" (pp. 475). The interpretation process was enhanced during both the data collection and analysis of this research due to the researcher's background understanding and interest in the phenomena under discussion.

2.3.5 Hermeneutic Circle

In the context of the hermeneutic approach to phenomenological research, the researcher has an own pre-understanding of the phenomena under study. These

pre-conceptions provide the background and frame of reference that provides meaning and understanding to the phenomena. These pre-conceptions were acknowledged and recorded during the data collection process by use of a reflective journal which was kept during both the interview process, and the transcribing process, and served to explore the researcher's own experiences and emotions etc. during this process, and was utilised during the analysis to provide meaning. (Figure 2.1 provides a diagram of the hermeneutic circle)

Figure 2.1 Diagrammatic interpretation of the hermeneutic circle



2.4 SETTING

The research was conducted in a three-bedded ICU within an urban district/regional hospital in the public sector in KwaZulu-Natal. The unit is a closed unit run by an intensitivist with an interest in end-of-life issues. A professional relationship

already existed between the researcher and the staff working in the department, which allowed for easy access for data collection. The researcher is also familiar with the unit's philosophy in dealing with end-of-life issues and the processes that are involved in withdrawing or withholding treatment. The researcher was thus in the unique position of having an established rapport with the participants, understanding the milieu of the unit, whilst at the same time being sufficiently removed from the unit, not having actively worked in the department for several years.

2.5 PARTICIPANTS

Initially a notice was placed in the department notifying the Registered Nurses of the research project and asking for volunteers. No volunteers were forthcoming at that stage. The researcher thereafter approached Registered Nurses working in the department who met the criteria. (Table 2.1 Inclusion and Exclusion criteria for the study) Registered Nurses, both those with whom the researcher had worked previously and those with whom she had not, and who had various levels of experience in the ICU, were approached to participate in the study.

Table 2.1: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
ICU Trained Registered Nurses	Non-ICU trained
More than 2 years' experience in the unit	Less than 2 years' experience in the unit
Willingness to participate	Not willing to participate

There appeared to be a general reluctance to discuss DNR issues in the ICU among most of the staff approached. Once the research process and topic was fully explained to them, all but two agreed to participate. Those who were unwilling to participate were both senior members of the unit. One of those who did not participate did not refuse or decline. The second, when asked why she did not want to participate stated, "I don't want to talk about such things". This response to the research topic appears to support the researcher's preconception that the DNR process is a difficult and painful experience for all concerned, and that there is a general reluctance to discuss this.

Phenomenological studies tend to rely on a small sample number and continue to gather data until saturation is reached (Polit and Beck, 2008, p.357). Individual interviews were conducted with seven participants, thus ensuring data saturation and providing an in-depth view of the phenomena under study.

2.6 DATA COLLECTION

In keeping with the phenomenological approach to data collection, the data analysis and literature review were carried out simultaneously. This approach allowed the researcher to direct and redirect the interview process in light of the emerging themes and patterns, and thus to explore the phenomena in a deeper and more meaningful way.

Initial interviews were conducted with each of the participants in a quiet room away from the unit, in a disused area in the theatre complex, during the participants "on duty" time. One interview was interrupted by a commotion outside the room, but this did not appear to affect the participant in any way. Interviews were arranged at a time that was convenient to the participants, and the unit, and according to the availability of the venue and the researcher. Some difficulty was experienced with scheduling these interviews, and some had to be rescheduled due to unforeseen circumstances, usually, due to unavailability of the participants, e.g. changing of shifts; unit being busy, etc. On one of these occasions another participant agreed to be interviewed at short notice. One interview was cancelled by the researcher due to a previous unscheduled urgent meeting which she had to attend.

The above mentioned challenges resulted in the interviews taking place over a nine week period from 24 April 2010 to 30 June 2010. Prior to the interview, participants were requested to choose a pseudonym by which they could be referred to during the interview process to ensure anonymity and confidentiality. Each interview lasted approximately thirty to forty-five minutes, and was recorded, with permission, using a digital voice recorder. These interviews were transcribed verbatim by the researcher.

The interview process consisted of two parts. The initial questions asked related to the demographic information required to provide meaning to the data. (Annexure A provides an example of the interview guide) The second part of the interview

process was unstructured with variations of the following open-ended question being used to initiate the conversation:

"Tell me about an experience you have had relating to a DNR order. It can be your most recent experience, the most meaningful one, or one that stands out in your memory".

Subsequent questions were dependent on the participants' responses and were guided by the interview. One further planned question was asked regarding perceptions and experiences relating to the change of terminology from DNR to AND.

A second interview, to clarify and confirm themes was planned during the researcher preparation phase, but did not occur as the researcher felt that the themes that emerged from the initial interviews were consistent throughout all the interviews. During the interview process, emerging themes were confirmed during interviews with subsequent participants and therefore no further clarification was needed

After each interview conversations continued with the participants to ensure participants suffered no ill effects from the interview process and provide some "closure". These conversations were not recorded. During one post interview conversation the participant started talking about the topic further, providing new

insights, the recorder was subsequently switched back on and she was asked to repeat her comments.

2.7 TRUSWORTHINESS

In qualitative research, academic rigor is not judged using the concepts of validity and reliability, but is rather evaluated using the concept of trustworthiness. Trustworthiness consists of credibility, dependability, confirmability and transferability (Polit and Beck, 2008, p.539). These concepts were applied during the research process as follows: -

2.7.1 Credibility

Credibility refers to the "confidence in the truth of the data and interpretations of them" (Polit and Beck, 2008, p. 539) i.e. the data reveals what it is looking for. According to Lincoln and Guba (1985, cited in Polit and Beck 2008: 539) credibility involved two aspects, namely carrying out the study in a way that enhances believability, and taking steps to demonstrate credibility. Several steps are suggested to enhance credibility and these were applied during the research process as follows:

i) Prolonged engagement and persistent observation

According to Whyte, (1992, cited in Lowes and Prowse, 2001) the researcher's knowledge of the phenomena and milieu ultimately strengthens the validity of the research findings In keeping with this view, the researcher has extensive knowledge and experience in the field of critical care with nine years spent working in the target unit, and therefore is in the unique position to be able to

understand the milieu in which the participants practice, and to have an already established relationship built on trust and rapport with the participants. The researcher also had prolonged engagement in both the data collection process and interpretation which helped gain an in-depth understanding of the phenomena under study from the perspective of the experiences of the participants. Persistent observations were made as part of reflection and confirmation of emerging themes by the researcher's frequent visits to the ICU, and observation of the participants dealing with DNR orders.

ii) Triangulation

Triangulation refers to the use of multiple references which are then used to draw conclusions. As described previously, Heideggarian phenomenology embraces the researcher's preconceptions which enhance the interpretation process. Rodgers and Cowles (1993, cited in Lowes and Prowse, 2001) propose that credibility is enhanced by the researcher clearly stating his/her preconceptions and the possible effects of these preconceptions in the interview structure and the responses elicited by the participants. During the collection and analysis of the data, the researcher acknowledged her preconceptions through reflection and maintenance of a reflective journal. Triangulation of the data with data obtained from the literature was also carried out.

iii) Member checking

Member checking was done during the initial interview process. Themes that emerged during interviews were explored during interviews with subsequent participants to determine their reactions. Once the final themes that emerged were identified, all but one of the participants were asked to verify the themes during one-on-one, face-to-face discussions.

2.7.2 Dependability

Dependability refers to the stability of data over time and conditions (Polit and Beck, 2008, p.539). This was achieved by ensuring that detailed and complete records were kept of the research process. The data collected and documentation will also be available for an inquiry audit by an external reviewer. Throughout the research process the researcher was supervised, and the relevance of the themes was monitored.

2.7.3` Confirmability

As mentioned previously, hermeneutical phenomenology does not embrace the philosophy of bracketing, but rather believes that presuppositions of the researcher provide meaning (Ray, in Morse, 1994, p.120). Experienced researchers, including the research supervisor, reviewed the methodology and generated data. A reflective journal was kept during the research process inclusive of the researcher's preconceptions, as well as the perceptions and responses to the interviews. All

documentation and data collected will be available for review, for example, recorded interviews and transcripts, etc.

2.7.4 Transferability

Generalisation in qualitative research is always difficult due to the small sample size. This applies in the context of this study. Further problems related to the context of this study include the fact that the target unit is a unit in the public sector, is a closed unit, and is run by an intensivist with an interest in end-of-life issues. This has been guarded against by the use of thick descriptions of the context of the unit which may impact on the findings. Thick descriptions will allow the reader to choose to apply the data or research process in his/her context (Polit and Beck, 2008, p.550).

2.8 DATA MANAGEMENT

As mentioned previously, all interviews were recorded using a digital recorder and then transcribed verbatim. All recordings were downloaded onto a password-protected computer and labelled, using the participant's pseudonym and the date and time of the interview. The same password-protected computer was used to transcribe data. Back-up copies will be stored on a password-protected memory stick which will be safely stored.

2.9 DATA ANALYSIS

Allen (1986, in Gullickson,1993, p.1387) proposes that we "share meanings through language, skills and practices". Gullickson (1993) goes on to state that the participants tell their "own stories" and that, through analysis, the researcher interprets and gives meaning to the lived experience expressed in these stories.

According to Ashworth (1987, cited in Lowes and Prowse, 2001) data analysis involves reflection on the interview interaction and continues during the interview encounters and data generation. As mentioned previously, this principle was applied during the research process with data collection, data analysis and the literature review occurring simultaneously. Content analysis using Tesch's analysis process to identify meaningful segments and categorisation schemes were developed. The eight steps described by Tesch (1990, cited in Creswell, 2009, p.186) and used during data analysis are outlined below:

1. Transcripts were read through in order to get a sense of the whole, and notes were made of any ideas that came to mind.
2. Each interview was then read through and the underlying meaning behind the text was sought. Notes were made on the transcripts during the reading process.
3. A list of all topics was then made, and similar topics were clustered together. These topics were then mapped out as major topics.

4. The transcripts were then reviewed again in light of the identified topics, and the text was coded. New categories and codes were identified.
5. Descriptive words were identified in the text and used to describe the themes/topics. Related topics were grouped together.
6. Final decisions regarding the categories were then made.
7. A preliminary analysis was done.
8. Excerpts from the data supporting the identified categories and themes were coded and recoded where necessary.

During the analysis process the researcher applied the hermeneutic circle to gain understanding and interpretation. Ajjawai and Higgs (2007) describe the process as circular and repetitive, with the researcher gaining insight and understanding of a phenomenon through engaging in conversation with the study participants, analysing and interpreting the text of the conversation and applying meaning. Mak and Elwyn (2003, p.396) describe how the hermeneutic circle is used to combine the researcher's pre-conditioned truth and the stories of the participants through a process of "continual questioning, reflection… " . Validation of these interpretations occurs through ongoing conversations between the researcher and the stories told by the participants. Through this process, new understanding emerges which is refined continuously throughout the interpretive process.

This process was maintained throughout the analysis process. As previously described, all interviews were recorded and then transcribed verbatim by the researcher. Each transcription was checked against the recording by the researcher to ensure that it was a true reflection of the interview. The researcher subsequently went over the transcript of each interview several times, ensuring emersion in the data. During this back and forth process, coding for themes, patterns and categories occurred. Through continual reflection and immersion, categories, major themes and sub-themes were identified and refined continuously as insights were gained and understanding was achieved. These categories, themes and sub-themes were identified in the individual transcripts using colour coding. These extracts from the interviews were again examined and re-examined, and placed into meaningful groups to support the categories, themes and sub-themes. Relationships between the individual experiences and the themes and sub-themes were explored and interpreted and conclusions were drawn.

2.10 ETHICAL ISSUES

i) Independent review

The research proposal was submitted to the University of KwaZulu-Natal School of Nursing for approval. It was subsequently submitted to the University Humanities and Social Science Ethics Committee and ethical clearance was obtained (see Annexure B). Approval to conduct the study was obtained from the Department of Health with the support of the target hospital management (see Annexures C and D).

ii) Informed consent

Due to the principle of autonomy, subjects were required to sign an informed consent form which outlined and explained the study in full. Two copies of the consent form were signed, with the participant keeping one of the forms. The second form was retained by the researcher to ensure confidentiality and anonymity of the participants. This form contained the contact details of the researcher which the participants could use if they had concerns or questions regarding the study. (Copies of the information sheet and consent form are attached in Annexure E)

iii) Respect for recruited participants

Anonymity was compromised by the interview process, however, participants were assured that confidentiality would be maintained. Potentially sensitive information was revealed during the data collection process, and the participants were assured that they would not be identified in any way. This was ensured by participants selecting their own pseudonym by which they would be referred to during the research process, only the researcher had access to this information, ensuring that data confidentiality was maintained. Interviews were conducted away from the unit in a rarely used section of the hospital. Participants were also informed that they could withdraw at any time.

v) Favourable risk-benefit ration

Although the phenomenology could be described as minimal risk research the potential for emotional distress was considered due to the research topic. In order to minimise any emotional distress on the part of the participants the following precautions were taken: -

- On completion of the interview, the researcher continued to "chat" with the participants to ensure that they suffered no adverse effects from the interview process.
- Participants were also informed that if they should require further support a mental health practioner was available for counselling purposes.

vi) Scientific validity

Scientific validity was ensured during the study through the aforementioned trustworthiness

vii) Fair selection of study population

Study participants were selected using purposive sampling according to the specific inclusion and exclusion criteria.

viii) Social value

On completion of the research process the findings will be disseminated by ensuring that the institution in which the study was conducted and the Kwa-Zulu Natal Department of Health receive of copy of the study findings for use in practice, policy making, education and further research. The study will also be presented at relevant conferences and published to a wider community.

2.11 CONCLUSION

This chapter described the philosophical framework used in the study, and outlined the research methodology employed to explore the lived experiences of ICU nurses when dealing with end-of-life issues. The research approach was described with reference to the setting of the study, the participants, the data collection process, data management and analysis and ethical issues. The following chapter reviews the literature exploring relevant information regarding death and dying in the ICU, the DNR process, and the experiences and perceptions of ICU nurses when dealing with these issues.

CHAPTER 3:

LITERATURE REVIEW

3.1 INTRODUCTION

In phenomenological studies, the scope of the literature review varies and the timing is debatable. According to Polit and Beck (2008, p.105) phenomenologists frequently undertake a literature review at the onset of the study in order to identify experiential descriptions of the phenomena, and to expand their understanding from various perspectives. However, according to Burns and Grove (2001, p.95) phenomenologists believe that the literature review should be done after data collection so as not to be influenced by previous findings thus compromising the researcher's openness.

The researcher made a conscious decision not to do an extensive literature review prior to commencing the study, but rather to conduct a limited review to establish the following:

- To determine what research has already been done regarding the topic
- To gain some insight and understanding about what is already known about this topic in order to guide the research process

An extensive literature review was subsequently done during the data collection and analysis phase of the research in order to assist in the identification and clarification of emerging themes and to guide the analysis process.

The literature review will provide information regarding the findings of previous research studies relating to death, dying in the ICU, the decision-making process, as well as the perceptions, experiences and attitudes of ICU nurses when dealing with end-of-life decisions.

3.2 DEATH AND DYING

A plethora of literature exists regarding death and dying. The researcher, however, focused on studies relating specifically to dying in an ICU, and how the views of contemporary society regarding death and dying impact on the ICU and *vice versa.*

3.2.1 Death in Society

A paper published by O'Gorman (1998) reviewed death and dying in contemporary society. In this article, the author describes the rituals and significance that death has had through the ages, from the fifteenth century until the late twentieth century. Attitudes to death, according to O'Gorman, (1998) are dependent on institutional structures, deep seated myths and the social character prevalent at the time. O'Gorman (1998) postulates that during the first half of the twentieth century, society lost sight of the importance of the rituals that were associated with death and dying, and the need for appropriate death education. This loss resulted in both society and health professionals finding that they were unable to cope with death. The author goes on to say that during the second half of the twentieth century this lack of knowledge was recognised, resulting in the development of a more holistic approach to health care.

At the turn of the nineteenth century, death was familiar and was viewed as part of the routine of life (Aries, 1974, cited in Miller, Forbes and Boyle, 2001) and was associated with rituals that had been unchanged for centuries involving the whole community. These rituals and sharing of grief provided meaning and honour to the passing of human life. Miller, Forbes and Boyle (2001) state that medical science has replaced religion and nature in how society understands death, which is now viewed as a disease to be "treated and cured" and that, when death occurs, it is seen as a failure of modern science.

Kaufman, (1998) an anthropologist, did extensive research into how death occurs in hospitals, and alludes to the problem of death in America as being one of prolonging death rather than prolonging life. Kaufman (1998) outlines several factors that contribute to this complex problem. Some of the factors identified by the author (pp.724) include the desire for advanced age which is described as "cultural confusion about the nature and end of the human life span"; the fear of litigation, and the gap between the knowledge and understanding of the lay person in comparison to the medical professional.

Copp (1998) reviewed current theories of death and dying, and in so doing, highlighted the strength and weaknesses of each of the models discussed. These models included the Kubler-Ross five-stage model of dying (1969); Buckman's three-stage model of dying (1993); Glaser and Strauss's Awareness of Dying in hospital (1965) and Time for Dying (1968); Patterson's Living-Dying Interval (1977); Corr's Task-Based Approach to Coping with Dying (1992) and Copp's

Readiness to Die Theory (1996). In reviewing these theories, Copp (1998, p.390) notes a shift towards what she terms a "more interactive and eclectic" framework in keeping with the multifaceted aspects of death and dying and its impact on individuals. Brosche (2003) reviewed Kavanaugh's Seven Behaviours and Feelings as Part of the Coping Process (1972) and applied them to the ICU nurse. In this article, the author outlines the seven behaviours and feelings, and demonstrates how nurses apply them in the clinical setting as part of their coping strategies when dealing with death and dying on a daily basis

3.2.2 Dying In ICU

In the previously mentioned article by O'Gorman, (1998) the author discusses Illich's theory on death (1990) in which eight stages, regarding societal views on death, were identified through time. Stage six (pp. 1130) is dedicated to death in the intensive care unit, where the patient is no longer able to "set the scene of his own death", and O'Gorman (1998) cites Pietroni, (1991) stating that doctors and nurses consider death in the ICU as a failure. O'Gorman (1998) goes on to discuss the lack of rituals in modern western society when dealing with death. It is these rituals that provide meaning to death and form an essential part of the grieving process for the family. When patients die in the hospital's unit, family members are often "dispossessed of the roles they held in the outside world", (Goffman, 1963, cited in O'Gorman, 1998, p.1132) and feel both unwelcome and uncomfortable when entering the ICU environment.

Miller, Forbes and Boyle (2001, p.232) comment on what they term the "incompatibility of lay and medical knowledge". The authors describe this incompatibility as of particular relevance when discussing the ICU environment which patients and family are ill prepared for, and where a "vast gulf" exists between medical knowledge and the lay person's understanding due to his/her varied socio-cultural and educational backgrounds.

Shorter and Stayt (2009) allude to the grief experiences of ICU nurses as being different to those of the experiences of ward nurses when dealing with death. This difference in experiences appears to be related to the phenomenon of withdrawing and withholding treatment inherent in the DNR process. The authors describe the ICU experience of death as being less traumatic and more controlled, in that staff are prepared for an expected death, and that being in control eases feelings of guilt.

These studies relate to death in the ICUs in first world countries which may be significantly different from death in a South African ICU due to cultural diversity; availability of resources; population demographics in terms of age and disease profile/cause of death. South African studies were reviewed on the quality of death in the ICU and end-of-life issues in the ICU (Fouché, 2006; Langley and Schmollgrubber, 2006). These highlighted the nurses' priorities when managing death in the ICU and the ethical concerns surrounding end-of-life issues. Fouché (2006) discusses the importance of permitting families to conduct religious customs and rituals during the dying process.

A South African study exploring the influence that violent death has on emergency room nurses was also reviewed (Brysiewicz, 2002). Although this study did not involve ICU nurses, the experiences of the emergency nurse when dealing with death appear to have relevance to the ICU context. Brysiewicz (2002) describes how trauma nurses experience grief, guilt, anger and sadness as well as death anxiety. These findings are similar to those reported by ICU nurses when dealing with death and dying (Spencer, 1994; Lenart, Bauer, Diane, Johnson and Stringer, 1998).

3.3 THE DNR ORDER: WITHHOLDING AND WITHDRAWING THERAPY

3.3.1 The DNR order

As technology and advanced life support modalities become more sophisticated, so does the ability to prolong life (McDermid and Bagshaw, 2009). Medical technology does not, however have the ability to cure or prevent suffering in all instances, but rather sustains the patient without in fact improving the condition, i.e. prolonging death (Sidler, Arndt and van Niekerk, 2008). The physician working in the intensive care unit thus has to walk a tightrope, balancing these two dichotomies of providing treatment that may either prolong life or prolong death. Adding to this dilemma is the issue of scarce resources and the increasing pressure for beds. McDermid and Bagshaw (2009, p.2) describe this conflict as the "critical challenge" where the physician faces the dilemma of how to provide a limited resource and expensive therapy to patients who will possibly benefit, versus providing prolonged treatment to those patients who will not survive. Vincent

(2005) identifies the ethical principles that physicians apply when making these decisions as those of autonomy, beneficence, non-maleficence and distributive justice. Savory and Marco (2009) agree with the ethical principles outlined by Vincent, but substitute the term "stewardship of resources" for that of distributive justice, although the concept is the same.

Out of this dilemma has risen the concept of futile care. Sidler and van Niekerk (2008, p.284) define futility as, "Treatment with therapeutic effect but without benefit to the patient". They go on to say, "….futile means are not ethically indicated, and with few exceptions, should not be provided." Prolonging the process of dying, in this instance, goes against the principles of beneficence and non-maleficence (Winter and Cohen, 1999). Hodgson (2006) describes the decision-making process, in the South African context to ensure maximised utilisation of resources in terms of two concepts. Firstly triage, which is explained as the refusal to admit patients to the ICU who have a low likelihood of survival, with or without intensive therapy. Secondly, the concept of futility which Hodgson (2006, p.73) defines as the "withdrawal of therapy in patients who are failing to respond to intensive interventions".

Traditionally, the DNR order has been used to withhold cardiopulmonary resuscitation once cardiac arrest has occurred. Vincent (2005) outlines the concept of DNR in the context of the ICU as incorporating both the withholding and withdrawing of life-sustaining therapies. This is an accepted practice in the ICU environment internationally. Variations in practice exist, as demonstrated by the

following studies. Prendergast, Claessens and Luce (1998) reviewed practices in 131 American ICUs in 110 institutions involving the death of 5,910 patients, and concluded that limitation of life support prior to death was in fact the dominant practice in ICUs. The results of this study indicated that 70% of deaths had limits to life support with a median of 48% of deaths occurring following withholding, or active withdrawal of life support. Similar results were obtained from a study conducted in France (Ferrand, et al., 2001) where 53% of deaths were preceded by a decision to limit therapy, with futility and poor quality of life being cited most commonly as reasons for these decisions. A study conducted in Hong Kong (Buckley, et al., 2004) supported these findings, reporting that limitation of support occurred in 58.8% of deaths, with therapy being withheld in 30.8% and withdrawn in 28.0% of deaths.

Some debate exists in the literature regarding the ethics of withdrawing and withholding therapy and which is deemed to be more ethically acceptable (Levin and Sprung, 2005; Vincent, 2005). Vincent (2005) sees no difference between withholding and withdrawing therapy, viewing these concepts as ethically equivalent. Levin and Sprung (2005) however propose that withholding therapy may be preferable to withdrawing therapy, as it allows for the limitation of inappropriate therapy, but does not determine the outcome.

3.3.2 The DNR decision-making process

End-of-life decision-making practices vary considerably. The discussion of limitation of support is usually initiated by the physician (Buckley, et al., 2004; Chang, Huang and Lin, 2010).

Involvement of nurses in the decision-making process also varies considerably, with Buckley et al. (2004) reporting that the ICU nurse was involved in the discussion 73% of the time, and that discussions with the family once the decision was taken always included a senior nurse. In contrast to this, a study by Thibault-Prevost, Jensen and Hodgins (2000) found that 62.7% of nurses stated that they were infrequently involved in DNR decisions. In France, Ferrand et al. (2001) indicate that decisions were taken by medical staff with involvement of the nursing staff in 54% of cases, and without them in 34% of cases. Similar findings were reported in Europe, with only 38.2% of nurses reporting being asked to participate in the decision-making process (Latour, Fulbrook and Albarrain, 2006). These authors acknowledge that, although physicians are ultimately responsible for the DNR order, a collaborative decision-making model involving the physicians, nurses and family members would be the most appropriate. Miller, Forbes and Boyle (2001) describe the potential consequences of the lack of involvement of nurses in end-of-life decisions as the loss of the holistic and caring perspective, ultimately resulting in nurses becoming less visible and less credible.

Families were involved in the decision-making process in France (Ferrand et al., 2001) 44% of the time. Buckley et al. (2004) reported consulting with the family

only once the decision was made by the medical team. In the majority of cases, (95%) the family agreed with limitation of life support. In the cases where no family agreement occurred, therapy and discussions were continued. The majority of nurses agree that families should be involved in the decision-making process, but that this only occurred 60% of the time (Latour, Fulbrook and Albarrain, 2006).

Practices around the DNR process include withholding therapy, for example, inotropes and ventilation, or no further escalation of therapy, as well as withdrawing of ventilation and/or inotropes (Chang, Huang and Lin, 2010; Buckley, et al., 2004; Ferrand, et al.,2001). Winter and Cohen (1999) report that once the decision has been made and discussions with the family held, inotropes and vassopressors are discontinued and sedation may be increased. They indicate that ventilation is rarely withdrawn, but inspired oxygen levels may be reduced. Winters and Cohen (1999) point out however, that withdrawal or withholding of treatment does not equate with withholding or withdrawing care.

3.3.3 Communication as part of the DNR process

Dracup and Bryan-Brown (2005) indicate that the solution to dealing with the dilemma of end-of-life issues and dying in the ICU is effective and frequent communication between members of the healthcare team. Despite this, it can be seen from the previous discussions that nurses are frequently omitted from the end-of-life decision-making process.

Hov, Hedelin and Athlin, (2006) reported that despite ICU nurses' holistic knowledge of their patients, and their experience and professional competence, physicians tended to pay little attention to their contributions regarding decisions involving patient treatments. How seriously these contributions were taken, depended on the relationship between the nurse and the individual physician, with physicians being more interested in what their medical colleagues had to say. McMillen (2008) identified that the level of experience of the ICU nurse will impact on how much consideration is given to his/her views, and proposes that although the ICU nurses do not actually make the decision, they have an invaluable role to play, not only in terms of provision of support for the grieving family, but also in terms of clinical information and insight into the views of the family. McMillen goes on to indicate the desire nurses have to be part of the decision-making process, viewing the team approach as the most appropriate.

Several studies agree that the collaborative approach to decision-making would contribute to better communication and satisfaction between professions (Eliasson et al., 1997; Halcomb, et al., 2004; Hojat, et al., 2003; McMillen, 2008; Puntillo and McAdam, 2006). One of the barriers to effective communication is cited as nurses' "lower" position in the hierarchical structure within the institution (Halcomb, et al., 2004; Oberle and Hughes, 2001). Oberle and Hughes (2001) expand on this, stating that doctors expected nurses to remain silent and not to voice their opinion, even if they believed the choices being made were wrong. This air of dissatisfaction with the lack of communication and collaboration appears to be one-sided, with nurses expressing the need for greater involvement and collaboration, whilst doctors were

satisfied with the existing practice (Puntillo and McAdam, 2006; Hojat, et al, 2003). Halcomb et al. (2004) support the view that nurses desire more collaboration, but that inconsistencies and poorly defined parameters increase the tension and conflict.

Puntillo and McAdam (2006) describe how lack of consistent open communication and collaboration make the difficult issue of end-of-life decision-making even more challenging. The authors go on to explain how a lack of collaboration may potentially impact on the satisfaction that family members experience when considering patients' care, information and decision-making in the ICU.

For communication with family and patients regarding DNR orders to go smoothly, it is essential that all members of the multidisciplinary team agree regarding the patient's progress, prognosis etc., and that input from both physicians and nurses enhance communication with the patient and family (Eliasson, et al., 1997). Nurses express their concerns regarding communication in terms of the accuracy and adequacy of information provided to families, especially where decisions need to be made, and fear adding to the burden of the family. Concern was also expressed regarding the language used in discussions, as frequently no layman's terms are used (Oberle and Hughes, 2001). This view is supported by comments made by family members who expressed unmet communication needs (Norton, et al., 2003).

Good communication promotes shared decision-making and can thus improve outcomes for both patients and family (Pantilat, 2009). This may also be true for communication between members of the healthcare team. Spencer (1994) describes

how nurses felt more discussion between them and the medical staff would help them come to terms with their feelings.

3.3.4 Allow Natural Death vs. Do Not Resuscitate

Traditionally, when discussing withdrawing or withholding therapy, the clinician may summarise the decision as, "We will stop the breathing machine and antibiotics and if the heart stops we won't try and resuscitate", thus the focus is on what will not be done rather than on the care the patient will receive (Pantilat, 2009, p.1280). Family members frequently do not want a DNR order given for a patient, as this is interpreted as indicating that nothing will be done for the patient (Knox and Vereb, 2005). These authors go on to say that health workers know this interpretation is incorrect, but have difficulty in explaining what DNR means.

In 2000, Reverend Chuck Meyer, a recognised expert in ethics and issues surrounding death and dying proposed an alternative to the DNR order, i.e. the Allow Natural Death (AND) order (Knox and Vereb, 2009). Knox and Vereb (2009) elaborate on the AND order, stating that the clinician acknowledges that the patient is dying, and focuses on the provision of comfort measures. Thus the process is the same, but couched in a language more acceptable to patients and families. Whittmann-Price and Celia (2010, p.333) describe the DNR order as being easily interpreted as "cold and cruel", whereas the AND order is usually interpreted as "less negative and more humanistic", as it reinforces what will be done for the patient rather than negatively reinforcing what will not be done.

Whittmann-Price and Celia (2010) conducted a study to explore the perceptions of healthcare professionals about using AND as an alternative term when discussing end-of-life issues. In this study, the authors reported that the majority of healthcare workers indicated that they would be willing to consent to an AND order for a loved one, and hypothesise that if healthcare workers find the terminology more acceptable, they will feel more comfortable discussing end-of-life issues with patients and families.

3.4 EMOTIONAL IMPACT OF DEATH ON ICU NURSES

Shorter and Stayt (2009, p.165) state, "It would seem that critical care nurses cope with the deaths of their patients because they are an expectation of their role and an unavoidable burden that they have to endure." The toll that this burden has on ICU nurses was explored in the literature.

3.4.1 Grief and moral distress

A study done in 1972 by Hay and Oken (pp. 114) identified that death, in the ICU, provides a situation of repetitive object-loss which is pervasive, and that the nurse, " …must protect herself – from grief, anxiety, guilt, rage, over commitment, over-stimulation and all the rest." This implies that death results in psychological stress and may, if not adequately dealt with, result in burn-out. These same responses to death that applied in 1972 still apply today, and are perhaps intensified in the modern ICU with the advances in science and technology which increase the expectations of being able to save the lives of patients admitted to the ICU. End-of-

life issues remain one of the most serious problems facing nursing and medical professions today (Dracup and Bryan-Brown, 2005).

Doka (1989, cited in Brosche, 2007) describes the concept of "disenfranchised grief" where mourning the death of a patient is not part of the cultural environment of the ICU, resulting in nurses not verbalising their feelings, or feeling that they have no socially recognised right to grieve for the loss of their patients. This suppression of feelings may lead to compassion fatigue, moral distress and the stress cascade, which impacts on the care patients receive, customer service and retention of staff (Brosche, 2007). Nurses working in the ICU encounter end-of-life decisions and death on a daily basis. Some of these nurses conceal their personal grief when dealing with patients and family behind the façade of professionalism, and are seldom able to share their grief, keeping it hidden and crying privately (Lenart, et al., 1998; Brosche, 2003).

Nurses experience various emotions when dealing with death and dying in the ICU namely, sadness, anger, guilt, shock and relief (Spencer, 1994). Lenart et al. (1998) explore how these traumatic experiences present as physical symptoms, e.g. fatigue, insomnia, headaches, nausea and shaking, and emotional reactions such as anxiety, depression and emotional numbing. These reactions may impact on how nurses make decisions, concentrate and process thoughts. The authors recognise that not all deaths in the ICU can be deemed a traumatic experience, however, many of these symptoms form part of the grief response. Brosche (2003) takes the view that the high-tech environment of the ICU compounds the stress stimulus that ICU

nurses feel when dealing with death in the ICU. Due to the demands of this environment, nurses continue providing care to other patients, not allowing themselves time to grieve or receive adequate support. If the nurse does not possess adequate coping skills, this may result in emotional distancing and depression which are often described as a non-caring attitude, anger and burn-out (Brosche, 2003). This view is supported by various authors (Elpern, Covert and Kleinpell, 2005; Shorter and Stayt, 2009) who conclude that it is possibly the number of deaths that ICU nurses encounter that impact on their emotional state and their degree of moral distress. This frequent exposure to death provides no opportunity to completely, or adequately grief between individual deaths, thus experience results in an accumulative effect (Elpern, Covert and Kleinpell, 2005).

Moral distress in the ICU is potentially on the increase due to staffing shortages, increasing workloads and increasing expectations from families for a good outcome that the ICU appears to promise. However, the application of life-sustaining therapies may merely prolong the dying process rather than sustaining life. This is especially true when conflict exists between the nurses and the medical team regarding the appropriateness and duration of seemingly futile care, or when nurses have no input in end-of-life decision-making involving the patients in their care (Kaufman, 1998, Oberle and Hughes, 2001; Halcomb, et al., 2004; Elpern, Covert and Kleinpell, 2005; Latour, Fulbrokl and Albarran, 2009; McDermid and Bagshaw, 2009).

Oberle and Hughes (2001) differentiate between the perspectives that doctors and nurses have regarding the ethical concerns associated with end-of-life decisions, stating that doctors make the decision which results in a moral dilemma, whereas nurses have to live with a decision made by someone else which results in moral distress. This is supported by a study (Halcomb, et al., 2004) in which nurses complained that they were excluded from the decision-making process, but left to manage the dying process.

Factors that influence the degree of moral distress that nurses experience include the timing of the decision. McMillen (2008) indicates that timing is important, both from the perspective of the family and the nurses, in that, if the decision is perceived to have been taken prematurely, nurses may feel that they have accelerated the patient's death. The author further identified that nurses were more upset when involved in end-of-life issues if the patient was young, or was someone with whom nurses could identify in some way.

Empathy is also an emotion described by ICU nurses. Shorter and Stayt (2009) conclude that nurses strive to empathise with their patients, imagining themselves in the patients' place, and this allows them to develop a personal bond with patients and families. The authors explain the double-edged sword that developing this personal bond becomes for nurses; on the positive side, it is essential to establish this bond to ensure good nursing care, on the negative side, it makes their grief experience more upsetting. Halcomb et al. (2004) identified that on the surface, comments made by the nurses appeared to display empathy but, on closer

examination felt that the comments appeared flippant and failed to recognise the human tragedy being experienced by the family.

Long- term coping strategies employed by ICU nurses to deal with death and dying are described as the process of normalising death, and emotional dissociation (Shorter and Stayt, 2009).

3.4.2 A "Good Death"

The emotional impact that end-of-life decision-making has on ICU nurses appears to be related to the perception of what is termed a "good death". The degree of moral distress that nurses may experience appears to correlate with their perceptions on the care given to patients whilst in the ICU. Shorter and Stayt (2009) describe what constitutes a "good death" for ICU nurses as expectedness, control and nursing care. The authors explain that the grief experiences of ICU nurses is different to that of the experiences of ward nurses when dealing with death. In the ICU, the experience is less traumatic and more controlled, as they are prepared for an expected death, and that being in control eases feelings of guilt. Halcomb et al. (2004) reported similar findings, where nurses reported that providing good palliative care for their patients was a positive experience, as providing care to the patients and their families made them feel better.

3.5 SUPPORT SYSTEMS FOR ICU NURSES

3.5.1 Informal support

In a study by Spencer (1994) the author describes how 80.4% of nurses felt that they received support from their colleagues, but 19.6% felt that they did not. The author further states that half of the nurse felt the support was sufficient and the same number felt it was not. In the same study it was also reported that counselling junior staff also helped senior staff to deal with their own feelings.

Nurses find relationships with each other a vital form of support, describing a shared grief experience which they felt only their colleagues would be able to understand (Shorter and Stayt, 2009).

3.5.2 Formal support

Shorter and Stayt (2009) reported that nurses feel that formal support, in the form of debriefings and clinical supervision, is a good idea, in theory, however in practice, they do not access these services even if they are available, stating they would find it more difficult to open up in a more formal setting. This supports an earlier study by Spencer (1994) who found that not all of the nurses, in the institution under study were aware of the existence of the nurse counsellor.

3.6 CONCLUSION

This chapter reviewed the literature of the phenomena under study. Current views on death and dying were explored, both in society and in the ICU setting. The DNR process and its impact on ICU nurses was described. The role of communication and support systems in decreasing moral distress was also outlined. In the next chapter the research findings of this study will be presented.

CHAPTER 4

PRESENTATION OF THE RESULTS OF THE STUDY

4.1 INTRODUCTION

This chapter sets out the findings of the study, revealing the lived experiences of ICU nurses when dealing with end-of-life decision-making. Data was obtained through in-depth interviews conducted with seven ICU trained Registered Nurses working in the target hospital ICU. Written informed consents were obtained prior to each interview. These in-depth interviews aimed at revealing the participants' experiences of end-of-life decision-making, thus providing a deeper understanding of these experiences. In keeping with the philosophy of hermeneutic phenomenology the real meaning of these lived experiences is then determined.

Data was collected over a two month period and analysed concurrently, bearing in mind the objectives of the study. In the context of the hermeneutic approach to phenomenologic research, the researcher has her own pre-understandings of the phenomena under study which are then applied to the data collected during the in-depth interviews, in order to interpret and give meaning to the lived experience expressed by the participants (Gullickson, 1993).

4.2 RESEARCH FINDINGS

The research findings will be presented in two sections. The first section provides information regarding the profile of the participants. The second section will

outline the findings of the study inclusive of the views, thoughts and feelings expressed by the participants during the individual in-depth interviews

4.2.1 PARTICIPANTS' PROFILES

Seven participants were involved in the study. All participants were ICU trained with ICU experience ranging from seven years to more than twenty years. Ages spanned thirty years, with the youngest participant being in her early thirties and the oldest sixty. Only one of the participants had any significant experience in any ICU other than the target ICU. Table 4.1 provides the demographic details of the participants.

Table 4.1 Participants' Demographics

Chosen Name	Age	Number of years qualified as a Registered Nurse	Number of years of ICU Experience	ICU Trained	Number of years experience post-ICU
Jane	31	10	8	Yes	4
Katie	35	11	10	Yes	8
Sue	38	10	7	Yes	4
Renata	60	27	22	Yes	20
Taby	50	28	24	Yes	20
Sarah	40	14	12	Yes	6
Gugu	42	12	8	Yes	3 weeks

4.2.2 RESEARCH FINDINGS ACCORDING TO CATEGORIES, THEMES AND SUB-THEMES

As stated previously, this section presents the findings of the study. Data collected through in-depth interviews was analysed using manual data analysis techniques. Through this process themes and sub-themes emerged. The views of some of the participants are presented as direct quotations to support these identified themes and sub-themes.

Five categories of information emerged during the data analysis: -

- The impact of death and dying on the ICU nurse
- Communication in the DNR decision
- Accepting the DNR decision
- Support systems and coping strategies
- Naming the DNR process

These categories were then divided up into common themes and sub-themes (see Table 4.2).

Table 4.2: Categories, themes and sub-themes

No.	Category	Theme	Sub-theme
1.	The impact of death and dying on the ICU nurse	• Dealing with the family	• Grief - Sadness - Depression - Anger - Trauma • Empathy • Being Human vs. professionalism • No family available
		• Cultural clash	• Cultural practices and death rituals
2.	Communication in the DNR decision	• Making the decision	• Our opinion should count • Medical decision • Breaking the news • Taking the brunt
		• Barriers to communication	• Reservations and blame • More receptive to doctors

No.	Category	Theme	Sub-theme
3.	Accepting the DNR order	• Timing • Experience vs. inexperience • Conflict in carrying out the order	
4.	Support systems and coping strategies	• Informal support • Formal support • Coping strategies	• Shared experiences • Family and friends • Medical colleagues • Nobody cares about us • Talking about the experience • Rationalisation and understanding • Suppression and detachment
5.	Naming the DNR process	• Just words • More human vs. don't help them	

4.2.2.1 CATEGORY 1: THE IMPACT OF DEATH AND DYING ON THE ICU NURSE

4.2.2.1.1 THEME 1: DEALING WITH THE FAMILY

During the interviews all participants revealed the emotional impact end-of-life decisions had on them as individuals. This was particularly true when

discussing dealing with the families of patients during the patients stay and once the DNR decision had been taken. All participants identified this as being the most difficult aspect of the DNR process. Through exploration of this element of the DNR process several sub-themes emerged and these will be explored below.

i) Sub-Theme 1.1: Grief

When describing their feelings regarding the DNR process, recurring words such as "sad"; "depressed"; "very difficult and painful" were used by participants. Words such as "Traumatic" and "traumatised" were used by at least two of the participants with Sue using the word "traumatised" seven times when describing the process, in an interview that lasted approximately twenty-eight minutes. The use of these emotive words highlights the emotional impact that end-of-life decision-making has on the participants. Gugu, one of the more junior nurses expressed her feelings in the following extract.

> *"You'll just… ay you know what, sometimes you know you just don't even feel like coming to work. It's very traumatic, I can say…."*

Renata, a senior member of the nursing staff with more than 20 years ICU experience, expressed the following when describing the impact of these decisions:

> *"…..always psychologically it does affect us because most of my patients I can still remember, some that were DNR'd and how it affected us. I mean you may not show it by tears and, and outwardly, but it does affect us, because I can remember my patients from thooose days."*

Later during the interview she further stated:

> *" ……if anybody ever tells you that they have mastered it, they feel nothing, that means that they are lying, because it does hurt you, never mind how hard a person you are it does hurt you."*

During an interview with Sarah she expressed that she was becoming emotional whilst discussing the DNR process. When asked to explore those feelings she described feelings of anger as follows:

> "*Sometimes you do, you do feel anger, angry that people have go [through this] experience."*

When asked to elaborate regarding the reasons for her anger she replied,

> *"The decision, the patient, you know... the patient, why? Why did this have to happen? You, you. I think that would make you angry somehow. But ja, so you go through, you experience some anger, sadness."*

These and other similar statements made by other participants suggest that the DNR process is an emotional one for ICU nurses, and that the number of years working in this environment and the level of training do not serve to lessen the emotional impact end-of-life decision-making has.

ii) Sub-Theme 1.2: Empathy

Empathy is defined by the Paperback Oxford English Dictionary (2006, p.243) as "the ability to understand and share the feelings of other people". All participants of the study expressed strong feelings of empathy when dealing

with the families of patients when a DNR decision had been taken. The following extracts from interviews with participants outline this fact.

> *"You always put yourself in the patient's family, if it was your relative, how it would affect you. That's what happens to me, if it's like a very young person, or it's like an incident of an MVA, and things of that sort."* (Sue)

> *"You feel sad, you know, emotionally, you, you .ah..ah you empathise with the family, you can feel it, especially for me I know what its like to lose a loved one, like this"……. "It's sad, life, in some cases life is cut short, in some cases they have lived their life, you know. But…for the living that is here now and that has to deal with the emotions, ah, I.. I think it's sad in both cases, but now it's the living."* (Sarah)

> *"Because specially, uh, uh if you are a mother and you got kids, uh, it affects you more so……uh, it does affect you, and you always associate it with your child. It could have been my* [emphasis on my] *child could be lying there like that, you know, it does when you are a parent, it does affect you like that as well.* [Takes deep breath] *But besides that, ha, uh, uh it, it still does, even for others too, because that's a life, that could be somebody in the community and what have you."* (Renata)

> *"….we really tend to go out to feel for the patients."* (Jane)

Katie summed up empathy for the family by stating:

> *"But family is the biggest issue I think, because you feel as well, you know, for them"*

These feelings of empathy appeared to be expressed most strongly by nurses who are also mothers, or have experienced their own losses, or experienced

family members as patients in the ICU, i.e. can identify in some way with the patient or family.

iii) Sub-Theme 1.3: Being Human vs. professionalism

During the interview with Sarah, her concerns regarding how family members of patients perceive ICU nurses during their grieving process emerged. When discussing the terminology used and referring to end-of-life decision-making in ICU Sarah refers to the terminology of AND as:

> *"It's just words that sound better. It makes us feel human."*

The issue of being perceived as human was thus explored with the other participants, resulting in the emergence of the sub-theme of the human being vs. professionalism when participants described their interactions with patients' family members.

Two of the younger and less experienced participants, both with seven to eight years experience working in the ICU, expressed the need to remain in control of their emotions when dealing with the family. Jane expressed this as follows:

> *"Sometimes it's, it's simpler to deal with the families if we, you know, we maintain that, that barrier of, you know, I'm the nurse, you're the family and I'm explaining what's happening to you and you keep it like that."*

Sue revealed her feelings regarding this issue in the following conversation with the researcher:

> *"No it's not good if you're breaking down in front of the family." ……"It's not a good impression, because you're supposed to be providing support for them…"*

The interviews with older and more experienced participants, both with over twenty years experience, in the ICU revealed their views on the importance of human interaction with family members.

> *"The human person takes over definitely, you cannot be prim and proper now,….."* and
> *"We cannot be over-professional in times of death."* (Renata)

The following extracts from the interview with Taby explore her humanistic view when dealing with patients' families during the DNR process.

> *"I think when we share the emotion with them it actually does make a difference to them." ….. "Because they feel that, uh, we are feeling it with them." ….. It actually does help them." ….. "Or even just to give them a little hug."*[said laughingly]

After a big sigh she goes on to state:

> *"This is one time we sometimes lose our professionalism, because…umm, how can I explain?"... "It's a very emotional situation and we sometimes lose it* [laughs]. *I sometimes do! …I just take them as people that you know have just lost a loved one, and are in pain and grieving and.. so I'll try to be as human as possible with them."*

iv) Sub-Theme 1.4: No family available

Although all participants described dealing with the family as the most difficult aspect of the DNR process, Sarah and Jane expressed different views about the process when no family was available.

Sarah describes having no family available by saying:

> *"That's better. That's easier"*

Jane on the other hand feels very differently about the subject, sounding quite distressed as she expressed the following point of view:

> *"…but as I'm saying, you, you like. like try not to* [laughs] *to want to get sad about it, but you do think, you know what this patient's gone down, I wonder if they came to claim this body, I wonder if anybody came for them, if, especially if the people like that are unknown and things, it's even worse than the ones that's got a name and stuff*".

4.2.2.1.2 THEME 2: CULTURAL CLASH

During several interviews nurses expressed their awareness of the cultural beliefs and rituals that are associated with death and dying in the South African context. These beliefs and practices impacted on how they interacted with patients' families, as well as on their own practices.

i) Sub-theme 2.1: Cultural practices and death rituals

The awareness of the nursing staff regarding the diversity of cultural practices in South Africa, and their desire to ensure that families have an opportunity to practice their death rituals is revealed in the following statement made in response to a question about discussions relating to death that may occur in the ICU:

> *"….like different cultures, like what we do in, in a death, like when it comes to Muslims we try to hurry things up because we know they want to bury as soon as possible, when it comes to, to the Indians, the Hindi and Tamil and stuff, we know generally they, they want cremations, so, so we make sure that the doctors fills those forms in, you know in the*

> *ward beforehand and, um,* [clears throat] *with the blacks, it's a few days, they want time, you know things like that, that's what we basically discuss what , you know what each of us do at the time of the funeral at home, and it helps us understand, you know, how to act with the visitors at well, you need to like, if a Muslim patient dies and you need to do a PM, we try and make sure we tell the family beforehand - don't make your arrangements straight away, 'cause the patient's going need a PM, you know that kind of thing. So by, by talking about it, it's just understanding what we do, to help the, the, to help us in the future situation."*

During the interview with Gugu, the impact of dealing with death related to the DNR order on her cultural practices was revealed. She described the rituals that her family required her to follow when dealing with death, believing that if these rituals were not followed she would bring the spirit of the dead person home with her. With a sense of sadness she described the following:

> "*But, ah now, it's happening daily for me, and by the time I reach home I'm too exhausted and tired, so I must start all these routine things that my mother said I must do, ah ah, and I end up not doing them. I just told myself it's psychological, it's in you, if you think, they say it's bad luck, you'll have like misfortunes because…"* [does not complete the sentence]

Gugu also mentioned the importance of allowing different cultural practices to occur during the dying process as a means of assisting the family to grieve.

> *"So we allow them, because, that's, we're treating them also psychologically, at least, we don't like to be an obstacle if they want to pray, want to put on a string, they want to put their prayer note on the head, ashes, all those things, we allow them, you know, it's their belief and culture."*

Jane, in particular, was concerned with unknown patients' lack of family, and the impact this would have on cultural rituals associated with death and dying. She reveals this in the following extract:

> *"…I would feel sadder because this patient has died, there's no-one to find them, they, they, you don't know how long they'll lay in the mortuary, you don't what happens from the mortuary. And, and sometimes with a lot of cultural things that's involved you, you just think like, you know I wonder, who's gonna come for them, and nobody did this cultural thing that is supposed to be done, that kind of thing."*

4.2.2.2 CATEGORY 2 : COMMUNICATION IN THE DNR DECISION

From all the interviews conducted with the participants, the importance of communication during the process emerged as a strong theme. How this communication process was addressed impacted on the experiences of these ICU nurses when dealing with the DNR process either negatively or positively. Two themes and their sub-themes will be used to explore the impact of communication on the experiences of the participants.

4.2.2.2.1 THEME 1: MAKING THE DECISION

i) Sub-theme 1.1: Our opinion should count

All participants expressed their need to be involved in end-of-life decision-making involving the patients in their care. The feeling of a need to be part of the team and have their opinion heard was expressed. How comfortable the participants felt in expressing these opinions was revealed to be dependent on the approachability of the doctors involved in the decision-making, and the level of experience of the participant, with the older and more experienced

participants appearing to have no problems expressing their opinions. The following extracts from the interviews with the participants demonstrate how these ICU nurses feel about the decision-making process.

Sue and Jane were among the least experienced nurses interviewed, and describe their experiences as follows:

> *"I haven't ever personally ever raised a question to them, but uh, you know, about a DNR and stuff, but you get that sense of, of attitude that comes along, it's like, you know, we've done this, we've done this many times, we know what we're talking about, sort of thing, you know that's how it goes, so you know."* (Jane)

Sue states the following regarding the involvement of nurses in the decision-making process:

> "*They don't, they don't normally consult us, like previously they would ask, 'How do you nurses feel?', but these days they don't ask them."*

When asked if she thought it important to be asked, she replied as follows:

> *"I think so. … …Because we're nursing the patient most of the time compared to the doctors."*

In the following extract Sue explains that doctors do explain their reasoning for a DNR decision which the nursing staff felt was made too early, and admitted that in most instances this helps, however this is not always the case. She then describes how she feels when this occurs.

> *"The order still gets carried out* [sounds sad], *their decision is…* [sighs, sounds despondent]*"… "Sometimes you're very hurt by it."*

Sarah supports some of what Sue expressed, but voiced a different experience with regards to the response she would receive if she questioned the DNR decision.

> *"We aren't asked, but I know there was a time where we were asked on the ward round and the, ja, sister nursing the patient was asked, 'How do you feel, is everyone in agreement with the decision?' Now we don't get asked <u>but</u>* [emphasis] *if you voice your opinion and if I say, um, you know, 'Please let's, let's give one, let's give the patient one more day' then, uh, I think we will be taken into consideration."*

Later in the interview she expressed this in response to being asked if decisions would be harder to accept if she was not permitted to express her opinion.

> *"I think so. Yes, maybe it would be harder, because all our opinions should count, we are the ones nursing the patients, and we form that bond with the patient and the family and the family know, you know, you're nursing the patient and they come to you. So then I think it would be because we're also human, and we are also part of the team, so I think our opinion should count. I would…ja…"*

Katie and Renata supported Sarah's views as follows:

> *"I would say he suggests it, he would say... 'You know what, I think this would be a DNR'. But I don't think that it's his decision solely to make, because I think if I objected to any of it I don't think it would be a decision that would be made. It's just that we haven't had that where, I haven't had that where I objected to it, because most times I am in agreement with what he says…….*[adding] "*…because at the end of the day they are there for brief periods in the day and for any problems that arise, but at the end of the day you are the one with the patient for the entire period of your shift, which is like 12 hours in a day, and you can see how, you know what is actually happening with the patient. So I think our input is very important."* (Katie)

> *"One thing I must say our consultants are very considerate, they always ask our opinion, and if we disagree they don't do it."* (Renata)

Gugu, on the other hand, frames her view of the importance of nurses' participation in end-of-life decision-making in the ICU in terms of the nurses' role as the patient's advocate in the following statement:

> *"Yes it's very important. That is why they say we are patient advocates. Because at times, they will think the other way and then you've got some suggestions that you can just come out with, that will be profitable to the patient."*

Taby explains her experiences regarding the participation of nurses in the decision-making process.

> *"The nurses are very much involved, yes."* ……. *"It's very important because it helps you deal with it later."*

She goes on to explain her perceptions about her willingness to voice her opinions regarding DNR decisions in the following statements:

> *"Yes* [stated emphatically], *we do feel free, and the doctors actually do take it into consideration."* … *"You've got to substantiate your, your … your answer, I mean or your…whatever you're asking. If it's a valid enough reason then the DNR does not carry on.*"

Later she expressed her feelings when being asked her opinion:

> *"It makes me feel that at least we can participate in such things, it's not a one-sided thing, it's a collective, um, opinion"… "Part of the team ja. That at least I'm recognised, I'm not just a nurse or a body walking round in the ICU."* [laughing]

ii) Sub-Theme 1.2: Medical decision

End-of-life decisions, in the context of the unit under study, are made, based on the concept of medical futility. When discussing this issue, participants agreed with the philosophy that the DNR order is a medical decision and not a decision that the family should be required to make. The following extracts support this theme:

> *"……given half the chance, any family member will never want to actually… Uh, switch off a machine of, or a loved one. I don't think there's, I think there might be very few people that will actually have the guts to say – ok my Mum's now had her fair share, and I think the best decision – I think it takes a very strong person, and I don't think that there are many people out there that will actually make that kind of decision. So I think, in state hospitals it's not, the family's not given that decision, I think that the decision is made by the people looking after them, doctors and things like that. But, and so when it's explained to the family it's said in that's it's not that they're given a choice in the decision, it's a decision that's made by the medical personnel."* (Katie)

> *"Actually they um, they are just told because the decision is actually a medical decision, they've got no say in the decision-making of the DNR." …… "I think it's right because if they had a say in the decision, nobody wants their loved one to be taken off life support. Then a DNR would never go on with anybody because nobody will ever* [laughing] *say, 'Yes, take him off'. Although you far, here and far you do get some of them that say, especially those that have made the living will, that's why I say the living will makes our, our job so much easier. With those cases, our job is so much easier because you know what to do when such a crisis occurs."* (Taby)

> *"….. I think they, they need to be informed, as in 'this is what's going to happen and this is what we've done', and you know that, but not actually involved in the decision it's self because… no, no-body would actually, not no-body, a lot of people may not say…no-one is going to be happy, 'Yes, you know what, switch it off' sort of thing because a lot of us don't understand. Maybe us with some sort of medical background, if we , if our family member was there, we would be able to sit*

> *down and say, you know what, it does make sense, they're better off if we stop treatment and things, but if you look at the lay person and things, as long the person it there and alive, it doesn't matter to them, they are just alive as compared to being dead. So I don't think really think they should be involved in that whole, um, you know, decision-making, because then we're going to be left with lots of patients that are just going to be on machines."* (Jane)

Renata relates an incident involving a woman whose husband had died after a DNR order in the unit several years previously.

> *"And I won't forget, we had a patient that came after four years, she came here……her family up to today are saying she's the one who was instrumental in having her husband killed here. ……. And then the family blamed her to say that she's the one who said they must take off the ventilator, she agreed to it, and four years later she said it was still affecting her and they used to taunt her and she came here for closure."*

iii) Sub-Theme 1.3: Breaking the news

Family members of the patient are informed of the DNR order by a member of the medical team. It is the practice of the unit that the registered nurse looking after the patient for the day accompanies the doctor, and is present when the family is informed of the DNR decision and all it entails. All participants see this as an essential part of the DNR process, where it plays a vital role in the communication, ultimately impacting on how they themselves experience the DNR process. The three following areas of importance were identified during the interviews expressing the value the participants place on being present during this moment: -

- Providing a united front with the doctors, thus ensuring consistency of the information provided to the family members.
- Provision of emotional support to the family.
- Ensuring documentation regarding the discussion appears in the patients' notes for legal purposes.

This theme is supported by the following extracts from the interviews.

> *"……like sometimes if the doctor explains something in medical terms and they don't understand, you actually tell, you know, relatives or family in a simpler version, and also a bit of support you provide, and also for documentation, you know, what the doctors said for you to document, so for future references, they can't say this wasn't said and that wasn't said, they weren't informed." ……. "Now you understand how much the doctors told them and you also provide more, you know, based on what he's said you can provide more reassurance and comfort there."* (Sue)

Renata outlines two of the identified areas:

> "*Now imagine, me as the nurse telling them this, to the family, and the doctor is telling that, it doesn't correspond and puts a question mark…."… "That's number one. The number two for psychological reasons, because they bond with her more because she is there and they can… you know…"*

Taby, Katie and Gugu support this as follows:

> *"Because you look after this patient, and when the decision is made and you also have to participate in the decision-making and you are in, most of the time interacting with the family that comes to visit this patient. So you know from A to Z what's been happening, how the family feels about it, how they are dealing with it, 24/7 you're there with the family."* (Taby)

> *"……when dealing with family, there needs to be, to be consistency in what you said, I don't know if that's the word*

I'm looking for, but there needs to be, you know, consistency, like what the doctor is saying must equal what the nurse is saying. So, so you're on the same level, so the family doesn't hear different, uh, you know, get different information from the nurse and get different information from the doctor. I think that that's important. So when dealing with family that's also tricky, so, because when families are grieving they want to, to always grasp onto hope and uh, something positive that goes on. So if you like sort of slip, and then they, you know, then they grasp at that straw of hope and then it becomes difficult for them. So I think that if you and the doctor are on the same level, are on the same, uh, thing, I think it's easier for them, and it's easier for you." (Katie)

"And then if you are there it's okay, because they can see that you were present for the explanation. The doctor will ask are there any questions or anything that you would like to comment on, and much as it's been explained by the doctor they will pretend that they understand, but the next day it will be something, even over the phone, you'll be answering phone calls from different members, you know, expecting change."……..*"It's just to build that trust. The doctor is there, it's like, um, a multiple disciplinary team should be there and then they can maybe take it as something right." …. "… because there must be one word. I cannot say something different and then the doctor comes and explains something, eh, totally. Because they can just hold on that and they'll say 'but sister promised us that he will wake up.'"* (Gugu)

Jane expressed her feelings as follows:

"*So if that nurse is there for the first meeting and there's a different set of relatives that come back afterwards, and the patient is still alive, she may be able to, to say a similar kind of, give a similar explanation then, like what was given as compared to giving two completely different things. So I think that it's best that they are there."*

iv) Sub-Theme 1.4: Taking the brunt

Taby described the patient's family as "….. *the most important people actually with this DNR it's the relatives because they're the ones that suffer after this person is gone and DNR'ed."* It can thus be said that communication with these relatives plays an important role in the DNR process. The brunt of this communication, after the news is broken, falls on the shoulders of the nursing staff. This experience was described by several of the participants.

Taby acknowledges the role of the doctor in breaking the news but elaborates further stating the following:

> *"……And another thing with this DNR, I feel the relatives, umm, sometimes they're misinformed, or they're not, uh, informed well enough. … … They don't get given enough time to deal with these things, and us nurses are the ones that have to cope with it. We have to try and explain why... Although the doctors do explain, but the ultimate end of this whole story is that the nurse has to explain to the relatives."*

And later she states:

> *"But I have encountered some problems where the family has not even been informed properly, they still come to me for extra information or have not understood, or whether the doctors speak too 'high fluted'* [high faluting: referring too speaking in too formal or complex a manner] *for them or what it is. But at the end of the day, the nurse is still faced with this problem."*

Gugu describes the challenge ongoing communication with family members has for nursing staff even after extensive discussions with the doctor:

> *"Eh, the family most of the time you will find that they are in denial, much as a lot of things have been explained, into their*

level of understanding, but they will have denial, and most of the patients have got the belief that maybe one day, because of somebody who was in a coma for three months, four months, and then he, he survived after that, after everything was said, so they still have that, and that makes it difficult even to keep on convincing them, each day, daily they will be expecting changes, of which there are no changes. It's even worse if the patient like has that jerky movement, and then they will say, they will just think maybe it's the beginning of life again. It's no more like the doctors have been explaining that, you can do this but …" [sounds sad]

4.2.2.2.2 THEME 2: BARRIERS TO COMMUNICATION

i) Sub-theme 2.1: Reservations and blame

Participants also described some reservations they have whilst communicating with the patient's relatives which impact on how they communicate and form barriers. These reservations were expressed by both Katie and Gugu:

"I don't think I'm very comfortable answering all of the questions because, um, people have this tendency, especially when they are grieving, I don't know what it is, but they twist and turn everything around, and as much as you want to provide them with the information that you've given them, it actually sometimes works out to your disadvantage because they, they hear what they want to hear, and they see what they want to see, and I think, you know, at the end, as much as you feel sorry for them and you want to answer all of their questions, I think I do feel reserved in answering a lot of questions, and I think I prefer to stick to the condition is the same or there has been a slight deterioration, or this has been explained to you or this or that. But I don't think that I would, you know go, go very deep into explaining a lot of things." (Katie)

Gugu explains how she feels relatives "blame" the nurses for the decisions:

"As I can tell you, they, uh, look for anything to complain about, or to blame on, and then sometimes even think it's the nurses' mistake, it's nurses' carelessness or something, much

as it's been explained to them by the doctor. Explaining the physiological changes and everything to the relative, but it does happen" and*"It's even worse when the family that is even against you, like blaming, looking for all those things."*

Katie also expressed worries about giving family members false hopes when discussing the patient's condition with them.

"So when dealing with family, that's also tricky, so when families are grieving, they want to, to always grasp onto hope and uh, something positive that goes on. So if you like sort of slip, and then they, you know, then they grasp at that straw of hope and then it becomes difficult for them."

ii) Sub-theme 2.2: More receptive to doctors

Renata stressed the importance of doctors being available to discuss issues with family members, citing the social standing of nurses as being a barrier to effective communication, as relatives do not take account of information being provided by nurses, preferring to hear the same information from the doctor.

"*…..as I say, it's nice to have it from both sides, from doctors and nurses. You know, I don't know, society, if a nurse tells them something, they take it with a pinch of salt, but if a doctor tells them something, they are more, you know, more to follow or accept it in a better way, from my years of experience, this is what I gather. So when something comes from the doctor they are more receptive. So, never mind how nicely you can say it, but generally it is like that.*"

Gugu expresses the response that family members may have if only nurses are involved in communications relating to patients' conditions and prognosis. Her comments relate to Renata's comments regarding the social standing of nurses.

Gugu explains why it is important that doctors are involved in family discussions and available to answer questions as follows:

> *"It's very important, because sometimes they believe that you might be lying, you know, you're not telling something, that you are not actually in charge of the patient*."

4.2.2.3 CATEGORY 3: ACCEPTING THE DNR ORDER

How nurses experience the DNR process is ultimately determined by how "comfortable" they are with the decision taken. Several factors were identified as impacting on how acceptable the participants found the decision. These factors are outlined below as themes.

4.2.2.3.1 THEME 1: TIMING

The timing of the DNR decision appears to greatly influence how acceptable all participants found the decision. Participants frequently retold their experience with this process, citing that the reason why that patient's DNR process was memorable was due to the timing of the decision. Participants appear to be more comfortable when the patient is deemed to have been "given a chance" or received "maximum therapy". Most participants stated that they were uncomfortable with decisions made for patients who had been in the unit for less than twenty-four hours. This, participants explained, often occurred due to the ever-increasing pressure for beds.

Jane describes an incident where the suspect of a particularly horrific crime was admitted to the unit. He had been in the unit less than twenty-four hours when the DNR decision was made. Jane expresses concerns about the timing of the decision and questions why the decision was made in the following extract.

> "*It stands out 'cause it was like, you know, very abrupt, it um, there was like, you know" ……. "….. they tend to normally give the patient 24 to 48 hours and then, you know, reassess, but with him it was just you know what, that's it, let's just stop. It didn't feel right in the sense because of what he'd done. He'd done something rotten, but, you know, we didn't have a say in, you know, should we carry on or should we wait or anything."*

Taby describes the increasing pressure for beds.

> *"It's, it's happening quite a lot lately. Before, when I started working in ICU it wasn't so much so. But now, because we are really pressed for beds …… it's, it's becoming more and more pressure." ……."It makes me feel that these patients are not given enough time to…, to actually show signs of recovery, even if they were to recover, they were not given enough time. I think they are just nipped in the bud before they show any progress."*

When asked if she thought decisions were being made too early she replied:

> "*They are, decisions are definitely being made too early. Some decisions, some cases are given 24 hours, maybe they should be extended to 72 hours."*

Taby differentiates between her acceptances of the DNR order in patients who had been in the unit for a short period compared to those who have been in the unit for an extended period of time.

> *"…….when it's short term I don't think they are given enough time to show any signs of, of, of improvement.*

Whereas if they have been given three or four weeks, whatever, they have been given enough time, they have been given all they can and they have not responded. And so I, I respond differently, because I feel that everything has been done for them that needed to be done and they still did not respond. So there's only so much you can do. Whereas with the short term ones, I feel they should be given more time in case they do respond to treatment."

Sue agrees stating:

"…if you see it's a patient that you've given him a chance and you see you're not getting anywhere with it and you DNR, it's not so bad. If it's somebody young, and they haven't given him sufficient time and they DNR, then it actually gets to you." …… "Like say they DNRed a patient two days after admission to ICU, I feel that's a bit too soon, like that, whereas compared to someone who's been like 15 days and they DNR and you see, oh the organs are failing, and you know that, you know, there's no way for the patient to survive."

Katie describes the DNR decision as being justifiable and reasonable as follows:

"After you've given the patient a sufficient, you know sufficient time to declare, himself, like, like you know you've tried everything, I mean if you, if you've got a patient that's in, um, that, that, that you've corrected what you could on the patient. If the blood pressure's dropping and you've started your inotropes, you've reached your maximum, if, you know, the, the patient is, um, septic, you've started your antibiotics. If the patient's oozing, and in DIC, and you've done your FDPs and bloods and whatever, and having, and despite all of that, the patient is still now deteriorating you know that there is no going back, so, I think in, as long as you've given your, given a fair, you know try, you know to save the patient's life. After that there's nothing. I don't think it's, it's a decision that can be made within a day or so."

Renata agrees that the timing of the decision plays a vital role in how it is viewed and accepted:

"Because you can see as time goes by that definitely there's nothing that can be done, you know, and you, you can say it to yourself that we've given him the chance, he didn't make it" …… "So time is very important."

4.2.2.3.2 THEME 2: EXPERIENCE VS. INEXPERIENCE

Although only ICU trained and experienced nurses were interviewed in the research, they described how their perceptions and reactions to the DNR process had changed as their levels of knowledge, understanding and experience grew. Being able to understand and rationalise end-of-life decisions impacts on the experience in terms of how nurses respond emotionally, and the coping strategies they employ. Some of these experiences regarding these changing perceptions and responses to DNR orders are outlined below.

"……when you're new in this situation you think you, you literally say, 'Ahh they're killing the patient!', you know, and you don't see anything else, you don't see, ay, this is end stage ARDS or end stage High Five and things like that. You just see the person, the individual, that we're taking away their life, you know it's like, uh like, ...Okay, but as time goes by, with experience and seeing and, then you, you able to take a DNR more easily. Eh, initially, you don't even want to make the changes on the ventilator when the doctor comes and says 21% and extubate or T-piece, you don't want to do it, you say doctor do it, or senior or somebody else do it, but as time goes by, it becomes part, not that you, you are becoming heartless or hardy or something, but you, you, you getting to grips with it, you're seeing for yourself that sometimes there is nothing more you can do." (Renata)

Katie describes her experience of the DNR process shortly after starting in ICU.

> "……*it was quite scary, because you, you really didn't have sufficient information, although everything looked bleak, you don't have enough information to like really, you know, think about it and whatever. So it was, that was it, it was a harsh decision, that's what I felt to just terminate life. I was of the opinion that it should happen naturally, you know."* ……..
> *"… it was one of the first that I had to deal with. I think that, that's why it sticks out so."*

She goes on to explain how her perceptions of the process have changed, taking on a more pragmatic approach.

> *"I'm more realistic. I mean with everything that goes along with the government sector, uh, there's finances to consider, there's a lot of other things that play a role in decision-making, and with the knowledge that we've gained, and together with experience, um, we can…when a DNR order is made you can, you know, that it is the right decision, deep down, you know that okay, it is justifiable, and you are in agreement with that decision, because at the end of the day we also have to look at death, you know, with dignity as well, so we want a death….you don't want to prolong, um, you know, agony. So as long as it's justifiable, as long as, you know, there is reason for it and we know that the prognosis is poor, I think I'm, I'm okay with the DNR order because I can reason it out and say, you know what, this is it, you know there is no turning back from there."*

Sue and Taby describe how their perceptions have changed with knowledge and experience:

> *"When I first came here, I didn't accept it at all, even if it was an old person because, ummm. Prior to that I worked in Casualty, and there you resuscitate, like you know, every patient, no matter what. And then all of a sudden here, we're like stopping and capping like treatment. So it did affect me initially."* …… *"I gained more experience in ICU, and I've worked, um, more with critically ill patients and seen the prognosis now."* (Sue)

> *"Initially I just thought this was cruel to mankind and, uh, how can they not give this person more time, the family broke*

> *down. I just looked at the whole thing as being a cruelty, rather than, uh…uh… stopping the discomfort."* [laughs]…… "*Well, before I used to, as I say, just fall apart and cry, and, you know, but now I'm able to stand and understand why these things are done, and what benefit it is to the patient and to the relatives, uh, to the unit, to everybody. Now I've got a better understanding."* (Taby)

4.2.2.3.3 THEME 3: CONFLICT IN CARRYING OUT THE ORDER

Once the DNR order has been given how is it then implemented? In the context of the target ICU the nursing staff individually choose whether or not to actively remove or discontinue therapies themselves, or to rely on a doctor to carry out the order. Renata explains this as follows:

> *"If she feels she is not happy doing it, then she tells the doctor, and he does or any one of us, she asks that we can do it. So it's no hard and fast rule that she has to do it, because, eh, we have to consider people's psychological…uh…balance, because if they feel they are not happy doing it, rather not let them do it personally, because they might feel that they are killing somebody, you know what I mean. So, uh, like that we do it. Like we've go no set pattern, rules or anything, we just take each situation as it comes*."

What determines the level of comfort in carrying out the DNR order appears to be influenced by other themes already discussed as part of the process of acceptance of the decision, i.e. the timing and the experience level of the nursing staff involved. More junior staff at times appear reluctant to question DNR orders, but rather than carrying out the order adopt a stance of passive resistance.

Jane recounts two of her experiences of DNR orders which she was not comfortable with and how she responded:

> *"…..when the order was given we were like just all looking at each other, and I think the doctor realised, you know, we were being reluctant to just stop everything, so he did it himself."*
>
> *"It depends, as I say, if I understood, you know, what was the process behind the whole thing, and then I know, okay, we're doing this, and I understand why and things, then it's fine, but if, if I'm still unsure of, or unhappy about why you just do it and you're just a bit upset and try and drag out the inotropes for a little longer, or you say you know what, just now it's visiting hours and maybe they'll get visitors. You know you just try and buy a little time. Or sometimes, you just wish the patient doesn't die with you, you know, till your shift is over, 'cause then you don't want to be left with, with knowing that the patient died with me, you know, that kind of thing."*

Sue describes her experiences similarly:

> *"…… like if it's a patient that you can see the prognosis is, uh, poor, and, uh, if the order is given, you know by the doctor then… I have switched inotropes off, because doctors said to switch them off." …..*
> *"When I feel like, the patient wasn't given sufficient time, like the decision was made too quickly, then I don't feel comfortable doing that." …….. "There were, uh, incidences when they asked us to switch it, you know, off, and I refused and told the doctors they must do it themselves."*

Taby discusses the reluctance of junior nurses to physically implement the withdrawing of support as part of the DNR order:

> *".. the junior staff is like, they just don't <u>want</u>* [emphasised] *to do it because they feel <u>responsible</u>* [emphasised] *that they've ended the life of a patient. And that is actually not so, because it's, it's an order, it's an order from the doctor."*

Katie describes what she see as a change in the way the DNR order gets implemented, with nursing staff being less involved in carrying out the order themselves. In the following extract from her interview she describes the changes that she has experienced, puts forward her reasons why she thinks this has occurred, and expresses her views on carrying out the order.

> *"……we used to actually carry it out ourselves, um, but recently I see that the consultant does it, he, he actually turns off, you know, puts the patient off, or extubates, or disconnects, whatever it is, we don't actually do it any more. It's done by the consultant."*
>
> *"I think it has to do more with the nurses' emotional state. I don't think that a lot of people were comfortable with, with having to do it themselves. I, I think that's just why it's changed ……."*
>
> *" As I said, I am in agreement with, with, with them doing the order, so I really think that the actual, if you're in agreement with the decision, the actual turning off is not the point, because if you've agreed in your mind that the patient is not doing well, so I don't think the actual turning of your knobs and disconnecting your patient is going to make much of a difference from a religious point of view, because I think that's where that stems from. Uh, you know, this whole idea of them not turning off if you are agreeing, if you are not agreeing you have to not agree, you know vocally, you have to say "I'm not agreeing with this kind of thing" and whatever and. So I don't think the actual deed has any kind of, you know, relevance*."

4.2.2.4 CATEGORY 4: SUPPORT AND COPING STRAGEGIES

Category 1 addressed the emotional impact that end-of-life decision-making has on the nurses involved in the process. To determine how the participants' process and deal with the emotional impact of the DNR order their support systems and coping strategies were explored.

4.2.2.4.1 THEME 1: INFORMAL SUPPORT

The provision of emotional support by colleagues emerged fairly strongly during the interviews. Support systems will be discussed using three sub-themes, namely the support provided by nursing colleagues, family and friends and medical colleagues.

i) Sub-Theme 1.1: Shared experiences

All participants except one, described, with appreciation, the support they received from their fellow nurses working in the ICU. The support that senior nursing staff provided to more junior staff appears to play an important role in how nurses experience DNR orders. The more junior staff interviewed related how they relied on the more senior ICU nurse to provide explanations, understanding and comfort.

> *"Because we share, we share all these experiences. Some of us are still* [clears throat] *junior, like they don't even have, they haven't had experience, and then by sharing, like* [mentions colleague's name]*, she's been in ICU for quite some time and she'll be explaining all these things, and then you see, oh it's not like the first time with me, you know. "* (Gugu)

This view is supported by both Jane and Sue:

> *"….we do have support amongst ourselves, not like where you'd get someone who sits you down to talk, but if you're like upset about, you know, how could they do this and stuff, there's people in the ward who would listen, you know, and give you that time to understand what you're trying to say. And maybe if we, there's some of us that are less experienced, and there are some of us that are more, uh, highly experienced than us, if you're, you're speaking to one of them, they probably would be able to explain*

> *something to you that you didn't understand, and then it clears up, you know, why, something, something that you didn't understand, they'd be able to clear it up for you."* (Jane)
>
> *"Most times in the ward, we verbalise and speak to each other in the ward. We've got senior sisters there that like, you know, sometimes will provide support for you. We normally discuss it in the unit, we'll speak how we feel."* (Sue)

However when asked if this was sufficient, she replied:

> "*No, it's insufficient, but that's all we have available at the moment."*

Taby explains how she tries to support the more junior staff in dealing with the DNR process.

> *"I personally have experienced it, I am able to tell them personally what I went through, and that, in time to come, they will be able to cope with it, because it happens all the time, as long as they are working there."* ……. *"whenever there is such an, a, an order given, or anything like this taking place, when I'm on duty, I make sure, because the young girls that come to the unit can, cannot deal with this initially because they, they just fall apart, but I speak to them afterwards, and I tell them that it is something that is done, and I know its hard to accept, that you will get used to it, but it takes time and if you, if you, you feel depressed or anything, speak about it, and if it's beyond control or whatever, we'll see what we can do, ……. We, the older ones try and explain why it was done and……..as the years go along, you will realise why these things are done, and of what help it was to the patient and to the family."*

No formal debriefing sessions are held in the unit as such. Tea and lunch time appears to provide the opportunity for staff to express their views, opinions or emotions. Support is provided on an individual basis as needed. This however

relies on the staff member seeking help, or the senior nurse realising that one of the junior staff is having emotional difficulties.

Sarah describes the mutual support that occurs in the unit:

> *"You know, find that at times, when* [mentions name] *my colleague also cries a lot and, and you know, we'll comfort each other…… She'll put her arms around me and say you know, it's, 'Sarah this is life and these things happen in life'. You know, ja."*
> *"It won't be, it won't be formal, it will be in passing, you know, where we'll just discuss, especially during tea or lunch, we're together, then it will be something informal when someone will say something. One of my colleagues will make a comment about what has maybe just happened, and then we'll all contribute to it an …ah… most of the time we'll all feel the same."*

Katie agrees that discussing issues in the tea lounge is an important means of processing events relating to end-of-life issues, and elaborates on the supporting role she feels senior ICU nurses need to play:

> *"……she needs to be* [meaning the senior nursing staff] *somebody that is approachable, you know, so that staff can actually feel free go to her and say, you know, I'm having a problem here, you know, I'm really stressed about this, or I don't feel happy with that order, or whatever…."*
> *"……..you know what they've done, this order, I mean they've made this decision on the ward round, I'm not, you know, totally happy with it, and this is the reason that I'm not happy with it …….. she* [referring to more senior nursing staff] *needs to take that a little bit further, and, you know, support her, and possibly you know, you know carry on the message to whoever, to the doctor or whatever."*

Gugu's experience of the support provided by her colleagues differed slightly. As seen in the previous quote extracted from Gugu's interview, she agrees that

colleagues do provide support to each other, especially when the DNR order relates to a patient who has been in the unit for a longer period when there is a collective feeling which she describes by saying, "….*you're just a whole family*". However, she also describes a different scenario where she felt she could have received more support.

> *"……and it's like nobody will counsel each other. But it's like you are solely responsible for that patient, ah shame Gugu. Oh the family. Ooh this and …. You have to take care of the family, and you know, especially when they are waiting for that hour, they're crying and so…"*

She then defends her colleagues' lack of support saying:

> *"But we, hey, we do, but it's like, but in ICU you've got your own patient too, so you cannot nurse a patient and nurse a nurse as well, because she's undergoing this see!"*

ii) Sub-theme 1.2: Family and friends

Family and friends also emerged as a source of important support. This was particularly true if a family member or friend was a healthcare worker. However, participants appeared to be reluctant to burden their family and friends who were not in the health care profession as they felt they do not understand.

Katie describes the role her husband plays as a support system. This was especially true when she first started working in the ICU, when she used to discuss issues with him, however, over time, this has decreased and she would rather discuss issues with colleagues as they understand.

> *"……you know it helped just to take it home and like, you know, I'm married, so it helped to, you know, just talk it through ,and this is what I did, and this is you know whatever. But overtime, I leave it there. I leave it there and that's it."……..".....but I think that taking it home is really not the ideal because they really don't understand, so, basically I find talking to people at work about it and ,you know, just airing your views and, you know, I think that that's a better option for me, I just generally talk to them at work and, you know, iron out anything if I have any feelings on it or whatever."*

Renata describes how she tries not to take work home, but at times needs to obtain reassurance from her family after a DNR order.

> *"I try my best not to, definitely, but, then as I say* [rueful laugh] *human nature takes over. Some things you might tell your spouse or your child that, you know, this is what I experienced and I feel so bad about it or something, and I just think if we could have done… It's just in general, you know, that you sort of want reassurance, or get over it."*

Taby and Sarah describe the role of the family as providing a means of relieving emotions.

> *"I'll just speak about it like a once-off thing. I won't go on about it and make it like an over dinner conversation". ……"Ja, it does help, because if you're upset or saddened about something, to actually talk about it, it makes you feel better because you've actually taken out what's worrying you, whereas if it bubbles inside you, it builds pressure, builds pressure until one day you crack!"* [laughs] (Taby)

> *".....there are times when I am very quite, and my children and husband will say, 'what happened, why you are so quiet?', and I'll say, 'No it was just a sad day at work'. That's all I'll tell them, and then my husband would ask me……..uh, what broke me up, and I tell him we had a sad case, this is what happened and it was sad, you know. Uh, uh the way the relative cried, it was too heart-breaking and ja, as all he can do is listen."* (Sarah)

iii) Sub-theme 1.3: Medical colleagues

Experiences regarding the support provided by medical colleagues varied.

> *"Sometimes we have very good doctors, very approachable doctors in the ICU, and then we would sit and speak to them."* (Sue)

This view is supported by Taby, who explains when discussing one of the consultants in the unit,

> *"……he is actually very good about it, because if anybody is upset or did not cope with the DNR or whatever, he is always there to speak and explain, and over and over to try and, you know (what's the word I want to say?)…um… to try… ….and show them that it's not the first and the last time, it's something that's ongoing, and going to happen so ……you have to try and accept it, and that these things are done in the ICU."*

As opposed to Jane and Gugu:

> *"…… I just think that the doctors need to be a bit more careful and more helpful in, in the way they do it 'cause not all of us are on their level to understand how this functions and that functions, and now, when it's packed off, it's just not going to recover, you know that kind of thing. We, we still need to be explained the finer things that we haven't been taught, so if, if in those sense if we've been taught those things or explained it better, we'd be able to accept……"* (Jane)

> *"……they are always like in a rush, busy there, theatre and sometimes they are just called out in front of you. They are just called for emergencies, trauma, somewhere else. It's not like even if they can, but sometimes the time, and the way that they're busy."* (Gugu)

4.2.2.4.2 THEME 2: FORMAL SUPPORT

i) Sub-theme 2.1: Nobody cares about us

Both Gugu and Sarah stated, "Nobody cares about us" and "We don't have anyone", respectively highlighting the lack of support systems available for nurses working in the ICU. For Sarah, this seemed a particularly poignant fact which she only seemed to realise during the interview process.

None of the participants had experienced any form of support from the institution. When asked about this subject the following responses were made:

> *"No!. There is no other support system in the hospital" …….. " It just makes me feel that the nurses aren't looked after. You know, because at the end of the day we are also humans*." [and] "…..*because I actually think that we don't have enough support in the ICU to deal with these things. People are just pushed into this sea and they must just swim or sink."* (Taby)

> *"Because doctors, ah, policemen and paramedics, don't they have psychologists that they can go and speak to? We don't have anyone*!" (Sarah)

> *"No, not that I know of, my many years of being in ICU no, besides our colleagues, there's no other support that we get." (Sue)*

> *"…..we don't have any real structures…….. But we don't have a like psychologist who we can see, or a psychiatrist, we don't have it, have a person in place from whom you can seek stress management* [emphasis] *and things like that, no, or trauma management."* (Renata)

The Employee Assistance Programme (EAP) was not functional in the institution at the time of the interviews; the subject was broached during the interviews to determine whether this was a potential support system. Most

participants indicated that they had either not considered utilising the programme, or stated they would not utilise the programme if it was functional.

> *"So far the, .eh..the ones that I've seen are busy-bodies, that is why I don't trust them"* (Sarah)

> "'*Cause sometimes you just feel like, you know from, from when you just talk to people and things, you get that impression that not everything you'd say stays amongst who you're talking to, so I'm, I'm not personally guaranteed that if I'm going to go there and say, you know what, certain doctors did such a thing, you don't know whether they'd, the person speaking to you might take it as, you know what that could be something that's a hazard, a medico-legal hazard in your ward, and that doctor should be taken up, and then it becomes a big issue after that. So … it's like you're not going there to complain about the doctors, you just want some help for yourself if you need it, so I wouldn't want to"*

> *"Me personall, not, I'd prefer not to use any hospital, if I, you know, wouldn't use something like that." …… "I just don't trust that it's confidential, or you know, thing. I don't know, it, it was just like…..I don't know, I can't actually say much about it, but I just felt that the person there was you know…"* (Katie)

Taby expressed a different view:

> *"……we've never thought of referring like staff that are battling with this DNR to such programmes" …"I think it will* [be a good support system] *especially with the new staff coming to ICU and coming into contact with this DNR process. I really do think it will be of great help to the junior staff*."

4.2.2.4.3 THEME 3: COPING STRATEGIES

Throughout the previously discussed themes, the emotional impact of end-of-life decision-making was explored. How nurses working in the ICU manage these emotions will be addressed as sub-themes.

i) Sub-theme 3.1: Talking about the experience

All participants, regardless of their level of experience, identified that the most important strategy for coping with DNR orders was to talk about the experience, etc.

> *Ja, it really does help, because if you're upset or saddened about something, to actually talk about it, it makes you feel better, because you've actually taken out what's worrying you, whereas if it bubbles inside you build this pressure, builds pressure until one day you crack."* (Taby)

> *".....I talk, I'm someone that does talk, and I'll talk, I'll tell them this is how I'm feeling, and, and most of the time they'll give me advice. ……., we'll talk about, you know, the experiences we're having. I'll often go to* [mentions names of senior colleagues] *and talk and they give me advice. Yeah we talk" …. "I'll get the support at that time."* (Sarah)

> *".....the only thing is we talk about it to each other and we, you know, we discuss how we feel, and I think talking about something is the best treatment. You know, how you feel you take out, you sort of take it off your chest, and that does help because you do find some of them give you some positive, this thing."* (Renata)

ii) Sub-Theme 3.2: Rationalization/understanding

The ability to rationalise and understand why the decision was made helps process the experience and provides comfort. The need to be able to understand the DNR was of particular importance to Jane.

> *"Sometimes I'm okay with it, because I completely understand, you know, the whole process that they're talking about, you know, from where the patient started off, to where the patient is. And when I've completely, when I've understood that we've tried this line of therapy, they've tried that, and that and there is nothing else we can do. Then its fine 'cause I understand what is happening, but then when I*

don't, and, and you're not happy with what, what's going on, it's like….I just do what we have to do."

She further rationalises the decision:

"..'cause you look at it and ..you know what, it's for the better, 'cause the patient was suffering a lot, 'cause you know some of them come in in very bad conditions and, and feel like, you know what, they're actually suffering more by lying here and us fidgeting and poking, and knowing that we're not getting anywhere but we're still doing all these things."

Renata rationalises the doctors' DNR decision-making process stating:

"But he's trying, uh, maybe to prevent the person, allowing them to die with dignity, you know what I mean. Instead of prolonging the agony and the family's agony. You must always remember when we are prolonging the patient's agony, we're prolonging the family, the loved ones' agony."

iii) Sub-theme 3.3: Suppression and detachment

During their interviews, both Sarah and Jane verbalised how the interview process had made them think about issues they thought they had dealt with, indicating the possible suppression of emotions.

Jane states when discussing how the DNR process makes her feel:

"I won't say traumatising, 'cause you know, after a while you see other patients and things, and you just carry on, but it's like for that moment you, you feel a bit upset and things, 'cause you think maybe you could have done something else, or something to that effect, but uh, after a while you just carry on."

When asked if she thought she suppressed her emotions she replied,

> *"I say may….to a certain extent, because after a while, uh as you, when you first asked me if there was something that stands out, then there's, there's a situation that stands out, which obviously means that somewhere in me that still stayed in me, you know, hadn't like completely gotten out, like you know what, he's, the patient died, and that's it sort of thing."*

Sarah experiences particular difficulty with suppressed emotions which appeared to surface during the interview. She stopped at one stage, stating:

> "*You know you are actually making me have feelings that I never thought of, it's buried. You know! .."* ….. *"You know it's actually buried all this time. You know I really think we need counselling! Hey"* [laughs] ……. *"It's actually feelings that I never… I can actually burst out crying right now"* [laughs]. *"At the moment I feel very emotional, I didn't realise it because as I'm speaking to you there are other cases that are coming into my mind you know."*

Sarah had previously stated that she feels very emotional at the time the patient dies. When asked what she does with those emotions she replied:

> *"You've just, you've got to suppress them, because, I didn't realise I was suppressing it, but you do push it behind, because when you get a phone call, you're going to admit another patient, so I have to prepare myself for another patient who is just as critically ill."*

Sue also reveals her tendency to suppress her emotions as follows:

> *"Sometimes it does affect you, and you, and if it affected you a lot in the ward, then sometimes at home you still sit back and think about it."*

When asked how she then dealt with those feelings, she did not immediately respond, and only replied once asked, "Do you shut it off or do you actually process it?" To which she replied, "*No, I just shut it off."*

Katie describes how she detaches as a coping mechanism.

> *"But, uh, that's where you learn to detach you know, that's, that's it, you know what I mean. I've learnt not to carry it with me and take it with me wherever I go, and, you know, works, work, and this is what I do, and I leave it there and then…….otherwise I'll be depressed."*

4.2.2.5 CATEGORY 5: NAMING THE DNR PORCESS

Participants were asked to express their thoughts on the proposed changing of the terminology when referring to end-of-life decision-making from "Do Not Resuscitate" to "Allow Natural/Normal Death". Two themes emerged regarding this topic.

4.2.2.5.1 THEME 1: JUST WORDS

Although Sarah was of the opinion that AND sounds better than DNR she clarified this further stating:

> *"It seems, it's more um, it sounds much better you know, allow natural, allow normal death, than do not resuscitate. It does sound much better"…" It's just words that sound better. It makes us, uh, feel human* [laughs] *we're allowing natural, er, normal death, but er, I don't think it will make any difference to how you feel."*

Katie tends to agree with this sentiment:

> *"No. It's just a change in terminology to me. It's just, 'cause essentially it's the same thing."*

4.2.2.5.2 THEME 2: MORE HUMAN VS DON'T HELP THEM

Both Taby and Renata expressed the following perspective:

> *"Yes it should make a difference because the DNR sounds quite harsh, Do Not Resuscitate, whereas Allow Natural … it sounds more… ... subtle, the natural way."* (Taby)

> "*Like Do Not Resuscitate that means you're not going to do anything, you're going to let the person, like this one, you're not, you're not going to do anything, you're just letting them go naturally because you can't do anything."* (Renata)

Jane supports this view:

> *"It sounds much better. But I think the way it's being done is basically the same, 'cause from what I've understood from allow natural death, it would mean you did everything, and now you leave the patient, as in you're doing your basic nursing care, and you allow the patient to go on their own, which can take any number of hours to days even. So I think it just sounds better than DNR." ……. "'cause do not resuscitate, like you know, especially if a person was to look for the meaning of resuscitate and then they see it says, do not do this, then it's you know, saying don't help the person, you know that kind of thing*."

4.3 CONCLUSION

This chapter discussed the research findings in depth, identifying five categories under which various themes and sub-themes were described. These categories included issues regarding the emotional impact of DNR orders on the participants; communication in the DNR decision; accepting the DNR order; support systems and coping strategies and naming the DNR process. The following chapter discusses the identified themes, describes the limitations of the study, and presents a conclusion and recommendations derived from the study.

CHAPTER 5

DISCUSSION OF THE MAJOR FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

5.1 INTRODUCTION

This chapter discusses the findings of the study which are in keeping with the purpose and objectives, and bear in mind the philosophical approach of hermeneutical phenomenology. The study reveals the lived experiences of ICU nurses when dealing with end-of-life issues in relation to the DNR order. The findings will be discussed according to the following five major categories and their themes and sub-themes that emerged during the in-depth interviews with the participants (see Table 4.2):

- The impact of death and dying on the ICU nurse
- Communication in the DNR order
- Accepting the DNR order
- Support systems and coping strategies
- Naming the DNR process

This chapter will also discuss the limitations inherent in the study, the recommendations and conclusions with the support of other studies relating to this phenomenon.

5.2 THE IMPACT OF DEATH AND DYING ON THE ICU NURSE

During the interview process, the participants revealed the impact and emotional toll which death and dying, related to the DNR order, exacted on them. During the analysis process various themes and sub-themes emerged which will be discussed.

5.2.1 DEALING WITH THE FAMILY

Dealing with the family emerged as one of the most difficult aspects of the DNR process, thus how the participants experienced this will be discussed. It is acknowledged that the death and dying process experienced by a nurse working in the general ward is a difficult, and possibly a traumatic experience, however how ICU nurses experience this process may differ. With the development of technology and medical advances, expectations regarding the outcomes of patients have increased, especially when that patient is admitted to the ICU. Thus when death occurs in the ICU environment, it is seen as a failure of modern science (Miller, Forbes and Boyle, 2001). These increased expectations may therefore place an increased burden on ICU nurses when dealing with family members.

5.2.1.1 Grief

Emotive words such as sadness, depression, hurt and anger were used by the participants to describe their feelings. The DNR process was described, frequently, as a traumatic experience. These descriptions reveal the psychological impact that DNR orders have on ICU nurses, and which is supported in the literature (Leneart et al., 1998; Spencer, 1994). This impact is not lessened by experience, but may in

fact increase according to the number of deaths and frequent exposure to death that the ICU nurses have, as there is no opportunity to completely or adequately grieve between individual deaths (Elpern, Cover and Kleinpall, 2005; Shorter and Stayt, 2009). How ICU nurses cope and deal with their experiences and emotions will effect their decision-making processes and concentration (Lenart et al. 1998) and unless they posses good coping skills, may result in a non-caring attitude, anger and burn-out (Hay, 1972; Brosche, 2003). Brosche (2003) concludes that ICU nurses do not have the time to proceed through the stages of grief and the importance of this is seemingly ignored.

5.2.1.2 Empathy

Participants frequently expressed feelings of empathy, especially when dealing with the family. This was particularly true when they could identify with some aspect relating to the patient or family members, this was also documented by McMillen (2008). One of the participants had had an experience of a brother dying in ICU, another had a child who had been admitted to ICU and could therefore identify closely with the emotions experienced by the families of their patients. These feelings of empathy have been revealed in a similar study (Shorter and Stayt, 2009) in which the authors described nurses as imagining themselves in the patient's place. This is supported by the experiences of the participants in this study.

Halcomb et al. (2004), on the other hand, identified that nurses appeared to display empathy, however, when their comments were examined more closely, they

appeared flippant and did not appear to recognise the human tragedy of the situation. Careful examination of both the verbal and non-verbal cues of the participants of this study did not support the findings of Halcomb et al. (2004). Participants appeared genuinely distressed by the experiences recounted and the emotions expressed.

Brosche (2003) reviewed Kavanaugh's (1972) seven behaviours and feelings as part of the coping process when dealing with death and dying. These stages of grief are not linear, nor do they occur in a specific order, some stages may be bypassed or last only a few minutes. The author applied these behaviours and feelings specifically to the ICU nurse and formulated a Grief Care Plan. This care plan describes feelings of loss and loneliness which the nurse deals with by approaching the next patient and family with "empathy and genuine compassion…". This appears to support the responses of the participants when dealing with DNR orders.

5.2.1.3 Being Human vs. professionalism

The manner in which ICU nurses approach and respond to the families of patients who have had a DNR decision made appears to be dependent on their level of experience. The more junior participants expressed the importance of maintaining the appearance of professionalism, appearing to use this as a shield behind which to hide their emotions. This need to hide behind professionalism to conceal their personal grief is supported in the literature, where it is described that nurses keep their grief hidden and cry privately (Lenart et al., 1998, Brosche, 2003). Brosche

(2003) assesses this behaviour as being in line with Kavanaugh's (1972) feelings of shock and denial, where the nurse focuses on the tasks at hand keeping emotions hidden, and acting in a manner that is socially acceptable, being strong and in control.

The more experienced nurses appear more at ease with expressing their emotions when dealing with the family. Participants described crying with the family, giving the family members a hug, and the importance of "being as human as possible", (Taby) believing that this helped the family members. This understanding, acceptance and acknowledgement of the nurses' own grief develops with experience and is described by Brosche (2003) who identifies this process with Kavanaugh's (1972) behaviour of re-establishment, where the ICU nurse, after several years of experience, recognise their own need to grieve, thus allowing them to assist the grieving process in others, including family members and colleagues.

5.2.1.4 No family available

If, as previously described, dealing with the family of the patient who has a DNR order is the most difficult part of the process; it could then be assumed that when no family was available the process would be less traumatic. This was, in fact the case for most of the participants however, for one of the participants this was also distressing, as she worried about who would claim the patient's body, describing this as being worse in fact than when the patient was known.

This phenomenon has not previously been described. However, most studies published originate from first world countries which differ considerably from the South African setting, where ICUs are, in general, located in urban settings resulting in patients being transported distances far from their place of origin. These long distances, poor transport services and poverty thus deny family members access to the patient. Add to this, the migration from rural to urban areas, the disintegration of the nuclear family, poor/costly communication services, and the high incidence of violent crime and road accidents, (frequently involving pedestrians), unknown patients are frequently admitted to ICUs and may only be identified several days after admission, after their death, or never claimed at all.

5.2.2 CULTURE CLASH

5.2.2.1 Cultural practices and death rituals

Miller, Forbes and Boyle (2001) describe how religion and nature have been replaced in society by medical science, resulting in the loss of rituals and shared community grief when dealing with death and dying. O'Gorman (1998, p.1132) cites Goffman in describing how families often feel unwelcome and uncomfortable in the ICU, being denied the roles they play in society when dealing with the grieving process.

These views were not supported by the experiences expressed by the participants during the interview process in this study. The experiences revealed by participants are in keeping with the philosophy of Heidegger's hermeneutics, and what Koch

(1995) describes as understanding. Koch proposes that the background of each individual provides his/her history and will influence the way s/he views the world. South Africa is a diverse society with diverse cultures, religions and beliefs that are mixed together in close proximity. The participants are part of the South African community, and therefore their understanding of the rituals of death and dying of this diverse community informs their experiences of the DNR process in the ICU. This was revealed by Gugu's description of her cultural rituals that she was expected to practice, but abandoned, after encountering death at work.

Participants explained how, in ICU, discussions regarding death centred on the various cultural and religious aspects associated with death and dying, in order to gain understanding, and to facilitate these rituals to assist the family. Emphasis was placed on the importance of allowing the family free access to perform whatever rituals they required. This view is supported by Fouché (2006) who describes the importance of allowing families to conduct religious customs and rituals during the dying process.

5.3 COMMUNICATION IN THE DNR PROCESS

Communication plays a vital role in the DNR decision-making process and how well issues are communicated will impact on the way everyone involved in the outcome of the decision experiences that decision, and will influence the degree of distress/satisfaction. The role of communication in the DNR process is complicated, with many aspects and role players involved, and is therefore

discussed under the themes and sub-themes that emerged during the interview process.

5.3.1 MAKING THE DECISION

Dracup and Bryan-Brown (2005) see the solution to solving the dilemma that surrounds end-of-life decision-making as being effective and frequent communication between all members of the healthcare team.

5.3.1.1 Our opinion should count

All participants, without exception, expressed their need to be involved in the decision-making processes relating to DNR decisions made about the patient in their care. How involved the participants felt in the decision-making process was dependent on their level of confidence and comfort in expressing their views. Confidence and comfort levels were in themselves determined by the level of experience, and the relationship between the individual and the doctor involved in making the decision. It was the more experienced and senior participants who felt confident and comfortable voicing their opinions regarding DNR decisions, feeling confident that, as long as they could substantiate their input, their opinions would be considered and taken account of when the final decision was made. The degree of confidence and comfort correlated directly with the level of experience and time spent working in the unit. These findings are directly supported by the following studies. Hov, Hedelin and Athlin (2006) identified that how seriously communications were regarded by the physician, depended on the relationship between the nurse and the individual physician. Similarly, McMillen (2008)

revealed that the level of experience of the ICU nurse impacts on how much consideration is given to his/her views. It is evident, in this study, that the more senior participants appreciated being provided the opportunity to voice their opinions, and for Taby, particularly, this increased her job satisfaction and self-worth.

The reasons that the participants cited as to why their opinions should be heard support those published in the literature, namely, their holistic knowledge of the patients' and families' views; that this involvement helped them come to terms with their feelings and accept the decision; the fact that nurses think differently from doctors and may therefore have something unique to contribute (Spencer, 1994; Hov, Hedelin and Athlin, 2006; McMillen, 2008).

The more junior participants revealed feelings of being left out of the decision-making process and felt hurt when decisions were taken without their input being considered. This lack of involvement of nurses in DNR decisions has been reported in several studies conducted internationally (Thibault-Prevost, Jansen and Hodgins, 2000; Ferrand, et al., 2001; Latour, Fulbrook and Albarrain, 2006). Only one study conducted by Buckley et al. (2004) contradicted these findings. These authors reported that 73%, of ICU nurses surveyed in their study, reported being involved in the decision-making process. Miller, Forbes and Boyle (2001) warn of the possible consequences of nurses not being involved in the decision-making process

which include loss of an holistic and caring perspective, and ultimately result in nurses becoming less visible and less credible.

Oberle and Hughes (2001) differentiate between the perspectives that doctors and nurses have regarding the ethical concerns associated with end-of-life decisions, stating that doctors make the decision which results in a moral dilemma whereas nurses have to live with a decision made by someone else which results in moral distress. Moral distress has been defined as the painful feelings or psychological disequilibrium that results when the known ethically right course of action is not followed (Elpern,Cover and Kleinpell, 2005). This is especially true when conflict exists between the nurses and medical team regarding the appropriateness and duration of seemingly futile care, or when nurses have no input into end-of-life decision-making involving the patients in their care (Kaufman, 1998; Oberle and Hughes, 2001; Halcomb, et al., 2004; Elpern Covert and Klienpell, 2005; McDermid and Bagshaw, 2009; Latour, Fulbrook and Albarran, 2009).

The literature is clear that a collaborative approach to decision-making regarding end-of-life issues is desirable, and would result in better communication and satisfaction among professions (Eliasson, et al., 1997; Hojat, et al., 2003; Halcomb, et al., 2004; Puntillo and McAdam, 2006; McMillen, 2008). It is evident from the views expressed by some of the participants regarding their experiences with end-of-life decision-making that they are dissatisfied with the current status, and, in keeping with published research desire a more collaborative approach (Hojat, et al.,

2003; Halcomb, et al., 2004; Puntillo and McAdam, 2006). Good communication between doctors and nurses would promote shared decision-making and improve outcomes for both patients and their families (Pantilat, 2009).

5.3.1.2 Medical decision

End-of-life decision making practices vary. In France, the decision is taken by the medical staff and only involves the family 44% of the time (Farrand, et al., 2001) Buckley, et al. (2004) reported consulting with the family once the decision had been made by the medical team. Latour, Fulbrook and Alabarran (2006) propose the use of a collaborative decision-making model involving physicians, nurses and family. These same authors reported that the majority of nurses agreed that families should be involved in the decision-making process.

The findings of this study directly oppose those reported by Latour, Fulbrook and Alabarran (2006). All participants in this study appeared to feel fairly strongly that family members should not be part of the decision-making process, but should rather be kept fully informed of the patients' progress, and prepared, as far as possible to accept a DNR decision once made. All participants agreed that the DNR decision should be a medical decision, based on the concept of futility, taking into account the best interests of the patients. Family members, they agreed, should be informed once the decision is taken, and should be given an opportunity to ask questions and come to terms with the decision and agree where possible. It was indicated that, on the few occasions where the family did not agree, they were given

time with discussions between them and the medical team ongoing, however the final decision was a medical one.

Reasons that participants gave for not including family members in the decision-making process were concerns regarding the psychological burden such decisions would cause the family members. One participant (Renata) related a story regarding the long-term social consequences for the wife of a patient whose family members perceived her as having made the decision to terminate life support thus causing his death. Four years after the incident, the wife was still carrying the burden of a decision that she had not made, but had not contested.

Involvement of family members in DNR decision-making in the South African context thus poses what could possibly prove a unique challenge due to the diversity that exists in population groups. Patients and their family members may range from being highly educated and sophisticated in terms of understanding of technology, etc. to those who are illiterate, and are unfamiliar with the most basic of technological advances. Add to this the cultural and religious factors and the process becomes more complicated. The vast gulf between medical knowledge and understanding and the lay persons' socio-cultural and educational backgrounds described by Miller, Forbes and Boyle (2001) thus exists in the context of the ICU from which the participants were drawn.

5.3.1.3 Breaking the news

Once the DNR decision has been made it is communicated to family members by the doctor, accompanied by the nurse caring for that patient. All participants agreed on the importance of involving the ICU nurse caring for the patient in this process, citing three reasons for this involvement, namely, providing a united front with the doctors thus ensuring consistency of the information provided to the family members; provision of emotional support to the family; ensuring that documentation regarding the discussion appears in the patients' notes for legal purposes.

The provision of consistent information to family members and the presentation of a united front, however, appeared to be the most important reasons for involving nurses in this process. Participants also reported that, at times, family members did not fully understand or grasp the information discussed during these meetings, and that the nurses would thus have to explain over and over again to ensure understanding after the meeting, or to family members who had not been present at the meeting themselves. Thus the presence of the ICU nurse during communication with family members is vital to ensure consistency of information, so preventing possible confusion and dissatisfaction due to misunderstandings which may result from conflicting information. In this way, family members develop a trust relationship with the healthcare team, and the nursing staff are able to assess and monitor how the family is processing information and dealing with the dying process.

Thus it can be seen that communication is one of the most important factors during the DNR process. Lack of consistent, open communication and collaboration makes the difficult end-of-life decision-making process more challenging, and may impact on the satisfaction of the family members' experience (Puntillo and McAdam, 2006). Ensuring consistent input from both the doctors and nursing staff enhances communication with the family, ensuring that the DNR orders go smoothly (Eliasson, et al., 1997).

5.3.1.4 Taking the brunt

Dealing with the family of a patient once the DNR order has been given can be extremely stressful, even when extensive consultation has occurred. Kaufmann (1998) explains that families frequently fail to differentiate between technologies that support body functions and those that save lives. Nurses may experience moral distress when faced with dying patients, fearing that they are prolonging death and causing suffering by inflicting pain during procedures on dying patients as part of treatment (Dracup and Bryan-Brown, 2005).

These factors did not emerge from the interviews conducted with the participants of this study, however the participants did express feelings about being left to deal with the aftermath of the DNR decision when doctors were frequently not available to provide support. It is the nursing staff who are left to deal with the family, providing support, explanations and comfort (Thiabault-Prevost, Jensen and Hodgins, 2000).

How the news of the DNR decision is broken to the family impacts on the experiences that ICU nurses have during the dying process. Participants described how, even after extensive discussions between the doctors and family members, the burden of communication with the family falls to the ICU nurse. Family members frequently do not understand or grasp the concepts discussed during formal meetings with the doctors, requiring constant reiteration and explanations, clinging to the smallest change in the patient's condition as a sign of hope. Participants expressed the same concerns reported by Oberle and Hughes (2001) regarding communication in terms of the accuracy and adequacy of the information provided, as well as the language used in discussions, as no layman's terms were used. These factors re-emphasise the importance of the previous discussion relating to involving nurses in meetings with family members when discussing DNR orders.

5.3.2 BARRIERS TO COMMUNICATION

5.3.2.1 Reservations and blame

No references to the sub-theme of reservations and blame appear to have been reported previously. Participants revealed that they either felt the need to be cautious when answering questions from families, or felt that family members were in fact blaming them. On closer analysis, these feelings could perhaps be interpreted as feelings of unacknowledged guilt. Being questioned by family members could be interpreted by ICU nurses as though they were in fact being questioned regarding the care provided to the dying patient, thus threatening the goal of what is described in the literature as a "good death" (Kaufmann, 1998;

Shorter and Stayt, 2009). The degree of moral distress that nurses experience directly correlates with their perceptions of the care given to the patient (Halcomb, et al., 2004; Shorter and Stayt, 2009). Thus it could be said that questioning nurses equates to questioning the care provided, thus increasing the moral distress experienced by the ICU nurse.

In the grief care plan proposed by Brosche, (2003) the feelings of guilt described by Kavanaugh (1972) result in nurses reviewing nursing care standards to ensure that optimal care was given, and thus the nurses reassure themselves that they did everything possible, and that the death of the patient was not their fault in any way. In this context, it could also be suggested that by questioning the nurses, family members create doubts with regards to the care being provided and this results in feelings of guilt.

5.3.2.2 More receptive to doctors

The social standing of nurses in society was called into question by at least two of the participants. These participants expressed concerns that family members would either not believe the information provided by nursing staff regarding the condition and prognosis of their relatives, or did not take what they were told with the gravity it deserved until they heard the same information from the doctors. This supports the need for nurses to be seen to be involved in the decision-making process, and perhaps indicates that nurses have become less visible and less credible as predicted by Miller, Forbes and Boyle (2001).

5.4 ACCEPTING THE DNR ORDER

The degree of moral distress that nurses experience will be dependent on how they accept the DNR order. Moral distress is increased where conflict exists between nurses and the medical team regarding the issue of a DNR order.

5.4.1 TIMING

All participants agreed that the timing of the decision of a DNR order was of great importance in determining how they accepted the decision. Two aspects regarding the significance of the timing of the DNR decision have been discussed in the literature in terms of causing moral distress for nurses. Moral distress results when nurses feel either that futile care is being provided inappropriately, (Halcomb, et al., 2004; McDermid and Bagshaw, 2009) or if the decision was perceived to have been made prematurely, causing the nurses to feel that they had accelerated the patient's death (McMillen, 2008).

Participants in this study expressed concern regarding what they perceived to be premature decisions, and their experiences support those reported by McMillen (2008) in that they may be hastening the patients' death. It emerged that nurses have a need to feel that everything possible has been tried on the patient, and that the patient has been seen to be "given a chance" to respond to therapy. It would appear that decisions taken within the first forty-eight hours of admission to the ICU create doubt and distress for the nursing staff who have to carry out the orders.

Decisions taken when the patient has been in the unit for a few days and appears not to be responding to maximum therapy are easily accepted by nursing staff.

5.4.2 EXPERIENCE VS. INEXPERIENCE

All those who participated in the interviews were ICU trained registered nurses and had several years experience of working in the ICU with the least experienced participant having worked in the ICU for seven years.

When the participants initially started working in the ICU environment, they were all qualified registered nurses, who had had a minimum of five years of nursing experience behind them, and had surely encountered death and dying in the general ward setting. On arrival in the ICU however, all participants could clearly recall how they responded to DNR decisions when they first encountered the phenomenon. This clear recollection indicates the impact the DNR process has on individuals when it is first encountered. Participants described how they felt they were killing patients, and how they initially found the process difficult to accept. How their views and experiences related to DNR orders has changed over the years, and was also described by participants in terms of accepting decisions more easily as their levels of knowledge and experience grew, resulting in a clearer understanding of the impact the disease process had on the patient's ability to survive, despite the availability of technology. With knowledge and experience came the ability to rationalise DNR decisions, resulting in their ability to perceive a DNR order as relieving suffering and pain rather than killing the patient.

This reaction to the DNR process by qualified registered nurses entering the ICU environment for the first time exposes the gap of knowledge and understanding between the wards and the ICU environment, and demonstrates how ill-equipped nurses are to deal with death and dying as a result of a DNR order. Imagine then the impact that such events have on the lives of the family members of patients who have had a DNR decision taken. It is possibly those same ill-equipped nurses who are struggling with their own issues surrounding the DNR process who are required to support and comfort those family members, and unless they receive adequate support and assistance from more experienced and knowledgeable ICU nurses, will suffer extreme moral distress impacting on patient care and resulting in burn-out (Borsche, 2003).

5.4.3 CONFLICT IN CARRYING OUT THE ORDER

If nurses have been involved in the decision-making process and feel that their opinions have been heard and given due consideration, they appear to be more willing to be actively involved in carrying out the DNR order in terms of withdrawing or withholding therapy.

This was revealed during the interview process, where the junior participants, who felt that they did not have a voice often requested doctors or senior colleagues to carry out the DNR order. This supports previous discussions relating to moral distress and the perspective put forward by Oberle and Hughes, (2001) who differentiate between the moral dilemma that doctors face when making the

decision, and the moral distress caused to nurses who have to live with the decisions made by someone else.

No regulations are available in the South African context to provide guidance to ICU nurses in these circumstances.

5.5 SUPPORT SYSTEMS AND COPING STRATEGIES

Support systems and coping strategies for dealing with feelings associated with the DNR process are essential to prevent the development of a stress cascade. Unless these support systems and coping strategies are available, and effectively utilised, maladaptive coping skills may develop, resulting in decreased staff morale, decreased efficiency of care, decreased customer service, and increased staff turnover, thus increasing costs to the hospital and nursing shortages (Brosche, 2003). The availability and utilisation of these support systems and coping strategies will be discussed according to the identified themes and sub-themes.

5.5.1 INFORMAL SUPPORT

5.5.1.1 Shared experiences

Participants revealed the importance of talking about their experiences of death and dying related to the DNR process with their nursing colleagues, describing a shared experience. This was especially true in relation to long-term patients where a collective experience was described. The more junior participants described the important role the senior nursing staff played in explaining issues and providing

support. Senior nurses also described how helping and supporting junior nurses helped them process issues and events. However, this support, although valuable, is considered insufficient. These findings support those of Spencer (1994) who revealed that the majority of nurses felt that they received support from colleagues, but that 50% of these nurses felt that this support was insufficient. Shorter and Stayt (2009) described similar findings regarding the sharing experiences with colleagues who would be able to understand. This was a vital form of support.

The value of this form of support is not in dispute, however it does rely on individuals seeking support themselves, or senior members of the nursing staff being able to identify and offer support where needed. This may result in the more reserved or shy nurse being overlooked, and unable to cope, while receiving no support.

5.5.1.2 Family and friends

Participants described the value they placed on receiving support from family and friends. This was particularly true of nurses who had family or friends who were healthcare professionals as they could understand the experiences described. However, there also appeared a reluctance to discuss issues surrounding death and dying, fearing that they would place a burden on their family members who could not understand or appreciate the circumstances. Participants therefore preferred to discuss issues with colleagues at work. This issue appears to have been previously unexplored in the literature.

5.5.1.3 Medical colleagues

The degree to which doctors provide support to nurses when dealing with the aftermath of a DNR decision varied, and was dependent on the personality of the doctor involved, and the relationship between the doctor and the individual nurse. The level of experience of the participant also impacted on how the support provided by doctors was perceived, and possibly influences the relationship between the doctor and nurse, with the more experienced nurse feeling more comfortable and able to discuss issues with the doctor.

These perspectives have previously been explored in the literature (Hov, Hodelin and Athlin, 2006; McMillen, 2008) where it was identified that the level of experience of the nurse, and the relationship between the nurse and the individual physician impact on how much consideration is given to their views. The nurses' position in the hierarchical structure has also been cited as a barrier to effective communication between doctors and nurses (Oberle and Hughes, 2001; Halcomb, et al., 2004) and may also provide explanations as to why nurses perceive a lack of support from doctors.

It must also be acknowledged that doctors themselves may be ill-equipped and ill prepared to cope with the DNR process, and therefore unable to provide support. This was not, however within the scope of this research project.

5.5.2 FORMAL SUPPORT

5.5.2.1 Nobody cares about us

None of the participants had received any form of emotional support from within the institution itself. There was in fact a general feeling of distrust regarding the Employee Assistant Programme with concerns regarding confidentiality being raised. It was generally felt that some form of support, over and above that provided by colleagues was needed, but participants were hesitant about accepting support from outside the ICU environment, as it was felt that there would be a lack of understanding of the processes involved in the DNR order. Therefore, the provision of any support system by the institution would need to be carefully considered and accepted by the staff working in the unit if they were to access such support.

These findings substantiate those reported by Shorter and Stayt (2009) and Spencer (1994) who suggested that nurses feel formal support is a good idea in theory, but are reluctant to access such support if it is available.

5.5.3 COPING STRATEGIES

5.5.3.1 Talking about the experience

As previously discussed, the major from of support available to ICU nurses is that provided by nursing colleagues and takes the form of informal discussions at tea and lunch time. Participants clearly agreed that talking about and sharing their experiences relating to DNR orders was the most beneficial way to cope with and

process their feelings. Brosche (2003) compares these behaviours to the relief and re-establishment behaviours described by Kavangaugh (1972). Brosche (2003) applies these behaviours in the proposed grief care plan, describing relief behaviours as the nurses' ability to communicate with peers and having them listen which facilitates feelings of peace. Brosche (2003) applies re-establishment to the more experienced nurses who are described as having the experience to face their own grief in a healthier way, as well as having a need to help their colleagues.

5.5.3.2 Rationalization/understanding

The previously discussed principles of a "good death" could also be used to describe how nurses rationalise the DNR process in terms of relieving pain and suffering, on both the part of the patient and family members, when allowing a patient to die, rather than prolonging death. Nurses feel less traumatised when they are prepared for a death to occur and have some control over how patients die, i.e. the provision of good palliative care (Halcomb, et al., 2004; Shorter and Stayt, 2009). The same principles maybe applied to understanding the physiological process and pathophysiology of a patient's condition. When these concepts are fully understood by the nurse caring for the patient, s/he is able to rationalise that allowing the patient to die is therefore in the patient's best interests.

5.5.3.3 Suppression and detachment

Shorter and Stayt (2009) describe the processes of normalising death and emotional detachment as long-term coping strategies employed by nurses. Disenfranchised

grief (Doka 1989, cited in Brosche, 2001) is used to describe the grieving process experienced by nurses in an environment where mourning the loss of a patient is not part of the accepted culture, and in a society where nurses have no recognised right to grieve the loss of their patients. This results in nurses suppressing their feelings which can have serious consequences, in the long-term, both for the nurses, the patients and the institution.

Suppression of emotions was evident during the interviews with some of the participants who expressed that they were feeling emotions they did not know they had when discussing the DNR process, and remembering cases that had affected them in the past. This was also evident when one recollection after another readily came to the surface during the interview process, highlighting issues that had not been resolved and had caused emotional distress at the time of the incident. Emotional detachment was also identified as part of the coping mechanism employed by at least one of the participants.

These coping strategies allow ICU nurses to continue functioning. Brosche (2003) again identifies these behaviours as part of Kavanaugh's (1972) shock and denial and disorganisation stages. In both stages, the ICU nurse becomes task-orientated, keeping busy so as to give some order to his/her thought processes. These behaviours are common in the ICU, as nurses involve themselves in immediately preparing for the next patient, or ensuring that documentation is complete, etc. so denying and suppressing their feelings.

5.6 NAMING THE DNR PROCESS

Whittman-Price and Celia (2010) hypothesise that if healthcare workers find the terminology used to describe the DNR process more acceptable, they will feel more comfortable discussing end-of-life issues.

Participants revealed mixed feelings regarding the proposed change in terminology when discussing DNR orders. On the one hand, they agreed that, in principle, the term Allow Natural Death sounds much better, but would not change how they responded emotionally to the process asserting that it was just a change in words. However, on the other hand, some of the participants felt that the change in terminology was a positive one in that it focused on the provision of care for the patient, rather than what would not be done. This supports the views expressed in the literature regarding this topic. Knox and Vereb (2005) indicate that the process may be the same, but the language used is more acceptable to patients and families. The focus of the AND order is on what will be done for the patient rather than negatively reinforcing what will not be done (Pantilat, 2009; Whittman-Price and Celia, 2010).

Participants were all ICU trained registered nurses with several years of ICU experience behind them, and thus have experienced and fully understand the DNR process. It is thus possible that their views on this topic do not represent the impact that a change in terminology would have on registered nurses new to the ICU environment. How participants described the impact of the DNR process when

they first encountered it early in their ICU careers, using words such as "cruel to mankind" (Taby) and "a harsh decision…… just to terminate life", (Katie) indicates the negative perceptions that the DNR order fosters among nursing staff. The AND order is usually considered less negative and more humanistic, reinforcing what would be done for the patient rather than negatively reinforcing what would not be done (Whittman-Price and Celia, 2010) thus perhaps it would impact on how the process is perceived by nurses new to the ICU environment, and decrease the emotional impact they suffer.

5.7 CONCLUSONS OF THE STUDY

A small sample of ICU trained nurses was used to explore the objectives of this study. The findings of this study indicate the emotional impact that end-of-life decisions have on nurses working in ICU. Participants identified that dealing with the family of the dying patient was the most difficult part of the DNR process, and that how participants responded to the family was determined, in a large part, by their level of experience. The importance of death rituals and cultural practices for both the families and nurses was also revealed.

This study indicated the important role communication plays in the DNR process. How effective the communication process is, determines the level of acceptance of the decision. Participants also described the importance of being able to express their opinions, and have input into the end-of-life decision-making process. The importance of a consistent message being provided to the family was also

highlighted, further emphasising the need for a collaborative approach to decision-making. The more experienced ICU nurses in this study felt comfortable in voicing their opinion, and felt confident that they would be heard and their opinions considered.

Factors determining the acceptability of the DNR order included the timing of the decision, experience level, and an understanding of how the decision was made. The difficulty that these participants described in coming to terms with the DNR process when it was first encountered highlights the gap in nursing training, and how ill-equipped nurses are to deal with this phenomenon.

Participants revealed that the only real support they received was provided by each other, and the value of the shared experience was emphasised. No institutional support was provided, and there was a feeling of distrust that prevailed for the structures which were possibly available. Ignoring the need for support for ICU nurses who are dealing with high levels of moral distress can have serious consequences for the individual nurse, the quality of care given to patients, customer service and the institution.

No real conclusion could be drawn regarding the proposed change to the terminology when discussing end-of-life decisions. Participants thought AND sounded better, but did not feel that it would make much difference to how the process made them feel.

5.8 RECOMMENDATIONS

The recommendations are based on the findings of this study and other studies published in the literature which informed the presentation and discussion of the research findings. The recommendations will relate to the proposed significance of the study and aim to address the identified gaps, as well as to propose possible further research areas.

5.8.1 The impact of death and dying on the ICU nurse

- During the interview process, the participants described how ill-prepared they felt when dealing with death and dying, especially in the context of the DNR order. Educators need to consider how this topic is addressed during basic training programmes, and not just in relation to post-basic ICU courses. In a healthcare system where resources appear to be under increasing pressure, coupled with the impact of the HIV/AIDS and TB epidemics, nurses are increasingly finding themselves confronted with situations where treatment has been capped, and patients are no longer being offered aggressive treatment regimens, but the focus is rather on the provision of palliative care during the dying process. Taking these factors into account, curricula need to be developed that address these issues and prepare nurses with sufficient knowledge of the dying process, and ensure the provision of the necessary coping skills to adequately manage their own grief.
- Although nurses may have extensive experience in dealing with death and dying and the provision of palliative care in the general ward setting, encountering the

DNR process for the first time may prove to be a traumatic experience. There is a definite difference between allowing the natural process of death to occur and actively removing life-sustaining therapies. Thus nurses encountering the ICU for the first time need to undergo a period of induction where the DNR process is fully explained, including the rationale for such decisions being taken, prior to the nurses encountering the phenomenon. ICU nursing staff need to be cognisant when a new member of staff encounters the DNR process in the practical setting for the first time, and ensure that the process for that particular patient is fully explained. It is suggested that a mentoring system would assist the new ICU nurse through the process until a level of comfort is achieved.

- Students entering post-basic ICU courses may or may not have encountered the DNR process prior to their training, depending on their years of experience prior to the course or the unit in which they worked. Bearing this in mind, ICU Educators need to include the DNR process and the management of the dying patient in the ICU curriculum, and ensure that ICU students are equipped to manage this process and to provide support to patients and family.

5.8.2 Communication in the DNR decision

- Communication is the most important aspect of the DNR order, and to ensure satisfaction with the process for both healthcare workers and family members a collaborative effort needs to be achieved.
- It is accepted that the final decision regarding the institution of a DNR order is the prerogative of the physician, however ICU nurses need to be involved in the

decision-making process. ICU nurse have a holistic perspective regarding the progress of the patient and their response to treatment, as well as insight into the attitudes and emotional responses of family members to the patients' admission to ICU. ICU nurses may thus have valuable insights to offer that may assist in the decision-making process, and they need to be encouraged to voice their opinions and at the same time need to have their opinions heard.

- ICU nurses need to ensure that they have a solid, up-to-date, theoretical background in order to be able to substantiate and justify their opinions and remain credible. Having a good knowledge base will provide courage for nurses to voice their opinions with confidence. In order for this to occur however, nurses need to become more active and visible in the profession and critical care society. It is hoped that the proposed introduction of requirements for Continual Professional Development (CPD) will promote and encourage this process. At the same time, employers need to encourage and support financially nurses' attendance of workshops and congresses, etc. which are frequently beyond the financial resources of nurses.
- ICU nurses need to be involved in all levels of communication that the physician has with family members in order to ensure that a united front is promoted, and that consistent information is provided to family members in order for confusion to be prevented and trust in the healthcare team to be fostered.

5.8.3 Accepting the DNR order

- Doctors need to be aware of the varying levels of knowledge and experience of ICU nurses working in the unit, and to ensure that when a DNR decision is taken they provide a clear explanation and rationale as to why the decision was taken, especially when this occurs shortly after the patient's admission.
- The South African Nursing Council needs to provide clear guidelines with regards to the scope of practice and role of ICU nurses when initiating a DNR order.

5.8.4 Support systems and coping strategies

- Senior ICU nurses need to be conscious and aware of the impact the DNR process has on individual nurses entering the ICU environment for the first time, and appreciate the value of shared experiences. Utilisation of a mentoring system may assist new nurses and provide a mechanism by which the more senior staff can assess the impact of the DNR process on individual nurses.
- The responsibility for recognising coping problems and providing support can not solely be the responsibility of the more senior ICU nurses, therefore the provision of other methods of support needs to be considered by the institution in its own best interest. Previous research and the findings of this study indicate that formal support structures are not freely utilised by staff and there is possibly a lack of trust in such systems. Brosche (2003) advocates that a formalised coping programme be utilised by institutions. These programmes

consist of several aspects such as focus group discussions to assist with crisis therapy; a grief team made up of nurses who are familiar with the ICU environment; defusing; stress management programs and staff education. An adaptation of such a programme needs to be considered in the South African context. At a minimum, some form of counselling needs to be provided for ICU staff by someone whom they trust and who has an understanding and knowledge of the DNR process.

5.8.5 Recommendations for future research

- This was a small scale, qualitative study and should be explored further in other ICU's to determine if the same views and experiences hold true for other ICU nurses.
- The feasibility and efficacy of support programmes such as that proposed by Brosche (2003) needs to explored in the South African context.
- Further research is required to determine whether changing the terminology when discussing end-of-life issues will impact on how new ICU nurses experience the process.

5.9 LIMITATIONS

The nursing staff targeted for participation in the study all belonged to the same unit which, as stated previously, is a small, general, closed public sector ICU run by an intensivist with an interest in end-of-life issues. This will potentially influence the way withdrawing or withholding treatment is approached and dealt with.

It also needs to be considered that the presence of the researcher may have influenced the responses provided by the participants, all participants had either previously worked with the researcher, or knew of the researcher's previous position within the unit and therefore could possibly have given answers which they thought the researcher would like to hear. A further limitation of this study was the small sample used due to the methodology chosen.

Taking these above factors into account, the results obtained may possibly not be representative of the perceptions of nursing staff working in other intensive care units and cannot be generalised beyond the context of this study.

5.10 CONCLUSION

This chapter reviewed and provided a discussion of the findings of the study, keeping in mind the objectives. Discussions focused on the emotional impact the DNR process has on ICU nurses; the important role of communication, and the need for nurses to have their opinions heard; factors which impacted on how ICU nurses accept the DNR order; support systems and coping strategies utilised; and perceptions regarding the use of the AND terminology when discussing end-of-life issues. The conclusions of the study were outlined, recommendations were proposed and areas for further research were indicated. The limitations of the study were also examined.

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ANNEXURE A
PARTICPANT INTERVIEW GUIDE

Participant Demographics

1. How old are you?
2. How long have you been qualified as a registered nurse?
3. How long have you been working in ICU?
4. Have you worked in any other ICU?
5. Are you ICU Trained?
6. When did you do your ICU training?

Essential questions:

Variations of the following essential questions were used to solicit views and experiences from the participants

- Tell me about an experience you have had relating to a DNR order. It can be your most recent experience, the most meaningful one, or one that stands out in your memory.
- How do you feel about the change in terminology from DNR to AND?

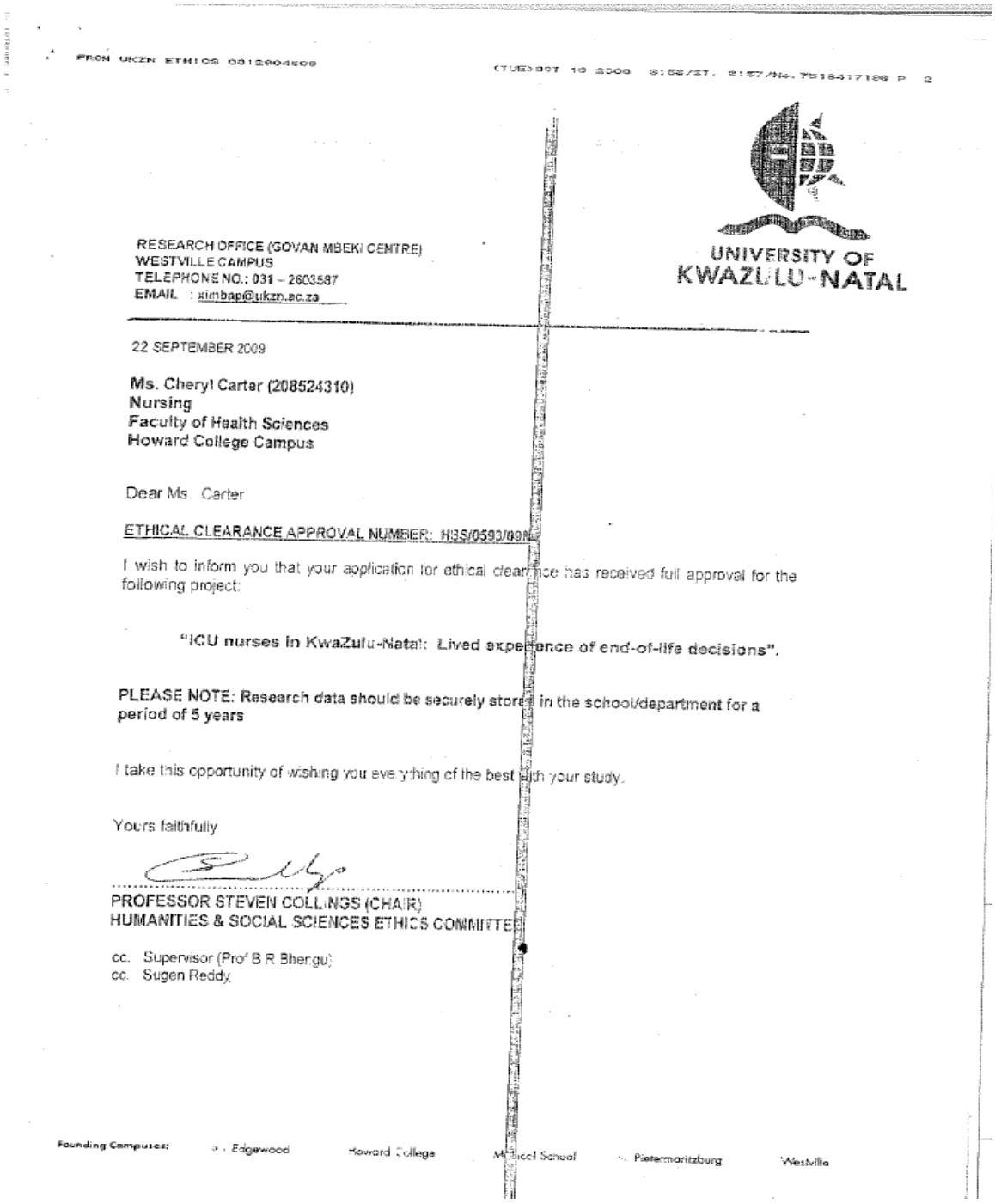
Probes and prompts

Probes and prompts were used during the interview process based on participant responses and conversation with the participants, e.g.

- How did that make you feel?
- Is there anything further you would like to tell me?

ANNEXURE B: Ethical Clearance from the University of KwaZulu-Natal

Humanities and Social Science Ethics Committee



FROM UKZN ETHICS 0312604609 (TUE) OCT 13 2009 8:58/ST. 8:57/No. 7518417169 P 2

UNIVERSITY OF KWAZULU-NATAL

RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL : ximbap@ukzn.ac.za

22 SEPTEMBER 2009

Ms. Cheryl Carter (208524310)
Nursing
Faculty of Health Sciences
Howard College Campus

Dear Ms. Carter

ETHICAL CLEARANCE APPROVAL NUMBER: HSS/0593/09M

I wish to inform you that your application for ethical clearance has received full approval for the following project:

"ICU nurses in KwaZulu-Natal: Lived experience of end-of-life decisions".

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

PROFESSOR STEVEN COLLINGS (CHAIR)
HUMANITIES & SOCIAL SCIENCES ETHICS COMMITTEE

cc. Supervisor (Prof B R Bhengu)
cc. Sugen Reddy

Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

ANNEXURE C: Hospital Support for Project and Request for Approval from KwaZulu-Natal Department of Health

HEALTH
KwaZulu-Natal

ADDINGTON HOSPITAL
OFFICE OF THE HOSPITAL MANAGER
Postal Address: P.O. Box 977, DURBAN, 4000
Physical Address: 16 Erskine Terrace, South Beach
Tel.: (031) 327-2970, Fax.:(031) 368-3300
Email.: addington.management@kznhealth.gov.za
www.kznhealth.gov.za

AD/9/3/2

Enquiries: Dr J E Hurst
Extension: 2970 / 2568

21 January 2010

Head of Department
Department of Health
KwaZulu-Natal
Private Bag X9051
PIETERMARITZBURG
3200

Attention: Dr S S S Buthelezi - Chairperson: Health Research

Fax No.: (031) 342 9427

Dear Dr Buthelezi

RE: PERMISSION TO CONDUCT RESEARCH - ICU NURSES IN KWAZULU-NATAL: LIVED EXPERIENCE OF END-OF-LIFE ISSUES

The attached request in the above regard refers.

Management supports the request.

Authority is sought for the abovementioned research to be conducted.

HOSPITAL MANAGER

JEH/jc

c.c. Sr C Carter

ANNEXURE D: Kwazulu-Natal Department of Health Approval for Study

HEALTH
KwaZulu-Natal

Health Research & Knowledge Management sub-component
10 – 103 Natalia Building, 330 Langalibalele Street
Private Bag x9051
Pietermaritzburg
3200
Tel.: 033 – 3953189
Fax.: 033 – 394 3782
Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference : **HRKM 010/10**
Enquiries : **Mrs G Khumalo**
Telephone : 033 – 3953189

29 January 2010

Dear Ms Carter

Subject: Approval of a Research Proposal

1. The research proposal titled **'ICU Nurses in KwaZulu-Natal: Lived experience of end-of-life decisions'** was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken at **Addington Hospital**.

2. You are requested to take note of the following:
   a. Make the necessary arrangement with the identified facility before commencing with your research project.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mrs G Khumalo on 033-3953189.

Yours Sincerely

Dr S.S.S. Buthelezi
Date: 03/02/2010
Chairperson, Health Research Committee
KwaZulu-Natal Department of Health

ANNEXURE E: Participants' Information Sheet and Informed Consent

Project Title:	ICU nurses in KwaZulu-Natal: Lived experience of end-of-life decisions
Aim of the Project:	To describe and interpret the experiences and practices of nurses, working in a public sector Intensive Care Unit (ICU), when dealing with withdrawing or withholding of treatment associated with the Do Not Resuscitate order / Allow Natural Death order.
Name of Researcher:	Cheryl Carter
Affiliation:	University of KwaZulu-Natal, Durban
Qualification:	BCur (Ed; Admin); Diploma Critical Care Nursing RM; RN
Contact details:	School of Nursing, 5th Floor, Desmond Clarence Building, Howard College Campus, University of KwaZulu-Natal, 4041, Durban Tel:0837896260 email:Cheryl.Carter@kznhealth.gov.za
Name of Supervisor:	Professor B.R. Bhengu
Affiliation:	University of Kwa-Zulu Natal, Durban
Contact Details:	School of Nursing, 5th Floor, Desmond Clarence Building, Howard College Campus, University of Kwa-Zulu Natal, 4041, Durban (031)2601134 email:bhengub2@ukzn.ac.za

I am currently in the process of completing my Master's Degree and am inviting you to participate in the study I am conducting. Your participation is completely voluntary, and if you agree to participate you will be required to take part in two to three individual interview sessions. The first interview will be an in-depth interview lasting 30-45 minutes and any subsequent interviews will be in order to clarify information.
All interviews will be taped, however your name will not be mentioned or appear on any documentation. Your privacy and confidentiality will be maintained at all times and only the researcher will have access to the information you provide.

If you wish at any stage to withdraw from the study, you are free to do so without any negative consequences.

I _____ the undersigned

was informed about the study and voluntarily agree to participate in the study.

_____	_____
Participants signature	Date
_____	_____
Researchers signature	Date

ANNEXURE F: Sample of In-depth Interview with Participant.

Transcript of Interview with Taby 29.6.10

Present **Cheryl**
Taby

Cheryl	Good Morning
Taby	Good Morning
Cheryl	This is the interview conducted with Taby on the 29.6.10 at 10h50. Thank you for agreeing to participate in my research Taby.
Taby	Okay
Cheryl	As I mentioned, just a couple of demographic questions before we start, just to have a bit of background about you. How old are you now?
Taby	50
Cheryl	And how long have you been qualified as a registered nurse?
Taby	28 years
Cheryl	And when did you do your ICU training?
Taby	1990
Cheryl	Ja – I was trying to think when I did it because we did it together. [Both laugh] Umm and other than your ICU have you got any other post-basic qualifications?
Taby	No
Cheryl	Okay
Taby	Just - Midwifery isn't post-basic?
Cheryl	Well it is – when we did our training. And how long have you been working in this ICU?
Taby	24 years

Cheryl And have you ever worked in any of the other ICU's?

Taby Yes

Cheryl Where?

Taby Uh – St Augustine's Surgical ICU

Cheryl As a sessions basis?

Taby As a sessions basis

Cheryl Okay. Right. Thank you. Ok, um, what I would like you to do, if you could describe to me either the most recent experience you've had with a DNR, or one that sticks out in your memory, or one that has special meaning or whatever.

Taby Okay. Umm I'll describe the most recent.

Cheryl Okay

Taby It happened last week. It was a male patient who came in. He was a gunshot victim. He was robbed and he was shot through the stomach and the bullet went down through the spine and he became a paraplegic. And, uh, the first 24 hours he did really well. He was extubated and then afterwards he decompensated and needed reintubation. And he was reintubated and secondly we tried to wean him, and we could not wean him and the doctors made a medical decision that he's never going to come off the ventilator because his chest infection just progressed to ARDS and it became unweanable, so they made a medical decision that they were going to stop treatment [laughs].

Cheryl How ….

Taby He was young, he was 19 years old and, okay , the fact that he was a paraplegic was an indication of what quality of life he was going to have if he did live. Okay, although that was not the basis of the, uh, the termination of the treatment, his, uh the ongoing chest problem, and it was, it became to the stage that the lungs were getting fibrosed, that was unreversed, so the doctors decided to cap treatment. So I was quite affected by that, the fact that he was young, the fact that he wasn't a robber or a hijacker, and he was an innocent party in this situation. So I was quite disturbed by that.

Cheryl How did you …. you say the word 'disturbed'…. how do you mean, how did it make you feel?

Taby Umm…. [pause]… it upset me, and I had a bit of depression [laughs – almost seems embarrassed].

Cheryl So what do you do in those cases when you feel upset?

Taby Okay. I speak about it - to my colleagues, I speak to the doctors as well, although when the doctors make the decisions we do take part and, um, [pause], at that stage you think of the patient and the suffering, but later on it actually does affect a person to think that this is just another young life gone instantly. Could I have done anything different? Could I have said no, the discussion of the DNR? Was this of any benefit to the family or to the patient? You actually sit and question yourself, that's how I actually deal with it. [laughs]

Cheryl In this period of actually dealing with it, is it a short-term thing, or do you find over the next few days or weeks you keep thinking about it…?

Taby No, to me, because I've been doing it for so long, it's actually become a short …. Initially I did struggle with it, but now it's actually become a short-term thing. I get quite, I get over it quite …..

Cheryl So your process is that you rationalise it in your head……

Taby Yes

Cheryl ….and come to terms with it that way…..?

Taby Yes

Cheryl …..and then you are able to move on?

Taby Yes.

Cheryl Okay. Do you find that there's a difference in the way you respond to DNR orders having spent 24 years in ICU? Can you remember those days when you…..?

Taby Yes, no, definitely I do! I do respond differently.

Cheryl How did you respond in the beginning?

Taby I …uh [laughs]. Initially, I just thought this was cruel to mankind and, uh, how can they not give this person more time, the family broke down. I just looked at the whole thing as being a cruelty rather than, uh…uh… stopping the discomfort. [laughs]

Cheryl So you now view it as more of stopping the discomfort?

Taby	*Ja,* Yes [laughs]
Cheryl	So you've changed your perspective?
Taby	I've changed my perspective now than before
Cheryl	And now …do you think that new people coming into the ICU now, in 2010?
Taby	Yes
Cheryl	Because things have changed in the last 24 years quite a bit
Taby	Yes
Cheryl	And if you think about how you used to feel when you first came into ICU and how new people coming in today?
Taby	Yes
Cheryl	Do you think your experiences make you more empathetic to the new people coming in? Do you think there is more support provided to then?
Taby	Yes there is. They actually have more support than I really did uh, because, because I personally have experienced it, I am able to tell them personally what I went through and that in time to come, they will be able to cope with it because it happens all the time, as long as they are working there. [laughs]
Cheryl	Do you find that you, you make sure that you go and speak to the people after the event?
Taby	Yes I do and most of the time whenever there is such an, a, an order given or anything like this taking place, when I'm on duty I make sure, because the young girls that come to the unit can, cannot deal with this initially because they, they just fall apart, but I speak to them afterwards and I tell them that it is something that is done, and I know it's hard to accept, that you will get used to it, but it takes time, and if you, if you, you feel depressed or anything speak about it, and if it's beyond control or whatever we'll see what we can do, because I actually think that we don't have enough support in the ICU to deal with these things. People are just pushed into this sea and they must just swim or sink [laughs].
Cheryl	Do you think it would benefit, um, I mentioned it with one of the other girls that I've done interviews with, if there was a period of, almost like an induction period where before they actually start in….

Taby Yes (sounds enthusiastic)

Cheryl .. with working in ICU, we went through the process involved, especially around DNR, because this is not something that happens…

Taby Often

Cheryl ….. outside ICU. I think it's specific to ICU..

Taby No it doesn't. Yes I think there maybe should be an induction programme where the people should be taught how to deal with this because it's quite, um, touchy [laughs].

Cheryl Do you find that, um, because you said that – now you feel that there is more support to newcomers into the department…?

Taby Mmmm [agrees]

Cheryl …Um, do you think there is more interaction between the doctors and the nurses in terms of explaining things?

Taby Yes, I think there is especially in [mentions name of consultant] he is actually very good about it, because if anybody is upset or did not cope with the DNR or whatever he is always there to speak and to explain and over and over to try and, you know (what's the word I want to say?)…um… to try…

Cheryl Rationalise?

Taby … and show them that it's not the first and the last time, it's something that's ongoing and going to happen so ….[stutters]…you, you don't have to accept it but you have to try and accept it and that these things are done in the ICU. [laughs]

Cheryl Do you think that your acceptance of the DNR decision-making over the years is due to, um, the experience, just the repetition, have you become desensitised to it, because it happens so frequently, or do you think it's because your, because your knowledge and understanding….?

Taby It's both!

Cheryl Both?

Taby I think it's both, knowledge and desensitised because it's happened so often, and the knowledge that I've gained through the years also helps a lot,

because I've got a different perspective of DNR than I had initially when I started in ICU.

Cheryl What, what is that different perspective?

Taby Well before, I used to, as I say, just fall apart and cry and, you know, but now I'm able to stand and understand why these things are done and what benefit it is to the patient and to the relatives, uh, to the unit, to everybody. Now I've got a better understanding.

Cheryl Um.. and when this DNR order is given, who actually, well …First of all you said that you are consulted, so the decision is taken at the bedside on the ward round…?

Taby Yes. *Ja*

Cheryl …um, and the nurses, are…are they involved?

Taby The nurses are very much involved, yes.

Cheryl Do you think that's important?

Taby It's very important because it helps you deal with it later.

Cheryl So from the perspective of helping you deal with that process?

Taby Yes

Cheryl How does it help you?

Taby It helps you that you understand why things are done and…uh…on different types of patients or different types of injuries or whatever. It helps you understand why a DNR is actually done.

Cheryl And, uh, if you felt that the patient shouldn't be DNR'd do you feel free to express that opinion?

Taby Yes [stated emphatically], we do feel free and the doctors actually do take it into consideration.

Cheryl Does the decision still go ahead or….do they?

Taby You've got to substantiate your, your … your answer, I mean or your…whatever you're asking. If it's a valid enough reason then the DNR does not carry on.

Cheryl And do you think that it's important that nurses are listened to?

Taby It is very important.

Cheryl Why?

Taby [Pause] That the nurses listen?

Cheryl No are listened to, that their opinions…

Taby That they, yes, because the nurses are the ones that spend most of the time with these patients, you interact with the patient from the time s/he comes in there until such a time as the DNR decision is made, you interact with the relatives. And another thing with this DNR, I feel the relatives, umm, sometimes they're misinformed, or they're not , uh, informed well enough. And, and the most important people actually with this DNR it's the relatives, because they're the ones that suffer after this person is gone and DNRed or what have you. They don't get given enough time to deal with these things, and us nurses are the ones that have to cope with it. We have to try and explain why... Although the doctors do explain, but the ultimate end of this whole story, it's the nurse has to explain to the relatives.

Cheryl Do you feel once the decision is made, and the family's been informed, um, that, nurses are basically abandoned and told to get on with it with very little support from the medical side?

Taby No they're not. Not in our unit, Dr. Hodgson is actually very supportive and he is actually very good in explaining to the family and, uh, explaining to the nurses why he's made such a decision, 'cause ultimately he makes these decisions …collectively with the other doctors and the nurses

Cheryl But then once the decision…he's not in ICU 24 hours a day or …

Taby Yes

Cheryl ….once he's done the round he's got other responsibilities….

Taby Yes

Cheryl So once he's left the department, he's had the chat with the family, he's left the department, um, [Taby clears throat in background] do you think that the support then provided to your, because you're the ones who now…

Taby Left to deal with it - Yes

Cheryl ….. you said you're the ones who are now left to deal with the whole thing in terms of the family and them asking…..

Taby Yes

Cheryl ….questions, etc. Do you think you're given enough support in terms of…., do you think you're, it's appreciated , um how dealing with the family, how difficult it is?

Taby [Pause] I don't think we're appreciated, but I think the families do appreciate us. I, I think the families really do appreciate it because even after they've cried and the person has, has, has gone, and has died, they still come back and say thank you, and that the sense of appreciation for me. That's all you need to say. I don't need flowers, I don't need anything else. You can just say thank you

Cheryl And you mentioned that, um, the family, are, you think, not given enough time. What do you mean?

Taby Some decisions are made too quickly I feel.

Cheryl When would you consider a decision being made too quickly?

Taby [Pause whilst thinking] Ummm……I don't know, because it differs, because some patients are given a longer time, others are just given 24 hours. But I suppose it depends on the severity of the injuries or the disease process or what have you. But I have encountered some problems where the family has not even been informed properly, they still come to me for extra information or have not understood, or whether the doctors speak too 'high fluted' [high faluting, or in too formal or complex a manner] for them or what is it. But at the end of the day the nurse is still faced with this problem.

Cheryl And how, how are the family informed? Are they informed, or do they participate in the decision-making, or are they just told?

Taby [Clears throat]… Actually they um, they are just told because the decision is actually a medical decision, they've got no say in the decision-making of the DNR.

Cheryl Do you think that's right?

Taby I think it's right because if they had a say in the decision, nobody wants their loved one to be taken off life support. Then a DNR would never go on with anybody, because nobody will ever [laughing] say, 'Yes, take him off'. Although you far, here and far you do get some of them that say, especially

those that have made the living will, that's why I say the living will makes our, our job so much easier. With those cases our job is so much easier because you know what to do when such a crisis occurs.

Cheryl You know how the patient would feel themselves?

Taby *Ja*

Cheryl When the family is informed how is that done?

Taby Normally the consultant or whatever, the doctor in charge of ICU and the sister looking after the patient, they go and speak to the family. We call the next of kin and tell them about…, okay the… they asked them if…how, how much they know about the patient's illness or have they been informed…....how, what do they know about the patient. Then the doctor starts telling them what's happened, it was an injury or a gunshot, or a stab wound, and if it's a chest infection and what have you. They start explaining the disease and how far the process of the disease has gone. And that we have done everything that we can do in our power, and the disease is irreversible or it's, although the patient is being treated, the condition is getting worse and there's nothing more we can do for the patient. They're just told outright exactly what is happening and that their medical decision is now to stop the treatment because, it's, whether we're giving the treatment or not, it's not gonna help, the disease is far gone and it's irreversible.

Cheryl And who's present at that meeting?

Taby It's normally the next of kin, like if it's; it's, it's a son, it's the parents or brothers and sisters and the doctor, normally a consultant, our consultant speaks to them, Dr. Hodgson, and the doctor running the ICU and the sister looking after the patient.

Cheryl Do you think it's important for the sister to be there?

Taby Yes I think it is important

Cheryl Why?

Taby Because you look after this patient and when the decision is made and you also have to participate in the decision-making and you are in, most of the time interacting with the family that comes to visit this patient. So you know from A to Z what's been happening, how the family's feel about it, how they are dealing with it, 24/7 you're there with the family.

Cheryl And when it, um, actually comes time for the order to be carried out who carries it out in terms of actually disconnecting the ventilator or switching

off the inatropes, or whatever the process is for that particular patient, who does it?

Taby Most of the doctors do it in the ICU

Cheryl Do the nurses ever switch off things …?

Taby No, the junior staff is like, they just don't want [emphasised] to do it because they feel responsible [emphasised] that they've ended the life of a patient. And that is actually not so because it's, it's an order, it's an order from the doctor. [laughs]

Cheryl And then how do you…obviously you allow the doctor to do it, but how do you, um, how do you then....

Taby Feel about having to do it?

Cheryl *Ja,* you, obviously if you..

Taby If I'm ordered to do it? Given the order to do it?

Cheryl *Ja*. Are you comfortable with doing it?

Taby At this stage I am quite comfortable with doing it.

Cheryl Why do you think there is a difference between the junior staff, their perception and your perception?

Taby Because I think they can't deal with it

Cheryl Why?

Taby They feel guilty, they feel that they are responsible for ending that patient's life, they don't take it as an order.

Cheryl And why do you not feel guilty then?

Taby I don't feel guilty because I think at this stage this is what's best for the patient [laughs]

Cheryl So it comes back to that perspective again

Taby Yes

Cheryl Age and wisdom?

Taby *Ja*, age and wisdom [laughs]

Cheryl Then how do you deal with those girls? Do they ever come to you and say "You know Taby the doctor says switch the inatropes off, or put the vent, put the oxygen on 21, and I don't want to do it". Or does the doctor just step in? [pause] Do they verbalise they are not happy to do it?

Taby They actually do verbalise, they do verbalise, and I actually explain to the doctor that the girls are not comfortable to do it, could you step in and do it [laughs]

Cheryl So do they come and verbalise to you or are they comfortable verbalising to the, the doctor?

Taby They're comfortable both ways, they verbalise to the doctor and to me.

Cheryl Okay [deep breath and sigh]. In terms of the family, um, because you kind of intimated, you said that the relatives, that the relatives are the most important, um, people in this whole process..

Taby Yes

Cheryl …because they're the ones who are going to be suffering basically?

Taby Yes

Cheryl What do you find so difficult about dealing with them?

Taby You know in all the time I've worked in ICU, up to this day, the most, the thing that I find most difficult to do is having to tell the family that their loved one actually died, it's something you can't get used to and I personally can't get used to something like that.

Cheryl How does it make you feel?

Taby [Pause]. It makes me feel <u>sad a</u>nd um…[pause]….empathetic. I feel it for the family

Cheryl And do you feel, um, able to show that emotion to the family or do you shut it down?

Taby [Pause] It's, it's different cases. Sometimes I do shut it down and in some cases I emotionally feel it with them. [sounds sad]

Cheryl Do you ever cry with the relatives?

Taby	Some, some cases I actually have cried
Cheryl	And how does that make you feel?
Taby	It makes me feel terrible Cheryl [laughing for quite a while]
Cheryl	Do you think, how do you think relatives view us, 'cause this is one of the issues the other girl also brought up, she said she wonders how the family actually perceive us and view us? [Pause]
Cheryl	Do you think it makes a difference if we share that emotion with them or if we are….
Taby	Cut off?
Cheryl	…detached. *Ja*
Taby	I think when we share the emotion with them it actually does make a difference to them
Cheryl	Do you think..
Taby	Because they feel that, uh, we are feeling it with them.
Cheryl	You think it helps them?
Taby	It actually does help them.
Cheryl	And then…
Taby	[interrupts] Or even just to give them a little hug [laughs]
Cheryl	And then how do you think that reconciles with the need to be professional? [Pause] Do you then as nurses think we have a problem showing emotion in that we feel that we must have this professional, we're the nurse they're the family or do you think….how do you feel about that?
Taby	[Pause $\pm$ 10 secs] [Big Sigh] This is one time we sometimes lose our professionalism, because…umm, .[how can I explain?] ..it's a very emotional situation and we sometimes lose it [laughs]. I sometimes do!
Cheryl	*Ja*
Taby	I just take them as people that you know have just lost a loved one, and are in pain and grieving and.. so I'll try to be as human as possible with them.

Cheryl So it's a human relationship rather than a professional relationship?

Taby Yes. Umm

Cheryl Okay. In terms of support, um, in, you said that you don't feel that there's much support offered in, besides your colleagues, and besides being able to discuss things with your colleagues…

Taby Mmmm [in agreement throughout]

Cheryl …….do you feel there are any structures, um, within the hospital that allow … If you are having a particularly difficult time in dealing with a death, or not maybe even you specifically…

Taby Ja

Cheryl …..because you said you've kind of learned to deal with it. But some of the new girls, if you found that there's one particular one who was really struggling, and although you had spoken to her you found she was still struggling, are there any other support systems available?

Taby No [almost shotgun like replay – very adamant sounding]. There is no other support system in the hospital

Cheryl And how does that make you feel?

Taby It just makes me feel that the nurses aren't looked after. You know, because at the end of the day we are also humans.

Cheryl Do you think anybody cares about you? [Pause with no response] Is it just that it's ICU get on with it? Do you think people outside ICU understand what ICU's about?

Taby No, I don't think so. I don't think the people care. I don't think the people ask about ICU that people understand about what goes on here.

Cheryl Do you think, do you feel isolated from the rest of the hospital in ICU?

Taby Yes I, we do. We feel very isolated and even the comments that get thrown to us make us feel…

Cheryl What kind of comments?

Taby Oh things like that … 'You think you're a better person you're working in ICU'. I won't go into depth with the others, because they are just trivial things, they don't matter to me because I've really grown and [laughs]

Cheryl What about things like the employee assistance programmes, your EAP programmes, do you not think that's where we could offer staff more support?

Taby Ja it is a good programme but, umm…..[pause] we've never thought of referring like staff that are battling with this DNR to such programmes. Do we still have EAP?

Cheryl I don't think it's particularly active at the moment.

Taby Because since Lorna left…I don't think it's existing

Cheryl Do you think it would, if it was up and running, that it would be a good ….

Taby Support system?

Cheryl …route to take?

Taby Yes [sounds enthusiastic] I think it will, especially with the new staff coming to ICU and coming into contact with this DNR process. I really do think it will be of great help to the junior staff.

Cheryl The…have you ever heard of the term. .well you have because I mentioned it with the consent, with the term Allow Natural Death?

Taby I have, yes.

Cheryl How do you feel about that?

Taby [Pause] [Big Sigh]. I think we should allow natural death.

Cheryl You, you.. But do you think changing the terminology from this DNR to AND makes a difference?

Taby Yes it should make a difference, because the DNR sounds quite harsh, Do Not Resuscitate, whereas ..Allow Natural … it sounds more…[thinking] ... subtle, the natural way.

Cheryl Do you think psychologically it's gentler?

Taby Psychologically it's definitely gentler [laughs]

Cheryl And, um, I'm just going to come back to the relatives again, have you ever had a family or relatives who have totally disagreed with the doctor's decision to DNR the patient?

Taby Yes I have

Cheryl And how do you deal with those people?

Taby Well I, I didn't have much to deal with it, [mentions name] was handling the case and uh, he's actually very good about it.. When it came to a conclusion the DNR was actually postponed, because on that particular day they were not actually dealing with it, and it was, it was postponed to the next day, and he spoke to them until it came a point where they actually accepted it.

Cheryl So it was a case of, you took into account how they were feeling and their opinions about the thing…

Taby Yes

Cheryl ….and gave them a longer time.

Taby A longer time

Cheryl So this time, because you said that relatives are often not given enough time, so in particular cases that time will then be extended.

Taby Yes, yes

Cheryl Some of the other girls have also mentioned sometimes they feel that, uh, the pressure for beds, it, informs decisions. So if they know that patient is not doing particularly well or has got a poor prognosis, and the decision is there, I'm not saying that they make the decision because of the pressure for beds, but the decision is based medically, if the patient is not improving and they cap treatment. Sometimes they feel that the process is rushed if there's the pressure…

Taby The need for a bed?

Cheryl .....for beds. Do you find that?

Taby Yes, yes. It's, it's happening quite a lot lately. Before when I started working in ICU it wasn't so much so. But now, because we are really pressed for beds and our beds have been decreased since Albert Luthuli opened, it's, it's becoming more and more pressure.

Cheryl But how does that make you feel?

Taby It makes me feel that these patients are not given enough time to….to actually show signs of recovery, even if they were to recover, they were not

given enough time. I think they are just nipped in the bud before they show any progress.

Cheryl So do you think that decisions are being made too early?

Taby They are, decisions are definitely being made too early.

Cheryl What do you think would be an appropriate timeframe then to make such a decision?

Taby [Pause] Ehhh --- Some decisions, some cases are given 24 hours, maybe they should be extended to 72 hours.

Cheryl So it gives the patient time.

Taby Because it gives, Ja, the patient time to, for a turning point [laughs]

Cheryl Okay. In terms of your patients that are long-term patients in the ICU vs your short-term patients, do you think there is a difference in the way the DNR then affects you? So if you've got a patient that has been in the department say for two or three days and the DNR order is given, do you think you respond differently to that than if it's a patient that's been in the department two or three weeks, or a month or two months?

Taby Yes I do. I do [sounds emphatic] I respond differently.

Cheryl Why…

Taby Because…

Cheryl ….and how?

Taby When there, it's short-term, I still repeat, that's why I say when it's short-term I don't think they are given enough time to show any signs of, of, of improvement. Whereas if they have been given three or four weeks, whatever, they have been given enough time, they have been given <u>all</u> they can and they have not responded. And so I, I respond differently, because I feel that everything has been done for them that needed to be done and they still did not respond. So there's only so much you can do. Whereas with the short-term ones I feel they should be given more time in case they do respond to treatment

Cheryl So it's basically it's, it's more of a comfort zone. You fully understand the patient's been given the best chance possible….

Taby Yes

Cheryl ....it makes it easier then, if it's a short-term patient ?

Taby Yes.

Cheryl What about from the perspective with your long-term patients do you not become more emotionally involved perhaps with maybe the patient themselves, or definitely with the family, than your short-term patients?

Taby No I don't think so, because to me a DNR is a DNR, a death is a death. Emotionally I'll feel the same about the death.

Cheryl And some of the girls also mentioned that if it's a patient that's been in the unit for a long time, there's more of a collectiveness from the staff because more people have had the opportunity to nurse that patient.

Taby Yes, yes

Cheryl So when the patient is DNR'd like a shared, um

Taby Emotion?

Cheryl Yeah, shared emotions whereas if it's a patient that's short-term they're often like it's your patient get on with it…

Taby Yes

Cheryl ....there's not that collection. Do you think that's true?

Taby *Ja* that is true, especially for the junior girls, but with me, with more experience it doesn't make any difference. Because I think it's more of a psychological thing than a real process a DNR, or whether the patients been there long term or short term. If s/he has to be DNR'd then s/he has to be DNR'd

Cheryl It, it sort of came across from one or two of the interviews that I've done where the girls said that , umm, they felt if it was a patient who has been in the department for a short time people weren't really, it's not that they were reluctant to help or anything, but it was, but they felt emotionally kind of isolated, that it was their patient to get on and deal with. Whereas if it was a patient who had been in the department longer, staff kind of rallied round them and were a little more supportive

Taby Yes, yeah. That's what I was saying, to me it doesn't matter at this stage of my life, but to the younger girls it does matter because it does affect them that way. It affects them very differently compared to me.

Cheryl How do you see them respond?

Taby They, they just emotionally collapse, they, they feel it with depression, they cry, they just cannot handle this whole DNR process and they don't cope.

Cheryl Do they come to you and tell you that they are not coping, or do you just see that they're not coping?

Taby It's obvious, you can actually see.

Cheryl Are they crying in the unit, or do they….?

Taby No, no, no they don't cry in the unit because there's other staff and there's other family, but I feel in the unit there's a lot of girls that do come to me and, and they voice feel about things, as they call me. I'm approachable [laughs]

Cheryl I'm just trying to think if there's anything else.

Taby And I have gotten through to some of them, I've tried to help a lot of them and some of them are getting on alright, they're trying to accept this whole thing, that this type of thing happens in ICU, I'm going to work with it, if I'm going to stay any longer I have to cope with it, try and cope with it.

Cheryl Do you think there is a lot of guilt attached to, um, the DNR orders with the younger staff?

Taby Yes, definitely

Cheryl That they are contributing to the death of a patient?

Taby They do, they do!

Cheryl Whereas older and wiser you rationalise it out?

Taby You deal with it. You rationalise, yes definitely!

Cheryl In terms of family support, do you ever go home and if you've had a bad day at work discuss a death or anything with your family?

Taby I do

Cheryl And how do your family respond?

Taby They get very sad, they say, like [mentions son's name] will say, 'Oh Mum rather you than me' and they, but they don't get emotional like me who was

directly involved with it. I'll just speak about it like a once-off thing, I won't go on about it and make it like an over-dinner conversation.

Cheryl And do you think your family understand?

Taby *Ja,* they do, they do

Cheryl And do you think that helps

Taby It does help *ja*

Cheryl Just having someone to voice it to?

Taby *Ja*, it really does help, because if you're upset or saddened about something, to actually talk about it, it makes you feel better, because you've actually taken out what's worrying you, whereas if it bubbles inside you build this pressure, builds pressure until one day you crack .[laughs]

Cheryl Do you think there are people in the unit who suppress dealing with the grief that they feel or the sadness that they feel, that they just shut it down?

Taby No most of the girls they speak about it

Cheryl So you think it's important to have someone like you in the unit where they can come and talk about things?

Taby Yes, I think it is important

Cheryl Do you think it would benefit them to have an external person come in and have kind of like debriefing sessions if there has been a DNR?

Taby Yes it will help, but that person has to understand fully, okay they probably would bring maybe a professional person in who knows about DNR's and things like that

Cheryl So you think it would benefit?

Taby It will benefit, should benefit them

Cheryl Um, is there any time when you sort of sit down and sort of discuss DNR in the unit sort of collectively in a group, or is it just on a one-to-one basis?

Taby No, sometimes we do, maybe at tea, we do, we do voice our opinions about some other DNR cases, and you'll find that the younger girls or the girls who are new in the unit will always say, 'Oh no, I wasn't happy about this', and we the older ones try and explain why it was done and……..as the years

go along, you will realise why these things are done and of what help it was to the patient and for the family. For example ,with that paraplegic case, I mean, if you don't have good family support or background, how are you going to look after this paraplegic, no money nothing, you've, you've got to take all those things into consideration. We've made them realise you know sometimes these things were best for the patient, some of them that are quads will depend on a ventilator for the rest of their lives, and who's going to be walking around with a ventilator for another 10 years, and these things are expensive to maintain, they need oxygen, they need this, they need that [laughs quietly]

Cheryl So you try and give them the bigger picture, perspective?

Taby Yes, yes

Cheryl In terms…..I've forgotten what I was going to ask you now. There was something. [Pause]

Taby About the patient, the relatives?

Cheryl No as you were talking …. I can't remember – it couldn't have been important
[Both laugh]

Cheryl Anything else Taby?

Taby To sum it up [laughing], to sum it up I think, okay, a DNR is quite a difficult thing to accept, uh, for this the junior staff, the family and as you work longer in the unit you do tend to accept it, and [deep breath] understand it and see where the doctors are coming from and why you have to do these things. In other words, as you say you get older and wiser, and with my experience in ICU I've definitely gotten older and wiser, because sometimes Dr. Hodgson will actually ask me for my opinion and I'll tell him exactly how I feel about it

Cheryl How does it make you <u>feel</u> when he asks you for your opinion?

Taby I'll tell him how I feel about it at that time, about that patient.

Cheryl But how does it make you *feel* that he's asked you, that he's bothered to ask you?

Taby It makes me feel that at least we can participate in such things, it's not a one-sided thing, it's a collective, um, opinion

Cheryl It makes you feel part of the team?

Taby	Part of the team, *ja.* That at least I'm recognised, I'm not just a nurse or a body walking round in the ICU [laughing]
Cheryl	[Also laughing] The skiv
Taby	[Still laughing] The skiv
Cheryl	Thank you very much Taby, unless there's anything else?
Taby	No there's nothing else I'd like to add
Cheryl	Thank you very much

ANNEXURE G: Excerpts from Researchers Reflective Journal

Preconceptions:

- Dealing with DNR order is an emotional event that causes inner conflict. For most patients on one hand you know and understand that the patient will die due to their disease process and that nothing you do will probably make a difference and that carrying out a DNR order just allows the inevitable to happen. On the other hand by carrying out the order you actually "cause" the patient to die
- Death is painful especially for the ones left behind. Watching the pain and suffering of those people who are grieving is difficult. When you don't have to watch this grieving process carrying out the DNR order is easier.
- Some deaths are easier to accept than other. The most difficult one are those that are "senseless" as a result of violence or the very young. What would they have achieved in life if they had lived.
- No-one finds the DNR process easy it does not matter how many times you have been involved there is always a sadness attached to the death. It gets easier with experience.
- Putting on a "strong" front is important in front of others, crying is for private quiet times.
- Showing emotion in front of the family is okay as long as it is controlled
- Lack of support in general. Some understanding from the other nurses in the unit but non from management – think they think that ICU is just a breeze with comments like "All your patients are on machines why do you need so many staff"
- Doctors almost have the easy part of the process, they make the decision and then leave. Nurses are the ones who are felt to pick up the pieces, literally at times picking the family up off the floor
- Nurses generally do not want to give opinion often saying "I have just taken over" when asked their opinion on the ward round. The more senior nurses do have input in decision making and often advocate for a DNR in patients that are not doing well. Looking after patients who are not responding to treatment is stressful
- Nurses should be present during all communication with family members to ensure that consistent information is provided.

21.4.10

Finally starting my data collection today. Have interview scheduled with one of the more senior girls who I have worked with previously and really like. Identifying participants to interview was a bit of a challenge. In general there appeared to be a reluctance to talk about end-of-life issues. It was interesting to note that those more senior, or should I say those who have been working in ICU seemed the most reluctant to participate. When asked they just said "No Cheryl I don't want to think about those things'. This seems to be particularly true of the "black" staff. A couple of the more senior staff willingly agreed to participate but pinning them down to a day has proved difficult as there always seems to be an obstacle. Others agreed very readily and some need a bit of coaxing.

Post-interview: Was a bit nervous prior to interview as I was unsure how "Sarah" was going to respond. The interview went off quite well I think. The venue was nice and quiet

and neutral well away from the unit and even hidden from access by anyone else so it felt "safe". I think were both a little hesitant at first but the conversation flowed fairly well.
I have known "Sarah" for many years as a colleague. I think we were both surprised by some of the topics discussed. Sarah seemed to have a strong empathy with the relatives of her patients. This possibly stems from her own personal experiences regarding the death of her brother in an ICU in CT. this was a fact that I never knew and perhaps emphasis that we "protect" ourselves, as discussed during the interview, from other peoples pain even our colleagues. Sarah mentioned that when someone in the unit suffers a loss due to death it is not really discussed and everyone just gets on with it. People just tend to ask if the person is ok and when they reply "fine" take it at face value even when they are not.
There also seems to be a level of support for each other. One sister was mentioned several times with reference to providing support and comfort, after a death, to other staff.
I was very conscious of time throughout the interview not wanting to keep Sarah away from her patient. It was interesting to note that half way through the interview Sarah became emotional, although she remained very controlled, and stated that the conversation was bringing up that she did not even know existed and making memories surface. She has a pervading feel or air of sadness whenever death and families were discussed. She commented on the suppression of feelings that enabled her to do her job. I had a strong feeling of empathy and agreement with her during this part of the interview and could identify with what she was saying. I could in fact feel my own sadness and had to prevent my mind wandering to its own memories of suppressed emotions relating to my experiences in ICU when dealing with DNRs. I was also very touched when Sarah expressed her trust in me based on out previous relationship.
I think Sarah enjoyed being interviewed but found that it forced her to confront issues that she would rather not confront and that had been deeply suppressed.

<u>5.5.10</u>
Have been having difficulty scheduling interviews – conflict in duties; night shift, leave etc. When participants are available I am not available or venue is not available. It is very frustrating. I had an interview scheduled for today but it was cancelled but managed to get one of the other girls who had agreed to be interviewed to substitute at short notice.
Interview I had with Gugu I found quite challenging – she did not seem to be answering the questions I was asking but still think I managed to get some interesting info. Found it difficult because every time I thought she had finished talking and started to ask her something else she carried on talking again so I felt as if I was interrupting her all the time. I worried that I was impacting on her responses. Hope I am not asking leading questions and am trying to keep my body language and facial expressions neutral but it is difficult at times. Reflecting immediately after the interview is also difficult as I am busy at work and have to get back to things.
It came out quite strongly during the interview with Gugu that she felt unsupported stating "Nobody Care" I guess I have fairly strong pre-conceptions regarding this issue and identify with that statement as it reflects how I felt when I was working in the unit

7.5.10

Interview with Jane today, a bit concerned that she was giving me answers that she thought I want. Ist interview with someone that I haven't worked with so found it quite interesting. Some of the participants that I plan to interview and Sarah, I think I can predict the answers that they will give. This interview was new territory, was happy with how it went.

18.5.10

Have not managed to schedule an interview for the last week or so due to work commitments. Did have interviews scheduled with on of the participants on 3 previous occasions but they have been cancelled, by her on 2 occasions as she couldn't leave the department. I had to cancel once as a meeting time was changed. This is very frustrating. Have started transcribing – a long process. It is interesting to go back over and listen to them. I think that I have got some interesting information. Have an interview scheduled today – hope it goes ahead!

15h00

Finally got the interview with "Katie". Good Lord it certainly took an unexpected turn. She went into a rant about the charge nurse in the unit at the moment Katie has actually moved out of ICU since our interview was first scheduled and is now working in CCU. One of the reasons that emerged was the relationship with the charge nurse who she feels is unapproachable and unsupportive emotionally. I must admit I didn't know how to respond when she went down that route. I decided just to let her talk and when she finished tried to redirect her away from that situation and refocus on end-of-life issues. However she went back into the rant. I must say I felt very sad that that was how she felt, wondered if I was perceived that way when I was in charge. Again didn't quite know how to react but decided that this might actually be relevant for end-of-life issues as if staff feel unsupported in anyway emotionally this would support the emergence of the theme that they don't fee supported emotionally – "nobody care about us" was mentioned by one of the other participants. Katie went on to say not receiving any emotional support in this way added to the stress they were also under when a DNR order is given. I think perhaps that Katie took this opportunity to vent may support that fact that the nurses feel that they have no-one to talk to and that no-one listens and when some-one takes the time to listen it all comes out. Katies said it was not only her that had the issues with the charge nurse but that it was a general feeling in the ward. None of the other interviewed to date have raised the issue though. Maybe I should gently probe this in future interviews and see how it goes. Reassured Katie that all the information I get from her is confidential. She is also no longer in the unit so know no-one knows she participated in the study. Have now interviewed 2 fairly senior staff and 2 fairly newly ICU qualified staff. Think I need to try and schedule interviews with one of the the most senior girls who has been in the unit > 20 years.

19.5.10

Have been transcribing the interviews. Interesting to go back over them. Have been thinking a lot about the issues raised. I have a sense of some themes starting to emerge. There appears to be a lot of pain and sadness around DNR. Certainly the lack of support is coming through. There also appears to be a strong need to part of or included in the decision making process. Nurses want their voices heard as the feel they have something

valuable to offer as they spend so much time with the patient. Have another interview scheduled for today, so will se what emerges.
14h00
Interviewed "Sue" today. Found this interview the most difficult to date. I have never worked with Sue and only know her from a few interactions in the unit. Also had quite a serious headache and had taken some Adcodol about an hour before the interview and my brain was definitely feeling sluggish. Generally found the interview heavy going, not sure if it was my brain or Sue's personality. She tended to give fairly concise answers that didn't lead anywhere. It was the first time I really battled to think of things to ask.. had actually finished the interview when as we were packing up she mentioned something very relevant, so quickly put the tape back on and asked her to repeat what she had been discussing and asked a couple of questions more. Not sure if I got any new or useful information from her. One thing that did stand out was the use of the word traumatic when discussing the DNR event. Will see how I feel after playing back. Tried to schedule an interview with one of the really senior girls for Friday. She said she would have to wait and see as they were so short staffed. Excuse or reality? Will see what happens.

<u>27.6.10</u>
Planning to go through the transcribed interviews today to check they are verbatim and as it is so long since I looked at them, see what has been said and perceptions. Interview planned with one of the senior girls later this week. There is some reluctance on my part to get into data – am not sure why.
Have just been trough the interview with Sarah. I think I now understand my reluctance with the data. Just listening to the tape and reading the transcript brings a sense of sadness and memories that are always just below the surface and when allowed reveal themselves even after more than 10 years of not working in that environment. Sarah's whole interview seems to have a shroud of sadness over it. She genuinely appears to be shocked when she realizes she has all these emotions about end-of-life decisions and comes to the conclusion that she has just suppressed them. When discussing support it appears to be something she has not considered before. She has the support of here husband who is also a nurse and understands to a degree her experiences, as well as the support of her colleagues in the unit who she feels free to talk to and gets support and comfort from. She feels very emotional and tearful at one point although she remains controlled. It appears when contemplating the support issue she is shocked and surprised by the lack of support available as evidence by her statement "*….policemen and paramedics don't they have a psychologist that they can go and speak to? We don't have anyone!" Nobody cares about us* appears to be a theme and statement from one of the other interviews that also applies here. Sarah also brings up emotions of *anger* relating to the whole process and how "*unnecessary"* this all is asking the questions *"Why did this have to happen"*
Sarah also appears to have a strong empathy with the family of patients who have been DNR'ed possibly related to her own experiences surrounding her brothers own death in ICU and the lasting hope a family has even when they know there's no hope – as experienced by herself.
Maintaining professionalism and appearing to be strong appear to be important to Sarah but she also worries about not being perceived as human. This emerged when discussing the AND terminology when she states *"It's just words that sounds better. It makes us feel*

human" and when asked if she thought people perceived her as not being human she states emphatically *"Yes yes, I think the family ''sometimes sometimes I wonder how they see us."*
There is just a feeling of sadness that comes through this interview and strong elements of empathy.

Interview with Gugu
As at the time this interview was quite difficult. Gugu did not directly answer the questions asked, it was more like she tried to give expected/correct answers. Discussing her feelings and emotions was not easy.
Impressions were that she finds the DNR process very difficult, painful, traumatic, sad. It was also interesting to note that she felt that relatives had a tendency to blame nurses- this emerged twice during the interview. She also brought up the lack of availability or support from the doctors. May be a different focus – they are under pressure to provide a bed and need to move patients whereas the nurse is focused on the patient already her care – being the advocate.
The importance of being involved in the decision making process. The feeling that the nurse is in-charge of the patient for the day.
Gugu also emphasized the difference between long and short term patients. Long term patients – although the bond between patients/family may be stronger there is also a collective sharing of experiences between nursing staff as more of them had cared for the patient and thus provided support to the primary care giver whereas with short term patients there was more of a sense of isolation as evidenced by "..but in ICU you've got your own patient too, so you cannot nurse a patient and a nurse as well because she's undergoing this see". Gugu laos emphasized th importance of cultural practices and beliefs and the role they play in psychological support for family and staff.

Interview with Jane
On re-listening to the interview with Jane and r-reading the transcript I feel as if she kept something of herself back. I didn't get a deep feeling of emotion from her – not sure if that is because she deals with things and has a very pragmatic approach or does not want to admit of the emotions – I think possibly the later.
I got some new information from Jane relating to the importance of communication between nurses and the doctors. How accepting and comfortable Jane is with carrying out the order is dependent on her understanding and rationale evident behind the decision. Nurses feel the need to be involved and considered as part of the decision making process. It is interesting to note that rather than protest or asking questions to gain understanding there appears to be a passive resistance approach that is taken when the nurses are not comfortable. They take 2 approaches – ask the Dr, to DNR themselves or drag out the withdrawal of treatment hoping the patient will survive to shift change.
Jane also brought up a similar topic to Gugu where doctors are in a rush – give order, don't explain rationale adequately and then leave nurses to deal with the actions and family after the initial consult. The importance of family involvement also comes through – forms part of the empathy staff appear to have. They need to know what is happening, consistent information etc. It was interesting to note that Jane felt more sadness when the patient was unknown and appeared very concerned in those cases with who would claim the body, how

long the body would remain in the mortuary and the fact that cultural practices required on death might not be carried out.
The perception offending suffering as part of the DNR order was also mentioned. There was also a sense of guilt if Jane felt that not everything had been done for the patient – comes back to understanding the rational for decisions. Patients need to be given a chance – 24 -48 hours minimum.
Colleagues support came through again as well as lack of trust for EAP – which I have to agree with as some of the practioners do appear to talk a lot.
Empathy comes trough but also the need to maintain a barrier "I'm the nurse, you're the family…"

29.6.10
Interview with Katie
I have just rechecked the authenticity of the interview with Katie – some new aspects emerged.
There definitely appears to be a change in the way DNR orders are perceived as a new RN coming into the unit than with the perceptions and experiences of those with knowledge and experience. I think this ties with my own experiences and came through with Katie's interview as well. She describes "It was a harsh decision that's what I felt just to terminate life. I was of the opinion it should just happen naturally." as her view when she first started in ICU. Whereas after a few years of experience and gaining of knowledge she describes was she terms as being "I am more realistic.." taking a more pragmatic view using words like "Justifiable", "prolonging agony" Describing justifiable as being when the patient has been given the best chance possible. Katies also expressed interesting views of the concept that if you agree with the DNR decision you should morally be happy with withdrawing support yourself. Issue of perceptions towards the DNR orders from when she first started in the unit as ahe is now able to rationalize and justify the order as long as she feels the patient has been given the best chance possible.
Again the importance of nurses being/feeling involved in the decision making process was mentioned as they are the ones left with the patient for 24 hours.
Katie also mentioned that there appears to be a shift, although unspoken, that nurses are no longer actively, in general, involved in discontinuing treatment – she mentioned previously that this is a little morally wrong.. she was also the first person, I think, to mention detaching herself in terms of the family she states "I do feel sorry and bad for the family….that's where you learn to detach …. I have learnt not to carry it with me." She goes on to say if she did not do so she would become depressed. She also later in the interview alludes to the fact that you either learn to deal with this aspect of ICU or you will end up in Townhill.
Again the issue of initially discussing the issues at home with family members was raised – after a period no longer going to discuss issues. Working through issues with staff at work.
On re-reading Katie's issue with the management style in the unit some valid points were raised and I will try to explore this in my interview planned with a senior staff member.
Lack of trust with EAP came through.
The need for an induction and preparation of new staff was also raised and felt to be of a help.

Katie also brought up a new concept where she viewed the counseling sessions with family actually helps the nursing staff process the information as well. She also expressed the need to be guarded when answering questions fro relatives.

Pre-Interview
Am interviewing a senior member of the nursing staff this morning. She and I worked together for a long period. It will be interesting to see what her perspectives are as she has been mentioned by several of the participants a someone who provides a lot of support to the staff. I want to try and clarify some of the issues some of the others have brought up e.g. change over from nursing staff to doctors carrying out the DNR order. Specifically I would also like to see how her views on DNR have changed over the years working in ICU. I am looking forward to the interview.
Post-interview
As I thought it was an interesting interview. Taby confirmed that her perceptions regarding DNR order have changed fairly distinctively over the 24 years she has been working in ICU. The same unit. I cannot remember the words she used but when she first encountered a DNR she appeared to have been quite shocked. She is conscious of this and the impact these events have. It was interesting that she feels that new staff have more support than she did when she started. Some information I did not catch on the recording as it emerged after the interview whilst packing up and just chatting. Taby spontaneously brought up the management style in the unit and the fact that the staff do not find the IC approachable and that they are not able to discuss issues with here or get support from her emotionally. In fact she feels that people leave the unit because of the way she speaks to them. This confirms Katies view and would definitely impact on the stresses around DNR orders.

30.6.10
Interviewed Renata today. Found the interview fairly difficult. She had a tendency o ramble on and I felt she was putting up a front to some extent. She has an interesting perspective on new young staff coming into the unit – she appears to have the view that they have "less human feelings" and carrying out a DNR order is like carrying out any other order. She herself comes across fairly cold and unfeeling. She has a very reserved and controlled personality type. It is interesting how we all try and hide our true emotions and feelings – self preservation and protection?

5.11.10
Finally finished the initial rough draft of my findings and sent them through to Busi for comment. Am happy with the themes and feel they are a true reflection of the experiences of the girls I interviewed. Have been going over the data again and again, examining the responses and themes and trying to examine how may preconceptions of the DNR experience have influenced this process. My initial response to the degree of empathy described by the girls was surprise but when thinking about my own experiences I think that this is true. When I contemplate how I responded to DNR the pain and distress I felt was aimed not at the patient but the family and I imagined what they were going through and how they must be feeling – empathy I guess! I also had a strong sense of isolation in many ways – the need to be strong and in control in front of others in the unit especially

junior or new staff and doing my crying alone. When the girls speak of lack of support, except for colleagues, I also identify with the strongly. I think reflecting back, that I became really angry with the institution, with their demands and lack of understanding – comments like "why do you need more staff your patients are on machines" and "you only look after one patient what are you stressed about?" or "you just switch patients off in ICU". I could identify strongly with these issues when mentioned during the interviews and think this created a feeling of shared history and understanding especially when talking to Taby and Sarah. I really identified a lot with what they had to say. Their knowing that I knew and understood what they were feeling and talking about I think enhanced the interview process and I think that that was true in varying extents with all the interviews