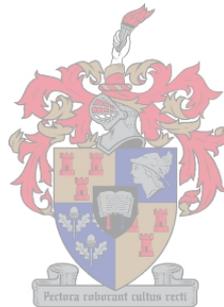


# **Experiences of nurses involved with neonatal deaths in Neonatal units in a Saudi Arabian Hospital**

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Thesis presented in (partial) fulfilment of the requirements  
for the degree of Master of Nursing Science  
in the Faculty of Medicine and Health Sciences  
Stellenbosch University

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**April 2019**

## Declaration

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## Abstract

**Background:** Nurses who care for patients in neonatal intensive care units (NICU) address all their efforts to care for seriously ill newborns and their families. The death of a newborn and the grieving process is profound for families and the emotional involvement experienced by the nurses can be complicated. Many nurses do grieve when their patients die yet this is not often acknowledged or discussed. A need was identified in a NICU in Saudi Arabia where the researcher observed that some expatriate colleagues were struggling to come to terms with a neonatal death in the study setting. The aim of this study was to explore and describe the nurses' experience following the death of a neonate in their care in neonatal units in a Saudi Arabian hospital.

**Methods:** An exploratory descriptive qualitative design was applied to elicit the participant's psychological experience of neonatal loss in their care. Fifteen participants who had experienced a neonatal death in their care were sampled from the staff establishment (N=56) in the research setting to participate in individual interviews conducted by a field worker. Consent to conduct the study was obtained from the Health Research Ethical Committee of Stellenbosch University and from the institution where the research was conducted. Informed consent was obtained from the participants at each interview including the use of a recorder. Interviews took place at a location of the participant's choice, were audio-recorded, transcribed verbatim and member-checked by a field worker. The interviews were analysed thematically according to the Terre Blanche, Durrheim and Kelly method and the themes that emerged were emotional grief, support available for the staff, colleague or family support, spiritual or other rituals, religion and spirituality.

**Results:** Findings show that the neonatal care nurses in this study experience a range of emotions, including professional self-doubt and protracted grief. A need for support and clear communication channels from the employer emerged that could assist with the development of coping strategies. Cultural training could be provided during orientation at the commencement of the employment contract on the needs and expectations of the parents.

**Key words:** Nurses, neonatal loss, support needs, psychological experiences, multiculturalism.

## Opsomming

Neonatale intensiewe sorgeenhede voorsien sorg aan pasgeborenes in lewensbedreigende toestande met baie lae geboortegewig, infeksies, geboorte trauma, veelvoudige komplekse aangebore afwykings en misvorming. Die effek, reaksie en rouproses van verpleegkundiges wat so intens en nou betrokke is by hierdie eenheid, kan 'n baie langdurige, pynvolle en stresvolle verlieservaring wees, insluitend affektering van verhoudings tuis en met hul medewerkers.

Hierdie studie het plaasgevind in 'n Saoedi Arabiese NICU-eenheid en ICN waar 657 babas in 2017 toegelaat was. In hierdie NICU het die navorser waargeneem dat verpleegpersoneel sukkel om hul ervarings uit te druk of te deel wat dikwels sosiale onttrekking van ander spanlede tot gevolg het.

'n Verkennende, beskrywende, kwalitatiewe navorsingsontwerp wat semi-gestruktureerde individuele onderhoude gebruik het, is aangeneem om te verken en te beskryf hoe neonatale verpleegkundiges die dood van 'n neonaat in hul sorg ervaar en hul hanteringstrategieë. Die totale populasie met die aanvang van die studie was N=56 neonatale spesialis-opgeleide en ervare verpleegkundiges wat in hul lande van herkoms geregistreer was, wat Saoedi Arabiese burgers en buitelandse verpleegsters van Fillipyne, Indië en Suid-Afrika was.

Etiese goedkeuring is verkry van die Gesondheidsnavorsings-etiekkomitee van Stellenbosch Universiteit en die Institusionele etiese hersieningsraad. Ingeligte skriftelike toestemming was verkry van die deelnemers, insluitende die gebruik van 'n elektroniese stemopnemer en notas opname. 'n Veldwerker het 15 Engelssprekende vrywilligers ondervra en hulle van anonimiteit, vertroulikheid en geheimhouding verseker aangesien hulle aan die navorser bekend was. Die Terre Blanche, Durrheim en Kelly-metode is gebruik om die data uit die woordelike transkripsies te onttrek, te organiseer en te analiseer.

Die analise het aan die lig gebring dat die deelnemers 'n verskeidenheid emosies ervaar – van 'n gevoel van prestasie om hul beste te doen tot gevoelens van professionele onbevoegdheid geweldige hartseer, wanhoop en verwarring; veral onder uitlanders van verskillende kulture. Die gebrek aan erkenning, en in sommige gevalle vir wie die bestuur blameer het, het hul nood vererger. Dit word sterk aanbeveel dat professionele ondersteuning vir die individu en die verpleegspan in die NICU-eenheid oorweeg word, insluitende outentieke medelydende mentorskap wat gereeld met indiensopleidingsessies aangebied word.

**Sleutelwoorde:** verpleegsters, neonatale verlies, ondersteuningsbehoefte, psigologiese ervaringe, multikulturalisme.

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# CHAPTER 1:

## FOUNDATION OF THE STUDY

### 1.1 INTRODUCTION

This chapter introduces the scientific basis for the study. Presented in this chapter are the rationale, significance, problem statement, research aim and objectives in addition to the methodology and ethical considerations.

### 1.2 RATIONALE

Literature reveals that advancements in technology and research have improved the survival rate of infants born prematurely or with life-threatening problems (Lewis, 2017:96). Early and late foetal death, including miscarriage and stillbirth, occur in about 25% of all pregnancies (Hutti, Armstrong & Myers, 2013:18).

Pye (2016:4) notes that providing end of life care for the critically ill neonate and their families is within the complicated care continuum. The continuum of care covers the delivery of health care over time and refers to care provided from birth to end of life. Daily in the NICU the exposure to the complexity of the patient's diagnosis, treatment and care is challenging. Nurses may find it difficult to verbalize their experiences and emotions in a way that nonmedical people can understand (Cook, Lawrence, Grady, Liner, Hickey & Connor, 2012: e11).

In the researchers clinical experience nurses feelings differ when a death of a neonate occurs and range from a sense of accomplishment (Almeida, Moraes & Cunha, 2016:122) in providing the best care to a sense of failure, as there is a perception that the purpose to promote health and wellness was futile. Nurses' distress and feelings of powerlessness are compounded by the necessity to follow institutional policies, a lack of administrative support, inter-professional conflict, conflict in religious practices and legal constraints. Nurses develop their own strategies to manage their distress. Many nurses grieve when patients die, however, nurses' grief is not often acknowledged or discussed (Jonas-Simpson, Pilkington & MacDonald, 2013:1). The process of death and grief is partially due to the manner in which nurses face the process of dying. It is related to their cultural origins as well as personal and professional experiences (Almeida, Moraes & Cunha, 2016:119). Moral distress is recognized as one of the major sources of stress for nurses who provide end of life care for neonates (Zhang & Lane, 2013:1) and that the negative impact of patients' death may be short term emotional reaction such as fear, severe grief and burnout (Muliira & Muliira, 2016:52). In addition, the short-term adverse outcomes can initiate long term consequences such as

compassion fatigue and withdrawal from practice among nurses with inappropriate coping skills.

An aspect that can influence how nurses cope with the death of a neonate in their care can relate to their worldview. Since nurses employed in the Middle East are multicultural and the majority of nurses working in the NICU are expatriates, their own belief systems are sometimes in conflict with their host country since their own religious practices around health and death may differ.

The benefits of the proposed study will be new knowledge generated with regard to the experiences of nurses involved with neonatal death in the study setting. The findings may contribute to stronger support systems within the institution.

### **1.3 RESEARCH PROBLEM**

In the study setting, the researcher has observed amongst her colleagues who are predominantly expatriates, that some neonatal nurses find the death of a neonate in their care to be extremely distressing. The vulnerability of their NICU patients and the special bonds that they appear to form when caring for the patient and their families may contribute to withdrawal from interaction with the multicultural team and emotional and physical symptoms including headaches, fatigue and depression. This may result in burnout and attrition from clinical practice. This relationship exposes nurses to intense and recurrent experiences with unresolved loss and grief when their patient dies. Health professionals may experience a variety of emotional and physical symptoms including headaches, fatigue and depression. The emotional strains associated with end of life and bereavement care does not only affect nurse's health but can also affect their relationships at home and as mentioned, with their co-workers.

### **1.4 RESEARCH QUESTION**

How do nurses experience the death of a neonate in their care in neonatal units in a Saudi Arabian Hospital?

### **1.5 RESEARCH AIM**

The aim of this study was to explore and describe the nurses' experiences following the death of a neonate in their care in neonatal units in a Saudi Arabian hospital.

### **1.6 RESEARCH OBJECTIVES**

- To explore and describe
  - the nurses' experience following the death of a neonate in their care
  - the support provided to the staff by the employer

- the support system available from colleagues and family
- the coping strategies used by nurses
- the cultural differences that may hinder their interaction with the parents.

## **1.7 RESEARCH METHODOLOGY**

The research methodology applied to this study is briefly described here with further detail in Chapter 3.

### **1.7.1 Research design**

The study followed an exploratory descriptive qualitative research design employing individual interviews to describe the real-life experiences of neonatal nurses in a Saudi Arabian hospital (Grove, Gray & Burns, 2015:66). This design is appropriate for the exploration of unique issues, health problems, or situations that lack clear description or definition (Grove, Gray & Burns, 2015:140).

### **1.7.2 Conceptual framework: Sunrise Model of Transcultural Nursing Care**

The researcher selected the Sunrise Model of Transcultural Nursing Care conceptual framework to identify aspects of culture to be considered when communicating with patients, families, colleagues and other cultures (Grove, Gray & Burns, 2015:74). This theory acknowledges the diversity and universality within nursing that continuously needs to be nurtured.

### **1.7.3 Study setting**

The study was conducted in a Saudi Arabian Hospital's neonatal unit with the nurses, predominantly expatriates, who care for the neonates. The unit is divided into two neonatal intensive care units with 10 beds and the intermediate care unit has 15 beds. Six hundred and fifty-seven neonates were admitted to the units in 2017. This data was collected from the admission book of both neonatal units. Most of neonates admitted are severely premature below 30 weeks gestational age and frequently have congenital abnormalities.

### **1.7.4 Population and sampling**

For the purpose of this study, the target population refers to all nursing staff working in a Saudi Arabian hospital's neonatal unit. Fifty-six nurses are employed in both units. All nurses are professional nurses with specialist training or experience in neonatal nursing and are registered as such in their countries of origin. The participants are registered to practice in Saudi Arabia with the Saudi Arabian Nursing Council. The study topic was introduced at a departmental meeting and all willing participants were invited to participate who met the inclusion criteria. Fifteen participants volunteered. The purpose for accepting all fifteen

volunteers, was to ensure that a wide range of experiences could be elicited from them including their coping mechanisms. Authors differ in their definition of saturation as explained by Greeff, (2005:287), since a sufficient number of interviews should reflect the range of participants that make up the population. O' Reilly and Parker (2012:190) state that in the light of transparency data saturation in qualitative research is an inappropriate marker for quality. The authors argue that there is no singular way to measure quality due to its diversity (O' Reilly & Parker, 2012:191).

#### **1.7.5 Specific sampling criteria**

The inclusion criteria for this study were all English-speaking professional nurses working in the neonatal units who have experienced a neonatal death in their career. The purpose of recruiting nurses with no specific time-line when they experienced this phenomenon was to establish a variety of experiences and coping mechanisms that could provide useful strategies for future interventions in the study setting.

#### **1.7.6 Data collection tool: Interview guide**

As the researcher is a member of the neonatal nursing team, a trained field worker conducted the data via one-on-one semi-structured interviews with probing questions in a venue of the participants choice to ensure anonymity and privacy. As recommended by Grove, Gray and Burns (2015:82), semi-structured interviews are appropriate to ascertain the participant's thoughts, ideas, perceptions and meaning of the phenomenon to obtain rich data (Appendix 1).

Audio-recordings with verbatim transcription took place and field notes were kept. The fieldworker fulfilled the function of member-checking of the transcribed interviews with each individual to protect their anonymity and confidentiality.

#### **1.7.7 Pilot Interview**

A pilot interview was undertaken by both the researcher and the field worker with a participant who met the inclusion criteria for the study. The participant gave consent for the researcher to be present. An explanation was given by the researcher that if the participant felt any discomfort the researcher would immediately. This provided the researcher and the field worker with the opportunity to engage with the participant, refine the semi-structure interview guide and test the recording devices. The data was rich and relevant to the study and is included in the findings.

### **1.7.8 Trustworthiness**

The soundness of qualitative research is evaluated by its rigor or trustworthiness (Goldblatt, Larnieli-Miller & Neuman, 2011:390). Carlson (2010:1103) states that qualitative inquirers mindfully employ a variety of techniques to increase the trustworthiness of the research they conduct, meaning how much trust can be given by the reader that the researcher did everything possible to ensure that the data was appropriately and ethically collected, analysed and reported.

A detailed explanation of how the researcher maintained trustworthiness is presented in Chapter 3.

### **1.7.9 Data collection**

Interviews were conducted over three weeks. The interviews were audio recorded, transcribed immediately and field notes were kept. Two recording devices were used for each interview to secure data in the event of equipment or power failure. The written material will be stored in a secured place and the electronic data will be stored in a password protected electronic file for five years.

### **1.7.10 Data management and analysis**

Data analysis in qualitative research includes becoming immersed and familiarised with the data, transcripts and field notes. The researcher audio-recorded and transcribed the interviews verbatim. This entailed listening to the recordings a number of times.

In this study thematic data analysis was performed according to Terre Blanche, Durrheim and Kelly's (2012:322) 5-step strategy for qualitative data analysis, namely, familiarisation and immersion, inducing themes, coding, elaboration and finally interpretation and checking.

A detailed explanation of the management and analysis of the data is described in Chapter 3.

## **1.8 ETHICAL CONSIDERATIONS**

The importance of protecting the human rights of the participants at all stages of the research process was meticulously observed. Informed consent was obtained from all study participants after explaining the purpose of the study. The consent described the purpose of the study, how confidentiality would be maintained and it indicated that they may withdraw from the study at any time without penalty.

### **1.8.1 Right to self determination**

Self-determination relates to the autonomy and respect of the participant. At a unit meeting the staff were informed about the study and invited to participate voluntarily. The participants

were not coerced or deceived. As previously mentioned, each participant provided informed consent, to the recording thereof and were free to withdraw at any stage without penalty.

### **1.8.2 Right to confidentiality and anonymity**

The participants had the right to anonymity and the right to assume that the data collected will be kept confidential (Grove *et al.*, 2015:106). Confidentiality is the researcher's safe management of data shared by a participant to ensure data is kept private (Grove *et al.*, 2015:107).

Participants were informed that their names will not be used in the data and that a number will be allocated to the interview. All interviews were confidential and although they were read by the supervisor of the study, no personal identifiers reflected on the transcripts. Participant verification of data ensured the credibility of the data that was recorded and transcribed (Grove *et al.*, 2015:107).

### **1.8.3 Right to protection from discomfort and harm**

According to Grove *et al.* (2015:108), the right to protection and discomfort in the study is based on the ethical principle of beneficence, which states that one should do good and above all do no harm. Individual comfort was ensured by conducting the research in a venue of their choice and at their convenience. Grinnel and Unrau (cited in de Vos *et al.*, 2013:116) note that beneficence is understood as maximizing benefits and minimizing possible harm. The researcher should ensure that the benefits of the study outweigh the risk (Grove *et al.*, 2013:175). In addition, fair treatment is based on the principle of justice (Grove *et al.*, 2013:174). Benefits relate to health or psychosocial benefits as well as the contribution to knowledge (Grove *et al.*, 2013:175). Risks may be emotional and social embarrassment or sensitivity due to the nature of the topic (Grove *et al.*, 2013:174). In the event of any emotional vulnerability demonstrated by the participant, the researcher had arranged for the participant to consult with the psychology department in the hospital. The researcher is not aware whether the participants consulted a counsellor. However, the participants did not appear to be over distressed during the interviews.

## **1.9 DURATION OF THE STUDY**

Data collection commenced in August and was completed on the 3<sup>rd</sup> September 2018.

## **1.10 DEFINITIONS**

**Anticipatory grief** is described as a range of intensified emotional responses that may include separation anxiety, existential loneliness, denial, sadness, disappointment, anger,

resentment, guilt, exhaustion, and desperation. These symptoms may resolve eventually (Eldridge, 2018:1; Shore, Koch, Gelber & Sower, 2016:16).

**Disenfranchised grief** refers to the grief a person experiences that is not admitted, socially validated or publicly mourned, and there is no social recognition that the individual has a right to grieve or has a need for social support and sympathy (Kain, 2012:83).

**Ambivalence** is defined as the state of having mixed feelings, mixed beliefs, or contradictions of thoughts and feelings (Petty & Krosnick, 2014:8).

**Prematurity** is defined as an extremely low birth weight infant: (<1000gm), very low birth weight infant (<1000 - 1499gm) and near-term infant (more than or equal to 1500gm) (Al-Nemri & Al-Fifi, 2011:122).

**Neonatal death** refers to the deaths among live births during the first 28 completed days of life which can be further subdivided into early neonatal deaths (deaths between 0-7 completed days of birth) and late neonatal deaths (deaths after 7 days to 28 completed days of birth) (World Health Organisation, 2016:2).

## 1.11 CHAPTER OUTLINE

### **Chapter 1: Foundation of the study**

This chapter outlines the scientific foundation of the study. It includes a brief overview of the research, the rationale, methodology, philosophical underpinning, the research aim and the objectives. Ethical considerations are described.

### **Chapter 2: Literature review**

This chapter presents and discusses the current body of knowledge on the experiences of neonatal nurses following the death of a neonate.

### **Chapter 3: Research methodology**

A detailed description of the research methodology applied in this study is explained.

### **Chapter 4: Analysis**

The thematic analysis of the data and the interpretation with quotations is presented in this chapter.

### **Chapter 5: Discussion and recommendations**

The discussion, conclusions, recommendations and future research suggestions are presented in the final chapter.

### **1.12 SUMMARY**

In Chapter 1, an introduction and rationale for the research study was described. The aim, objectives, research methodology, ethical considerations and philosophical underpinnings were outlined.

### **1.13 CONCLUSION**

In the researcher's clinical experience in a Saudi Arabian hospital NICU she became aware that some nurses experience a range of emotions with the death of a neonatal in their care. In order to provide empathetic and constructive assistance to nurses in these circumstances, this research was envisaged as having the potential to contribute meaningfully to their coping skills.

Chapter 2 describes the literature that informed this study.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 INTRODUCTION**

This chapter presents the current state of knowledge on nurse's experiences of a neonatal death in their care.

The neonatal intensive care unit is a specialized environment for the care of newborns at term or preterm in life-threatening conditions that require continuous monitoring and specific therapies. In this unit, health professionals address all their efforts to care for seriously ill newborns and their families. An aspect that is of concern to the researcher is the needs of nurses who are struggling to come to terms with an infant who they nursed who had died. The experiences and coping mechanisms of nurses in these circumstances were explored in the literature.

### **2.2 LITERATURE REVIEW**

A literature review in a research project is an appraisal and synthesis of the existing theoretical and scientific knowledge about an identified research problem (Burns & Grove, 2011:541).

An initial literature review was conducted after the research topic was identified. It explored international publications over the last ten years on the experiences of nurses with the death of a neonate in their care in intensive care units. The search for literature continued following the interviews when the themes and subthemes were identified in the participant's transcriptions. This included amongst other aspects coping strategies, cultural challenges and support needs.

Databases such as Stellenbosch University Library and Information Service, EBSCOhost, PubMed, Science Direct, Wiley online and Google scholar were explored.

Keywords used included nurses, neonatal loss, support needs, psychological experiences and multiculturalism.

### **2.3 NEONATAL DEATHS**

Banu and Sultan (2013:59) state that nurses encounter death and dying in their everyday practice and the nurse's response and attitude may vary according to their previous experiences. Nurses are confronted daily with the complexity of their patient's diagnoses, treatment and care. Being constantly present at the bedside means that the death of an infant is a critical event. It can be a source of significant anxiety, discomfort and a sense of failure

(Bloomer, O'Connor, Copnell & Endacott, 2015:87). The effect, reaction and grieving process has been described as being a long-lasting, painful and stressful bereavement experience for nurses (Kain, 2012:80). Furthermore, nurses may find it difficult to verbalize their experiences and emotions in a way that nonmedical people can understand (Cook, Lawrence, Grady, Liner, Hickey & Connor, 2012:e11).

#### **2.4 CAUSES OF NEONATAL DEATHS GLOBALLY AND IN THE MIDDLE EAST**

According to the World Health Organization (2016:1) reducing maternal and newborn deaths is an integral part of the global agenda. Globally, forty-five percent of all under five child deaths are in their twenty-eight day of life (World Health Organization, 2016:1). The United Nations reported that 5.9 million children under the age of five died in 2015 (United Nations, 2015:np). The World Health Organization report on reducing newborn mortality states that seventy-five percent of neonatal death is said to occur during the first week of life, and between 25%-45% of the deaths occur within the first 24 hours of life.

The World Health Organization (2016:1) states that the main cause of neonatal death are prematurity and low birth weight, infections or sepsis, asphyxia and birth trauma during delivery which accounts for nearly 80% of neonatal deaths. As reported by Al-Nemri and Al-Fifi, (2011:122) in a study in Oman, prematurity is defined as an extremely low birth weight infant: (<1000gm), very low birth weight infant (<1000 - 1499gm) and near-term infant (more than or equal to 1500gm). In addition to prematurity-related conditions (61%) the causes of death are also due to multiple congenital anomalies (44%), followed by perinatal asphyxia due to meconium aspiration syndrome and congenital cardiac diseases. The authors further report that although the level and trends in Oman for child and neonatal mortality rates have dropped to a minimum value of 6/1000. Similar reports from other gulf countries including Saudi Arabia and Qatar, revealed neonatal mortality rate of 12/1000 and 5.1/1000 respectively (Abdellatif, Ahmed, Bataclan, Khan, Al Battashi & Al Maniri, 2013:422).

In the current research setting, a Saudi Arabian NICU, high numbers of neonates are admitted annually with the above-mentioned conditions. Loss of life continues to occur due to the pathophysiological conditions such as prematurity as described, complex congenital lesions, or malformations prevalent in the infants in the NICU. These conditions are not responsive to the current advances in neonatology intensive care.

#### **2.5 NEONATAL NURSES RESPONSES TO NEONATAL LOSS**

Diel, Gomes, Xavier, Salvador and Oliveira (2013:1082) note that in hospitals the death or dying process is still little debated and questioned among nursing professionals, and those are the individuals who perhaps are more exposed and affected by it in their daily work.

Shorey, Andre and Lopez (2017:26) states that death in specialized units such as a the NICU happens suddenly and during unforeseen circumstances and grief reactions among healthcare professionals are more severe and complicated.

Neonatal nurses experience feelings such as anguish, sadness, guilt and stress when they lose a neonate (Kain, 2012:80). Muliira and Muliira (2016:53) agree with these findings by stating that the death of a patient elicits feelings of anxiety and discomfort when it occurs. Conversely, some nurses experience a sense of accomplishment that they had done everything in their power (Almeida *et al.*, 2016:124).

Caring for the newborns who are dying and their families may be very difficult for nurses due to their intense and close involvement with the patients' care. Most of studies that the researcher has reviewed examined nurses who take care of adult patients and not neonates. Puia, Lewis and Beck (2013:321) assert that neonatal care nurses are privileged to be working with neonates from birth, until their death, they are with them continuously until they take their last breath. The preparation and the effort of the health care professional to maintain the life of the baby, including communicating with the grieving relatives, leaves scant time for the health care worker to address his or her own grief (Almeida *et al.*, 2016:120).

According to Ives-Baine *et al.* (2013:303), providing the nurses with a sense of security, regularity and control in the mist of emotional disorder can improve the health of staff.

### **2.5.1 The nature of neonatal nurse's grief**

Grieving the loss of a patient is most often researched with respect to nursing practice in oncology palliative care and critical care (Wilson & Kirshbaum, 2011:560). Diel *et al.* (2013:1082) states that despite death in the neonatal intensive care unit is a regular occurrence, it is unacceptable to the health care provider and is infrequently anticipated, as there is a belief that the infant will survive.

Adwan (2014:329) describes grief as an active, universal, extremely individualised process with a strong normative component, meaning it is influenced by the social context and origin of the individual. It is further described as a multi-faceted response to loss (Kain, 2012:80) and is a significant human experience (Pilkington, 2006:300) with physical, cognitive, behavioural, social and philosophical dimensions and is seldom recognized (Kain, 2012:80). This is further defined by Meller, Parker, Hatcher and Shehan (2017:2) and confirmed by Almeida *et al.*, (2016:120), as straight forward grief that can manifest in feelings of unhappiness, annoyance, self-blame, nervousness, isolation, fatigue and helplessness.

Almeida *et al.* (2016: 120) confirms this by stating that in their study in Brazil, the nurses reported the feelings of guilt, failure and denial of death emerge, representing difficulty in understanding the transition life and death at this moment. Irrespective of where the loss occurs, a health care provider is expected to perform his/her work in a highly professional manner for the relatives and the other patients (Muliira & Muliira, 2016:53).

A study done by Shore, Koch, Gelber and Sower (2016:16) describes anticipatory grief as a range of intensified emotional responses that may include separation anxiety, existential loneliness, denial, sadness, disappointment, anger, resentment, guilt, exhaustion, and desperation. The authors further state that anticipatory grief could become apparent as an extensive range of physical, emotional, cognitive and manifest as a wide spectrum of physical, emotional, cognitive and spiritual signs and symptoms. Kaneez (2015:18) states that individuals who are grieving demonstrate related forms of deep distress, nervousness, longing and preoccupation, and that these symptoms resolve eventually.

Wilson and Kirshbaun (2014:3) stresses that staff that experience the greatest grief-associated signs were persons who had worked for a long time in the institution, and had nearer and long-lasting relationships with the patient who died. Wilson Kirshbaun (2014:3) further states that the regularly reported responses to a patient's death were crying, thinking about their own mortality and the negative effect that the death had on their relationship at home. At work, their performance may be compromised as their ability to concentrate and focus on their work is influenced since they perceived they have failed in their professional actions (Banu & Sultan, 2013:359).

A sentinel paper published by Papadatou (2000:62), is included in this review since it meaningfully categorizes nurses' loss into 6 major categories.

1. The first is losing familiar connection with a specific patient. This relationship may result in varied degrees and forms of grief.
2. The second loss is due to the professional's empathy for the family members.
3. The third loss is of one's unmet life goals and expectations and the undermining of one's professional self-image and role.
4. The fourth loss is interrelated to an individual's personal beliefs and expectations about life. This is prevalent among health care providers who perceive life as orderly, structure and foreseeable. They assert that one can wield control and find a place in an equitable and just world.
5. The fifth loss is associated with previous losses or expected future losses of a neonate or even a personal loss. This feeling may also activate in the nurse a condition termed anticipated loss.

6. The sixth loss is the death of self that may activate nurse's thoughts of their own mortality and death (Almeida *et al.*, 2016:122).

Almeida *et al.*, (2016:122) observed that in other studies, feelings of disbelief, ambivalence and helplessness have been reported by nurses. Ambivalence is defined as the state of having mixed feelings, mixed beliefs, or contradictions of thoughts and feelings (Petty & Krosnick, 2014:8). As explained by Ives-Baine, Lindsay, Van der Wel, Barker, Saini and Cross (2013:np), feelings of loss and sadness is experienced by neonatal nurses because they could not change the outcome. They further state that many studies tend to concentrate on decision-making and ethical issues and less is explore on the experiences of health care providers. Exposure to death in the workplace can contribute significantly to physical ill health and retraction from the work environment, besides the emotional and psychological impact (Muliira & Muliira, 2016:53).

Individual resilience and understanding death as a natural part of the life cycle could assist health care providers to survive these circumstances while moderating suffering to a certain extent (Almeida *et al.*, 2016:123). According to Kain (2012:83) neonatal nurses are reluctant to undergo counselling to evade being viewed as "not coping" with their work responsibilities. The author further states that much can be implemented in terms of support for neonatal health care providers from an emotional work perspective.

Cook *et al.* (2012: 15) look at the experiences of nurses and categories them into four categories: boundaries, memories, disconnecting and labelling. Feelings of rumination was identified by the researcher of this study and it is described as similarity between anxiety and depression (Wehrenberg, 2016:1).

Kain (2012:81) asserts that there is no amount of experience that can prepare the nurse for the patient's death. In light of a loss, it should be understood that there is pain and anguish, therefore inadvertently health care providers need to protect themselves from psychological distress that arises from a loss by acknowledging that death may be a panacea to their pain and anguish (Diel *et al.*, 2103:1086). Furthermore, nurses who are new in the neonatal intensive care unit may feel that their lack of experience or proficiency has contributed to the failure in the resuscitation of the neonate especially if the death was sudden (Diel *et al.*, 2013:1083).

### **2.5.2 Feelings of failure**

Feelings involved when losing the patient is associated with the feeling of failure. Diel *et al.* (2013:1086) states that while negative feelings remain, it must be acknowledged that the loss

can be replaced by, it should be verified that the death can leave in its place a feeling of emptiness and pain, since the preservation and extension of the life are nurse's objectives and may feel frustrated when they do not get success in their strivings.

Almeida *et al.* (2016:119) on a study done in Brazil looks at the feelings that nurses in their study described where the participants reported feelings of impotence by their perceived failing to prevent the death of the newborn in their role of health promotion. Mostly the outcome of death in an intensive care unit is not accepted and generates feelings of frustration, sadness, loss, powerless, stress, professional failure and as mentioned guilt in the health care workers who face death at their workplace (Diel *et al.*, 2013:1086). This is supported by Shorey *et al.* (2017:34) who identified in their study that apart from feelings of guilt, nurses experienced internal conflicts with their own feelings while putting up brave fronts when looking after the parents. They further reported that nurses had a feeling of demotivation, overwhelmed, horrible and like crying and some reported posttraumatic stress disorder. Burnout was also reported in this study and yet few nurses even felt the urge to leave the profession.

### **2.5.3 Disenfranchised grief**

Disenfranchised grief refers to the grief a person experiences that is not acknowledged, socially validated or publicly mourned, and there is no social recognition that the individual has a right to grieve or is in need for social support and sympathy (Kain, 2012:83). Kain (2012: 83) expresses that it is possible that neonatal nurses may not feel they can express their grief and become self-disenfranchised. This may be due to the assumption that society expects them to remain strong in the face of death, and the expression of grief may give the appearance of vulnerability. This vulnerability may result in nurses developing ineffective ways of coping with grief.

Almeida de Amorim, Salim de Moraes and Cunha (2016:120) support this by saying that emotional involvement is inevitable because these professionals follow the newborn in their daily work shift, from the admission to the unit until time of their death or discharge.

### **2.5.4 Compassion fatigue**

Compassionate fatigue is defined as a state of tension and preoccupation with the cumulative impact of caring (Meller *et al.*, 2017:3) and is substantiated by Mumbue (2010:14) posits this as a concept associated with people who provide care for other people. It is a process that extends past the burnout stage of an emotional challenge and can be distinguished by how caregivers begin experiencing symptoms similar to the patients and their families. Houck (2014:45) supports this by identifying that the effects of compassionate fatigue may include

weariness, poor performance, and multiple physical complaints. Meller *et al.* (2017: 3) states that nurses are at risk of developing professional compassion fatigue due to the empathy they demonstrate, coupled with the exposure to patient suffering, trauma and death.

### **2.5.5 Burnout**

Muliira and Muliira (2016:53) states that nurses who do not engage in healthy grieving or use ineffective methods to cope with death situations can also experience burnout. According to the study done by Shorey *et al.* (2017:36) amongst the professionals working in maternity units who deal with perinatal death, these deaths had a negative impact on their psychological wellbeing as they felt depressed and burned out.

## **2.6 COPING SKILLS AND SUPPORT INTERVENTIONS**

Pye (2016:4) states that death of the neonate is a life changing and tragic experience for the individuals involved in the final moments of the infant's life. Nurses respond to this occupational exposure and experience of death and associated role expectations by finding ways to cope, and sometimes they use ineffective methods such as avoidance and separation of the experience that can result in exhaustion and other physical and emotional problems as opposed to healthy grieving (Muliira & Muliira, 2016:53).

In a study done by Kain (2012:85) nurses reportedly have their own coping skills through experience that is simply not acknowledging their work-related stress and grief.

Nurses grieve when a patient dies and when this grief is recognized, addressed, and supported, nurses cope by finding meaning in the loss according to their worldview of life and death (Houck, 2014:454). Houck (2014:454) further states, that symptoms of cumulative grief may include physical illness, substance abuse, suicidal thoughts, apathy, poor self-esteem, depression and anxiety. Nurses create a curtain of protection to mitigate the grieving process and to allow them to continue to provide supportive nursing care (Tranter, Josland & Turner, 2016:102).

Kain (2012:85) suggest that opportunities for debriefing sessions after difficult cases are important, and training to engender nurses with effective grief management skills and coping mechanisms are underutilized. The literature suggests that participation in grief rituals such as a patient's funerals can assist in bringing closure and assist health care professionals in dealing with grief (Kain, 2012:86).

Muliira and Muliira (2016:53) notes that the nurse's reluctance into talking about death may be the lack of knowledge and skills to handle death situations. The authors further state that literature has shown that many nurses in practice did not receive specific training or

preparation in dealing with death. Diel *et al.* (2013:1082) supports them by stating that professionals grieve for their patients, this is due to the bond nurses develop when caring for patients. Caring for a patient during process of dying requires the understanding of the complexity of such a process. Diel *et al.* (2013:1082) states that professionals should be helped in coping during this process, through the humanization of the hospital environment, assisting them in their emotional preparation so that before the process of death and dying of the child execute care actions in an ethical and professional manner. During this literature review nurse's feelings associated with the death of neonate has been identified. Currently most hospitals in the reviewed studies are implementing morality meetings where the death can be discussed and staff can be able to share their grief.

Moreover, most studies suggest that a framework be developed to help understand the process and to guide appropriate interventions for ongoing support. Coping with patient death is stressful and to continue working in their profession, nurses need to use effective strategies to deal with regular occupational exposure and experience of death. Nurse educators, researchers and employers have a central and critical role to play on curtailing the impact of neonatal death exposure and professional nurse's quality of life. It is necessary that the intensive care unit worker finds a space where he/she can talk about their emotions, so that the interactions that take place in this environment are less conflicting (Diel *et al.*, 2013:1082).

## **2.7 EXPATRIATE NURSES AND ACULTURATION**

Van Rooyen, Telford-Smith and Strümpher (2010:3), performed a qualitative study on the reflections and experiences of South African nurses working in Saudi Arabia. In the report they identified that cultural diversity was found to be the common thread that ran through the themes. They defined culture as the customary beliefs, values and ideas held by a group of people. This is corroborated by van Tonder, (2012:179) who asserts that health should be viewed within the specific community's socio-political, cultural, religious and interactive framework, and never in isolation. Diel *et al.* (2013:1086) asserts that difficulties emerge as a result of the socio-cultural context in which the professional is inserted, their daily experiences inside and outside of the hospital scope and in their religion. Since nurses employed in the Middle East are multicultural, their own belief systems are sometimes in conflict with their host country since their own religious practices around health and death may differ.

### **2.7.1 Death of a child in Islam**

Taheri (2008:2) defines death in Islam as the departure of the soul from the body in order to enter the afterlife. The Muslim confession of faith are the first words whispered into the ear of a newborn baby (van Tonder, 2012b:187) and are the last words that a dying Muslim will utter

before death. Any family member can perform the ceremonies, prayers and scripture readings at this time.

Children in Islam are considered a gift from God and are highly respected individuals with inherent rights (Hedayat, 2006:1283). A central tenant of Islam is the virtue of patience which includes bearing tribulations with fortitude in good times and bad, even when his/her child dies. A child is granted automatic entrance into heaven for having died in a state of innocence. A great solace to the grieving parent or family is the caveat: "This is God's will." Withholding and withdrawing care is considered euthanasia and is forbidden (Hedayat, 2006:1288) as suffering is considered a part of life and forbearance of hardship is rewarded in Islam.

### **2.7.2 Cultural diversity and competency**

Culturally competent care is acknowledged by Shaw (2014:85) as engendered uncertainty and a degree of disempowerment among professionals, in this case nurses, to not cause offence when responding to the needs of patients and relatives whose ethnicities or religious beliefs differ from their own.

For expatriate nurses working Saudi Arabia, a period of cultural adjustment takes place (van Rooyen *et al.*, 2010:5) including adjusting to working with colleagues from different countries and cultures including working with Saudi patients. Most patients have a family member or a "sitter" with them and communication with them is essential (van Rooyen *et al.*, 2010:6). Obeying the cultural norms of non-verbal communication such as eye contact, touch, space and distance is unwelcome.

Morally, it has to be accepted that the code of conduct taught to Western nurses is inappropriate to interpersonal interaction in Saudi. Decisions that are made by physicians may be in conflict with expatriate nurse's ethical practice such as the preservation of life in the face of what Westerners may consider a futile practice.

## **2.8 SUMMARY**

Chapter 2 summarized an extensive range of literature on the factors that contribute to nurses experiencing grief or not, following the death of an infant in their care. It included

### **2.8.1 Conclusion**

The literature review in this chapter reveals that neonatal nurse's grief following the death of an infant in their care is multi-faceted. The grieving process can be profound and protracted affecting the individual and their relationships with colleagues and family. Furthermore, the deaths of neonates in the Middle East, the setting for this study, are a frequent occurrence as they are born with multiple abnormalities. The risks associated with lack of emotional support

in the work setting may result in a breakdown in team cohesion and the resignation of skilled neonatal nurses from clinical nursing.

Chapter 3 discusses the research methodology adopted in this study.

## **CHAPTER 3: RESEARCH METHODOLOGY**

### **3.1 INTRODUCTION**

The preceding chapters described the background to the study and the literature review. This chapter presents a detailed description of the research methodology used in order to explore the nurse's experience following the death of a neonate in their care. The design, population and sampling strategy, interview strategy and analysis is explained. Measures used to ensure trustworthiness is described.

### **3.2 RESEARCH METHODOLOGY**

A qualitative research methodology is a systematic approach used to describe experiences and situations from the perspective of the person in the situation (Grove, Gray & Burns, 2015:67). The research plan or methodology describes the process the researcher followed to explore the research problem or to answer the research question (Brink, van der Walt & van Rensburg, 2012:199)

### **3.3 AIM OF THE STUDY**

The aim of this study was to explore and describe the nurses' experience following the death of a neonate in their care in a neonatal units in a Saudi Arabian hospital.

### **3.4 RESEARCH OBJECTIVES**

The objectives set for this study were to explore and describe:

- the nurses' experience following the death of a neonate in their care
- support provided to the staff by the employer
- the support system available from colleagues and family
- the coping strategies used by nurses
- the cultural differences that may hinder their interaction with the parents

### **3.5 STUDY SETTING**

The study setting is the location in which a study was conducted. The setting used to conduct a study in qualitative research is termed a natural, uncontrolled real-life environment (Burns & Grove, 2015:276). The location of the interviews, neutral and private was left to the participant's choice (Grove *et al.*, 2015: 276). The reason for this was to ensure the participants comfort and confidentiality. Most participants chose to be interviewed in the work environment. Three participants chose to be interviewed at their place of residence.

### **3.6 RESEARCH DESIGN**

A qualitative design with an exploratory descriptive approach was chosen as the most appropriate for the purpose of this study to explore the experiences of nurses following neonatal death.

An exploratory descriptive research design is used to describe unique issues, health problems, or situations that lack clear description or definition (Grove, Gray & Burns, 2015:140). This design provides information and insight into clinical or practice problems (Grove, Gray & Burns, 2015:77) in order to understand a situation or practice problem better for a solution to be identified (Grove, Gray & Burns, 2015:165). For this study the research design assisted the researcher to explore and describe the participants experiences following the death of a neonatal, the support provided by the employer, coping strategies used by participants as well as the cultural differences as most participants are expats.

### **3.7 CONCEPTUAL FRAMEWORK: SUNRISE MODEL OF TRANSCULTURAL NURSING CARE**

The nurse who increased the visibility and ethnography within nursing was Madeline Leininger who earned her doctoral degree in anthropology which is the study of cultures. The goal for using her Sunrise Model of Transcultural Nursing Care conceptual framework in this study was to identify aspects of culture to be considered when communicating with patients, families, colleagues and other cultures (Grove, Gray & Burns, 2015:74). This theory acknowledges the diversity and universality within nursing that continuously needs to be nurtured. Thus, it is furnished with a road map called the sunrise enabler to remedy problems brought about by these insufficiencies such as worldview (George, 2014:448). Worldview is the way people look at the universe and forms a picture of the world and their lives. This is followed by social and cultural dimensions (George, 2014:432). It involves the dynamic patterns and characteristics of the interrelated structural or organizational factors in a certain culture or society and includes the following: religious, social and legal, economic, educational, technological and cultural values. In addition, these factors may be interrelated and may influence human behaviour in a different or a transcultural environment (George, 2014:432).

### **3.8 POPULATION AND SAMPLING**

Population refers to all elements that meet certain criteria for inclusion in the study (Grove *et al.*, 2015:46). The population in this study refers to the nursing staff working in the neonatal facility in a Saudi Arabian hospital who have experienced neonatal death in their careers.

A sample is a group of a selected population for a particular study, and the members of a sample are termed subjects or participants (Grove *et al.*, 2015:46). Purposive sampling was

used for this study. Purposive sampling is where the researcher consciously selects certain participants, elements, events or incidents to include in the study (Grove *et al.*, 2015:270).

Sample size depends on the depth and credibility of information required and until data saturation is achieved (Grove *et al.*, 2013:371). Data saturation means that the researcher reaches a point in their analysis of data that sampling more data will not lead to more information related to their research question. Data saturation in this study was achieved on participant 10, the researcher continued to 15 participants with the hope of finding something. The goal of selecting the purposive sampling was for the researcher to be able to select information rich cases to obtain in-depth information for this study.

### 3.8.1 Inclusion criteria

Inclusion criteria are the characteristics that the subject or element must possess to be part of the target population (Grove *et al.*, 2015:251). The inclusion criteria for this study was all English-speaking professional nurses working in the neonatal units who had experienced neonatal death. All the participants in the research setting were female nurses as only female staff are employed in the neonatal care unit as decreed by Saudi Arabian cultural laws.

## 3.9 PILOT INTERVIEW

A pilot study or pilot interview is a smaller version of a proposed study and is used to refine the sampling and data collection processes and verifies whether relevant data can be obtained from participants with the same characteristics (Grove *et al.*, 2015:45). De Vos, Strydom, Fouche and Delport (2013:394) refer to this phase as a pilot study instead of a pilot interview. Furthermore, it assists in refining the interview guide and the nature of the probing words to ensure the interview guide thoroughly explores the phenomenon.

For this study, a pilot interview was conducted with one participant and it was included in the research data to ensure the participant's voice is heard. Furthermore, it assisted in refining the interview guide as it assisted in identifying further probes that could be used and rephrasing questions when required to assist the understanding of the participants. The nature of the probing questions and words ensured the interview guide thoroughly explored the phenomenon. The supervisor of the study read the verbatim transcripts and the field notes and, listened to the audio- recordings. Further questions were suggested to clarify what was shared by the participant as recommended by De Vos *et al.* (2013:395)

## 3.10 INSTRUMENTATION

The instrumentation used in this study refers to the researcher who collects and analyses the data by observing and interviewing participants (De Vos *et al.*, 2013: 65). In qualitative

research the researcher is involved in perceiving, reacting, interacting, reflecting, attaching meaning and recording of the data (Grove *et al.*, 2013:269). As mentioned earlier, a field worker performed the interviews since the researcher is known to the participants.

### **3.10.1 Semi-structured interview guide**

Interviews are structured or an unstructured oral communication between the researcher and subject or study participant during which information is obtained (Grove *et al.*, 2015:506). The researcher's goal was to obtain an authentic insight into the participant's experiences. The three recommended stages were to focus on the life and work history of the participant in order to acquire details of the phenomenon as experienced by the participant and finally to reflect on the experience of the participant (Grove *et al.*, 2015:83).

For this study, semi-structured interviews commenced with an open-ended question based on the study objectives and the preliminary literature review. Further questions were posed as the dialogue between the interviewer and participant continued. (Burns & Grove, 2011:85). Probes were used during the interview which are queries made by the researcher to obtain more information from the participant about the response to a particular interview question or discussion by the participant (Grove *et al.*, 2015:83). Additional literature was studied as the interviews progressed in order to probe the participant during the member-checking phase. The field worker met with the participants where they verified the transcription of the audio-recorded interview and the themes derived from the transcription. They were provided the opportunity to add more data. The use of recurring interviews allowed the researcher to explore evolving process and the relationship to develop. Reviewing of literature allowed the researcher to validate available information about the event, uncover details previously not known about the event, obtain views about the event not heard from previous research.

## **3.11 TRUSTWORTHINESS**

The soundness of qualitative research is evaluated by its rigor or trustworthiness (Goldblatt *et al.*, 2011:390). Grove *et al.* (2013:58) note that rigor in qualitative research is characterized by openness, thoroughness in data collection, analysis and having self-understanding. Self-understanding is important in the interactive process of the researcher and is shaped by personal history, biography, gender, social class, race and ethnicity.

Self-understanding allows the researcher to have insight into her own potential biases related to the phenomena of interest (Grove *et al.*, 2013:59). Reflexivity is described by Grove *et al.* (2013:707) as being aware of one's self and the interaction between self and the data during collection and analysis. This may reveal aspects such as personal feelings and experiences that could influence the study. To this end, the researcher put her own experience aside,

termed bracketing (Burns & Grove, 2011:96), in order not to influence the interpretation of the participant's experiences. De Vos *et al.* (2013:419) propose four measures to ensure trustworthiness, namely, credibility, transferability, dependability and conformability.

### **3.11.1 Credibility**

Credibility refers to the authenticity of data. Lincoln and Guba (1985: cited in De Vos *et al.*, 2013:420) outline various strategies for increasing credibility in qualitative research such as prolonged engagement and persistent observation in the field. Field notes are a written account of what the researcher, in this case the field worker hears, sees, experiences and thinks about during the interview (De Vos *et al.*, 2013:359). The field worker's notes enabled her to remember certain points and the process of the interview, and to identify and interpret what the participant's body language and gestures indicated. These notes further assisted the researcher during the analysis.

Furthermore, verification and peer debriefing which was achieved with the assistance of the fieldworker and the research supervisor of this study, ensured that the researcher's interpretation matched the participant's views. This further enhances credibility and validity of the data.

Internal validity was ensured by a detailed description of the interviewee's narrative by transcribing the audio recordings word for word. In addition, the field worker took field notes during and immediately after interviews with each participant to ensure that what the participant said or meant was accurately portrayed.

The researcher has aimed to demonstrate that the subject has been accurately identified and described. In addition, the researcher's interpretation of the participant's views should be accurately described and should correlate or not with the findings of previous studies.

### **3.11.2 Transferability**

Transferability relates to whether the process of data collection and the findings of the research can be transferred from one case or situation to another. It is confirmed that concepts and models guide data collection and analysis, which enhances transferability (De Vos *et al.*, 2013:420). The researcher should provide a detailed account of the setting and the participants including their narratives in order for the reader to evaluate whether the findings are relevant to their setting.

### **3.11.3 Dependability**

The researcher ensured that the research process was logical, well-documented and auditable. In addition, by providing a detailed explanation of the research design and a step-

by-step explanation of the research process the reliability of data is enhanced. As mentioned previously under credibility, the dependability of this study was enhanced by a clear audit trail of the process followed.

#### **3.11.4 Confirmability**

Confirmability captures the concept of objectivity. The researcher provides evidence that confirms the findings and the interpretation by auditing (Schurink *et al.*, 2013:421). This includes, as mentioned before, peer review verification of data by the study supervisor; an audit trail involving the audit of recorded materials, transcripts, question route, list of participants, and an explanation of theoretical, methodological and analytical decisions that were made (Plummer-D'Amato, 2008:125). It is further enhanced by the researcher practicing bracketing and explicitly avoiding her experiences from influencing the voices of the participants.

As already mentioned, an audit trail of the research process was kept. This was a systematic process of documentation that described what was discovered and how it was discovered. Furthermore, it provided an analysis of all decisions and actions taken during the research process (De Vos *et al.*, 2013:422).

### **3.12 DATA COLLECTION AND MANAGEMENT**

All 56 members of staff were invited to participate in the study during a unit meeting where the nature of the study was explained and their right to participate or not. Fifteen participants were willing to participate. The field worker met with the participants at a venue of the individual's choice, which mostly occurred in a private office inside the units. Three of the participants work in intermediate care unit and 12 participants work in the NICU. The interviews with 3 participants took place in their homes.

Interviews were conducted over three weeks from 13<sup>th</sup> of August-3<sup>rd</sup> September 2018 by the field worker. Each participant signed consent in agreement to the interview and the recording thereof. Using a semi-structured interview guide, the field worker conducted the interviews at a venue of the participant's choice. The interviews were conducted in English since this is the official language used in the study setting. The participants' names were not used in the transcription of the interviews but were coded numerically. After explaining the purpose of the study and obtaining consent the following open-ended question was asked: "Please tell me how you came to work as a neonatal nurse in this hospital?"

All interviews were audio-recorded and field notes were kept of the unstructured observations observed and the field worker's interpretation thereof (Polit & Beck, 2018:404). Two recording devices were used for each interview to secure data in the event of equipment or power failure.

The participant's names were not used in the transcription of their interviews and a numerical code was allocated to each participant. There was a need for successive interviews in some instances to clarify meaning and they were identified with a letter following the participant's numerical identifier, for example, 1a) or 1b).

A verification strategy, namely member-checking, was conducted by the field worker in order to attain reliability, validity and rigor of the study. The field worker met with the participants where they verified the transcription of the audio-recorded interview and the themes derived from the transcription. They were provided the opportunity to add more data. All transcripts are stored in a password protected computer file for 5 years to which only the researcher has access.

Table 3.1 below represents the participant's biographic data and interview dates

**Table 0.1: Participant biographic data and interview schedules**

<b>Participants</b>	<b>Work experience in years</b>	<b>Interview date</b>
Pilot interview	18	13 August 2018
Interview 2	9	14 August 2018
Interview 3	25	15 August 2018
Interview 4	31	15 August 2018
Interview 5	10	18 August 2018
Interview 6	9	18 August 2018
Interview 7	15	19 August 2018
Interview 8	15	27 August 2018
Interview 9	7	29 August 2018
Interview 10	17	29 August 2018
Interview 11	9	01 September 2018
Interview 12	29	02 September 2018
Interview 13	20	02 September 2018
Interview 14	7	03 September 2018
Interview 15	14	03 September 2018

### **3.14 DATA ANALYSIS**

Data analysis is a rigorous process (Grove *et al.* 2015:88) and it assists in reducing, organizing and provides meaning to the data (Grove *et al.*, 2015:45). The analysis included reflection by the researcher, which involved her bracketing her possible subjective interpretation of the phenomenon in order to avoid misinterpretation of the participant's experience.

In this study thematic data analysis was carried out according Terre Blanche, Durrheim and Kelly's (2012:322) five-step strategy for qualitative data analysis.

### **Step 1: Familiarisation and Immersion**

Data analysis in qualitative research includes becoming immersed and familiarised within the data, transcripts and field notes. As mentioned previously, the participant interviews were audio-recorded by the field worker and followed by verbatim transcription by the researcher. This entailed listening to the recordings a number of times to identify similarities or differences between participants. Familiarisation occurred over a number of days. The researcher found that her understanding of certain aspects changed as the nuances of the interviewees' description became more apparent. Furthermore, similarities and differences between the participants' experiences heightened her awareness of the majority of the interviewees' experiences. Discussion took place between the researcher and the field worker in order to clarify and ratify the researcher's interpretation of the recordings in light of the field notes.

### **Step 2: Inducing themes**

In this step the researcher organised the raw data into groups of similar themes in which the participant(s) articulated their experiences. As recommended by Terre Blanche *et al.*, (2012:323) the wording of the themes mirrored that of the participants' language they used to explain their experience. This is considered a bottom up approach as it authenticates the participants' vocal expression of their experience. Initially the themes were labelled using the language of the participants and then were grouped in light of the themes in the literature review on the topic (Terre Blanche *et al.* 2012:323).

### **Step 3: Coding**

Coding refers to the reduction of data into labelled meaningful pieces which are later grouped to develop themes (Terre Blanche *et al.* 2012:325). Coding entails identifying a word, phrase, line, or a paragraph that relates to the theme under construction (Terre Blanche *et al.*, 2012:324). Terre Blanche *et al.* (2012:326) recommend the method of cutting and pasting the relevant parts to collect them under the themes that are being developed (Terre Blanche *et al.* 2012: 325). During this process, the themes and codes merge as the process of coding takes place (Terre Blanche *et al.*, 2012: 326). In this study, the researcher printed the typed interviews and cut them into segments to arrange under the identified codes which then created the themes. Some of the parts extracted from the transcripts were relevant to more than one theme and duplicates were pasted under the relevant themes.

### **Step 4: Elaboration**

This step involved a closer scrutiny of the themes developed so far to identify the essence of the meaning as shared by the participant. In addition, further verification of the aspects that

were initially undetected following which the coding was reviewed (Terre Blanche *et al.* 2012: 326).

### **Step 5: Interpretation and checking**

The interpretation of the experiences of the participants was then documented in this step according to the themes identified during the previous steps (Terre Blanche *et al.* 2012:326).

Member-checking was performed with each participant by the field worker to ratify that what the researcher deduced from the transcripts is what the participant meant. A verification strategy, namely member-checking, was conducted by the field worker in order to attain reliability, validity and rigor of the study. The field worker met with the participants where they verified the transcription of the audio-recorded interview and the themes derived from the transcription.

### **3.15 SUMMARY**

After receiving ethical approval an exploratory descriptive study exploring the neonatal nurse's experiences following the death of a neonate was conducted. Interviews were conducted and audio recorded by a field worker in a setting chosen by the participant after obtaining informed consent. The interviews were transcribed word for word by the researcher in conjunction with the observations recorded in the field notes. The data was analysed using thematic analysis of Terre Blanche *et al.* (2012:320).

### **3.16 CONCLUSION**

Chapter 3 described the methodology that was applied to this study.

Chapter 4 describes the findings of this study.

## CHAPTER 4: FINDINGS

### 4.1 INTRODUCTION

Chapter three described the methodology used in this study which explains the meticulous process of attaining trustworthy findings. Themes that emerged from the interviews are presented in this chapter.

### 4.2 SECTION A: BIOGRAPHICAL DATA

The following biographical data represents the participants of the study interviewed in a Saudi Arabian neonatal unit regarding their experiences with neonatal death. All participants are professional registered nurses in their country of origin and are registered to practice in Saudi Arabia with the Saudi Arabian Nursing Council.

As described in the previous chapter, the study was introduced by the researcher in a unit meeting and explained in detail. Fifteen participants who were willing to take part in the study contacted the researcher. Thirteen participants are NICU experienced and 2 participants are NICU trained. Their neonatal work experience ranged from 7-31 years.

At the first meeting with the participant, the field worker once again explained the aim of the study and ensured anonymity and confidentiality. Each participant read and signed the consent form and was informed that they were under no obligation to share information if they felt uncomfortable in any way.

### 4.3 SECTION B: THEMES EMERGING FROM THE INTERVIEWS

The following table illustrates the themes and subthemes that emerged from the interviews.

**Table 4.1: Themes and Sub-Themes**

Themes	Sub-themes
1 Psychological effect of patient loss	Emotional distress and reaction Emotional grief Anxiety
2 Management / hospital involvement	Support not available for the staff Need for bereavement debriefing sessions
3 Coping strategies	Colleagues or family support
4 Cultural Differences	Informing the mother Length of stay in the unit and cultural burial practices Comforting the parents Communication challenges Language barrier

By addressing the objective of the study, to explore the nurses experience following the death of a neonate in their care, five themes emerged and are identified below:

### **4.3.1 Theme 1: Psychological effect of patient loss**

#### **4.3.1.1 Emotional distress and reaction**

Emotional labour of nurses is under-recognised. Emotional labour of nurses is said to be hidden behind the calm, capable abilities of the nurse and is a tacit part of the neonatal intensive care unit culture (Roberta, 2014:617). Participant 5 expressed that she had to be calm so she could be able to emotionally support the mother. Badolamenti, Sili, Caruso and FidaFida (2017:48) supports this by stating that nurses have to manage their expressions of their emotions as well as their behaviour in order to provide the best care as expected from a professional nurse.

Nurses go through several emotions associated with the death of a neonate including guilt that they could have done more. Participant 14 expressed sadness and she explained that she could have done more. This was also experienced by Participant 3: “Feeling of guilt as you think you didn’t do everything well...”

#### **4.3.1.2 Emotional Grief**

Banu *et al.* (2013:e59) states that care of a sick individual with fatal and irredeemable disease remains a sensitive and emotional-laden for those who provide nursing care in these departments. Grieving was identified during the collection of data, as 4 of the participants mentioned crying during the death of a neonate. Grieving a loss is a devastating universal human experience that affects our emotional, physical and spiritual wellbeing (Duteau, 2017:18).

Many nurses grieve when patients die; however, nurses’ grief is not often acknowledged or discussed (Kain, 2012:80) and that neonatal nurse’s grief is seldom recognized, leaving them with a sense of despair and bewilderment. The following participant illustrated that “I felt like my colleagues were blaming me for the death of the neonate, I was anxious, stressed and I cried ... I have trauma in taking care of cardiac patients...” (Participant 14).

According to Kain (2012:80) neonatal nurses experience feelings such as anguish, sadness because they could not change the outcome as they question themselves “why this family, or this infant”. Guilt, stress and also a sense of accomplishment was experienced in the participants as they understood they did their best for the newborn and the family. As found in this study, participant 9 expressed that she felt sadness when losing a neonate, but knowing that she did her best was a positive factor for her.

A participant articulated that “I felt thankful that I could be part of the baby’s life, and knowing I did everything humanly possible for the baby...” (Participant 11). The care of critically ill infants is a challenge, irrespective of the results whether they grow towards health and are discharged home or fade in their capacity and die (Thompsons, 2009:3).

#### **4.1.3.2 Anxiety**

The participants identified that colleagues and managers express feelings of anxiety after the death of a neonatal. Anxiety may be associated with the thought that the nurse has failed in her role as protector. Muliira and Muliira (2016:53) posit that the death of a patient is not easy for nurses, because it stimulates feelings of anxiety and discomfort.

Ruminating about the event or events was identified when the participants relayed their experience. A participant expressed that “I still have a picture of what happened...” (Participant 1). Another participant (13) stated “I can still remember milestones the neonate was at as though the death occurred recently.” The researcher concluded that loss is something that does not go away, but rather, human beings learn to live with loss in new ways. The death of a neonate has been explained as being a long- lasting, painful and stressful bereavement encounter for nurses (Kain, 2012:80).

Increased and prolonged exposure to neonatal death can expose staff to compassion fatigue. The loss of the neonate where the loss is not acknowledged by the nurse was identified by the researcher in the clinical setting. In this study participant 9 stated that “I was not affected by the death of the neonate but, what affected me with the death was seeing the parents...” The loss is seen as part of the nurse’s role to care for the dying and move on with their professional work without recognising that the death has impacted them (Wilson & Kirshbaun 2011: 559).

The study by Montserrat, Gual, Joaquin, Doleres and Royo (2014:1) supports that the nurses continuous contact with emotional suffering of others can increase their risk of developing compassion fatigue.

Disenfranchised grief refers to the grief a person experiences that is not admitted, socially validated or publicly mourned, and there is no social recognition that the individual has a right to grieve or need for social support and sympathy (Kain, 2012:83). With the long-term care of neonates, the researcher identified that, the participant had disenfranchised grief as the participant talked about performing the last offices and sending the body to the morgue. Participant 11: “I was shocked I stood alone with the baby and had my own feelings to work through....” This expresses the pain she felt of being alone to perform the last offices of death.

This she explained this as very depressing and it was a shocking culture for her as a new staff member. Grieving a loss is universal human experience that affects our emotions (Duteau, 2010:18).

Participant 5 expressed that she does not experience any strong feelings when a neonate dies in her care: "I don't have any feelings for the death of neonate, and I'm not affected with the baby's death because I was expecting it, but what affected me was the mother when she was crying and verbally saying "why Lord why me ... she was rolling over the floor ..." This could be interpreted as shutting out of feelings or "psychic numbness". According to Staff (2017:1) psychic numbing, also referred to as compassion fatigue, is a product of past traumatic stress disorder and anyone can be susceptible to it. The study conducted in Australia by Kain (2012:83) identified the reluctance of participants to acknowledge their feelings when a neonate dies as grief. However, the symptoms of grief such as anger, denial, bargaining, depression and acceptance can be prevalent.

Gerow, Conejo, Alonzo, Davis, Rodgers and Domain (2010:122) explain that health care workers put up a shutter of defence toward diminishing grieving while continuing to deliver compassionate nursing care. Participant 9 "I tried doing everything to keep the baby alive..." This statement was identified by the researcher as the retreating to practical tasks in order to cope with the situation. The study done by Curcio (2017:8-14) explained how the participants of the study diverted to physical care of the neonate after knowing that the neonate was dying. Zheng, Lee and Bloomer (2017:e42) identified in this study that nurses use avoidance or distancing as a coping strategy.

Another participant expressed that "the baby was big, though the baby was cardiac but was on room air, I didn't expect the baby to die (Participant 14)". These findings provide evidence that even if death is common in the neonatal unit it is still not accepted and expected. Diel *et al.* (2013:1082) states that it is an expectation that all infants are healthy and alive regardless of occasional deaths that occur in the NICU.

Participant 10 expressed that "I didn't want the baby to die under my care ... I didn't know how to prolong the baby's life." Pye (2016:4) notes that providing the end of life care for the critically ill neonate and their families is within the complicated care continuum. The continuum of care covers the delivery of health care over time, and may refer to care provided from birth to end of life. Anticipatory grief is explained by Eldridge (2018:1) as the grief that commonly commences before death. Shore, Koch and Gelber *et al.*, (2016:16) describe anticipatory grief as a range of intensified emotional responses that may include separation anxiety, existential aloneness, denial, sadness, disappointment, anger, resentment, guilt, exhaustion, and

desperation. The authors further state that anticipatory grief can manifest as a wide spectrum of physical, emotional, cognitive, and spiritual signs and symptoms.

Emotional distress was identified during the interviews as participant 1 and 14 mentioned being called by the manager and asked what happened it made them feel as if they had been blamed for the neonatal death. Emotional distress is described by Karakachian and Colbert (2018:14) as common in nursing it arises when the individual faces grief. The research done by Cleveland Clinic (2012:1) states that emotionally distressed individuals may become more short-tempered or violent, restless or display excessive activity.

The difference in nurse's country of origin, age and years of experience in the nursing profession in the sample who participated in this study could not be seen to have a great impact as most of the nurses that participated in this research grieved for the neonate's loss in one way or the other.

#### **4.3.2 Theme 2: Management / hospital involvement**

##### **4.3.2.1 Bereavement debriefing sessions**

This subtheme describes the availability of support for the staff in the institution.

Caring for patients with life threatening conditions can have a profound effect on health care professionals (Keene *et al.*, 2010:1). Without being able to manage one's response to the death of a patient, health professionals may experience physical, emotional, cognitive, behaviour or spiritual distress which could have implications for their professional practice. Opportunity for professionals to process personal response to death is important yet lacking in institutions.

The above is supported by Cook *et al.* (2012:e20) who identified the importance of supportive colleagues and resources available for nursing staff while caring for sick and dying neonates. Puia *et al.* (2013:331) emphasizes that perinatal death can have a long-term effect on nurses and support is needed in helping them deal with the consequences of such a trauma.

According to Ives-Baine *et al.* (2013:303) to improve the health of nurses it is recommended that nurse should be afforded a sense of security, appreciation and control in the mist of emotional disorder. In this study participant 1 expressed the expectations she had from the management, and that a sense of security and appreciation would be helpful. The participants expressed lack of management support and some of participants felt intimidated or as if they had caused the death of the neonate since they were called to the manager's office to explain "what happened." In contrast, participants 2 expressed finding support when the manager

asked her how she was feeling and patted her shoulder. One participant mentioned in-service education offered by a psychiatric nurse to be useful. The topic was on how to cope with work related stress. This topic was provided by the psychiatric department as they have identified the increase in numbers of staff who came to their unit to seek advice on coping with patient death.

Most participants identified their colleagues as their support system in coping with losing a neonate. Some participants identified the questions asked by some colleagues as depressing for example the question “what happened?” Participant 4 explained that this question made her feel as if she didn’t perform her duties well when she was called to the manager’s office and asked what happened to the baby which made her feel unsupported as if her level of care was inadequate.

In the research setting it appears that no formal debriefing is offered after the death of neonate, although the psychiatric department provides in service education for all units in the hospital. These focus on how to identify stress at a work place and how to deal with depression. The institution does not have an Occupational Health and Safety department. Diel *et al.* (2013:2) highlight that in hospitals the death or dying process is still little debated and questioned among nursing professionals, and those are the individuals who perhaps are more exposed and affected by it in their daily work.

Kain (2012:85) suggests that opportunities for briefing sessions after difficult cases is important, and training to empower nurses with effective grief management skills and coping mechanisms are underutilized. This was identified when all participants in this study pointed out that there are no briefing sessions after the death of a neonate.

Family support was identified as playing a major role during this experience for the nurse. “I get support from my husband as he is in the same medical field ... he understands how it feels like to lose a patient.” (Participant 2). Domrose (2011:3) explains that spouses and family try to offer support but they cannot fully understand what a nurse goes through. For participant 2 the fact that her husband is a doctor helps her in express her feelings to someone who understands. The researcher concluded that, nurses find strength to cope with the experience primarily from three sources: faith, relationship with fellow health care providers, and their own families.

The participant from the pilot interview expressed the lack of support and that “the only support I got was from my roommate ...” (Participant 1). Cook *et al.*, (2012:e19) state that having their own network to support each other is essential for nurses. The authors further explain that

nurses find networking with other people more helpful in coping with the experience of caring for the dying.

### 4.3.3 Theme 3: Coping Strategies

The researcher wanted to understand the coping strategies used by nurses, the resources accessed and to identify any helpful methods in coping with neonatal death to foster a supportive work environment. The spiritual and ritual aspects emerged as subthemes, as all participants mentioned that their spirituality supported them in coping with the death of the neonate and each participant had their own ritual of coping. Cook *et al.* (2012:e18) identified religion as a factor that sometimes influenced the nurse's ability to cope.

Most of the participants were Christians and they prayed for comfort from the loss of a neonate in their care. Houck (2014:4) addressed the importance of spiritual self-care for nurses, by focusing on self-awareness and promoting meditation to promote spiritual health for nurses after losing a patient. Participant 4 and 1 expressed that they prayed a lot as their coping mechanism.

Kain's study (2012:83) concluded that the length of stay of the patient in the unit did not alter the emotional involvement of the nurses. Participant 4 stated that she received the neonate that was admitted in the morning, but she was still emotionally affected by the neonate's death.

Participants shared that they develop defensive coping mechanisms to shield themselves from emotional demands arising from the situation. Participant 8 displayed shifts of emotions by focusing on the parent's feelings. Participant 11 shifted the emotional demand by ensuring that the neonate died in comfort. One participant expressed that "I cope by going shopping and travelling to relieve stress..." (Participant 3).

Many medical personnel associate the provision of palliative care as the physical end of life care interventions that focus on comfort with the goal of peaceful death (Pye, 2016:14).

"Talking to colleagues when the topic arise about the death helps..." (Participant 11). This was found in the studies by Cook *et al.* (2012:e17) and Domrose (2011:3) who emphasised the importance of talking to co-workers as a helpful coping strategy with patient death.

The researcher identified that some nurses cope by keeping memories of the neonate. For example, participant 15 expressed that she remembers the smile the neonate had. Cook *et al.* (2012:e17) defines memories as moments one holds onto and reflects on while recalling previous experiences after the death of the patient.

Whenever religious or spiritual explanations are of no comfort, professionals tend to attribute meaning to the death of a patient by focusing on the seriousness of a disease that medicine is, as yet, unable to effectively cure (Pye, 2016:18). Participant 9 expressed that the infant was young and was comforted by the reassurance that the neonate in a better place. Cook *et al.* (2012:e12) stated that the age of the patient, experience level of the nurse, role models, peer support, length of time caring for the patient, family involvement and religion are important elements in coping with loss.

Thompsons (2009:3) identified that taking care of a sick neonate is a challenge. The participants in this study expressed that it is a challenge to nurse a very sick baby, do everything they can do to save its life but, due to previous experience they anticipate a poor outcome. “Participant 5 “the baby was really sick but before the baby died our doctor wanted the mother to cuddle the baby, the death was expected because of the condition.” Participant 9 expressed that “the baby was term and no history of abnormalities; the baby was very sick and died in less than 24 hours of delivery....” Participant 7 “the baby was critically ill and we coded several times before the death and after 3 hours the baby died.”

#### **4.3.4 Theme 4 Cultural Differences**

This theme was based on exploring the different cultures of the participants as the unit has nursing staff from outside of Saudi Arabia. The theme for this category was the religion and spirituality of the participants and whether working with neonates and their parents from a different culture to their own was difficult. Lovering (2008:14) describes culture as a pattern of behaviour or the possessions and symbols of a particular group, including their ideas, beliefs and values.

##### **4.3.4.1 Informing the mother**

It was identified during the interviews that most of the time the mother is not informed of the neonate’s condition, as the father frequently instructs the staff that the mother should not be informed as he will break the news to her. In Saudi Arabia, the father is the first person to be informed of the neonate’s condition (Shaw, 2014:85). In addition, the father requested that the mother should not be allowed to see the neonate when critically ill.

This practice made it difficult for nurses as they wondered how the mother coped with the news of death. Participant 11: “The father is the one informed of the death and I always wonder and wish to know how the mother coped with the news.” However, in a study by Sameer *et al.* (2011:1) in Saudi Arabia, the preferences of mothers with being present for the breaking of bad news concerning a newborn was researched. The research discovered that 64% of mothers preferred be given news together with the father.

#### **4.3.4.2 Length of stay in the unit and cultural burial practices**

If the neonate was in the unit for a short time the nurses were not afforded the opportunity for closure and to pay their last respects. Participant 7 expressed that in India, after all the official paperwork is completed, the parents take the baby home to perform their rituals. However, in Saudi Arabia the neonate is taken home for burial immediately after death and this practice is corroborated by Shaw (2014:89) who explains that immediate burial is decreed by the Qur'an. Shaw wrote that the participants in her study explained that between death and burial, the body and soul is deemed especially vulnerable and any bodily trauma is considered far more painful at this time than in life (Shaw, 2014:89).

Kaneez (2015:21) reveals that a number of religious spiritual practices are done to assist emotional processing and it strengthens a sense of identity including relationships through specific devotions, behaviours and memorial rituals to deal with death. This comforts the griever as it affirms that they belong to the wider community. In Saudi Arabia the participants in this study witnessed the parents praying for the baby. Cultural differences are explained in chapter 2 where the researcher discusses cultural diversity.

Participant 12 expressed that although she is also a Muslim from the Philippines the rituals performed there are different to Saudi Arabia. According to Abundo (2015:5) death in the Philippines is a family strengthening occasion, where even people who live abroad come to pay their respects. As mentioned, the custom in Saudi is to bury immediately. Grieving and loss might trigger doubt in an individual's faith or it may strengthen their religious belief by affording a new understanding of the significance of life (Jonas-Simpson, MacDonald, Pilkington & McMahan, 2013:1). The participants in this study expressed their strength in prayer and this relayed their understanding of life.

#### **4.3.4.3 Comforting the parents**

Saudi Arabia's law does not allow a woman to touch a man unless they are married or are siblings. Only verbal comfort can be given to the father within the cultural restrictions or limited eye contact and interpersonal space. Participant 5 mentioned that she did not experience any cultural difficulties because the mother was present with the father of the neonate. She comforted the mother in a way she would have done in her country of origin by hugging the mother and speaking to her. She relied on the male doctor to comfort the father.

#### **4.3.5 Communication challenges**

Sharon (2018:1) states that in a multicultural workplace, obstacles to communication are to be expected, and may cause misinterpretations. The author further explains that besides the difference in language there are challenges that affect people who are trying to work

harmoniously together. Individuals from dissimilar countries have a different word view and may exhibit their feelings differently. Participant 1: “The manager calls you and ask what happened.” Participant 14 shared that “the way my colleagues looked at me [was] as if they were blaming me for the death of the baby.”

#### **4.3.5.1 Language barrier**

The language barrier was identified as problematic by ten participants. For example: one participant (14) felt excluded as she could not understand what the doctor explained to the parents. Another participant (1) expressed that the language barrier was a problem but fortunately for her the mother could understand some English.

### **4.4 SUMMARY**

In exploring the experiences of nurses with neonatal deaths in an intensive care facility, the findings show that in the majority of the participant’s interview in this study experienced deep emotional distress. However, whenever religious or spiritual explanations are of no comfort, some participants tend to attribute meaning to the death of a patient by focusing on the seriousness of a disease that medicine is, as yet, unable to effectively cure. Lack of support system from the management/ hospital was identified as distressing for nurses. Support from colleagues was a key finding and one participant suggested that a support group for nurses would be helpful. The participants’ strategies for coping with the nature of this particular job-related stress, are praying, talking with colleagues, shopping and travelling was identified as effective during these interviews.

### **4.5 CONCLUSION**

In this chapter the results of the analysis of data obtained from the interviews were presented and discussed. The research question was answered regarding the experiences of nurses of neonatal death in the research setting.

The aim and the objectives for the study were met to explore and describe

In Chapter 5, the findings will be concluded according to the objectives of the study. Limitations of the study will be presented. Based on the findings from this study, recommendations will be suggested.

## **CHAPTER 5:**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

The previous chapters contain a description of the rationale for this study and an in-depth literature review regarding experiences of neonatal care nurses with neonatal death. A description was also provided of the research methodology and data analysis for the purpose of this study.

The participants noted the mile stones the neonate was going through, there was a special bond shared. The researcher has witness this during the interview where participants talked of the long-term neonates. This grief is identified in the interview as most of the participants explained that they are mothers and they put themselves in the parent's shoes during the death of neonate. The loss of a neonate for some nurses is recognized as professional failure. The participants relayed that feeling as the was a mention of "I thought I could have done more to save the child".

The aim of this study was to explore and describe the experiences of nurses who during their careers had experienced the death of a neonate in their care. Caring for dying neonates and supporting their parents or family members is central to neonatal nursing. The death of a neonate is a life changing and tragic experience for the individuals involved in the final moments of the infant's life.

This chapter contains a discussion of the findings of the study, conclusions drawn from the analysis and recommendations based on the findings. Future research suggestions are proposed.

#### **5.2 DEMOGRAPHIC AND PROFESSIONAL PROFILE**

The majority of the participants were experienced expatriate nurses in neonatal nursing with a few who were specialist-qualified in neonatal nursing in their home countries. Despite their years of experience, the majority of them found the death of a neonate in their care upsetting. The difference in the nurse's country of origin, age and years of experience in the nursing profession could not be seen to have a great impact as all the nurses that participated in this research grieved for the loss of a neonate in one way or the other.

### **5.2.1 Objective 1: To explore the nurses' experience following the death of a neonate in their care**

As in the study done by Kain (2012:80), it was revealed that nurses in a neonatal intensive care do experience grief associated with neonatal loss and that the grief is seldom recognized leaving nurses with the sense of despair and bewilderment. Feelings such as anguish, sadness, guilt and stress are profound. Kain (2012:80) and Muliira and Muliira (2016:53) assert that the death of a patient elicits feelings of anxiety and discomfort and is a long-lasting, painful and stressful bereavement experience. In this study the memories of the events were long lasting as one participant could clearly remember the incident including the milestones the neonate was at as though the death occurred recently.

One participant expressed a sense of accomplishment as noted by Almeida *et al.*, (2016:122) that when her patient died she acknowledged that she had done her best while another expressed sadness at the mother's outpouring of grief and by imagining herself in the mother's shoes. Furthermore, guilt was expressed that the death might have been their fault and they reflected on what they might have done better to keep the neonate alive. A participant thought the neonate might have died due to her lack of experience, especially when related to particular health-related conditions.

Stress associated with lack of support from the management, was identified as 10 of participants expressed that there is no supportive system in place for the nurses. Further stress was verbalised by the participants that they perceived that their colleagues blamed the participants for the death of the neonate.

As corroborated by Thompson (2009:3) the participants in this study articulated that it is a challenge to nurse a very sick baby, do everything they can do to save its life but, due to previous experience they anticipated a poor outcome.

### **5.2.2 Objective 2: To explore support provided to the staff by the employer**

Support of staff that has experienced this phenomenon is essential in order to facilitate recovery and to continue to provide supportive nursing care. Ives-Baine *et al.* (2013:303) identify the importance of staff support by the management of the institution as the most important aspect in ensuring staff health. With this study the lack of resources available for the support of staff were identified. Staff felt intimidated when they were called to the manager's office to explain what had happened.

There are no debriefing sessions in this study setting for nurses to identify problems immediately after the death of a neonate. Participants expressed that there is in-service

education provided by a psychiatric nurse, but this seems to be inadequate to help staff cope with grief. Other staff felt they could not express their emotions in front of other staff members.

The researcher concludes that, there is still lack of discussion in the hospital environment with regard to nurses and their grieving for their patients as identified by Diel *et al.* (2013:np). Support from colleagues who can provide authentic, compassionate, education and mentorship, is highly recommended.

### **5.2.3 Objective 3: To explore the support system available from colleagues and family.**

Diel *et al.* (2013:2) highlight that in hospitals the death or dying process is still little debated and questioned among nursing professionals, and those are the individuals who perhaps are more exposed and affected by it in their daily work. Most participants identified a support system in their colleagues, flatmate and family. Some of the participants did not involve the family as they thought not sharing would protect the family from distress.

Since most nurses are expatriates and most family members live in their home countries, their flatmates provided the support. One participant expressed support from her husband. According to Ives-Baine *et al.* (2013:303) to improve the health of nurses it is recommended that nurse should be afforded a sense of security, appreciation and control in the mist of emotional disorder.

### **5.2.4 Objective 4: To explore the coping strategies used by nurses**

The researcher concludes that despite the cultural differences between them and the neonate's family, the coping strategies with the loss of a neonate are similar. Some nurses expressed that by praying for themselves, the deceased neonate and the family that has lost a neonate brought them comfort.

Rituals performed in different countries were expressed and since Saudi Arabia is a Muslim country the burial customs differ to Christian practices where a priest is summoned, before or after, a patient dies (van Rooyen *et al.*, 2010:3). The participants in this study articulated that staff in the research setting performed their spiritual rituals in private as only Islamic rituals can be performed in a public setting. This is in alignment with the findings of van Rooyen *et al.* (2010:3).

### **5.2.5 Objective 5: To explore the cultural differences that may hinder their interaction with the parents**

The language and cultural differences pose a major problem when the nurse feels she should comfort the parents. The law does not allow physical contact between the opposite sex thus

mostly the fathers are comforted by the male physician in attendance (Van Rooyen *et al.*, 2010:3). The restrictions in culture makes it difficult for the nurse to comfort the father.

The father is commonly the person who breaks the news of the death to the mother. This formality made it difficult for nurses since they were not able to comfort the mother personally. They reported wondering how the mother coped with the news.

### **5.3 RECOMMENDATIONS**

Based on the research study results, the researcher suggests the following strategies to assist neonatal nurses with the process of life and death in the clinical setting:

#### **5.3.1 Debriefing support**

The researcher recommends that the institution implement a system of non-judgemental debriefing sessions after the loss of a neonate. Puia *et al.* (2013:331) emphasizes that perinatal death can have a long-term effect on nurses and support is needed in helping them deal with the consequences of such a trauma. Since the nurse's experience distress which may affect their interaction with their colleagues, team-building events between peers are suggested to facilitate the discussion of their experiences and feelings in a supportive manner. Cook *et al.* (2012:e20) emphasizes the importance of supportive colleagues and resources available for nursing staff while caring for sick and dying neonates. This may assist with the adjustment of those involved in the event and the cause of death can be discussed with a view to care improvements in the future.

Involvement of management in supporting staff with grief over patient loss is essential. Hospital and nurse administrators could consider different ways of facilitating palliative care in their acute settings. For example, peer group support, bereavement teams and a supportive work environment.

### **5.4 LIMITATIONS OF THE STUDY**

The limitations of the study relate to the small sample in one research setting, although literature is not consensual on the optimal or minimal number of participants needed in an exploratory descriptive study to improve the trustworthiness of the findings. Using one research setting one research setting further limits its transferability. Despite this limitation, the findings will resonate with readers in other contexts.

### **5.5 RESEARCHER'S REFLECTION**

Although I had received training on interviewing skills, I felt underprepared for interviewing the pilot study participant on such a personal and sensitive topic. It also took significant effort to bracket my own experiences when listening to the recordings and when reading the

transcripts, because I empathised with the anguish the participants expressed. Despite this I am confident that I have described the participant's experiences truthfully and with respect.

## **5.6 SUMMARY**

In this chapter the findings from the interviews were discussed according to the objectives of the study. The aim of the study was to explore and describe the experiences of nurses involved in a death of a neonate in their care in a Saudi Arabian neonatal care unit. It can be concluded that nurses do experience strong emotions when they lose a neonate in their care. Staff that participated in the study expressed receiving support from other colleagues, family and an in-service psychiatric nurse educator. Most importantly, the need for management support was identified.

## **5.7 FUTURE RESEARCH**

Based on the research study results, the researcher suggests the following research opportunities:

- A study exploring the continuous need for education for nurses with regards to coping with loss.
- Focus group interviews might facilitate a deeper and more diverse discussion of experiences, resulting in a form of healing.
- Another future research recommendation could explore the meaning of the experience of end-of-life care in the labour and delivery units.

## **5.8 DISSEMINATION**

The researcher will present her findings at the nurse's day conference that will be held in 2019 in the hospital where the research was conducted. A publication in a peer reviewed journal will be developed.

## References

- Abundo, C. 2015. Filipino customs and traditions. *Pilipinas kong mahal*.  
[www.vigattintourism.com](http://www.vigattintourism.com). Date viewed 01 October 2018.
- Albdellatif, M., Ahmed, M. & Bataclan, M.F. 2013. The patterns and causes of neonatal mortality at a tertiary hospital in Oman. *Oman Medical Journal*, 28(6): 422-426.
- Adwan, J. Z. 2014. Pediatric nurse's grief experience, burnout and job satisfaction. *Journal of pediatric nursing*. United States of America. Date viewed: 08 November 2018.
- Alves de Campos, C.A.C., Bairros da Silva, L., Bernardes, J de S., Soares, A.L.C. & Ferreira, S.M.S. 2017. Challenges of communication in neonatal Intensive care unit for professionals and users. *RIO DE JANEIRO*, 41, N. ESPECIAL:165-171.  
[www.scielo.br/pdf/sdeb/v41nspe2/en\\_0103-1104-sdeb-41-spe2-0165.pdf](http://www.scielo.br/pdf/sdeb/v41nspe2/en_0103-1104-sdeb-41-spe2-0165.pdf). Date viewed:: 20 November 2018.
- Almeida, F.A., de Amorim, M.S. & Cunha, M.LR. 2016. Taking care of the newborn dying and their families: Nurses' experiences of neonatal intensive care. *Journal of School of Nursing Revista da Escola de Enfermagem da USP*. 50: 122-129.  
<http://dx.doi.org/10.1590/S0080-623420160000300018>.
- Al-Nemri, A.M. & Al-Fifi, S.H. 2011. Cause-Specific Neonatal Mortality at the Armed Forces Hospital, Southern Region Khamis Mushayt, Kingdom of Saudi Arabia. *The Medical Journal of Cairo University*, 79(1): 119-123.
- Bacon, C. 2017. Nurses experiences with patients who die from failure to rescue after surgery. *Journal of nursing scholarship* 49(1):1-9. Greensbro School of Nursing. Greensboro: North Carolina. Date viewed: 7 April 2017.
- Badolamenti, S., Sili, A., Caruso, R. & FidaFida, R. 2017. What do we know about emotional labour in nursing? A narrative review. *British journal of nursing* 26 (1). Date viewed: 10 November 2018.
- Banu, C. & Sultan, K. 2013. Attitudes and experiences of nurses toward death and caring for dying patients in Turkey. *Wolters Kluwer health*. Accessed 26 March 2018.
- Bloomer, M.J., O'Connor, M., Copnell, B. & Endacott, R. 2015. Nursing care for the families of the dying child/infant in paediatric and neonatal ICU: Nurses' emotional talk and

- sources of discomfort. A mixed method study. *Elsevier Australian Critical Care*. Available: [www.elsevier.com/locate/aucc](http://www.elsevier.com/locate/aucc). Accessed 28 December 2017.
- Brink, H. 2006. *Fundamentals of research methodology for health care professionals*. 2<sup>nd</sup> Ed. Cape Town: Juta and Company.
- Brink, H., Van Der Walt C. & Van Rensburg, G. 2012. *Fundamentals of research methodology for health care professionals*. 2<sup>nd</sup> Ed. Cape Town: Juta and Company.
- Burns, N. & Grove, S.K. 2011. *Understanding nursing research. Building an evidence-based practice*. 5<sup>th</sup> Ed. United States of America: Elsevier Saunders.
- Carlos, J. 2010. *Avoiding traps in member checking*. <http://nsuworks.nova.edu/tqr>. Date viewed: 16 August 2018.
- Chan, Z.C.Y., Fung, Y.L. & Chien, W.T. 2013. *Bracketing in Phenomenology: Only undertaken in the Data collection and analysis process*. (18). <https://scholar.google.com>. Date viewed 04 January 2018.
- Cleveland Clinic. 2012. *Warning signs of emotional stress*. <https://my.clevelandclinic.org>. Date viewed 14 November 2018.
- Cook, K.A., Lawrence, P., Grady, M.R., Liner, K.M., Hickey, P. & Connor, J.A. 2012. Coping while caring for the dying child: nurses experiences in an acute care setting 27: e11-e21. *Elsevier Journal of Pediatric Nursing*. Accessed 16 December 2017.
- Curcio, D.L. 2017. The Lived Experiences of Nurses Caring for Dying Pediatric Patients. *Pediatric Nursing*.43(1): 8-14.
- Diel, P.,Gomes, G., Xavier, D., Salvador,M. & Olivera,S. 2013. Nurses experiences before the death at the neonatal intensive care unit. *Journal of Nursing UFPE*. (Online). Universidade Federal do Rio Grande. Brazil. Date viewed: 5 April 2017.
- De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L. 2013. *Research at grass roots. For the social sciences and human service professions*. Pretoria: Van Schaik Publishers.
- Domrose, C. 2011. *Good grief: Nurses cope with patient death*. [www.nurse.com/blog](http://www.nurse.com/blog). Date viewed: 1 October 2018.
- Duteau. J. 2010. Understanding the lived experience of loss and grieving in persons with

- end stage renal disease: a human becoming approach. *Canadian Association of Nephrology Nurses and Technologists*.20(2). (online).  
<https://www.ncbi.nlm.nih.gov/pubmed>. Date viewed: 14 November 2018.
- Gatrad, A.R. 1994. Muslim customs surrounding death, bereavement, postmortem examinations, and organ transplants. [www.bmj.com](http://www.bmj.com). Date viewed: 01 October 2018.
- George, J. 2014. *Nursing theories: the base for professional nursing practice*. 6<sup>th</sup> Ed. England: Pearson Education Ltd.
- Gerow, L., Conejo, P., Alonzo, A., Davis, N., Rodgers, S. & Domain, E.W. 2010. Creating a curtain of protection: Nurse's experiences of grief following patient death. *Sigma*pubs.onlinelibrary.wiley.com. Date viewed: 30 September 2018.
- Goldblatt, H., Karnieli-Miller, O. & Neumann, M. 2011. Sharing qualitative research findings with participants: Study experiences of methodological and ethical dilemmas. *Patient education and counselling* 82:389- 395. [online] available  
:<http://ac.elscdn.com.ez.sun.ac.za/S0738399110007883/1-s2.0-S0738399110007883>-.  
Date viewed: 07 November 2018.
- Greeff, M. 2013. Chapter 12: Information collection, interviewing. In: De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L. *Research at grass roots. For the social sciences and human service professions*. Pretoria: Van Schaik Publishers.
- Grove, S.K., Gray, J.R. & Burns, N. 2015. *Understanding nursing research: building an evidence-based practice*. 6<sup>th</sup> Ed. St. Louis: Elsevier.
- Grove, S.K., Burns, N. & Gray, J.R. 2013. *The practice of nursing research. Appraisal, synthesis and generation of evidence*. St. Louis: Elsevier.
- Jonas-Simpson, C., Pilkington, F.B., MacDonald, C. & McMahon, E. 2013. Nurse's Experiences of Grieving when there is a Perinatal Death. *SAGE Open*. Date viewed: 9 November 2019.
- Hedayat, K.M. 2006. When the Spirit Leaves: Childhood Death, Grieving, and Bereavement in Islam. *Journal of Palliative Medicine*, 9(6): 1282-1291.
- Houck, D. 2014. Helping nurses cope with grief and compassion fatigue: An educational intervention. *Clinical Journal of Oncology Nursing*, 18(4). Date viewed: 7 April 2017.
- Hutti, M.H., Polivka, B., White, S., Hill, J., Clark, P., Cooke, C., Clemens, S. & Abell, H.

2016. Experiences of Nurses Who Care for Women After Fetal Loss. *Journal of Obstetric Gynecologic & Neonatal Nursing*. (online). Available at: <https://www.ncbi.nlm.nih.gov/pubmed/26815795>. Accessed:
- Hutti, M.H., Armstrong, D.S. & Myers, J. 2013. *Evaluation of the perinatal grief intensity scale in the subsequent pregnancy after perinatal loss*. [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov). Date viewed: 6 February 2018.
- International Council for Nurses. 2012. *The ICN code of ethics for nurses*. Geneva, Switzerland. [www.icn.ch](http://www.icn.ch). Date viewed: 10 October 2018.
- Ives-Baine, L., Lindsay, G., Van der Wel., Barker, C., Sain, J. & Cross, N. 2013. Essential engagement: NICU nurse's relationships within end of life care. *Illness, Crisis & Loss*, 21(4). [www.researchgate.net](http://www.researchgate.net). Baywood publishing company. Toronto. Canada. <http://baywood.com>. Date viewed: 09 April 2017.
- Kain, V.J. 2012. An exploration of the grief experiences of neonatal nurses: A focus group study. *Elsevier Journal of Neonatal Nursing*. Queensland. Australia. [www.elsevier.com/jneo](http://www.elsevier.com/jneo). Date viewed: 10 April 2017.
- Kaneez, S. 2015. Grief, Traumatic loss and coping following bereavement: Case study of women. *International Journal of Indian Psychology*. [www.oaji.net](http://www.oaji.net). Date viewed: 21 November 2018.
- Karakachian, A. & Colbert, A. 2017. *Moral distress: A case study*. [www.nursingcentre.com](http://www.nursingcentre.com). Date viewed: 14 November 2018.
- Keen, E., Hutton, N., Hall, B. & Rushton, C. 2010. Bereavement debriefing sessions: An intervention to support health care professionals in managing their grief after the death of a patient. *Pediatric nursing.net*. Date viewed: 29 September 2018.
- Lewis, S.L. 2017. Exploring NICU nurses' affective responses to end of life care. *National association of neonatal nurses*. 12(2). <https://www.ncbi.nlm.nih.gov>. Date viewed: 18 December 2017.
- Lincoln, Y. S. & Guba, E. G. 1985. *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lovering, S. 2008. *Arab Muslim Nurses' Experiences of the meaning of caring*. <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.458.8332&rep=rep1&type=pdf>. Date viewed: 18 October 2018.

- LoBiondo, W. & Haber, J. 2014. *Nursing Research: Methods and Critical Appraisal for Evidence-Based Practice*. St Louis:Elsevier.
- Meller, N., Parker, D., Hatcher, D. & Sheehan, A. 2017. Grief experiences of nurses after the death of an adult patient in an acute hospital setting: An integrative review of literature. *Collegian: The Australian Journal of Nursing Practice, Scholarship & Research*. (Online). Available at: [www.elsevier.com/locate/coll](http://www.elsevier.com/locate/coll). Date viewed: 07 November 2018.
- Montserrat, E.G., Dolores, B.P., Joaquin, T.S. & Royo, C.M. 2014. The impact of death and dying on nursing students: an explanatory model. *Journal of clinical nursing*, (23). (Online). <https://www.ncbi.nlm.nih.gov>. Date viewed: 12 November 2018.
- Muliira, J.K. & Muliira, R.S. 2016. A review of the effect of occupational experience of death and death situations on nurses. *Manipal Journal of Nursing and Health Sciences*. 2(1). Date viewed: 20 April 2017.
- Mumbrue, T.L. 2010. *The lived experience of nurses who encounter the unexpected death of a patient*. [www.https://pdfs.semantic scholar.org](http://pdfs.semantic scholar.org). University of Wisconsin Oshkosh. Oshkosh. (Online). Date viewed: 20 April 2017.
- National institute of mental health. 2016. *Depression*. <https://www.nimh.nih.gov>. (online). Date viewed: 30 May 2017.
- Nieuwenhuis, J. 2011. Introducing qualitative research. In: *First steps in research*. Maree. K. (Ed). Creswell, J.W., Ebersöhn, L., Eloff, I., Ferreira, R., Enankova, N.V., Jansen, J.D., Nieuwenhuis, J., Pietersen, J., Plano Clark, V.L. & Vander Westhuizen, C. Pretoria. Van Schaik.
- O'Reilly, M. & Parker, N. 2012. Unsatisfactory saturation: a critical exploration of the notion of saturated sample sizes in qualitative research. *Sage Journals*. Date viewed: 12 June 2018.
- Papadatou, D. 2000. *A proposed model on health professionals grieving process*. [www.psycnet.apa.org](http://www.psycnet.apa.org). Date viewed: 09 January 2018.
- Pilkington, F. B. 2006. Developing nursing knowledge on grieving: A human becoming perspective. *Nursing Science Quarterly*, 19, 299-303. [www.journals.sagepub.com](http://www.journals.sagepub.com). Date viewed: 30 October 2018.
- Petty, R.E. & Krosnick, J.A. 2014. *Attitude strength: Antecedents and consequences*. New

York, NY: Psychology Press.

Polit, D.F. & Beck, C. T. 2018. *Canadian essentials of nursing research*. 4thEd. Wolters Kluwer. Canada.

Plummer-D'Amato, P. 2008. Focus group methodology. Part 2. Considerations for analysis. *International Journal of Therapy and Rehabilitation*,15:123-129. Date viewed: 09 November 2018.

Plummer-D'Amato P (2008) Focus group methodology Part 2: Considerations for analysis. *Int J Therapy and Rehab* 15(3): 123-9

Phillips LJ, Jorgensen MW (2002) Discourse Anal Plummer-D'Amato P (2008) Focus group methodology Part 2: Considerations for analysis. *Int J Therapy and Rehab* 15(3): 123-9

Phillips LJ, Jorgensen MW (2002) Discourse Anal Plummer-D'Amato P (2008) Focus group methodology Part 2: Considerations for analysis. *Int J Therapy and Rehab* 15(3): 123-9

Puia, D.M., Lewis., & Beck, C.T. 2013. Experiences of obstetric nurses who are present for a perinatal loss. *Journal of obstetric, gynecologic & neonatal nursing*, 42:321-331. <http://jognn.awhonn.org>. Date viewed: 18 April 2017.

Pye, S.E. 2016. Making a difference: Evidence based palliative care education for neonatal nurses. *ScholarWorks*. Walden University. <http://scholarworks.Waldenu.edu/dissertation>. Date viewed: 19 April 2018.

Rapley, T.J. 2001. The art (fulness) of open- ended interviewing: some considerations on analysing interviews. *Qualitative research* 1 (3):303-323. [online]. Available online: <http://www.qrjagepub.com.ez.sun.ac.za/content/1/3/303.full.pdf>. Date viewed: 7 November 2018.

Roberta, C.L. 2014. *The need to nurse the nurse: emotional labor in neonatal intensive care*. [www.sagejournal](http://www.sagejournal.com). Date viewed: 09 November 2018.

Sameer, Y.A. 2011. Saudi mothers' preference about breaking news concerning newborns: a structured verbal questionnaire. *BMC medical ethics*. [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov). Date viewed: 17 July 2018.

Sharon, P. 2018. *Cultural communication barriers in the workplace*.

- [www.smallbusiness.chron.com](http://www.smallbusiness.chron.com). Date viewed: 20 November 2018.
- Shaw, A. 2014. Rituals of Infant Death: Defining Life and Islamic Personhood. *Bioethics*. (28)2: 84-95. Online: <https://onlinelibrary.wiley.com/doi/full/10.1111/bioe.12047>.
- Schimelpfening, N. 2018. *Grief vs. depression*. [www.everywellmind.com](http://www.everywellmind.com). Date viewed: 07 November 2018.
- Schurink, W., Fouche, C. & De Vos, A. 2013. *Qualitative data analysis and interpretation*. Pretoria: Van Schaik Publishers.
- Shorey, S., Andre, B. & Lopez, V. 2017. The experiences and needs of healthcare professionals facing perinatal death: A scoping review. *Elsevier International Journal of Nursing Studies*. Available: [www.elsevier.com.ijns](http://www.elsevier.com.ijns). Date viewed: 17 December 2017.
- Shore, J., Koch, L., Gelber, M. & Sower, E. 2016. Anticipatory grief an evidence-based approach. *Journal of Hospice and Palliative nursing*. [www.jhpn.com](http://www.jhpn.com). Date viewed: 05 September 2018.
- Simpson, C.J., MacDonald, C., Pilkington, B. & McMahon, E. 2013. Nurses experiences of grieving when there is perinatal death. *Sage* 3(2). Date viewed: 13 November 2018.
- Smith, K. 2018. *Grief and anxiety*. [www.psycom.net/anxiety-complicated-grief/](http://www.psycom.net/anxiety-complicated-grief/). Date viewed: 06 November 2018.
- Staff, G. 2017. *Psychic numbing might explain our desensitization to negative news*. [www.gaia.com](http://www.gaia.com). Date viewed: 07 November 2018.
- Streubert Speziale, H.J. & Carpenter, D.R. 2003. Qualitative research in nursing. *Advancing the Humanistic imperative*. 3rd Ed. Philadelphia: Lippincott, Williams and Wilkins.
- Taheri, N. 2008. *Health care in Islamic history and experience*. [www.ethnomed.org](http://www.ethnomed.org). Date viewed 01 October 2018.
- Terre Blanche, M., Durrheim, K., Kelly, K. 2012, Chapter 14. First steps in qualitative data analysis. In: Terre Blanche, M., Durrheim, K & Painter, D. 2012. *Research in Practice. Applied methods for the social sciences*. Cape Town. University Cape Town Press.
- Thompson, N. 2009. *Loss, grief and trauma in the workplace*. New York: Baywood publishers.

- Tranter, S., Josland, E. & Turner, K. 2016. Nurses bereavement needs and attitudes towards patient death: A qualitative descriptive study of nurses in a dialysis unit. St George Hospital. *Journal of Renal Care*. Sydney. Australia. Date viewed: 19 April 2017.
- United Nations. 2015. *Sustainable development knowledge platform*. New York. United States of America. <http://sustainabledevelopment.un.org>. Date viewed: 27 May 2017.
- Van Rooyen, D., Telford- Smith, C. & Strümpher, J. 2010. *Nursing in Saudi Arabia: Reflections on the experiences of South African nurses*. [www.researchgate.net](http://www.researchgate.net). Date viewed: 28 November 2018.
- Van Tonder, S. 2012. Religious and cultural forces in transcultural nursing. *Ethics in Healthcare*. 3rd Ed. Cape Town: Juta: 178-209.
- Wehrenberg, M. 2016. Rumination: problem in anxiety and depression. *Psychology today*. [www.margaretwehrenberg.com](http://www.margaretwehrenberg.com). Accessed 29 August 2018.
- Wilson, J. & Kirshbaum, M. 2011. Effects of patient death on nursing staff: A literature review. *British Journal of Nursing*. <https://doi.org/10.12968/bjon.2011.20.9.559>. Date viewed: 21 November 2018.
- World Health Organisation. 2016. *Newborns: Reducing mortality*. <http://www.who.int/medicentre/factsheets/fs333/en/>. Date viewed: 19 April 2017.
- Zhang, W., & Lane, B. 2013. Promoting neonatal staff nurses' comfort and involvement in end of life and bereavement care. *Nursing research and practice*, article ID 365329. [www.hindawi.com](http://www.hindawi.com). Date viewed: 08 November 2018.
- Zheng, R., Lee, S.F. & Bloomer, M.J. 2017. *How nurses cope with patient death: A systematic review and qualitative meta- synthesis*. [www.journalofclinicalnursing.com](http://www.journalofclinicalnursing.com). Australia. Date viewed: 09 November 2019.

## Appendices

### Appendix 1: Ethical approval letter from Stellenbosch University



UNIVERSITEIT  
STELLENBOSCH  
UNIVERSITY

15/08/2018

**Health Research Ethics Committee (HREC)**

**Approval Notice New Application**

**Project ID :7037 HREC Reference # N18/04/049 Title: The experience of professional nurses involved with neonatal deaths in neonatal units in a Saudi Arabian hospital**

Dear Miss Prisca Dlamini The **New Application** received on 04/06/2018 12:26 was reviewed by members of **Health Research Ethics**

**Committee** via **expedited** review procedures on 15/08/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **This project has approval for 12 months from the date of this letter.**

Please remember to use your project **ID (7037)** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

### **After Ethical Review**

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: [Links Application Form Direct Link](#) and the application should be submitted to the HREC before the year has expired. Please see *Forms and Instructions* on our HREC website ([www.sun.ac.za/healthresearchethics](http://www.sun.ac.za/healthresearchethics)) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

### **Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research. For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC

website <https://applyethics.sun.ac.za/ProjectView/Index/7037> If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

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Yours sincerely, Mr. Franklin Weber HREC Coordinator

*National Health Research Ethics Council (NHREC) Registration Number:*

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## Appendix 2: Ethical approval letter from Institution

**Date:** 2nd August, 2018  
**TO:** Whom it may concern  
**From:** Rasheed Kurawley

Ref: RK – Ref – PD – EA -18

**Subject: Prisca Dlamini : BN 27461 : Approval to conduct study**

This is to confirm that the above named nurse currently employed at the King Abdulaziz hospital presented her proposal to the Nursing Research Committee on the 26<sup>th</sup> July, 2018.

Her proposal to conduct her personal study for her Master's degree program on the following subject: "To explore and describe the professional nurse's experience following the death of a neonate in their care in a neonatal facility in a Saudi Arabia hospital "was discussed and approved.

Having discussed this proposal with Higher Nurse Management, ethical approval was granted to Prisca Dlamini to conduct her study.

Please do not hesitate to contact me directly at any time in respect of this approval.

Kind regards.

*Rasheed Kurawley*

RASHEED KURAWLEY



**Appendix 3: Participant information leaflet and declaration of consent by participant  
and investigator**

**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT:**

**The experience of nurses involved with neonatal deaths in an intensive/  
intermediate care facility in Saudi Arabia.**

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:**

**Prisca Sithembile Dlamini**

**ADDRESS:**

**P.O Box [REDACTED]**

**[REDACTED]**

**[REDACTED]**

**[REDACTED]**

**CONTACT NUMBER:**

**+966530567434**

**prisca.dlamini@gmail.com**

You are invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully

understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The study will be conducted in your hospital
- The study will be conducted in intensive care unit and intermediate care unit.
- The aim of this study is to explore, describe and understand the nurse's experience following the death of a neonate.
- This will increase the awareness of what health care workers go through when there is a neonatal death.
- The interview will be conducted for about 30 - 45 minutes. The setting will be your choice.
- The interview will be electronically recorded and will be kept confidential. Anonymity will be ensured. Your name will not be mentioned.
- No risks are identified for this study. In the event of emotional sensitivity/ stress you can be referred to a support structure in the hospital if you choose.
- The information from the interviews may be verified by the facilitator. Your names will not be included.

. Why have you been invited to participate?

- You have been invited because you can share your experience with the death of neonate.

What will your responsibilities be?

- To participate in interviews and to share your experiences following the death of a neonate.

Will you benefit from taking part in this research?

- The benefits of this study will increase awareness of what health care workers go through after the loss of the neonate.
- This information will help the new graduates to be more prepared during this period.
- This study can be of assistance to management in formulating support structures for professionals dealing with neonatal death.

Are there in risks involved in your taking part in this research?

- There are no risks involved in taking part in this study.

If you do not agree to take part, what alternatives do you have?

- If you choose not to participate in this study you have a right to do so.

Who will have access to your medical records?

- All information given to me will be confidential and stored in a safe place. Your name will not be mentioned in the research. The facilitator, who assists in the study, will see the information but is obliged to maintain confidentiality.

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

- There are no injuries identified in this study. If you feel too emotional to continue with interviews, you can be referred to a counsellor if you choose.

### **Will you be paid to take part in this study and are there any costs involved?**

No, you will not be paid to take part in the study.

### **Is there anything else that you should know or do?**

- You can contact the Health Research Ethics Committee of the University of Stellenbosch in South Africa at +27 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

### **Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled **“The experience of nurses involved with neonatal deaths in an intensive/ intermediate care facility in Saudi Arabia”**.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2018.

.....  
**Signature of participant**

.....  
**Signature of witness**

**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) .....on (*date*) .....2018.

.....  
**Signature of investigator**

.....  
**Signature of witness**

#### **Appendix 4: Interview guide**

Interview Guide: Proposed questioning route based on research objectives

Introductory questions: -

- Please tell me how you came to work as a neonatal nurse in this hospital?
- Probe: country where trained
- Probe: years of work experience

Key questions: -

- You have experienced the death of a neonate in your care. Please describe to me the events that led to the death?  
Probes: involvement with the bereaved parents/doctors/cultural differences
- Did you discuss the event with your colleagues or family?
- Probes: how did they support you?
- Did you receive assistance after the event from the organisation/hospital/human resource personal?
- What was the most helpful to you in your recovery after the event?

Ending questions: -

- What would you say were the positive and negative factors in your experience?
- What would you recommend to other nurses who experience this?

Closure: Is there anything that we haven't discussed that you feel is important?

## Appendix 5: Declaration by technical formatter and language editor



To whom it may concern

This letter serves as confirmation that I, Lize Vorster, performed the technical formatting of Prisca Sithembile Dlamini's thesis entitled:

**Experiences of nurses involved with neonatal deaths in specialised units in a Saudi Arabian Hospital**

Technical formatting entails complying with the Stellenbosch University's technical requirements for theses and dissertations, as presented in the Calendar Part 1 – General or where relevant, the requirements of the department.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Lize Vorster', is written over a simple line drawing of a pen nib.

Lize Vorster  
Language Practitioner

## West Coast Copy Editing and Formatting Services



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2 December 2018

**Ms PS Dlamini**  
**Student number: 16108655**  
**prisca.dlamini@gmail.com**

The above-named student's thesis titled: "*Experiences of nurses involved with neonatal deaths in specialised units in a Saudi Arabian Hospital*" was edited for grammar, spelling, syntax and referencing according to Harvard.

The revisions were recommended for the author's attention and integration in the final document. Formatting errors may have occurred during internet file transfers from the editor to the author. The author was responsible for checking for such manifestations and making the necessary adjustments.



**T. Pfeffer.**