Maternal hope experiences in a South African Neonatal Intensive Care Unit

Charné Buissinne

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Maternal hope experiences in a South African Neonatal Intensive Care Unit

by

Charné Buissinne

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SUPERVISOR
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- And then to our Heavenly Father for putting me on this journey and being my main source of hope throughout everything that I do.

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Declaration of Originality

I, Charné Buissinne (student number 10420747), declare that the dissertation, which I hereby submit for the degree Magister Educationis in Educational Psychology at the University of Pretoria, is my own work and has not previously been submitted by me for a degree at this or any other tertiary institution.

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Charné Buissinne

August 2018

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Ethical Clearance Certificate

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Faculty of Education

RESEARCH ETHICS COMMITTEE

CLEARANCE CERTIFICATE	CLEARANCE NUMBER: **EP 17/02/01**
DEGREE AND PROJECT	M.Ed Maternal hope-experiences in a South African Neonatal Intensive Care Unit
INVESTIGATOR	Ms Charne Buissinne
DEPARTMENT	Educational Psychology
APPROVAL TO COMMENCE STUDY	17 May 2017
DATE OF CLEARANCE CERTIFICATE	24 August 2018

CHAIRPERSON OF ETHICS COMMITTEE: Prof Liesel Ebersöhn

CC

Ms Bronwynne Swarts
Dr Alfred du Plessis

This Ethics Clearance Certificate should be read in conjunction with the Integrated Declaration Form (D08) which specifies details regarding:

- Compliance with approved research protocol,
- No significant changes,
- Informed consent/assent,
- Adverse experience or undue risk,
- Registered title, and
- Data storage requirements.

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Ethics Statement

The author, whose name appears on the title page of this dissertation, has obtained, for the research described in this work, the applicable research ethics approval. The author declares that she has observed the ethical standards required in terms of the University of Pretoria's *Code of ethics for researchers and the Policy guidelines for responsible research*.

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Charné Buissinne
August 2018

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Abstract

Maternal hope experiences in a South African Neonatal Intensive Care Unit

by

Charné Buissinne

Supervisor: Dr Alfred Haupt du Plessis
Degree: M. Ed. (Educational Psychology)

South Africa ranks 24th out of 184 countries with regard to its premature birth rate. According to data published by the Howson, Kinney, and Lawn (2012), eight out of every hundred babies born in South Africa are born prematurely. Giving birth prematurely can be a traumatic event (Evans & Madsen, 2005). Mothers who have premature infants in NICUs face multiple challenges and lose hope during the long period of hospitalisation (Charchuk & Simpson, 2005; Green, 2015). This study was undertaken to examine the experiences of a NICU mother and the ways in which her experiences could be related to hope. The study is theoretically framed within the field of positive psychology and hope theory, as adapted by Plaas (2007).

The participant described her personal understanding of hope and how, during her period of hospitalisation, she had experienced hope by drawing from both internal and external resources. This qualitative study was conducted from within an interpretivist paradigm and an exploratory case study research design was used. The specific case was bounded by the experiences of a mother who had given birth to a premature baby with a low birth weight (less than 1,500 g) in a South African government hospital's NICU and was housed in the mother lodger facility for the duration of the infant's NICU stay. Purposive sampling was used and data was collected during an individual in-depth interview, which included observational notes and keeping a reflective researcher's journal. A verbatim transcript of the interview was analysed by means of an inductive thematic analysis.

Primary research question: What are the hope experiences of a NICU mother at a government hospital in South Africa?

Key words

- Hope
- Hope experiences
- Neonatal Intensive Care Unit (NICU)
- NICU mother
- NICU infant

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Declaration – Language Editor

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TO WHOM IT MAY CONCERN

Herewith I, FJ OPPER, confirm that I undertook the language editing of Mrs Charne Buissinne's dissertation titled:

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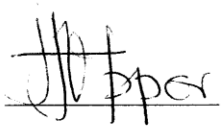

28 August 2018

Table of Contents

---oOo---

Page

Chapter 2
Literature Review

---oOo---

Page

Chapter 3
Research Design and Methodology

---oOo---

Chapter 4
Results of the Study

---oOo---

Chapter 5
Conclusion and Recommendations

---oOo---

List of Tables

Page

---oOo---

List of Figures

Page

---oOo---

List of Photographs

Page

---ooOoo---

Chapter 1
Introduction, Rationale and Overview

1.1 INTRODUCTION AND RATIONALE

Premature birth is the leading cause of death among children under the age of five years, and eight per cent of South African babies are born prematurely (Howson et al., 2012). South Africa ranks 24th out of 184 countries for its premature birth rate (Howson et al., 2012). In 2016 alone, 6,722 early neonate deaths were reported in South Africa (Statistics South Africa, 2018).

Although, based on economic standards, South Africa is seen as a middle-income country, its health system is more dysfunctional than those of many lower-income countries (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). Factors that contribute to this situation include gender, racial and socio-economic inequalities, dissolving family structures, high crime rates, failure in management and post-apartheid policies that were not effectively implemented (Coovadia et al., 2009).

Since preterm labour combines both biological and environmental risk factors, the presence of *a premature infant in the Neonatal Intensive Care Unit (NICU) is seen as a psychological crisis* (Carvalho, Linhares, Padovani, & Martinez, 2009; Evans & Madsen, 2005; Yaman & Altay, 2015). *Infants who are born prematurely often need specialised care in a* NICU. Evans and Madsen (2005) found that the hospitalisation of an infant is one of the most traumatic events that a mother can endure. Prolonged hospitalisation may cause additional challenges for the mother and could lead to feelings of isolation, depression, anxiety and a loss of control (Abad, Fearday, & Safdar, 2010).

The NICU environment is associated with both physical and emotional exhaustion, with mothers often feeling overwhelmed (Boucher, Brazal, Graham-Certosini, Carnaghan-Sherrard, & Feeley, 2011; Brethauer & Carey, 2010). *Both the infant's condition and the environment can elevate psychological distress* (Obeidat, Bond, & Callister, 2009). Mothers often experience high levels of anxiety, fear, guilt, depression and hopelessness within a NICU setting (Ardal, Sulman, & Fuller-Thompson, 2011; Wigert, Johansson, Berg, & Hellström, 2006). *Dealing with the aftermath of giving birth to a premature infant can be frightening* and may have a long-lasting effect on the wellbeing of both the mother and the child (Latva, Korja,

Salmelin, Lehtonen, & Tamminen, 2008; Yaman & Altay, 2015). Research has shown that, even years after discharge, parents remember this period as being one of the most devastating times of their life (Yaman & Altay, 2015).

Hope as a cognitive motivational system (Snyder, Harris, et al., 1991) may enhance the optimal functioning of NICU mothers and increase their overall wellbeing. High-hope individuals view crisis times as challenges that can be overcome through cognitive engagement to find alternative ways to reach their goals (Snyder, 1994; Valle, Huebner, & Suldo, 2006). Hope has been highlighted for its beneficial effects in terms of coping with medical challenges such as recovery from injury (Elliott, Witty, Herrick, & Hoffman, 1991), cancer (Hasson-Ohayon, Braun, Galinsky, & Baider, 2009), stress-related health problems (Fredrickson, 2002) and caring for a chronically ill child (Horton & Wallander, 2001).

According to Valle et al. (2006), hope can reduce the adverse effects of trauma. It has also been linked to happiness, perseverance, achievement and improved health (Fredrickson, 2000). Arnau, Rosen, Finch, Rhudy, and Fortunato (2007) maintain that hope is directly related to physical and psychological adjustment, which can be helpful to mothers during their transition into motherhood and caring for their premature infants. Hope is therefore likely to promote recovery by enabling people to experience positive emotions even when they are faced with challenges (Alim et al., 2008).

Mothers whose premature infants have been admitted to a NICU face multiple challenges and may lose hope during the long period of hospitalisation (Charchuk & Simpson, 2005). A gap that was found to exist in current relevant literature is that although the experiences of mothers have been reported (A. Bennett & Sheridan, 2005; Brethauer & Carey, 2010; Carvalho et al., 2009; Feeley et al., 2011; Shaw et al., 2006), most studies focused on mothers' perceptions of having a preterm infant in an NICU, and not on their hope-related experiences during this time. To date very little research has been reported on the role played by hope in NICU experiences in the South African environment.

My personal interest in the hope experiences of mothers was aroused while I worked as a counsellor in a government hospital's NICU and maternity wards in 2015. During that period doctors often reported that mothers in the NICU came from poor social circumstances. Some were rape victims, had had failed abortions, or were underage. The hospital had limited mental health resources in the form of counselling and

psychological intervention services. I observed that although the mothers were faced by many challenges, some did express an ability to sustain or even increase their hope during difficult times.

While several studies have been undertaken to determine stressors and their effect on the psychological wellbeing of mothers (Obeidat et al., 2009), the challenges faced by mothers in NICUs are rarely addressed in an asset-based manner. Mothers are often described as feeling powerless, depressed and anxious (Carvalho et al., 2009; Lefkowitz, Baxt, & Evans, 2010; Wigert et al., 2006). By exploring maternal hope, one NICU mother was able to describe her NICU experience by focussing not only on the challenges, but also on her own capabilities.

1.2 PURPOSE OF THE STUDY

The purpose of this research was to explore the hope experiences of a mother who had given birth to a preterm infant. The study was based on Plaas' (2007) Model of Hope in the NICU. This study was intended to describe the experiences of the mother of a premature infant during her time of hospitalisation in the NICU as it related to the hope theory. This mother described her personal understanding of hope and how she had experienced hope in the NICU environment during the time of hospitalisation. I aimed to investigate both the internal and external resources that provided hope to this participant. Challenges to hope experiences in the NICU were also identified. Currently very little data is available on sources of hope in a South African NICU, and whether hope provides psychological benefits in this context. This study therefore aimed at contributing to the multidimensional view of hope in the context of NCIUs in South African government hospitals.

1.3 RESEARCH QUESTIONS

1.3.1 CENTRAL RESEARCH QUESTION

What were the hope experiences of the NICU mother at a government hospital in South Africa?

1.3.2. SECONDARY RESEARCH QUESTIONS

- What is a NICU mother's personal understanding of hope?
- What were the resources of hope that a mother drew on in the NICU?
- What challenges to hope did a mother face in the NICU?

1.4 POTENTIAL VALUE OF THE STUDY

The findings of this research study may hold both theoretical and practical implications for medical staff, psychologists, social workers and counsellors who work in the medical environment. The research findings may be of value to institutions that aim to improve patient support.

NICU mothers may also find the information useful during hospitalisation and even after discharge. The participant was given an opportunity to elaborate on the factors that either challenged or increased her experience of hope during her time in the NICU. From a therapeutic perspective, talking about these experiences might have held benefits for the participant's wellbeing.

1.5 HOW THIS STUDY RELATES TO EDUCATIONAL PSYCHOLOGY

Educational psychologists assess, diagnose and intervene in order to optimise human functioning in learning and development (Department of Health, 2011, No. R. 704). Development and learning are rooted in the physiological, emotional and cognitive functioning of people and are life-long processes that are equally important in all life stages (Louw & Louw, 2009). Learning and development may therefore occur in a variety of environments, including medical care facilities. It is important to note that educational psychology is not limited to the school context (Eloff & Ebersöhn, 2004).

When hope is viewed as being integral to the process of psychological development in a crisis (Penrod & Morse, 1997), it makes sense to engage in research aimed at understanding how hope is experienced by the mothers of babies in a neonatal intensive care unit. This should enhance educational psychologists' understanding and their ability to develop psychoeducational programmes. Such programmes may be implemented as part of preventative (primary level) health care (Westmaas, Gil-Rivas, & Silver, 2007) to facilitate the improved emotional wellbeing of these mothers. In fact, it makes sense for educational psychologists to continue to contribute to this field of health care, capitalising on their expertise pertaining to learning and development.

1.6 WORKING ASSUMPTIONS

This study was based on the following underlying assumptions:

- Mothers with premature infants in NICUs face multiple challenges that influence their hopefulness (Borim Nejad, Mehrnosh, Seyyed Fatemi, & Haghghani, 2011).
- Premature births and NICU experiences have a long-lasting effect on the wellbeing of mothers and their infants (Latva et al., 2008; Wigert et al., 2006; Yaman & Altay, 2015).
- Hope is an important factor in coping with adverse medical events and life challenges (Valle et al., 2006).
- People are goal directed and have the capacity to experience a sense of hope (Snyder, Michael, & Cheavens, 1999).
- Utilising external and internal resources can lead to hope experiences in the NICU (Bernardo, 2010).
- Hope is interpersonal and developmental in nature (Scioli, Ricci, Nyugen, & Scioli, 2011)

1.7 CONCEPT CLARIFICATION

1.7.1 HOPE

Various definitions of hope exist and until recently the definition provided by Snyder, Harris, et al. (1991) was perhaps one of the most widely accepted in research. Larsen, Edey, and Lemay (2007) mentions that defining hope may be simplified into a unidimensional or a multidimensional understanding of hope. Although for the purpose of this study hope was not predefined as I was interested in the participant's unique understanding of hope, I did consider the underlying perspective of hope manifesting within various dimensions (multidimensional). Hope was further understood within the framework of a futuristic positive psychological construct.

1.7.2 MATERNAL HOPE EXPERIENCES

Maternal hope as a phenomenon is significant to the mother's health and quality of life, and her ability to gain inner strength and build self-confidence to make sense of situations in which change is in fact possible (Holtslander & Duggleby, 2009; Parse, 1999; Smith, 2007). Weingarten (2010) refers to hope as something that is done, and not given to a person, hope is reasonable in expectation which is relevant especially in the context of the NICU where uncertainty raises.

Plaas (2007) categorises hope experiences in the NICU according to three themes: 1) hope and the infant; 2) hope and others; and 3) hope and the mother. It was from this perspective that hope experiences were viewed during the current study.

1.7.3 NICU

The Neonatal Intensive Care Unit is a hospital unit containing a variety of sophisticated mechanical devices and special equipment for the management and care of premature and seriously ill infants. The unit is staffed by a team of nurses and neonatologists who are highly trained in the pathophysiology of the newborn (Stedman, 2012).

1.7.4 THE NICU MOTHER

The mother who participated in this study was a woman who had given birth to a premature infant in a South African government hospital during 2015. An infant that is born before 37 weeks of gestation and that had a very low birth weight below 1 500g (Fraser and Cooper, 2003).

1.7.5. THE NICU INFANT

An NICU infant is an infant born before 37 weeks' gestation with a birth weight below 1,500 g (Fraser & Cooper, 2003).

1.8 INTRODUCTION TO LITERATURE REVIEW

In this study a mother's hope-related NICU experiences were explored. It was therefore important to also examine different definitions of, and theories about hope, the purpose of hope, obstacles to hope and resources of hope in previous evidence-based research. The NICU context was also an important aspect for consideration within the South African context.

The literature review, which will be discussed in Chapter 2, therefore starts with a discussion on the history of hope, the theory of hope, extensions and variations on the theory of hope and South African research on hope. The possible effects of having an infant in the NICU on the psychological wellbeing of the mother and common challenges experienced in the NICU are also considered. Both international and South African studies on NICUs were reviewed. Research on hope and the NICU was linked to a discussion of research on hope in the NICU and the potential

value of hope in the NICU. The chapter concludes with a discussion of the theoretical framework for the study, based on Plaas' (2007) Model of Hope in the NICU.

1.9. UNDERLYING PARADIGM AND RESEARCH APPROACH

The methodological paradigm for the study was qualitative in nature in that I attempted to understand the mother's multiple realities within a unique time period and a specific place. Qualitative research is used to explore or understand the meaning of human experience as it describes social behaviour and thinking (Creswell, 2009; Yin, 2016). This enabled me to describe the phenomenon of maternal hope in the NICU as perceived by the participant, and to provide an in-depth look at highly sensitive issues (Boxill, Chambers, & Wint, 1997).

Through qualitative research, researchers study the beliefs, actions, thoughts and perceptions of people during experiences in an attempt to address diverse challenges faced in society (Luton, 2010) and give a voice to marginalised groups (Sefotho, 2015).

A further reason for my choice of a qualitative research method is that I aimed to provide an in-depth look at the meaning that the mother attached to her experience in the unique setting of the NICU. This mother formed part of a group that shared a specific social context while being hospitalised. Most of the research questions revolved around sensitive issues, such as her personal challenges, hopes and experiences. These experiences were informed by the mother's unique beliefs, perceptions and thoughts, which were shared through her in-depth descriptions. Qualitative data-gathering techniques included in-depth interviews, observations and photos provided by the participant (K. Maree, 2007).

An interpretivist paradigm was chosen for this study as it allows the researcher to focus on the unique meanings that people attach to events throughout their lives (Ritchie, Lewis, McNaughton Nicholls, & Ormston, 2013). This paradigm, which represents reality as being multifaceted, socially constructed, interpretive and subjective (K. Maree, 2007) and views phenomena as holistically constructed and the findings as interpreted perceptions that cannot be generalised (K. Maree, 2007), enabled me to consider the complexity of contextual factors during my research inquiry (Hook, 2012).

1.10. BRIEF OVERVIEW OF THE RESEARCH DESIGN

The research design was a single exploratory case study. A single case study often focuses on a specific setting or unit that is bounded in space and time (Løkke & Dissing Sørensen, 2014). This specific case was bounded to a mother who had given birth to a premature baby with a very low birth weight (less than 1,500 g) in the NICU at a government hospital during 2015, and who stayed in the NICU mother facility while the infant was being cared for in the NICU.

Data was collected during an individual interview, while making observations and keeping a reflective researcher's journal (K. Maree, 2007). The interview was guided by an interview schedule with open-ended questions about the mother's hope experience in the NICU and how hope relates to the NICU experience. The participant was requested to answer questions on the following topics: her understanding of hope, challenges to hope in the NICU, resources of hope in the NICU and the influence of hope on her experience in the NICU. As recommended by the Health Sciences Ethical committee, the participant was purposefully selected from a list of NICU mothers whom I had counselled pro bono in 2015.

Fathers were not included in the study since in this particular government hospital only the mothers of premature infants are required to stay in the NICU facility for mothers while their infants remain in the NICU. They therefore spend the entire period in the NICU and hospital environment. During the time of hospitalisation the mothers are the primary caregivers of the child.

1.11. QUALITY ASSURANCE

The quality of the research was enhanced by a crystallisation process during which multiple sources of data were used to determine whether a pattern emerged from the data (K. Maree, 2007). During this study, I made use of recordings and transcripts of the interviews (Klenke, 2008). Member-checks were conducted by asking the participant to verify the research results (Shenton, 2004).

The participant was willing to be interviewed and was encouraged to be completely honest throughout the research process. She was reminded that there were no correct answers and that she could refuse to answer a question at any time (Shenton, 2004). I frequently consulted my supervisor to ensure that the data was appropriately collected and analysed. I kept a research journal to constantly reflect on the research process.

1.12. ETHICAL CONSIDERATIONS

The research was conducted according to the ethical guidelines of the Ethics Committee of the Faculty of Education and the Faculty of Health Sciences. I had originally planned to collect data by using a focus-group discussion in the NICU of a government hospital, but my research proposal was amended by the Faculty of Health Sciences due to the vulnerability of NICU mothers. It was determined by the ethical board of Health Sciences that I should conduct an individual interview with mothers whom I had counselled in the NICU during 2015, rather than collect data from mothers while they were in the hospital. Only one such mother could be selected based on this amendment and availability.

During the process of informed consent the participant was informed of the purpose and nature of the study and what was expected of her as the participant. She was also informed that she had the right to withdraw at any time, and was asked to consent to the recording of the interview (Visser & Moleko, 2012). Information on the potential risks of in-depth interviews, confidentiality and anonymity was provided. No incentives for participation were offered. All of the ethical aspects are discussed in detail in Chapter 3.

1.13. OVERVIEW OF STUDY

- **CHAPTER 1: INTRODUCTION, RATIONALE AND OVERVIEW**

In this chapter I provided a background to, and rationale for this study. I stated the purpose of the research and discussed the research questions, key concepts and the potential value of the study, and also provided a brief overview of this mini-dissertation.

- **CHAPTER 2: LITERATURE REVIEW**

Chapter 2 contains a review of the relevant existing research on theories about hope, hope in relation to positive psychology and research on hope conducted in South Africa. It also elaborates on the challenges faced in the context of the NICU and concludes with a discussion of the theoretical framework of the study.

- **CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY**

The research methodology applied during this study is discussed in Chapter 3. The specific research method, data-collection methods, sample selection, quality-assurance methods and ethical considerations are explained.

- **CHAPTER 4: RESULTS OF THE STUDY**

This chapter includes information on the research results relating to the themes and subthemes, as well as a recursive literature review.

- **CHAPTER 5: CONCLUSION AND RECOMMENDATIONS**

In Chapter 5, the findings relating to the research questions and the conclusion derived from the results are discussed. I also discuss the limitations and contributions of this research and provide recommendations for future research and practice.

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Chapter 2
Literature Review

2.1 INTRODUCTION

This chapter commences with a review of the scientific roots of hope, hope theory, hope in relation to positive psychology, and South African research on hope. This is followed by a discussion of literature dealing with the potential effects of having an infant in the NICU on the psychological wellbeing of the mother, which includes common challenges experienced in the South African NICU environment. The potential value of hope in the NICU is then considered, and the chapter concludes with a discussion of the theoretical framework for the study, which was based on Plaas' (2007) Model of Hope in the NICU.

Figure 2.1 provides a bird's eye view of the literature presented in this chapter.

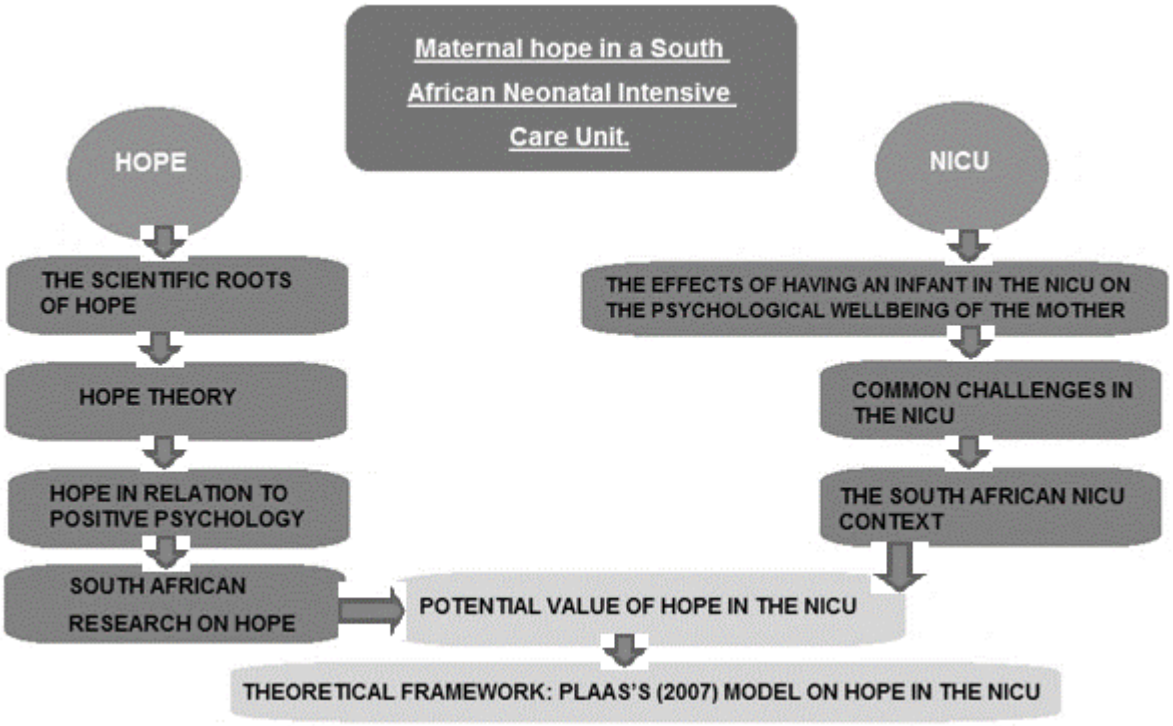

Figure 2.1: Outline of literature review

2.2 THE SCIENTIFIC ROOTS OF HOPE

The construct of hope, how it may work and how hope is defined in different fields have been debated over time. The concept of hope is certainly not new – even in

Greek mythology hope featured in the ancient tale of Pandora's box (Groopman, 2004; Snyder, Irving, et al., 1991).

Eliott (2005) states that hope is mentioned 75 times in the Old Testament and 58 times in the New Testament of the Christian Bible. According to this author, hope is seen as positive and future-directed in Christianity and is one of the three spiritual gifts or virtues, which also include love and faith. Hope also features prominently in religions such as Buddhism, Hinduism, Judaism, Islam and the belief systems of Native Americans, Africans and the Australian Aborigines (Scioli et al., 2011). This illustrates that hope is a universal construct found across religions and ethnicities.

Before the twentieth century, hope was revered more in religion than in science (Eliott, 2005). However, in the twentieth century hope was re-examined and introduced in areas such as the medical sciences and psychology (Scioli et al., 2011). Eliott (2005) points out that Marcel (1944) described hope as a personal attribute and maintained that hope is a positive response to a negative situation. He saw hope as intersubjective and not solely linked to a relationship with God. Scioli and Biller (2010) support this idea by mentioning the possibility that hope may also be present amongst atheist.

Hope is described by Mowrer (1960 as cited in Lopez, Snyder, & Pedrotti, 2003) from 'n behavioural point of view when he argues that hope leads to feelings of reinforcement, and that the positive reinforcement offered by hope leads to increased activity. Scioli et al. (2011) refer to Menninger (1959), who examined the role of hope in the field of psychiatry and believed that hope was a primary coping mechanism and a significant factor in patient recovery. Farran, Herth, and Popovich (1995) agree with this and describe hope as a prerequisite for coping with medical challenges.

Erikson (1964 as cited in Scioli et al., 2011) described hope as a developmental construct linked directly to goal- orientated thinking and maintained that hope forms during the developmental process of attachment and basic trust, and that it matures over time. This view informs a fundamental assumption of my research since hope is seen as interpersonal; therefore human interactions and the environment have a direct influence on hope. The developmental nature of hope is supported by researchers such as Farran et al. (1995), Morse and Doberneck (1995) and Scioli and Biller (2010).

From the above it is evident that even during the 1960s, hope was already a popular topic for research. In an attempt to clarify the value of hope, Stotland (1969)

examined the consequences and scientific significance of hope. He argues that hope is part of a person's mental schemas and is based on previous personal experiences and past goal achievements, and describes it as an expectation that a positive outcome is possible. Gottschalk (1974) and Staats' (1989) views of hope are also based on the expectations of positive outcomes. These conceptualisations support hope as a futuristic construct, as is assumed in the current study.

In the 1970s, hope was already a major topic in medical science (Scioli et al., 2011). Kübler-Ross (1969) examined the role of hope in end-of-life care. She states that hope gives meaning and is crucial in the relationship between medical staff and their patients. In line with my research, these authors highlight the crucial role of hope in a hospital-care context.

Bloch (1986) describes hope as a fundamental feature of the self and the most genuine emotion. According to them, hope plays a significant role in the forming of future expectations. They believe that hope is the opposite of anxiety and that it is not just an emotion, but a compounded cognitive process. They maintain that hope includes mental and emotional processes, is both involuntary and purposeful, includes subjective and objective qualities, and manifests in both individual and collective systems. I found this view to be consistent with recent multidimensional understandings of hope (Scioli et al., 2011). In my opinion this inclusive view on hope is essential to better understand the uniqueness of my participant's hope experiences.

From this review is it clear that hope has multiple definitions, dimension and sources. In an attempt to clarify hope as a construct, theorists developed a variety of theories on how hope is constructed. One of the most significant theories in psychological research is that of Snyder, Harris, et al. (1991), according to which hope is constructed by pathways and motivational strategies (agency) towards a goal. Lately some theorists have criticised and extended this theory of hope (Bernardo, 2010; Scioli et al., 2011; Tong, Fredrickson, Chang, & Lim, 2010).

Currently there are two main theoretical discourses on understanding hope. First, hope is seen as a goal-oriented unidimensional construct (Larsen et al., 2007). Snyder, Harris, et al. (1991) and some of the pioneers in research on hope whose ideas were discussed earlier in this chapter, such as Gottschalk (1974), Menninger (1959), and Stotland (1969), also share this view of hope. When hope is described as a unidimensional construct, the implication is that hope is a motivational force and

can be described as goal-directed thinking and actions. In other words, it is viewed as an individual process (Bernardo, 2010).

Second, hope is theoretically described as being multidimensional and is seen as an integrative network consisting of more dimensions than only goal attainment (Herth, 1992; Scioli et al., 2011), as a collective process (Bernardo, 2010) and as non-linear (Benzein, Norberg, & Saveman, 2001). In this study, I chose to use a multi-dimensional integrative view of hope to allow for a more holistic view of the participant's hope experiences in the NICU.

2.3 HOPE THEORY

Despite the magnitude of researchers, philosophers and theorists who have attempted to frame hope as a construct, as discussed by Scioli et al. (2011), it was perhaps Snyder, Harris, et al. (1991) who developed one of the first theories of hope. Inspired by the works of Stotland (1969), Snyder, Harris, et al. (1991) describe hope as an attribute that leads to motivation and as an active process during which people engage in taking action to achieve their goals. Snyder (1994) believes that an individual's expectations and his/her ability and motivation to reach goals are very important in attaining hope. He refers not only to goals, but also to pathways and agencies of hope. Pathways are the plans or strategies employed to attain a goal and agency to one's own capacity, motivation and other cognitions that will put a plan into action (Bernardo, 2010). A combination of agency and pathway thinking means that individuals are motivated and can identify and rely on their own resources to reach their goals (Tong et al., 2010).

Snyder's (1994) theory, which assumes that the agent of goal attainment is the individual and that it is not influenced by external agents, has since been extended by several other authors (Bernardo, 2010; Russinova, 1999; Tong et al., 2010). Russinova (1999) specialises in the use of hope to stimulate mental health recovery. She suggests the use of hope as part of a recovery model and states that hope has three different elements, namely perceived external resources, perceived internal resources and positive expectations. She thus recognises the importance of resources of hope that are found outside of the individual. This model also claims that when people make use of external resources of hope, new opportunities are generated, and when internal resources of hope are used it leads to motivation for change. This model also illustrates that hope is generated in the context of supportive relationships. This research contributes to my study as it acknowledges

the use of both internal and external resources of hope, which may result in finding meaning and purpose in life. This in turn may result in a new level of recovery (Russinova, 1999).

Bernardo (2010) confirms the importance of multiple sources of hope. He supports a conjoined model of agency by referring to the "internal and external locus of hope" (Bernardo, 2010, p. 945). The locus of hope examines whether the resources of hope are internal or external. The internal locus of hope is representative of the individual as the agent of goal-attaining cognitions, whereas the external locus of hope emphasises significant others and external resources as active agents of hope (Bernardo, 2015). External agents or resources of hope can refer to peers, family, the environment and spiritual beliefs. Bernardo's (2010, 2015) research implies that resources of hope are not only inter- or intrapersonal, but can be drawn from the surrounding environment, which is in line with my approach to this study.

Some studies re-examined the applicability of Snyder's (1994) theory of hope. Tong et al. (2010) argue that the majority of studies focus mainly on agency thinking (goal-attaining cognitions) and not on pathway thinking (goal-attaining strategies). In other words, people feel that they are capable of achieving a goal, but are not capable of constructing the steps to get there. Frequently people are hopeful, but feel that there is not much they can do to achieve their goals. There is thus a difference between what Snyder (1994) describes as hope and how people experience hope. Snyder, Harris, et al.'s (1991) theory gives us insight into the cognitive components of hope, while Tong et al. (2010) argue that the definition and application of hope in people's daily lives might be much more complex. According to Tong et al. (2010), hope is not always associated with pathway thinking and they regard Snyder's (1994) theory as being most relevant when people have the necessary control to change their environments, which may not be the case in the NICU environment in which this study was conducted.

Scioli et al. (2011) developed an integrative theory of hope, which they define as a future-directed, four-channelled emotional network, constructed through biological, psychological and social resources. According to them, there are four channels of hope: attachment, mastery, survival motives and spiritual beliefs. These four channels of hope are foundationally developed from birth. This implies that from the beginning of our lives we have a need for attachment, mastery, the will to fight for survival and to ultimately derive spiritual meaning. According to this theory of hope, attachment is formed by "unity, trust and connectedness" (Scioli et al., 2011, p. 90).

Hope as spiritual belief is rooted in cultural and religious references, which are defined as “transcendence, eternal truths and higher power.” Mastery is defined as “goals, empowerment and collaboration;” and survival as “coping, stress management and escape of danger” (Scioli et al., 2011, p. 90). Scioli et al’s. (2011) theory, which implies that hope is future oriented, has multiple resources and also has a significant effect on our thoughts and behaviour, was also engrained in the assumptions on which I based my research.

There seems to be a thrust in recent hope-related literature to expand research based on a multidimensional understanding of hope that is more inclusive and diverse in nature. My study assumed a multidimensional experience of hope, yet allowed the participant to construct her own perceptions of hope in the NICU.

2.4 HOPE IN RELATION TO POSITIVE PSYCHOLOGY

Positive psychology is the science of optimal human functioning (Lopez et al., 2006). Unlike a psychopathological perspective that focuses on abnormalities and deficits, following a positive psychological approach implies a focus on people’s resources, assets and strengths (Linley, 2006; Shogren, Wehmeyer, & Singh, 2017) it therefore emphasises human strength, actualisation and prosperity (Becker & Marecek, 2008).

Although hope is closely related to various other positive psychology constructs, it is also clearly distinguished in literature (Bruininks & Malle, 2005). While **hope** shares similarities optimism, **hope** remains distinct (Hellman, Worley & Munoz, 2018).Valle et al. (2006) view hope as a psychological strength, and Seligman and Csikszentmihalyi (2000) investigated the role of hope, wisdom, creativity and future-mindedness in mental wellbeing. In their conceptualisation of the different positive psychological experiences they state that contentment and satisfaction are linked to the past, while flow and happiness are connected to the present, and optimism and hope are rooted in the future. Park, Peterson, and Seligman (2004) describe hope as an optimistic, future-minded character strength. According to them, hope provides a person with a positive connection to the future. Hope is therefore part of a person’s emotional, cognitive and motivational outlook on the future (Park et al., 2004).

Hope is believing in the best when faced with the worst, which enables people to persevere even when faced with significant hard times (Fredrickson, 2009). Maier and Seligman (2016) describe hope as a habit of expecting that hard times will not be

permanent, universal or uncontrollable, but are rather temporary, local and controllable.

Lopez (2013) notes that hopeful people have certain core beliefs, which include that they have faith that the future will be better than the present, that they themselves have the ability to influence their futures, and that there are multiple routes by which they can achieve their goals, even though they realise that none of those routes will be without obstacles.

According to Fredrickson (2009), hope is not only important during the good times, but can also be experienced in times of fear and despair. She states that hope is the belief that things can change. Most positive emotions or cognitions, such as joy, gratitude, pride, inspiration and love, are present when a person feels safe and content, but hope mostly comes into play when people fear for the worst. This description adds to my research because it highlights the importance of hope in the NICU, where mothers of premature infants often fear for the worst. For the purpose of this study, I chose to use the lens of positive psychology to view my participant's experiences of hope as a potential buffer during adverse life events, in this case having a premature infant in the NICU (Seligman & Csikszentmihalyi, 2000).

2.5 SOUTH AFRICAN RESEARCH ON HOPE

Only limited research on hope has so far been done in South Africa. In their overview of research in the field of positive psychology in South Africa, Coetzee and Viviers (2007) state that only four South African studies on the construct hope were conducted between 1970 and 2006. However, recently there has been an increase in local research on hope. National research relating to hope included the development of a South African hope scale (D. J. F. Maree, Maree, & Collins, 2008), a national hope survey (Boyce & Harris, 2013), an exploration of African perspectives on hope (Cherrington, 2015) and research on the role of hope during in-hospital interventions (Du Plessis, 2016).

To my knowledge, Boyce and Harris (2013) conducted the only local empirical study on national hope levels, which involved an assessment and comparison of national and provincial hope levels. The results showed that hope levels were the highest in Gauteng and the lowest in Mpumalanga. Their findings indicated that participants from urban areas had higher hope levels than those from rural areas, and that hope levels were lower in groups that had been historically marginalised in South Africa, for example women, Africans and rural communities. These results are relevant

within the current study's context as the participant in my research was a female living in the Gauteng province.

Cherrington (2015) explored the perceptions of hope, strategies to enhance hope and personal definitions of hope of children living in rural communities. She found that they appeared to become less vulnerable if they were able to intentionally access strategies to enhance personal hope. This finding is useful to my research in that it emphasises people's ability to develop their own hope strategies, and that hope can decrease vulnerability in people who are facing life stressors, for example mothers whose infants are being cared for in NICUs. Likewise, I was also interested in the mother's perception of hope and what strategies or resources she used to enhance her hope experiences.

Cherrington (2017, p. 247) later defines hope according to an Afrocentric worldview as "simultaneously existing in one's context, within one's identity, in one's interaction and in the pursuit of meaningfulness in life as part of a hopeful connected community." According to her framework, "African hope is represented by a multi-layered and multidimensional experience, and founded on the description of hope as an emotional, future-directed system made up of three complex interrelated subsystems (attachment, mastery, and survival), which develop and function along six hierarchical levels: biological motives, contextual hope, personal hope, belief systems, relational hope and collective hope" (Cherrington, 2017, p. 76). I found this appealing as it allows for an understanding of the complexity of different definitions of hope. This multidimensional African view of hope, which shows similarities with Scioli et al.'s (2011) theory, helped me to understand that there may be different facets in my participant's understanding of hope and her hope experiences within the South African context.

Du Plessis (2016) developed a hope-based intervention after exploring total knee replacement patients' experiences. This intervention was based on Scioli et al.'s (2011) integrative hope theory, which conceptualises hope according to attachment, mastery, survival and spirituality. The results emphasised the important role of hope among in-hospital patients, which confirms the relevance of the current study.

An overview of South African research on hope provided insight into national hope levels and the development of a local hope scale, and provided an African perspective on hope and the value of in-hospital hope intervention. However, it was

evident that research on hope in South Africa is still very limited. This study was aimed at contributing to hope research within the unique South African NICU context.

2.6 THE EFFECTS OF HAVING AN INFANT IN THE NICU ON THE PSYCHOLOGICAL WELLBEING OF THE MOTHER

According to Shaw et al. (2006), having a premature infant in the NICU is an unexpected and traumatic event. Research has shown that mothers of premature infants experience severe levels of shock, sadness, grief, fear and psychological distress (Kersting et al., 2004; Khoza & Ntswane-Lebang, 2010).

In a study conducted by Cleveland and Horner (2012), some mothers reported that they did not always feel like mothers and that at times they struggled to nurture their babies (Cleveland & Horner, 2012). Wigert et al. (2006) reported that mothers often experience feelings of guilt or shame because they were unable to give birth to a healthy, full-term baby. In the same study mothers reported feeling worried, desperate, disappointed and powerless. These mothers often did not feel confident about their ability to take care of their infants and some even questioned their identities as mothers and felt that they could not cope.

Women with preterm infants are often faced with a sense of loss, meaninglessness, anger, anxiety, depression and hopelessness, which may last for up to 18 months after the birth of the infant (Yaman & Altay, 2015). Mothers who participated in a study by Wigert et al. (2006) still vividly experienced the birth and their subsequent stay in the NICU as an upsetting time, even six years later. This is relevant to my study as it indicates that mothers can still show signs of emotional distress long after discharge.

Mothers whose infants are placed in an NICU are also significantly more likely to develop acute stress disorder (ASD), post-traumatic stress disorder (PTSD) and postpartum depression (PPD) than those who give birth to healthy, full-term infants (Lefkowitz et al., 2010; Shaw et al., 2006; Yaman & Altay, 2015). Research found that the levels of ASD and PTSD experienced by parents of NICU infants are similar to those of patients with acute illness and injury (Lefkowitz et al., 2010). This highlights the impact of traumatic stress during and after the NICU experience.

The negative impact of the NICU experience on the wellbeing of NICU mothers could be due to multiple challenges faced during their time of hospitalisation. Mothers have reported that they were negatively affected by the physical appearance of their

infants, early separation from their infants and invasive medical procedures (Borimnejad, Mehrnosh, Seyyedfatemi, & Haghani, 2011). Other sources of stress include their exclusion from decision making (Ardal et al., 2011), fear of losing their infants (Yaman & Altay, 2015), lack of knowledge, a negative relationship with medical staff and an unwelcoming environment (Cleveland & Horner, 2012).

Many international and local studies on the NICU emphasise the adverse effects that time spent in these units have on mothers, and multiple challenges are mentioned. It is clear that the NICU presents mothers with unique contextual challenges, and most of the current research focuses mainly on the negative experiences associated with NICUs. In this study, I hope to shed light on the hope experiences of the participant while remaining aware of the challenges presented by time spent in the NICU, which might have had a significant influence on the participant's hope experiences. Some of these challenges are discussed below.

2.7 COMMON CHALLENGES IN THE NICU

2.7.1 PROLONGED HOSPITALISATION

The birth of a preterm infant with a very low birth weight (below 1,500 g) necessitates prolonged hospitalisation (Carvalho et al., 2009). Evans and Madsen (2005) found that the hospitalisation of an infant is one of the most traumatic events that a mother can endure. Carvalho et al. (2009) argue that the hospitalisation of preterm infants in the NICU could have an immense impact on families and could elicit intense feelings of stress and powerlessness in the mothers. Another disadvantage of prolonged hospitalisation is that it could lead to intense feelings of isolation and a sense of loss of control (Abad et al., 2010).

2.7.2 LACK OF PRIVACY

In a study undertaken by Cleveland and Horner (2012), NICU mothers reported a lack of privacy as a major challenge in the NICU. They reported that they often felt as if they were under strict surveillance by the nurses and did not feel free to pray or spend quality time with their babies. NICUs are often crowed spaces and mothers might feel that they are in the way of the nurses doing their jobs. They also reported that some nurses in the NICU were domineering and that they felt that they were not allowed to mother their infants (Cleveland & Horner 2012).

2.7.3 MEDICAL STAFF

Any mother who spends a prolonged period in the NICU is constantly in contact with the medical staff (Gooding et al., 2011). A study by Yaman and Altay (2015) found that the negative attitudes of medical professionals can be a major challenge for NICU parents. Additional psychological distress can occur if the mothers experience difficulties in their relationships with the doctors or nurses, who can sometimes be reluctant to adapt their role to include the emotional needs of the parents (R. Bennett & Sheridan, 2005).

Cleveland and Horner (2012) report that mothers in the NICU indicated that the nurses gave the impression that their presence in the NICU was unwanted, which often made them feel unwelcome. These mothers also experienced feelings of uncertainty as the nurses were mainly responsible for taking care of their infants. Although the mothers wanted to be involved, they experienced a power struggle between themselves wanting to nurture and the nurses wanting to nurse. In a study by Wigert et al. (2006), mothers even reported that they felt that their babies belonged to the nurses, rather than to them. This study reported that when mothers were not included in the child's care by the medical professionals, they often felt unwanted, unskilled, out of place and unwelcome in the NICU. Although these mothers felt that the care they had received from the medical professionals was inadequate, they did not feel that they could criticize the people who had possibly saved and constantly cared for their children.

2.7.4 LACK OF INFORMATION

R. Bennett and Sheridan (2005) state that mothers of premature infants often felt that they were not adequately informed about their babies' condition. Yaman and Altay (2015) reported that mothers perceived the information given about their children as inaccurate and that it was either exaggerated, or that the severity of the infant's condition was understated. The same study also reported that these mothers often felt emotionally overwhelmed that they struggled to comprehend the information given to them, or to make decisions. A study conducted by Cleveland and Horner (2012) reported that an infant's condition was often explained to the mother in a language other than her home language, with the result that crucial information was lost in translation. This left the mother with feelings of uncertainty and exclusion.

2.7.5 MEDICAL CONDITION OF INFANT

Cleveland and Horner (2012) state that the main concerns of NICU parents related to their baby's condition, their ability to provide for the baby and knowing how to properly take care of it. Medical complications are very common in the NICU. Premature infants have a higher rate of physical and neurodevelopmental impairment, such as motor, visual and hearing disabilities (Kersting et al., 2004). Parents can become very worried and stressed about an infant's current and future medical condition (Khoza & Ntswane-Lebang, 2010).

A study conducted by Akbarbeglou, Valizadeh, and Asad (2009) among mothers of NICU infants found that stressors included seeing their infants in pain, the isolation of the infants and medical procedures, for example intravenous or tube feeding. The parents of a premature infant may in fact experience shock due to the physical condition of the baby (Ionio et al., 2016). The fragile state of the infant's health can also prevent them from interacting with and caring for the baby (Holditch-Davis, Bartlett, Blickman, & Miles, 2003).

Boucher et al. (2011) point out that a premature infant needs special and constant care, which can prove to be very time consuming and exhausting for mothers. They also report that mothers complained about exhaustion during this period as they regularly had to travel to the hospital for feedings or to spend time with their babies.

According to Yaman and Altay (2015), parents in the NICU can experience a constant fear of losing their baby. When the infant's condition deteriorates, the anticipation of a child's death is extremely stressful. The impending death can force the parents to have to grieve for their dreams and wishes for their child (Gooding et al., 2011).

2.7.6 SEPARATION FROM INFANT

Mothers are often separated from their infants at an early stage and therefore struggle to develop a physical connection with the infants, which can have a negative impact on both the process of bonding between mother and child and future attachment styles (Cleveland & Horner, 2012; Gooding et al., 2011; Wigert et al., 2006). The lack of bonding opportunities may be due to mothers not being allowed to regularly interact with or visit their babies (Yaman & Altay, 2015). If mothers are denied the opportunity to care for and bond with their children, they are more likely to

become anxious and distressed (Wigert et al., 2006, p. 40). Carvalho et al. (2009) observed a very high level of overprotection, anxiety and insecurity in NICU mothers.

This overview of common challenges in the NICU helped me to understand the diversity of the difficulties that mothers face in the NICU. All of these challenges could have had a significant effect on the participant's experiences of hope. Research on these challenges also provided a richer description of the context of the NICU. Mothers not only face internal challenges, such as psychological depression, distress, anxiety and a sense of loss (Wigert et al., 2006; Yaman & Altay, 2015), but are also confronted with external stressors, which include a lack of information, prolonged hospital stay, medical complications and exclusion by medical staff.

Although frequent mention is made of the many challenges mothers face in the NICU, it is still unclear how they were able to overcome those challenges. The solutions that are mentioned focus mainly on what could be done for the mother, thereby placing the focus on external resources. This study aimed to explore both the internal and external resources on which the participant had drawn to create hope experiences in the NICU.

2.8 THE SOUTH AFRICAN CONTEXT

The following is a review of local studies on the NICU experience. During this literature review it was especially important to explore existing local research as knowledge of the context of the South African NICU was vital to a clear understanding of the circumstances in which mothers with premature infants find themselves. The information that I found not only provided background information on the unique context of the South African NICU, but also helped me to explore the different possible challenges to hope and the resources available to mothers in South African NICUs. Many of the existing studies focus on the mothers' needs, the impact of the NICU experience on parents and recommendations for support in the NICU.

Table 2.1 below provides a summary of South African literature on the needs of the parents/mothers with infants in NICUs, the impact that the NICU experience had on the mothers, recommended support strategies and the context of the South African NICU environment.

Table 2.1: Summary of South African research on NICUs

NEEDS	RECOMMENDED SUPPORT
• Mothers have unique communication, emotional, learning, individual and discharge needs (Lubbe, 2005). • Mothers want to feel included in the decision making (Herbst & Maree, 2006; Ranchod et al., 2004). • Mothers need to be fully informed on their infants' conditions (Khoza & Ntswane-Lebang, 2010; Labuschagne, 2015; Lubbe, 2005; Ranchod et al., 2004). • Mothers need sensitivity from the NICU staff (Herbst & Maree, 2006; Khoza & Ntswane-Lebang, 2010; Mabe, Thopola, & Kgole, 2015). • Mothers need privacy in the NICU (Herbst & Maree, 2006). • Mothers want to participate in caring for their babies and have a need for bonding activities (Bigelow, Littlejohn, Bergman, & McDonald, 2010; Herbst & Maree, 2006; Khoza & Ntswane-Lebang, 2010; Labuschagne, 2015; Leonard & Mayers, 2008; Lubbe, 2005; Mabe et al., 2015). • Mothers need information prior to admission (Herbst & Maree, 2006; Lubbe, 2005). • Mothers want to feel that their opinions are heard (Mabe et al., 2015).	• Mothers should receive counselling during their stay in the NICU (Labuschagne, 2015; Mabe et al., 2015; Ranchod et al., 2004). • Information sources, such as pamphlets on the conditions their babies are suffering from, can be helpful (Ranchod et al., 2004). • Trained interpreters within the NICU environment could ensure effective communication between mothers and staff members (Ranchod et al., 2004). • Mothers need support from medical staff (Herbst & Maree, 2006; Labuschagne, 2015; Leonard & Mayers, 2008; Mabe et al., 2015). • Mothers can benefit from support groups that include other NICU mothers (Labuschagne, 2015; Leonard & Mayers, 2008). • Mothers often need spiritual, emotional and physical or financial support (Khoza & Ntswane-Lebang, 2010). • Individualised care can make mothers feel supported (Labuschagne, 2015). • Mothers should receive support from spouses, friends and family (Labuschagne, 2015; Leonard & Mayers, 2008). • Post-discharge support is very important for NICU mothers (Herbst & Maree, 2006; Labuschagne; 2015).
IMPACT	CONTEXT
• NICU mothers often feel shocked, depressed and fearful (Khoza & Ntswane-Lebang, 2010). • Mothers feel a sense of grief and loss (Lubbe, 2005). • Mothers often experience physical exhaustion (Labuschagne, 2015; Leonard & Mayers, 2008). • Some feel unwelcome in the NICU (Mabe et al., 2015). • The NICU experience might have a negative impact on parenting styles (Labuschagne, 2015). • The mothers' relationships with their spouses and other children can also be affected negatively (Labuschagne, 2015). • Mothers reported feeling confused, in denial, emotional and worried	• Some South African NICU environments have limited technical and medical resources, and the mothers come from weak social conditions (Ranchod et al., 2004). • The resources available to the South African health system are not sufficient to cope with the high demand for medical care from the rapidly expanding population (Leonard & Mayers, 2008).

(Labuschagne, 2015). • Mothers in the NICU experienced anxiety (Herbst & Maree, 2006; Van der Heyde & Nolte, 1993; Leonard & Mayers, 2008).	

The needs of South African NICU parents, as identified by Lubbe (2005), include a need for information and communication, and emotional, learning and discharge needs. With regard to the more specific needs of mothers in the NICU, Herbst and Maree (2006) found that parents are empowered by informed decision making and being sufficiently prepared on what to expect. The same study also indicated communication, sensitivity from the medical staff and privacy in the NICU as potential needs. Mabe et al. (2015) point out that the mothers desire more support from the nurses and want their voices to be heard. Many local studies revealed that mothers wanted to participate in caring for their infants (Bigelow et al., 2010; Herbst & Maree, 2006; Khoza & Ntswane-Lebang, 2010; Labuschagne, 2015; Leonard & Mayers, 2008; Lubbe, 2005; Mabe et al., 2015). Mothers also need more bonding (Khoza & Ntswane-Lebang, 2010) and positive attachment opportunities (Leonard & Mayers, 2008).

Van der Heyde and Nolte (1993) are among the researchers who explored the impact of the NICU experience on parents. They found that parents' initial reactions after the birth included feelings of guilt and failure, and loss of self-esteem. According to Khoza and Ntswane-Lebang (2010), mothers in a Johannesburg government hospital's NICU felt shocked, depressed and fearful. Mabe et al. (2015), who explored the perceptions of NICU care in Limpopo, found that mothers often did not feel welcome in the NICU and were prone to feelings of anxiety (Herbst & Maree, 2006; Leonard & Mayers, 2008; Van der Heyde & Nolte, 1993). Labuschagne (2015) states that parents in the NICU are often confused, in denial, emotional and worried, and mostly display an overprotective parenting style.

In the light of the abovementioned needs and the impact of having a premature infant in the NICU, several support strategies have been suggested in local research. According to Khoza and Ntswane-Lebang (2010), mothers in the NICU require spiritual, emotional and physical or financial support. The involvement of counsellors, support groups and information sources was recommended to help support mothers in the NICU (Leonard & Mayers, 2008; Mabe et al., 2015; Ranchod et al., 2004). The presence of interpreters could be helpful in the South African NICU environment (Ranchod et al., 2004). Labuschagne (2015) states that parents in NICUs often rely on their closest family members and spouses for emotional relief; however, many

local studies emphasise the importance of support from medical professionals, which includes post-discharge support (Herbst & Maree; 2006; Labuschagne, 2015; Leonard & Mayers, 2008; Mabe et al., 2015).

When discussing the needs of mothers, support strategies and the impact of time spent in the NICU, the broader contextual setting must be taken into account. Leonard and Mayers (2008) regard the high perinatal mortality rate as evidence of the insufficiency of South Africa's current health system and state that South African health facilities lack the financial and physical resources needed to cope with the ever-increasing demand for treatment. Ranchod et al. (2004) also mention that limited technical and medical resources and poor social conditions hamper the improvement of NICU care for infants in government hospitals in South Africa.

As indicated in the literature review, the majority of the studies that were consulted focus on the challenges that mothers experience in the NICU and the impact of the NICU experience on them, and suggested different ways of supporting mothers. The review of the different needs, may potentially form part of the different challenges faced by NICU mothers, was therefore considered during my study.

The impact of the NICU experience on the mothers can be an indicator of other potential difficulties that they face in the NICU, which might influence their hope experiences. By identifying the different recommendations regarding ways in which mothers in South African NICUs could be supported, I obtained information on possible resources of hope. The information about the context gave me insight into the unique NICU environment in a South African government hospital.

2.9 POTENTIAL VALUE OF HOPE IN THE NICU

When facing various challenges in the NICU, mothers have to find ways of coping. High levels of hope may enable people to not only create coping strategies, but to also utilise them effectively (Felder, 2004; Onwuegbuzie, & Snyder, 2000; Snyder, Harris, et al., 1991).

Hope has been associated with the ability to cope during a medical crisis and with decreased levels of anxiety (Farran et al., 1995; Fredrickson, 2000; Jacoby & Keinan, 2003). Carvalho et al. (2009) found that feelings of anxiety and depression appear to be intense during the hospitalisation of a child in the NICU. High levels of hope can reduce the adverse effects of trauma (Valle et al., 2006).

Farran et al. (1995) mention that hope may even be experienced during times of ultimate despair. In such times, a person is faced with a stressful life event and ultimately lets go of beliefs or desires and holds on to the fundamental beliefs of survival. This view on hope, as channelled through survival, is shared by scholars such as Scioli and Biller (2009, 2010) and Scioli et al. (2011). According to Farran et al. (1995), hope is challenged and even lost in a health contaxt, ter may be revived through the mobilisation of resources.

Hope can help mothers in the NICU in the following ways: It can assist them to imagine multiple routes to problem solving (Shaw et al., 2006), and the stressful life event of having a premature infant can be reframed through hopeful thinking (Henry, 2004). People with hope can imagine numerous ways to overcome life challenges (Valle et al., 2006). Hope can reduce self-blame and help mothers in the NICU to feel empowered and to "see a light at the end of the tunnel" (Henry, 2004, p. 390).

Steinberg (2006) found that hope has a significant role to play in the NICU environment and remains the patients' only comfort in the face of unbearable adversity. She also states that in the NICU there is a fragile balance between life and death, and hope and hopelessness. This study aimed to explore the challenges to hope, and how hope enabled a mother to deal with these challenges in the unique NICU context of a South African government hospital.

2.10 THEORETICAL FRAMEWORK

2.10.1 PLAAS' (2007) MODEL OF HOPE IN THE NICU

Plaas' (2007) Model of Hope in the NICU, which was formulated as part of a study that presented an in-depth understanding of mothers' perceptions and resources of hope in the NICU, served as the theoretical framework for my study.

Plaas (2007) found hope in the NICU to be experienced in three diverse yet integrated ways, namely the mothers' hope relating to their infants (hope and the infant); hope in their relationships with significant others (hope and others); and the mothers' personal need for hope (hope and the mothers).

These three integrated ways are illustrated in Figure 2.2. According to this, our understanding of hope in the NICU is influenced by a triangular relationship of constant interplay between time, uncertainty and power. The mother, the infant and relationships with others compose the experience of hope, and changes on any of

the sides can reflect changes on the other. The “World of the NICU” is the context for the mothers’ experiences.

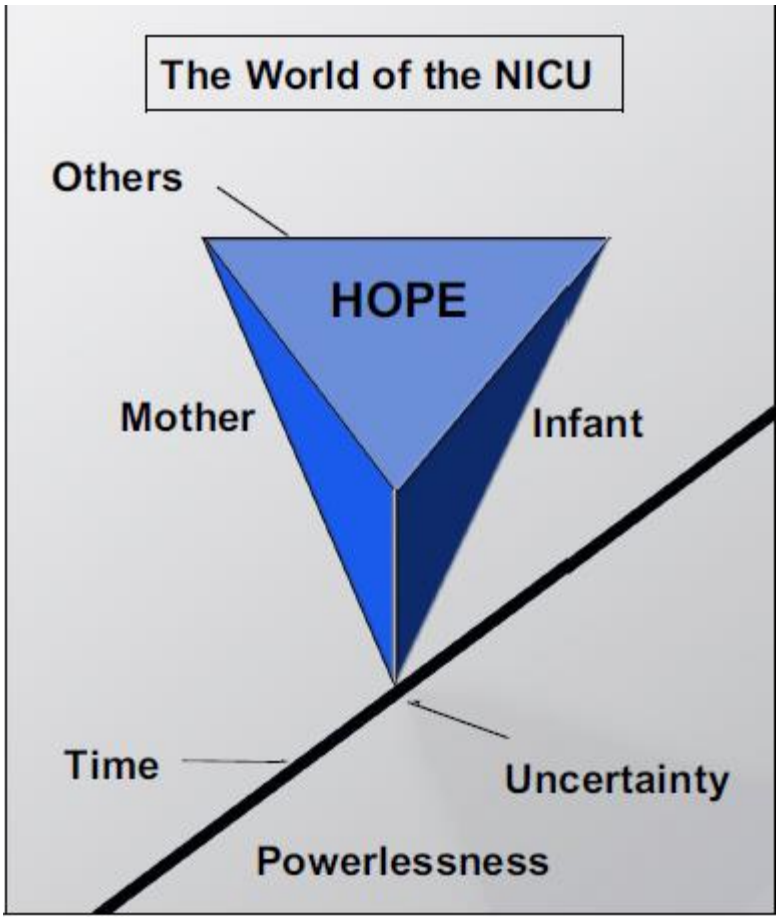

Figure 2.2: Hope in the NICU (Plaas, 2007, p. 42)

According to Plaas’ (2007) model, a mother’s hope is firstly related to the condition of her infant, and discouraging and encouraging events play a significant role in hope experiences. First, the condition of the baby has a direct effect on the mother’s level of hope and the mothers who participated in Plaas’ (2007) study reported that upon admission their hope levels were initially low due to their preoccupation with their babies’ condition and discouraging events. Mothers often did not allow themselves to hope and tended to expect the worst possible outcome. However, every time their infants made progress or reached an important milestone, they became more hopeful.

Second, hope is dependent on the support of others. Supportive medical staff, family and friends provided mothers with hope. When doctors or nurses act in a caring way or include them in the care of their infants, NICU mothers’ hope will increase. In turn, if negativity is perceived in nurses, a mother’s hope may be immediately diminished. Plaas (2007) reports that family and friends also play a significant role in mothers’

hope experiences. The idea that relationships have an effect on the hope experience is supported by other multidimensional integrative theorist, for example Dufault and Martocchio (1985), and Scioli et al. (2011).

Finally, the mother's personal sense of hope is the component of hope that tends to fluctuate the most. Plaas (2007) found that the mothers who had participated in her study had found it very difficult to regulate their own levels of hope whenever changes occurred during the time of hospitalisation. The mothers reported that being hopeful took a lot of effort and that the main challenge to hope was their fear of the unknown. Plaas (2007) concluded that a mother's personal hope experiences are dependent on her ability to keep all three components of hope in balance.

Mothers' levels of hope are also influenced by uncertainty, powerlessness and time aspects (Plaas, 2007). Because of the effect of uncertainty on the hope experiences of the mother, the triangle in Figure 2.2 is always balanced on the smallest point, which indicates that hope in the NICU constantly changes. Hope is therefore not securely positioned and remains context and time dependent. Time is represented by a diagonal line, which represents the journey from admission until discharge. Hope increases as time passes and as the child progresses towards discharge.

While numerous studies have been conducted on the topic of hope, and several on the NICU, research on hope in the NICU has been neglected. Since the literature review undertaken for this study identified Plaas' (2007) study as the only one that had explored hope in the NICU, it was considered to be highly suitable as a theoretical framework for the current study.

2.11 CONCLUSION

This chapter commenced with a review of the scientific roots of hope, which was followed by a discussion of the unidimensional and multidimensional understandings of the concept hope. The relationship between hope and positive psychology was reviewed and an overview of South African research on hope was provided. The effect that giving birth to a premature infant has on the wellbeing of the mother was considered and common challenges experienced in the NICU were highlighted. A review of South African studies on the NICU experience was provided and the potential value of hope in the NICU was discussed. In conclusion, I elaborated on my decision to use Plaas' (2007) Model of Hope in the NICU as the theoretical framework for my research.

The next chapter outlines the research process, design and methodology. It also describes the data-collection, analysis and interpretation methods that were employed.

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Chapter 3
Research Design and Methodology

3.1 INTRODUCTION

In this chapter I elaborate on the paradigmatic perspectives that informed my research. I then discuss the research methodology followed, the measures used to enhance research quality and the ethical considerations that guided the research.

The study was undertaken as an attempt to capture the personal meaning of a NICU mother's hope experiences. The extraction of personal meaning from experiences calls for a thorough exploration of the subjective understanding of a participant's lived experiences, as promoted through an interpretive paradigm (Kirn, Godwin, Cass, Ross, & Huff, 2017). Through interpretive studies, researchers attempt to understand phenomena by describing and interpreting people's perspectives on their experiences (Jansen, 2007). In order to study the phenomenon of hope experiences, a qualitative research design was used to examine the subjective reality of the participant in this study (Percy, Kostere, & Kostere, 2015).

3.1.1 META-THEORETICAL PARADIGM: INTERPRETIVISM

My study was based on the interpretivist paradigm. Research that is grounded in this paradigm focuses on the unique meaning that people attach to events that happen throughout their lives (Ritchie et al., 2013). According to Sefotho (2015), interpretivism acknowledges subjective perspectives and moves away from a single, objective scientific truth. Kelliher (2011) argues that when researchers choose this paradigm, they are concerned with exploring the uniqueness of people's understanding within specific social and cultural contexts. She further states that this may result in findings that portray the layered complexity of a phenomenon, which is what I hoped to achieve with the current study.

Chowdhury (2014) states that when researchers work from an interpretivist paradigm, they focus on the meaning and motives that underlie the participants' thoughts and actions. When working from this paradigm, researchers should therefore aim to offer an organic and non-judgemental glimpse into the real experiences of the participants (Chowdhury, 2014). I attempted to portray the experiences of the participant in my study by taking the necessary measures to ensure that the data accurately reflected the participant's views (see Section 3.3 on quality assurance later in this chapter).

By using this paradigm I aimed to present the personal subjective perspectives and views of the participant's lived hope experiences, which enabled me to consider social factors and the unique context of the NICU. Although this study tried to stay as true to the participant's personal narrative the findings were a presenation of my interpretation of the data. This paradigm allowed me to explore the complexity of contextual factors which, in the case of this study, was significant (Hook, 2012). Hook points out that the role of a researcher working from this paradigm is not only investigative, but also participative. I agree with this view. The experiences of my participant informed my findings and I was able to describe these unique experiences in order to create a better understanding of the phenomenon of hope in the NICU.

3.1.2. METHODOLOGICAL PARADIGM: QUALITATIVE RESEARCH

Qualitative research is undertaken in a naturalistic context with minimal involvement of artificial conditions (Yin, 2016). The researcher does not try to manipulate variables and research is carried out in a setting that is similar to the participant's real world (Niewenhuis, 2007a). For the purpose of this study, qualitative research was considered to be ideal for describing phenomena through the eyes of the participant and providing an in-depth look at her lived experiences (Boxill et al., 1997). A qualitative method enables the researcher to understand phenomena from within (Niewenhuis, 2007a). Qualitative research aims at addressing diverse challenges faced in society and often gives a voice to marginalised groups or individuals (Luton, 2010). Research in psychology, as also in this study, is often based on attempts to understand human behaviour and cognitive processes by making use of qualitative data-collection techniques, such as in-depth interviews and observations (Niewenhuis, 2007b).

I chose qualitative research as it enabled me to gain in-depth insight into the NICU patient's experiences during her hospital stay (Creswell, 2009), and in particular her social, behavioural and cognitive experiences (Yin, 2016). It also allowed me to describe the participant's beliefs, actions, thoughts and perceptions relating to hope in the NICU environment. This was achieved by using a semi-structured, in-depth interview, which is a qualitative data-gathering method (Brinkmann, 2014).

3.1.2.1 Criticism of qualitative interpretivist research

Although interpretivism as a paradigm is widely used and acknowledged for its holistic and subjective nature, it has not escaped criticism (Niewenhuis, 2007a). Like interpretivism, qualitative research methods are often criticised by those who support

a more positivistic research approach. Among the main points of critique are objections to the subjective nature (Rust et al., 2017; Sefotho, 2015), the contextual boundaries (Niewenhuis, 2007b) and non-probability sampling techniques (Niewenhuis, 2007c). Ritchie et al. (2013) state that qualitative research actions occur in a unique setting and cannot be reproduced in another setting.

Ritchie et al. (2013) also maintain that the most important variable in the qualitative paradigmatic perspective is based on the human variable, which cannot be scientifically regulated. Quantitative researchers have criticized qualitative research as lacking adequate theoretical guidelines, and the methods of data gathering and analysis are often seen as unstructured approaches (Boxill et al., 1997). Credibility and reliability can be difficult to prove in qualitative research (Niewenhuis, 2007c; Ritchie et al., 2013).

3.1.2.2 Response to the criticism of qualitative interpretive research

Tracy (2010) argues that if qualitative research is conducted in a transparent way, it has high research status. To enhance the quality of my qualitative research, I made certain that I set clear goals, as is required. These goals were reinforced by well-defined research questions. I further provided descriptions of the processes and procedures followed during my research. While I was conducting this single-case study, I was aware of its potential limitations and knew that the findings would be contextually bound to the participant's unique experiences. The aims of my study were therefore guided by the interpretive goals of representing subjective experiences based on confirmable research. Quality criteria, such as a researcher journal, close supervision, ethical conduct, member checking, independent verification of codes and avoiding generalisations (Niewenhuis, 2007c) were also introduced and will be discussed later in this chapter.

3.2 RESEARCH PROCESS

I started the research process by identifying the need for researching hope in the NICU. Thereafter I conducted a literature review of similar studies to explore the existing research on this topic. The literature review was followed by establishing a research aim and developing appropriate research questions for my study. Once I had decided on the focus of my study, I applied for ethical clearance. After having received ethical clearance, I sampled my participant and collected and analysed the data. This was followed by a member-checking process during which I received feedback on the preliminary research results from my participant. I then completed

the results verification before conducting a recursive literature review. Finally, I reported the findings, conclusions and recommendations of my research.

Figure 3.1 below indicates the different steps that were followed during the research process.

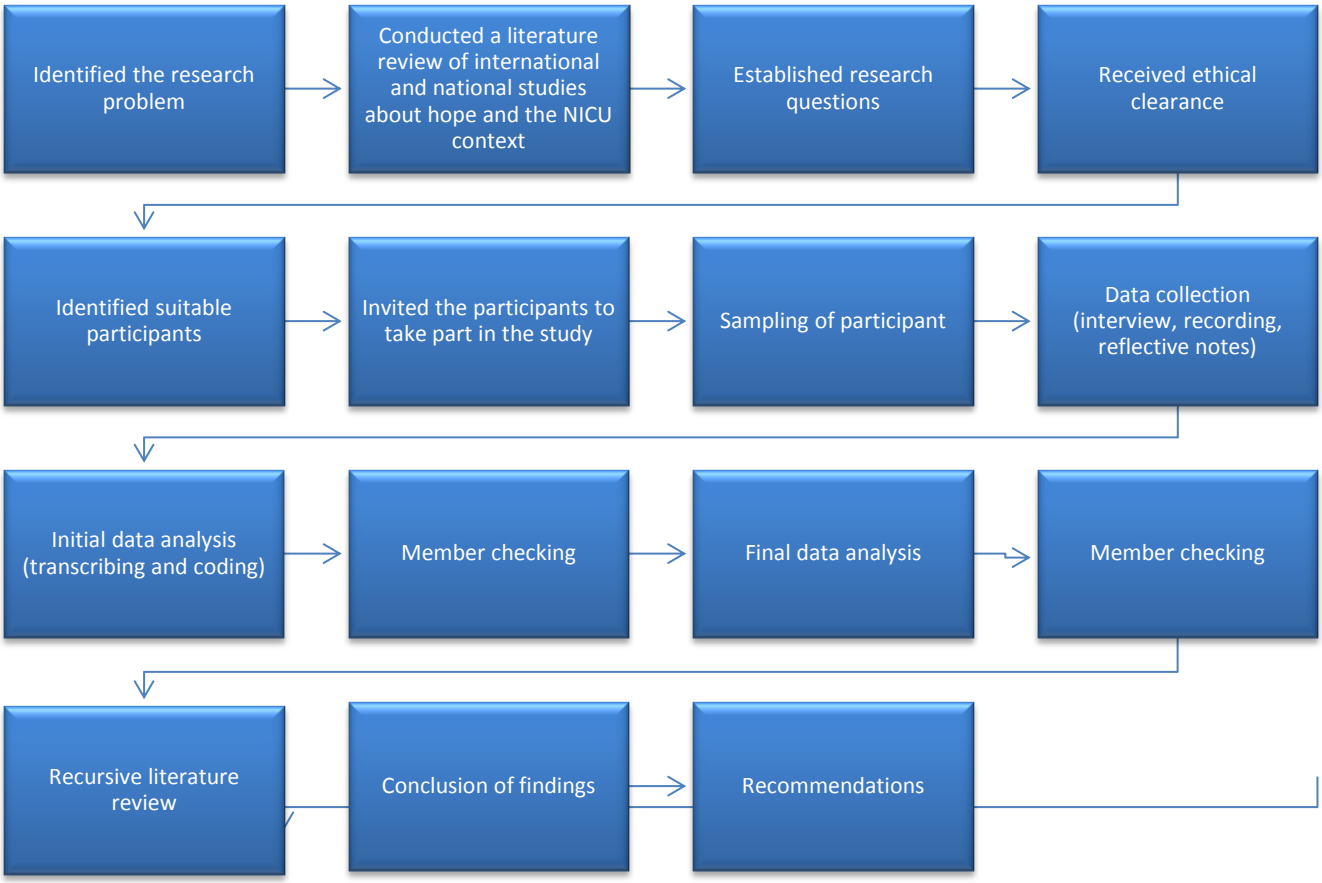

Figure 3.1: **Steps followed during the research process**

3.2.1 RESEARCH DESIGN: EXPLORATORY CASE STUDY

In this study I made use of a single exploratory case study design. This design enabled me to explore the phenomenon by asking questions about the participant's personal experience of hope within the context of the NICU (Yin, 1994). According to Zainal (2007), exploratory case studies can be useful for initiating further studies, and Yin (1994) maintains that small-scale and limited-scope case studies, such as the current study, may help inspire future endeavours and uncover underlying assumptions in order to prepare for future studies.

Yin (1984) defines case study research as empirical research that examines a current phenomenon within its real-life context and states that in case studies the boundaries between phenomenon and context are often not distinct. A qualitative case study often involves an in-depth understanding of complex conditions within a unique context (Yin, 2012). Flyvbjerg (2006) agrees that a single-case study is suitable for exploring a phenomenon within a particular space and time. This data design was used to describe the extreme, remarkable or unique experiences of a NICU mother.

Case studies aim to explore rare and interesting phenomena (Zainal, 2007). In this study I wanted to describe the unique or uncommon event as hope experiences in the NICU (Yin, 1994). By using this research design, I was able to build, challenge and expand my participant's perspectives (Yin, 2012).

Through this research I also attempted to develop an understanding of the environment that influenced the mother's behaviour and understanding. I was able to explore the complex relationships between the NICU context, hope, my participant and her infant (Yin, 2012). In the case study I used research methods that provided me with holistic, rich and in-depth data, and was able to triangulate my findings by using multiple data sources, which included my interviews, a reflective journal and observational notes and photos provided by the participant.

Andrade (2009) notes that one of the main contributions of case studies is the case as such, which can be defined as a bounded or limited instance of a phenomenon. The boundaries of my case were defined as having a premature infant with a very low birth weight (less than 1,500 g) in the NICU at the government hospital during 2015 and staying in the mother lodger facility for the duration of the infant's NICU stay.

My case study focused on the specific context of the NICU in a South Africa government hospital. Flyvbjerg (2006) mentions that case studies are context dependent, allowing for unique discoveries about a phenomenon within the context, and are very useful as they allow the participants' narratives to unfold. The current research explored the nature, resources and challenges of hope through the participant's experiences of the NICU, which may be of value for a specific audience.

3.2.2 SELECTION OF PARTICIPANT

3.2.2.1 Sample size

Despite numerous attempts to obtain a larger sample size, the study was restricted to a single participant. Due to the vulnerability of the population involved, the accessibility of the participants, their reluctance to participate and the limited scope of this study, a small sample was also recommended by my supervisor and the Health Sciences Ethics Committee.

3.2.2.2 Sampling strategy

For the purpose of this study, I made use of non-probability purposive sampling (Maree, 2007). On the recommendation of the Health Sciences Ethics Committee, I contacted patients whom I had previously counselled in the NICU at a South African government hospital. Potential participants, i.e. mothers who had given birth to preterm infants with very low birth weights (below 1,500 g) in the Neonatal Intensive Care Unit (NICU) of the identified South African government hospital during 2015, were identified and were subsequently invited to participate by agreeing to an in-depth individual interview. When answering interview questions about the hope experiences in the NICU, the participant had to be able to express themselves well in either English or Afrikaans.

3.2.2.3 Access to the participant

Access to the participant was made possible through the database of NICU mothers that I had developed while working as a counsellor doing pro-bona cases at government hospital. Once I had received ethical clearance, I approached possible participants who met the criteria for my study.

Finding and selecting participants for my study was challenging due to the fact that many of the patients did not live in close proximity of the hospital and the majority had changed their contact details. Some mothers were also not willing to participate due to the sensitive nature of the study. Ultimately only one of the four possible participants who had been approached agreed to participate in the research. Participant X agreed to take part in the study through written consent (see Appendix A) and subsequently participated in an interview and a member-checking session.

3.2.2.4 Description of the participant

Participant X was a 29-year-old Afrikaans-speaking female who lived in Pretoria West, South Africa (see Appendix B). On 13 May 2015, when she was 26 weeks pregnant with twin boys, she went into labour and was admitted to the identified South African government hospital, where attempts were made to prolong her pregnancy by using different medical procedures. These attempts failed and her twins were born three and a half months prematurely. One of the infants passed away shortly after birth, but the second, weighing only 600 g at birth, survived. Because of his low birth weight and the medical challenges, both the infant and his mother had to stay in the hospital for four months. The participant had one older son. She was specifically approached for participation due to her prolonged hospitalisation, the very low birth weight of her infant and her first-hand experiences in the NICU.

3.2.3 DATA COLLECTION AND DOCUMENTATION

It is well known that case studies make use of multiple sources of data. Each source provides a piece of the puzzle and helps the researcher to gain a better understanding of the phenomenon being studied (Baxter & Jack, 2008). Although this study made use mainly of an individual, semi-structured interview, it was further informed by observation notes, field notes (see appendix F) and a thorough literature review. During the interview the participant volunteered to provide photos taken during her time in the NICU and those photos were also included as a data source to further support and illustrate the research findings. To ensure reflexivity, I also kept a researcher's journal throughout the research process.

As a qualitative researcher working from an interpretivistic paradigm, I was an active agent in the data-collection process. This implies that I had to be able to ask appropriate questions, and had to possess the reflective listening skills and interpretation abilities needed to make sense of the answers (Rowley, 2002). I constantly reflected on the data, identified gaps in the data collection, or in my understanding, and planned for further data gathering if needed (Niewenhuis, 2007c). According to Niewenhuis (2007b, p. 81), data collection is an "on-going, cyclical, iterative process."

3.2.3.1 Semi-structured interview

In the early stages of this study, I considered collecting data by way of a focus-group discussion in the NICU of a government hospital. However, during the ethical clearance process this data-collection method was denied due to the vulnerability of NICU mothers in a hospital. It was proposed that I change my data-collection method to an individual semi-structured interview with previous patients in a neutral setting (outside of the hospital).

During a semi-structured individual interview I collected information from a mother who had given birth to a premature infant in a government hospital in 2015. The interview was guided by an interview schedule (see Appendix C) with open-ended questions about the mother's experience in the NICU and the perceived role that hope had played during the period of hospitalisation (Klenke, 2008).

The reason for using a semi-structured interview was that it enabled me to remain focused on the purpose of my research while also allowing both the participant and me a chance to elaborate, probe and clarify answers (Niewenhuis, 2007b). The interview schedule's wording and the order in which the questions were asked were flexible to suit the unique setting and the participant's needs, and to allow for spontaneous reflection (McCusker, Turner, Pike, & Startup, 2018). Another advantage of this method of data collection was that it created an informal atmosphere in an environment in which the participant felt comfortable to discuss her hope experiences.

The interview was conducted at a place and time that was suited the participant. With her permission, the interview was audio recorded and a verbatim transcription was made for member-checking and data-analysis purposes (see Appendix D). Member checking enhanced the trustworthiness of this study. I allowed the participant to comment on the themes and findings at two separate occasions (Chase, 2017).

3.2.3.2 Audio recording and transcriptions

The audio recordings and transcriptions (see Appendix D) provided me with a record of the participant's responses during the interview. Verbal data on her definition of hope, challenges during hospitalisation and resources of hope were arranged into themes by identifying recurrent topics in the transcription (Klenke, 2008).

3.2.3.3 Observation notes

Since the behaviour or patterns in the behaviour of a participant and other occurrences cannot be captured in audio recordings and transcriptions, I made use of observation notes. These notes helped me to gain a deeper understanding of the mother's emotional and behavioural reactions regarding her experiences of hope during hospitalisation (Niewenhuis, 2007b).

In Table 3.1, the different advantages and disadvantages of the data-collection methods that I experienced during the duration of my research process are listed. It also shows how these methods were aligned with my research questions.

Table 3.1: Data-collection and documentation methods used in the study

Data-collection method	Alignment with research questions	Advantages	Challenges
Individual interview, including a semi-structured interview schedule	The interview schedule provided guidelines and focus for important topics that needed to be discussed during the interview. It helped me to obtain relevant information to answer the research questions about the participant's definition of hope, her challenges in the NICU and her resources of hope.	This method allowed for an in-depth exploration of topics. The participant's perspectives were captured in the interview session.	Advanced researcher skills were needed to conduct the interview, especially when the more sensitive incidents that occurred during her NICU stay were discussed.
Audio recording and transcription of the interview	It provided a record of responses to the research questions. Verbal data on the participant's definition of hope, challenges during hospitalisation and resources of hope were arranged according to themes by identifying recurrent topics in the transcription.	The transcriptions were very helpful during the thematic analysis. I was able to go back to the permanent record of the interview to structure the themes.	Transcribing the audio recordings was a time-consuming task. Audio recordings and transcriptions did not capture non-verbal information, but did provide a large volume of information that was at times difficult to reduce to identify the relevant information.
Observation notes	These notes described the participant's non-verbal reactions.	Observational notes provided a record of the real-life situation. It was a source of data that did not rely on the	The observations were my subjective interpretation of the participant's behaviour. Some observations may

Data-collection method	Alignment with research questions	Advantages	Challenges
		participant's ability to provide information.	have caused the Hawthorne effect, which would have occurred if she had behaved in the way she thought I expected her to behave (Paradis & Sutkin, 2017).

3.2.3.4 Researcher's reflective journal

This journal was very useful during the current research study as it addressed challenges associated with the data-collection techniques by enhancing researcher reflexivity. The reflective journal helped me to gain a deeper understanding of my own objectives and the events that occurred during my study (Roberts-Holmes, 2018), and to organise my own thought processes and track my personal development (Ortlipp, 2008). It provided me with a record of how my study was progressing and of the decisions I had made during this process (Morrow, 2005).

3.2.4 DATA ANALYSIS AND INTERPRETATION

3.2.4.1 Inductive thematic analysis

By using an inductive thematic analysis strategy, I allowed findings to emerge from recurring, presiding and significant themes (Niewenhuis, 2007c). Since exploratory case studies do not begin with propositions, the inductive thematic analysis method enabled me to identify, analyse and report on patterns in the data (Braun & Clarke, 2006). Inductive thematic analysis starts with specific content derived from the data collected and moves towards broader generalisations (Alhojailan, 2012). As I worked from the interpretivist paradigm, I preferred such inductive thematic data analysis, which allowed room for multiple realities that could be understood within a specific context (Niewenhuis, 2007c).

3.2.4.2 Phases in data analysis

I used the following thematic data-analysis guidelines as described by Braun and Clarke (2006).

- **Phase 1: Familiarise yourself with the data**

The analysis process started once the interview had been transcribed. I immersed myself in the data by reading the transcription many times. While reading, I also listened to the audio recordings to confirm the accuracy of the transcription.

- **Phase 2: Generating open codes**

Open codes are basic segments of data that might initially be meaningful and relevant to the phenomenon of interest (Braun & Clarke, 2006). Segments of information that related to my research questions were marked as different open codes in the transcription. These statements or open codes served as initial markers, but were not yet connected to any meaningful themes. I did not attempt to order or label the statements at that time. All the statements were considered to be of equal value.

- **Phase 3: Searching for themes**

I examined my initial open codes to identify data patterns, which were marked to form subthemes or axial codes (Jones & McEwen, 2000). I then listed the inclusion and exclusion criteria for each subtheme. Evidence of the themes was provided by way of verbatim quotes to report on them (Alhojailan, 2012). Where the criteria for a subtheme did not include an open code, a new theme was formed (Moerer-Urdahl & Creswell, 2004).

- **Phase 4: Refinement of themes**

Once I had organised my open codes into themes, I realised that some themes lacked the evidence required for stand-alone themes. I had to decide which themes should be discarded, which could be placed under other themes, or which could be combined to form a new theme. I then made sure that every open code was coherent and relevant to the theme and met all the inclusion criteria. Every theme had distinct boundaries, which were clearly described and defined.

- **Phase 5: Defining and naming of themes**

In naming the themes, I had to ensure that the titles were neither too narrow, nor too diverse. I took care to avoid overlaps between themes and any repetitions of research findings (Alhojailan, 2012). In naming the themes, I had to ensure that the name of each theme described its content and parameters, and that it was a true reflection of the participant's narrative. An audit trail defining the themes is provided in Appendix G.

This data-analysis procedure was not seen as a linear, once-off procedure, but as a constant process of searching, reflecting, connecting, reviewing and defining (Braun & Clarke, 2006).

3.2.4.3 Advantages of using inductive thematic analysis

Some of the advantages of using inductive thematic analysis were that I could examine the data in great detail. The data analysis provided extensive evidence and insights into the experience of the research participant (Braun & Clarke, 2006).

Braun and Clarke (2006) describe thematic analysis as a flexible method of analysis. This type of analysis offered theoretical freedom and was compatible with my research paradigms and methods. By creating a thematic order in the data, I could achieve a holistic perspective from which to understand the participant's experiences.

3.3 QUALITY ASSURANCE MEASURES

As mentioned earlier in this chapter, the aim of the study was not to generalise the research findings, but to provide credible, trustworthy results (Lincoln, Lynham, & Guba, 2011). The following measures were taken to enhance the trustworthiness of the study:

3.3.1 CREDIBILITY

Credibility refers to the level of certainty that the findings that are presented are a true representation of the data that was gathered (Shenton, 2004). Measures that were taken to enhance the credibility of my study included encouraging the participant to give honest responses, the crystallisation of data and member checks (Jansen, 2007).

It was important for the participant to willingly participate in the study and to feel comfortable enough to freely share her experiences with me. I was able to establish an open and trusting relationship with her, which I believe enhanced the credibility of my findings. The participant was reminded that there were no correct answers and that she was free to refuse to answer any of the questions at any time (Shenton, 2004).

The credibility of a qualitative study can be enhanced by crystallisation. Crystallisation involves a process during which multiple sources of data are checked to determine whether a pattern emerges (Jansen, 2007). This study made use of

transcripts, observational notes, photos provided by the participant, field notes (see Appendix E) and my reflective journal (see Appendix F). The field notes provided my description of the environment and process before, during and after the interview. The observational notes were the participant's behaviour and non-verbal cues during the interview. These behavioural decriptions were added to the verbatim quotes during the process of data analysis to provide the reader with behavioural context. By using more than one data source, I could explain the phenomenon in greater detail (Shenton, 2004). The data that had been collected was also verified by the participant herself through a process known as member checking.

The process of member checking refers to the participant's validation of the research which enhances the trustworthiness of a study (Birt, Scott, Cavers, Campbell, & Walter, 2016). I allowed the participant to evaluate, respond to or comment on the preliminary findings, interpretations and conclusions of my study (Niewenhuis, 2007b). Her answers to the questions were repeated back to her at the conclusion of the interview to make sure that they had not been misinterpreted (Shenton, 2004). During the data analysis I also asked the participant for feedback. Significant initial and final themes were summarised and discussed with the participant.

Niewenhuis (2007b) and Shenton (2004) maintain that the credibility of research findings can be enhanced if other researchers are invited to assist with the interpretation of data. I therefore asked my supervisor to verify the significant themes I found in the data. The different sets of data analysis were compared to determine whether similar themes had been identified.

3.3.2 TRANSFERABILITY

Qualitative researchers do not attempt to generalise their research results since the findings of such research are usually bound to a specific context, time and culture, and to specific values (Shenton, 2004). The purpose of this study was not to generalise information about an experience to the wider population, but to take an in-depth look at the unique hope experiences of a mother in the NICU (Mayring, 2007; Niewenhuis, 2007a). In this case study, I took care in describing my participant and her unique context, which may contribute in transferring the research findings to similar contexts.

Qualitative case studies often use samples that are smaller than those used when purposive non-probability sampling techniques are employed. Since the participant in my research was selected with a specific criterion and purpose in mind, my findings

might not be representative of the general population (A. Bennett, 2004; Niewenhuis, 2007a).

Flyvbjerg (2006) states that even if a study is bounded to a specific case and cannot be generalised to the wider population, it can however be useful for developing theory on a small scale. Such theory can then potentially be implemented and tested in other studies to expand on the research knowledge base.

3.3.3 DEPENDABILITY

In qualitative research, dependability refers to the stability of the findings if the study is replicated by another researcher in another space or time (Morrow, 2005). Due to the uniqueness of the cases that are studied, dependability is often harder to achieve in case studies (Shenton, 2004). In any case study, the focus is on the context in which the actions of the participants take place, and since those actions take place in a unique setting they cannot be reproduced in another study (Ritchie et al., 2013).

To enhance the dependability of my study, I diligently kept a reflective diary and analysed the verbatim transcripts (Niewenhuis, 2007c), and continuously reflected on my choices with regard to the research design and data-collection and analysis techniques. I also kept a record of the feedback I received after sessions with my supervisor. Through the in-depth analysis of the data, my themes captured the meaningful events of the participant's experience in the NICU (A. Bennett, 2004). While I was writing and reviewing the different chapters, my documentation was systematically organised according to the different phases of progress throughout the whole research process (Yin, 1984). By providing a full description of the research process, documenting my progress during each stage, writing a reflective journal and keeping track of my consultations with my supervisor I was able to provide an audit trail of my research procedures (Shenton, 2004).

3.3.4 CONFIRMABILITY

Confirmability refers to the neutrality and objectivity of the research (Shenton, 2004). It is an indication of the likelihood that another researcher would be able to confirm the research findings of this study. Since in case studies researchers work very closely with the participants, it is difficult to prevent researcher-induced bias (Zainal, 2007).

Although qualitative research is rarely objective, it should still be authentic (Morrow, 2005). Research findings are subjectively interpreted by the researcher and not calculated and proven through quantitative statistics (Graneheim & Lundman, 2004).

According to Bunniss and Kelly (2010), the researcher must be aware of any personal thoughts, feelings, opinions and experiences that might influence what he or she observes. My researcher bias was minimised as I clearly stated my role and my history with the participant before starting with the research (Allmark et al., 2009).

After having received ethical clearance, and before starting with the data-collection process, I was fully cognisant of the fact that my relationship with the participant had changed from being her counsellor to being a researcher, and that my former client had become a participant in my research endeavour. This was clearly communicated to and understood by the participant.

In order to avoid being influenced by bias, I once again made use of member checking to enhance the credibility of my findings (Shenton, 2004). The findings were verified by the participant. I also kept a detailed reflective journal (see appendix F) in which I commented on my thoughts, feelings, observations and decisions. Morrow (2005) maintains that it is important for a researcher to report on the actual data and the situation, and not on his or her personal thoughts about it. I therefore provided proof of my themes and findings by using quotations from my conversation with the participant to prove that the findings were based on the data and not my own opinion (Shenton, 2004). I also included detailed criteria for inclusion and exclusion under the various themes. I also kept a detailed reflective journal in which I commented on my thoughts, feelings, observations and decisions.

3.4 ETHICAL CONSIDERATIONS

Ethical clearance for this study was received from the Ethics Committee of the Faculty of Education and the Faculty of Health Sciences. The initial proposal and procedures (which would have included a focus group of NICU mothers in a South African government hospital) was presented and was reviewed and adapted during the Faculty of Health Sciences Ethical Board committee meeting. The research was subsequently conducted according to the ethical guidelines of the Ethics Committees of the abovementioned Faculties (Protocol number: EP 17/02/01).

3.4.1 INFORMED CONSENT

Prior to the data collection procedure, the participant signed an informed consent form. This form provided adequate information about the purpose and nature of the study, what was expected of the participant and the researcher, and the right to withdraw from the study. It also requested permission to make audio recordings of the interview (Visser & Moleko, 2012). I was aware of the fact that qualitative research involves more personal interaction, that it is not always possible to clearly indicate the nature of the questions to be asked or other interactions in advance (King, 2010), and that informed consent should therefore not be seen as a single action, but rather as an on-going process of negotiation (Allmark et al., 2009).

The participant was informed beforehand that her involvement in the study would include participation in a semi-structured individual interview during which sensitive aspects of her stay in the NICU would be discussed.

3.4.2 CONFIDENTIALITY

Confidentiality protects the right of participants in research to remain anonymous (Visser & Moleko, 2012). As a qualitative researcher I was interested in confidential information about my participant's experiences. Due to the nature and purpose of my research, I was able to protect the identity of the participant confidential (Ensign, 2003). Only pseudonyms were used (Participant X and Baby X) and the hospital's reputation was also protected by referring to it only by the codename Hospital ABC (Richards & Schwartz, 2002). The use of these pseudonyms ensured that the participant and the hospital could not be identified (King, 2010).

3.4.3 VOLUNTARY PARTICIPATION

Participation in this study was completely voluntary. The participant had no obligation to the researcher and did not receive any incentives. The participant was informed that she was free to withdraw from the study at any time without having to give a reason for her decision. If she had decided to withdraw from the study, no information provided by her would have been used (King, 2010).

3.4.4 PROTECTION FROM HARM

During the interview, we discussed the participant's experience in the NICU. This may have elicited negative and traumatic feelings caused by the participant's

experiences following her baby's premature birth and her subsequent prolonged stay in the hospital's NICU. I was aware of the potential risks of in-depth interviews and always approached my participant with sensitivity. The participant was informed that should she feel that she needed counselling, free counselling services would be made available to her. Before the data was collected, a registered counsellor was informed that her services might be required. The participant was not exposed to any acts of deception and her physical safety was assured by conducting the interview in a safe venue.

Once all the required data had been collected and the interview was over, I reminded the participant about how it would be used and invited her to elaborate on how she had experienced the interview and the post-interview process. I gave her my contact details in case she later remembered any concerns or questions she wished to discuss with me. I also reminded the participant that she would have access to the report that would emerge from the study (King, 2010).

3.4.5 MY ROLE AS THE RESEARCHER

One of the main ethical concerns in qualitative research is the dual role played by the researcher. The researcher can easily become too involved and might find it difficult to distinguish between his or her role as researcher, versus the role of therapist (Allmark et al., 2009). While I was conducting the research, there were limitations to my role and I had to carefully consider my position in the research field (Visser & Moleko, 2012). I was constantly aware of the importance of ensuring that a balance was maintained between having an open relationship with the participant and remaining within the professional research boundaries.

As mentioned in the section that dealt with sampling, the Health Sciences Ethics Committee recommended that I invite a client whom I had previously counselled to participate in my study. The client I approached and who agreed to participate had been counselled by me during her hospital stay in 2015, and as a result the risk of role confusion became especially important in my study. Before the commencement of the research, I explained my role as a researcher, indicated my boundaries (Richards & Schwartz, 2002) and informed the participant that I would not be allowed to provide psychological counselling during the data-collection interview. The participant understood that should a need for counselling arise, I would refer her to another registered counsellor. I also consulted my supervisor for support in establishing my role as a researcher.

3.5 SUMMARY

This chapter commenced with a discussion of the ethical considerations that guided this study and included the research design and procedures that were used to collect, analyse and interpret the data. It also incorporated the paradigmatic perspective of the study and the measures that were used to enhance quality and trustworthiness.

In the next chapter I will demonstrate and discuss the data analysis process, report on the results obtained from the inductive thematic analysis of the data and discuss the research findings before concluding with a case discussion by way of a recursive literature review.

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Chapter 4
Results of the Study

4.1 INTRODUCTION

In this chapter I present the reader with the results of this study. My findings were based on the insights gained into the participant's hope experiences in the NICU, through the analysis of data obtained by way of an in-depth, semi-structured interview, my observational notes and my reflective researcher's journal.

4.2 DATA-ANALYSIS PROCESS

As already indicated in the preceding chapter, this study was based on the interpretivist paradigm, which values the unique experiences of participants. My aim was to allow the participant in my study (Participant X) to provide me with her own narrative of her hope experiences, which were analysed by way of inductive thematic analysis. Verbatim Afrikaans quotes and their translations into English are included.

During the translation process, I made use of bilingual dictionaries and Google translate to translate the content to inform the monolingual reader of the meaning of the source text, while remaining as true to the original words as possible. I repeatedly reviewed the translations and had them independently verified to ensure the quality of the narrative. Finally, I had them approved by an accredited translator.

4.3 LAYOUT AND DISCUSSION OF THEMES

In this section, I first provide a diagram showing the main data themes and subthemes (Figure 4.1), which is followed by a discussion of each theme and subtheme. The subthemes are defined and the indicators, as well as inclusion and exclusion criteria for each, are provided, followed by a summary of Participant X's responses and verbatim quotes. I also include photos illustrating her NICU hope experiences. Participant X had volunteered to make these photos available for use in this study. Lastly, the findings are related to existing literature by way of a recursive literature review.

The results of my data analysis can be presented according to the following main themes: the nature of hope, internal and external resources of hope, and short-term

and long-term barriers to hope. Each of these themes could be divided into subthemes, as discussed later in this chapter.

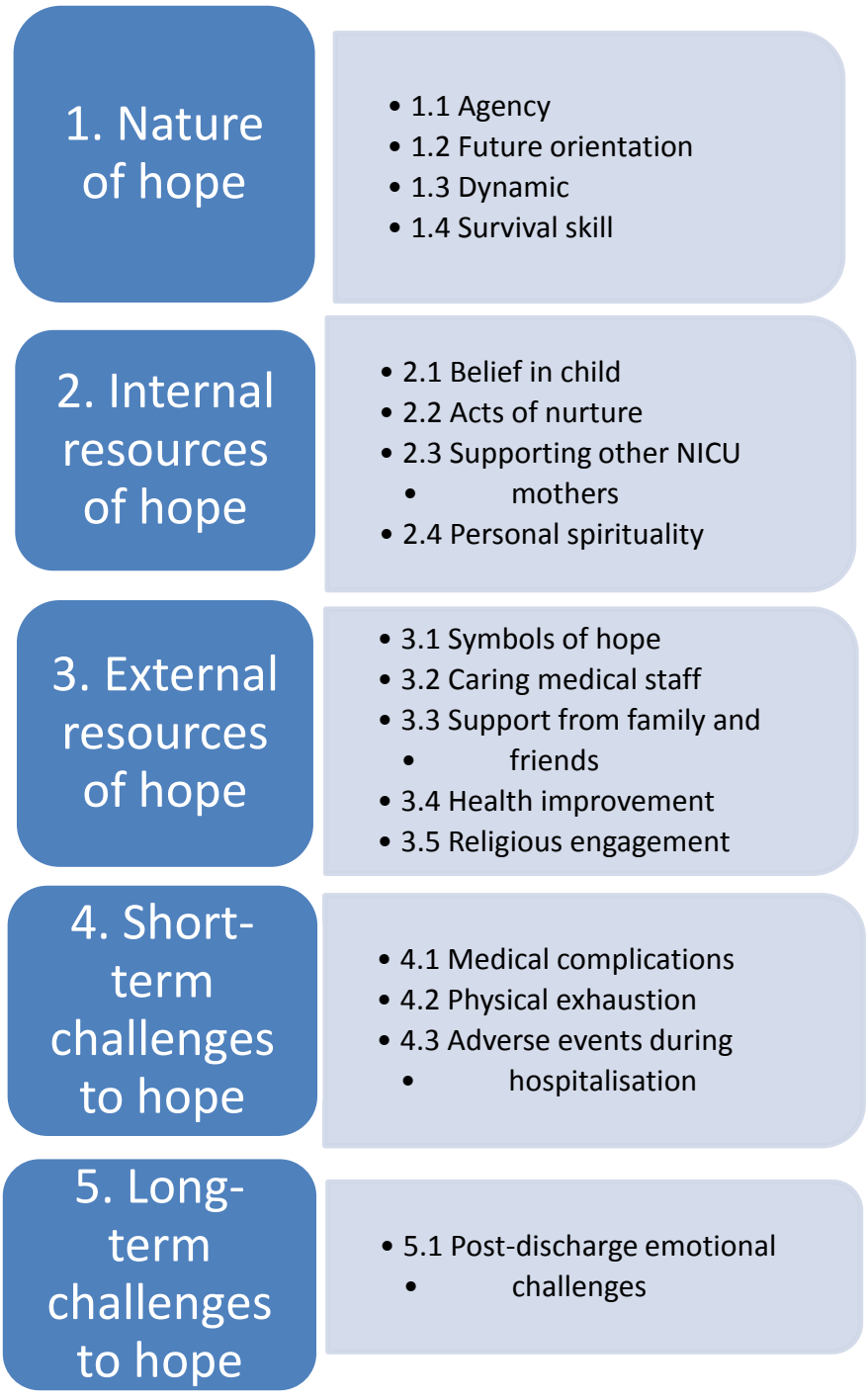


Figure 4.1: Summary of main data themes and subthemes

See Table 4.1 for the frequency distribution of each subtheme.

Table 4.1: Frequency scores of the subthemes

Theme	Subtheme	Frequency of reference to indicators
1. Nature of hope	Future orientation	7
	Agency	9
	Survival skills	3
	Dynamic	7
2. Internal resources of hope	Belief in child	7
	Acts of nurture	7
	Supporting other NICU mothers	4
	Personal spirituality	4
3. External resources of hope	Health improvement	4
	Caring medical staff	6
	Support from family and friends	5
	Religious engagement	2
	Symbols of hope	14
4. Short-term barriers to hope	Medical complications	7
	Adverse events during hospitalisation	5
	Physical exhaustion	6
5. Long-term barriers to hope	Post-discharge emotional challenges	12

4.4 THE MAIN THEMES AND SUBTHEMES OF MATERNAL HOPE EXPERIENCES IN A SOUTH AFRICAN NICU – A DATA ANALYSIS

4.4.1 THEME 1: THE NATURE OF HOPE

The nature of hope represents the essence or essential characteristics, attributes or qualities that hope presented to Participant X. This was indicated by the participant's personal understanding of hope and what it can do for, or give to her. Under this theme the following subthemes could be identified: agency, future orientation, dynamic and survival skills.

4.4.1.1 Subtheme 1.1: Agency

Table 4.2: Agency

Definition	Cognitive, motivational and emotional components towards goal-attainment and the future (Seligman, 2004; Snyder, Harris, et al., 1991). The realisation of new goals, plans or missions in life, gaining new insight into identity, control over destiny, or feeling strengthened (Healy & O'Donnell, 2008). A self-directed mastery experiences towards personal efficacy (Bandura, 1989).	
Indicators	References to her wanting to achieve a goal, pushing through it, experiencing a feeling of excitement and a sense of achievement	
Criteria	<u>Inclusion</u> References to motivation, mastery and the emotion of excitement	<u>Exclusion</u> Data not referring to motivation, mastery or the emotion of excitement. Pushing through with the help of family members or medical staff

Participant X stated that hope had kept her going during her stay in the NICU and had contributed to her determination to get out of the hospital which can be related to agency (see Table 4.2). She explained that she had experienced a sense of mastery through hope and mentioned that, looking back, it was amazing to realise where they had been and how, time after time, she had known that they were improving. She related hope to the feeling of excitement, which further motivated her to remain hopeful, and said that she had been the most excited and hopeful when they were moved out of the ICU.

Verbatim quotes that support this subtheme are:

- ***Dit was vir my die excitingste deel gewees*** (lines 77–78*). That was the most exciting part for me.*
- ***Ek kan dit [hoop] nie as iets anders beskryf nie, jy was net excited … Jy's meer excited …*** (lines 84–85*). I cannot describe it [hope] as something else, you were just excited … You're more excited.*
- ***Want jou mikpunt is om by die hospitaal uit te kom met daai kind*** (line 86). *Because your goal is to get out of the hospital with that child.*
- ***Jis, dit [hoop] het vir my en die kleintjie deurgedruk*** (line 97). *Jis, that [hope] pushed me and the little one through.*
- ***… want jy is so excited en jy kan dit nie beskryf nie, 'n trots in jou om die kind daar te hê …*** (lines 234–235). *… because you are so excited and you cannot describe it, a pride in having the child there ...*

- ***Maar as jy weer terugdink, dan weet jy dis verby. Kyk waar is ons*** (lines 316–317). *But if you think back, then you know it's over. Look at where we are.*
- ***En partykeer kyk ons terug en dan sê ons: 'Kyk waar was ons en kyk waar is ons nou, en weet jy wat, ons gaan net verbeter' (wys vordering met hande). En so verbeter ons elke keer*** (lines 399–401). *And sometimes we look back and then we say look where we were and look where we are now and you know what we're just going to improve (shows progress with hands). And so we improve every time.*
- ***Daai hoop is eintlik die belangrikste. En ek glo dis wat ons deurgebring het … daai hoop. Daai verband wat ons gehad het met die hoop*** (lines 501–503). *That hope is actually the most important. And I believe that's what brought us through ... that hope. That connection we had with hope.*

Seligman (2004) states that hope is part of our emotional, cognitive and motivational perspective on the future. Hope as motivation towards mastery of the NICU challenge is featured in the results of this study. This is aligned with Snyder, Harris, et al.'s (1991) theory of hope and many other prominent definitions on hope. The unidimensional understanding of hope is based on hope as having agency (the will) and pathway thinking (a way) to reach goals (Snyder, 1994).

Arnau et al. (2007) and Lee, Park, and Hwang (2016) also view hope as a driving force towards a goal that leads to positive motivational thinking. This is in line with the findings of my study in that Participant X's goal was to eventually leave the hospital with a healthy infant. This goal motivated her, provided her with hope for the future and enabled her to carry on.

According to the findings of my study, agency includes motivation and mastery, which are both goal driven. Scioli et al. (2001) identify mastery as one of the three key aspects of hope. According to Alim et al. (2008), an important factor reported in recovered patients versus the critically ill was a sense of mastery. The same study reported that a sense of mastery appears to decrease PTSD symptoms and depression.

According to Snyder (1994), the emotional component of hope is directly linked to goal achievement. When people achieve their goals, they experience positive emotions, and when they fail to do so they experience negative emotions. Participant X described hope as the emotion of excitement. Scioli et al. (2011) also acknowledge the emotional component of hope in their multifaceted definition of hope.

Although hope has not been linked directly to one emotion in other studies, it has been described as a positive-outcome emotion (Hu & Kaplan, 2015), a positive uncertain emotion (Ahmad & Laroche, 2015) or a forward-looking emotion (Gratch, Cheng, & Marsella, 2015), which are all connected to agency. One connection to the specific emotion of excitement that was linked to hope is mentioned by Grant (2015), who found that when studying hope there was a constant interplay between feeling excited and wanting to be realistic about reaching one's goals.

4.4.1.2 Subtheme 1.2: Future orientation

Table 4.3: Future orientation

Definition	A perspective aimed at striving for pre-defined outcomes (Purkis & Bjornsdottir, 2006). This is also connected to the term 'future time perspective,' which is defined as the present anticipation of future goals (De Volder & Lens, 1982).	
Indicators	References to going forward, the way ahead, getting the image going forward, thinking about her child day by day, knowing where she is going	
Criteria	<u>Inclusion</u> Data referring to direction, the future or going forward. Also included when a future orientation had an effect on the present	<u>Exclusion</u> Data referring to the past

According to Participant X, hope provided her with a present focus and forward motion based on her future expectations or orientation (see Table 4.3). Her belief in a better future therefore provided a present focus and direction. She focused on the day-to-day and short-term progress and sometimes only thought of the next few hours. She noted that hope gave her direction during her NICU experience. The following extracts support this subtheme:

- ***Dit het jou die hoop gegee vorentoe en jy het geweet daai kind gaan dit maak. Dit was my hoop gewees, vorentoe*** (lines 86–88). *It gave you hope going forward and you knew that the child was going to make it. It was my hope, going forward.*
- ***Jy sien die pad vorentoe vir die kind en hoe meer hy gesond raak hoe meer sien jy die pad en jy glo*** (lines 154–155). *You see the way ahead for the child and the more he heals the more you see the way and you believe.*
- ***Kry die image vorentoe. Wat sien jy van jouself en die kind en so dan sit en dink jy wat sien jy vir julle ...*** (lines 225–226). *Get the image forward.*

What do you see for yourself and the child and then you sit and think what you see for you all …

- When the participant worried about whether her child would survive and when she saw other babies die in the NICU she said it helped her to do the following: ***En dan sien jy elke dag … moenie dink aan maande nie, dink aan dag vir dag en dit het my gehelp. Partykeer het ek aan uur vir uur gedink*** (beduie met haar hande) (lines 227–228). *And then you see every day … do not think of months, think about day to day and that helped me. Sometimes I thought about hour by hour* (demonstrates using her hands).
- ***Want jy weet nie waarna toe om [uit] te sien as jy nie hoop het nie*** (line 498). *Because you do not know what to look forward to if you do not have hope.*

Throughout the literature that was reviewed, hope is described as a future-oriented construct. Bloch (1986), and also McCoy and Bowen (2015) maintain that hope creates future expectations, while Peterson and Seligman (2004) define hope as a future-oriented character strength and Seligman (2004) explains it as a way of thinking and motivating oneself towards the future. Scioli et al. (2011) describe hope as a future-oriented, multidimensional construct, and Abler et al. (2017) and Lopez (2013) maintain that people who have hope anticipate a positive future.

Hope is closely connected to our view of our future selves and our preparation for future change (Callina, Snow, & Murray, 2018; Kornadt, Voss, & Rothermund, 2015). This was confirmed by this study as Participant X defined hope as going forward and imagining the future.

4.4.1.3 Subtheme 1.3: Dynamic

Table 4.4 contains information about the definition, indicators and criteria of Subtheme 4.4.

Table 4.4: Dynamic

Definition	The state of continuously changing or developing (Cambridge University Press, 2008) The presence of constant movement (Collins English dictionary, 2014)	
Indicators	References to losing and building hope, passing and going back, and ups and downs	
Criteria	<u>Inclusion</u> References to the changing experience of hope	<u>Exclusion</u> A lack of references to the changing experience of hope

Participant X described hope as dynamic (see Table 4.4) and ever changing. She stated that when her child was sick she sometimes lost hope, but was able to regain it as she knew that the hardships would pass. She frequently spoke about the ups and downs of her NICU experience, which had a long-lasting effect. Verbatim quotes that support this subtheme are:

- ***Ja, dan kom die hoop weer. So jy het geweet half die goeie dae is daar*** (line 26). *Yes, then hope comes again. So you knew the good days were there.*
- ***… kind is so erg siek … dan verloor jy maar hoop, maar jy bou hoop weer op (beduie met hande hoe dit opgaan)*** (lines 101–102). *… the child is so sick … then you lose hope, but you build up hope again (uses hands to show how it goes up).*
- ***Soos daai tyd was dit negatief en dan kom dit positief*** (lines 129–130). *Like at that time it was negative and then the positive comes.*
- ***So ons het die ups en downs, maar dis meer ups as wat ons die downs het (knik kop)*** (lines 272–273). *So we have the ups and downs, but more ups than we have downs (nods head).*
- ***… jy kry maar jou ups en downs [in hoop] … maar jy kom eintlik sterkter uit [in jou hoop]*** (lines 528–529). *… you get your ups and downs [in hope] … but you actually come out stronger [in your hope].*

As is the case in Plaas' (2007) model, the participant in this study recognised the dynamic nature of hope in the NICU. She described the ups and downs of building

and losing hope. Plaas (2007) states that these different experiences of hope are in constant interplay as the NICU is a context filled with uncertainty. According to the same study, hope can increase and decrease as conditions change over time, and seems to increase as mothers move closer to being discharged. Participant X also mentioned that she had been the most hopeful when she heard that she was being moved out of the NICU to the next ward.

Some hope theorists differentiate between different types of hope. Weingarten (2010) argues that reasonable hope can coexist within doubt, contradictions and despair. A strong feeling of hope may be present despite grim circumstances and may persist during ups and downs, as expressed by the participant in this study. Such hope was expressed in the Subtheme 1.4.

4.4.1.4 Subtheme 1.4: Survival skill

Table 4.5: Survival skill

Definition	The state or fact of continuing to live or exist, typically in spite of difficult circumstances (HarperCollins, 2004; Survival skill, n.d.). According to Scioli et al. (2011), the survival component of hope is an individual's terror-management capacity.	
Indicators	References to survival or 'making it'	
Criteria	<u>Inclusion</u> Data referring to hope as a survival mechanism or last resort	<u>Exclusion</u> Data referring to any function or purpose of hope other than survival

Participant X described hope as a survival skill (see Table 4.5) and believed that without hope neither she nor her baby would have made it. She stated that hope was the most important thing and to keep hoping was her only option during this time. The following quotes prove this theme:

- ***Sonder hoop sou nie een van ons twee dit survive het nie*** (lines 97–98). *Without hope, neither of us two would have survived it.*
- ***… maar dis al wat jy kan doen … jy kan maar net hoop*** (line 277). *… because it is the only thing you can do … you can just hope.*
- ***Want as jy nie hoop het nie, wie maak dit? Nie jy of die kind nie (skud haar kop). Die hoop is die belangrikste deel ...*** (lines 277–278). *Because if you do not have hope, who will make it? Neither you nor the child (shakes her head). Hope is the most important part ...*

Scioli et al. (2011) also include survival in the conceptualisation of hope, which connects with the findings of this study. They theorise that hope encompasses survival in that it draws on coping strengths and weaknesses (Scioli, Aceto, Cofrin, Martin, & Holloway 2000). Plaas (2007) states that when the NICU mothers did not know where to turn to or what to do, they turned to hope to get them through the experience. Participant X also described hope as a type of survival when she mentioned that it had, at times, been her only option.

4.4.2 THEME 2: INTERNAL RESOURCES OF HOPE

The concept internal resources of hope refers to the individual as the agent of goal-attainment cognitions (Bernardo, 2010). These resources were provided by the participant and consisted of her personal beliefs and actions. Under this theme, the following subthemes were identified: belief in the child, acts of nurture, supporting and encouraging other NICU mothers and personal spirituality.

4.4.2.1 Subtheme 2.1: Belief in the child

The definition and boundaries of this subtheme is presented in Table 4.6.

Table 4.6: Belief in the child

Definition	To have firm faith, confidence, or trust in the NICU infant's ability to survive the NICU experience (Nunberg & Newman, 2011)	
Indicators	References made to her hoping for the best, believing in her child, seeing her child as a miracle, seeking the light	
Criteria	<u>Inclusion</u> References to the participant's belief that things would work out well, hoping for the best	<u>Exclusion</u> Positive thoughts and actions of people other than the participant. Negative or neutral thoughts about the infant and the NICU experience

She experienced hope by believing that her child would make it through the NICU experience. Even when things seemed hopeless, she still hoped for the best. She described her child as a miracle. These quotes sustain this subtheme:

- ***En as hy (Baba X) agteruitgaan, dan het jy nogsteeds gehoop vir die beste en dan maar gewag*** (lines 14–15). *And if he (Baby X) regressed, you still hoped for the best and then just waited.*
- ***Ek sal sê glo in jou kind, glo in jou kind. Dis 'n miracle en hy sal daardeur kom (kry trane in haar oë)*** (lines 107–108). *I would say believe in*

your child, believe in your child. It's a miracle and he'll get through it (starts to get tears in her eyes).

- ***Want as ek nie in hom (Baba X) geglo het nie sou hy nie hier gewees het nie (skud kop)*** (lines 141–142). *Because if I hadn't believed in him (Baby X), he would not been have here (shakes her head).*
- ***Jy soek die lig, maar soos ek sê as jy in daai kind van jou glo … Hy gee vir jou die lig*** (lines 151–152). *You are looking for the light. But as I say, if you believe in that child of yours … He gives you the light.*
- ***Elke keer wat ek in hom geglo het, het hy net beter en beter geraak (beduie vordering met hande)*** (lines 183–184). *Each time I believed in him he just got better and better (demonstrates progress with hands).*
- ***Kyk watse wonderwerk is dit [dat haar baba dit oorleef het]*** (lines 318–319). *Look at what a miracle it is [that her baby had survived].*

In line with the findings of this study, Rossman, Greene, and Meier (2015) state that it is important for mothers to believe in their NICU infants even when conditions take a turn for the worst. They found that when mothers were rooting for their babies they were more capable of dealing with the challenges experienced within the NICU context. Plaas (2007) also found that when mothers believed that their children would survive the NICU, they experienced confidence and hope. She also states that it is important for mothers to believe in their infants' ability to overcome temporary setbacks. Lindberg and Öhrling (2008) found that when mothers realised that their children could survive and believed that they would, it gave them the strength to cope. Grosik, Snyder, Cleary, Breckenridge, and Tidwell (2013) maintain that if parents could remain optimistic about their NICU infants, hope could be regained.

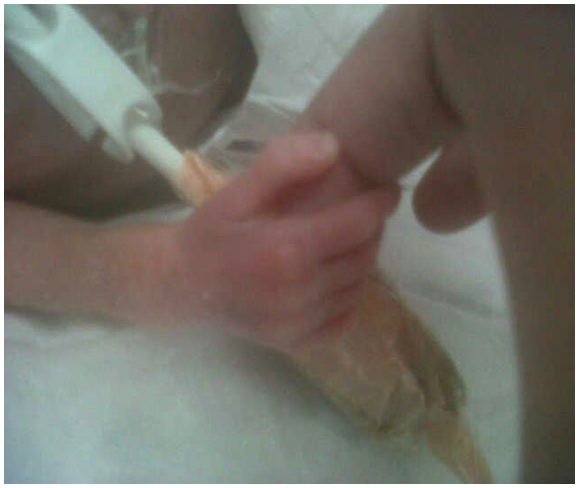
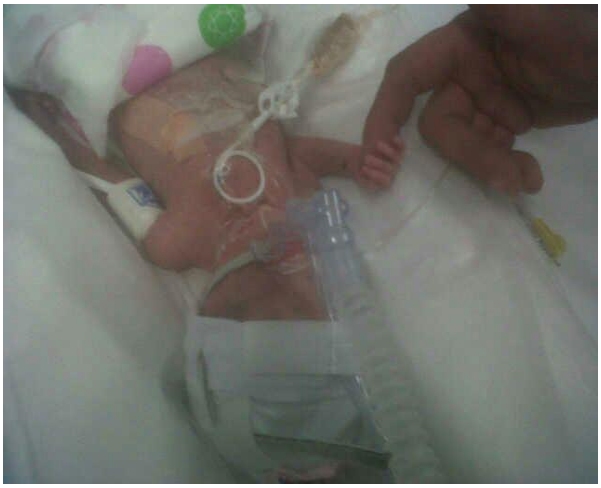
4.4.2.2 Subtheme 2.2: Acts of nurture

Table 4.7: Acts of nurture

Definition	To take care of, or to protect someone or something (Cambridge University Press, 2008). Something that nourishes, for instance to feed or support (Collins English Dictionary, 2014).	
Indicators	References made to nurturing acts like singing, kissing, feeding and holding her infant	
Criteria	<u>Inclusion</u> Any act that involves the participant caring for or nurturing her own child	<u>Exclusion</u> Any reference to an act not related to the participant caring or nurturing her infant. Acts of caring for or supporting other NICU mothers and their infants. Nurturing acts performed by the medical staff

During the interview, Participant X described how nurturing activities (see Table 4.7) provided her with hope during the NICU experience (see Photograph 4.1 & 4.2). She talked about singing to her child and said that this had been their special time alone. She stated that while she sang, smiled, fed or held her child, she felt more hopeful. She also mentioned how she regularly went to check up on him and gave him kisses, which also increased her experience of hope. Sometimes she held him and looked at him with pride and did not want to let him go. Even when she was very tired, she still got up to feed her child and she felt that these nurturing activities sustained her. It was as if by nurturing her child, she was also nurturing her own hope. These acts strengthened her hope. The following quotes support this subtheme:

- ***… elke keer as ek vir hom 'n liedjie sing … dan voel ek rustig … So vir my was sing die beste*** (lines 46–48). *… every time I sang him a song … I felt calm… So for me singing was the best.*
- ***So hoe meer ek hom vasgehou het en gesing het, dit het my gehelp* (glimlag)** (line 48). *So the more I held him and sang, it helped me (smiles).*
- ***En elke keer as ek smile en ek hou die kind vas (sit hand op bors) dan het die kind se suurstof elke keer stabiel gebly en van daar af het hy begin gewig optel en hy het net beter geraak*** (lines 212–214). *And every time I smile and I hold the child (puts hand on chest), the child's oxygen stayed stable every time, and from there he started to gain weight and he just got better.*
- ***Dan stap ek elke uur op en dan gaan check ek en gee hom 'n soentjie en dan loop ek weer af*** (lines 229–230). *Then I walk up every hour and then I go and check and give him a kiss and then I walk down again.*
- ***Jy wil hom net daar vashou en hom nie laat gaan nie*** (line 234). *You just want to hold him and not let him go.*
- ***… elke halfuur moes ek mos gaan melk gee … dit het my deurgedruk*** (lines 242–243). *… I had to go to give milk every half-hour … that carried me through.*
- ***… maar jy staan op vir daai kind, maak nie saak hoe moeg jy was nie*** (lines 245–246). *… but you got up for that child, no matter how tired you were.*

	
Photograph 4.1: Participant X holding her infant's hand in the NICU	**Photograph 4.2: Participant X holding her infant's hand in the NICU**

Several other studies (Bigelow et al., 2010; Herbst & Maree, 2006; Khoza & Ntswane-Lebang, 2010; Labuschagne, 2015; Leonard & Mayers, 2008; Lubbe, 2005; Mabe et al., 2015) confirm the finding of this study that it is very important for NICU mothers to bond with their babies. When mothers interact with their premature infants, they feel more in control and have more confidence (Wigert et al., 2006). Gooding et al. (2011) also found that a parent's presence and participation in caring for and nurturing an infant seems to increase positive emotions in the NICU.

By encouraging physical contact between a mother and baby, the mother's active participation in the care of her infant can be promoted, which can in turn provide a sense of involvement, bonding and hope (Carvalho et al., 2009). The development of their maternal identity can be promoted if mothers are included in the daily care of their premature infants (Wigert et al., 2006).

Bigelow et al. (2010) researched the impact of skin-to-skin contact with a premature baby on maternal sensitivity and found that it seemed to increase maternal sensitivity, decrease depression and helped with attachment and bonding.

As seen in the findings of this study, it is important to allow the mother time to bond with her baby. Bonding or nurturing activities have a positive impact on the mother's emotional state. Singing, kissing, holding, breastfeeding and caring for the infant increased the mother's feelings of hope. In support of the important role of nurturing activities in increasing mothers' feelings of hope, Plaas (2007) found that one thing that stood out as prominent in the mothers' hope-experiences was the intense need to feel like a mother. Like Participant X, the mothers in Plaas' study had the desire to

feed and care for their infants, and when they were given a chance to do so it increased their sense of hope.

4.4.2.3 Subtheme 2.3: Supporting other NICU mothers

The definition of indicators and criteria of this subtheme is discussed in Table 4.8.

Table 4.8: Supporting other NICU mothers

Definition	The provision of reassurance, acceptance and encouragement in times of stress to other NICU mothers (Miller-Keane & O'Toole, 2003). T act of helping or encouraging others in order to let them succeed (Cambridge University Press, 2008; Mosby's medical dictionary, 2006)	
Indicators	The participant's references to praying with and for the other NICU mothers, showing them how to care for their infants, and other acts and words aimed at encouraging them	
Criteria	<u>Inclusion</u> Participant X's acts or words intended to support and encourage the other NICU mothers	<u>Exclusion</u> NICU staff, other NICU mothers or family members' acts or words of support and encouragement to help the participant. Personal spiritual activities or religious engagement.

Participant X mentioned how she had prayed with and for other NICU mothers. She also motivated them by comparing their infants' progress to that of her own infant to make them feel better. She told them that if her baby could make it, theirs could as well. During her hospital stay she helped other mothers by showing them how to care for their babies. The following verbatim quotes from the participant validate this subtheme:

- ***Ek het baie saam met hulle*** [die ander NICU ma's] ***gesit en saam met hulle gebid en vir hulle gesê moenie ophou bid nie*** (skud kop) (lines 187–188). *A lot of times I sat and prayed with them [the other NICU moms] and told them not to stop praying (shakes head).*
- ***Partykeer as hulle nie geweet het [wat om te doen] nie, dan het ek gesê, kyk my kind, hoe was my kind … omdat ek so lank gelê het … vier maande en hulle maar twee, drie maande daar, dan het ek gesê kyk hoe was hy, kyk hoe klein was hy, moenie dit [hoop] verloor nie*** (lines 188–190). *Sometimes if they did not know [what to do] then I said, look at my child, how my child was ... because I laid there for so long ... four months and they only two or three months, then I said look at how he was, look how small he was, do not lose it [hope].*

- ***… elke keer het die susters gesê: 'Wys vir hulle [ander NICU ma's] as hulle sukkel' en dan sê ek: 'Okay, bring gou die mamma' en dan het ek vir die mamma gewys*** (lines 247–248). *… every time the sisters: 'Said show them [other NICU moms] when they struggled' and then I said: 'Okay, quickly bring the mom,' and then I showed the mom.*
- ***… ek onthou dan moet ek altyd vir die mamma wys hoe moet ek die doeke sny*** (wys met haar hande) ***… hulle het so gelag en dan gaan hulle na hulle kind toe en dan sê hulle dit het hulle dag gemaak en so dan elke keer het hulle so positief geraak en hulle kinders het voor hom*** [Baba X] ***huis toe gegaan …*** (lines 198–202). *… I remember then I always showed the mom how to cut the nappies* (demonstrates with her hands) *… then they laughed and then they went to their child and then they said it made their day and so every time they became so positive and their children went home before him* [Baby X].

Wigert et al. (2006) found that mothers in the NICU often feel as if they do not belong. They find it difficult to relate to mothers who have their infants with them. When mothers in the NICU support each other, they can relate to someone who has gone through the same experience (Carvalho et al., 2009). According to Rossman et al. (2015), peer support in the NICU can help mothers to normalise their experience. Parents in the NICU can offer valuable information and advice to one another (Labuschagne; 2015; Leonard & Mayers, 2008).

Former NICU parents can volunteer to provide bedside or telephone support (Gooding et al., 2011). Mothers can talk to one another about the different stages of their infants' development and can receive guidance that is tailored to the specific phase that they are going through (Carvalho et al., 2009). According to the Family-centred Model, the support of other NICU parents can positively influence parental coping and parent-infant interactions (Gooding et al., 2011).

As indicated by the findings of this study, NICU mothers often find comfort in communicating with other mothers who are in the same situation. This type of interaction can provide them with positive expectations and a sense of hope. The research results for this subtheme illustrate Participant X's attempt to offer hope to others (Bernardo, 2010). By providing support and encouragement to other NICU mothers, she might have enhanced "collective hope experiences" (Elliott & Sherwin, 1997, p. 121).

4.4.2.4 Subtheme 2.4: Personal spirituality

Table 4.9 summarised personal spirituality as a subtheme and lists the indicators and inclusion and exclusion criteria.

Table 4.9: Personal spirituality

Definition	Spirituality is transcendence, eternal truths and a person's reference to a higher power (Scioli et al., 2011). The transcendent is that which is outside of the self, and yet also within the self – and in Western traditions often relate to God or a higher power (Koenig, 2012).	
Indicators	References to Participant X's praying, believing and trusting that she will get her answers in the afterlife	
Criteria	<u>Inclusion</u> Data referring to Participant X's own spiritual acts or beliefs	<u>Exclusion</u> Praying, specifically for other NICU mothers, as a form of support. Spiritual acts performed by other people or the religious leader

Participant X stated that she frequently prayed and hoped for the best throughout her NICU stay. She also mentioned that although she did not have all the answers and regretted not having held her baby's twin who had passed away, she believed that one day (in Heaven) she would receive all the answers. The following quotes confirm this subtheme:

- ***So dit was bietjie baie erg, maar elke keer het jy maar net geglo en gebid en gehoop … vir die beste*** (lines 10–11). *So it was quite, bad but every time you just believed and prayed and hoped … for the best.*
- ***Ja, [ek het] gereeld gebid …*** (line 177). *Yes, [I] frequently prayed*
- ***Maar ek sê vir myself jy sal nooit weet nie, tot eendag wat jy daar bo is dan sal jy weet*** (lines 442–443). *But I tell myself you will never know, until one day when you are up there you will know.*
- ***Tot jy eendag daar bo is dan sal jy maar jou antwoorde kry*** (lines 445–446). *Until you get up there one day, then you will only get your answers.*

According to Fredrickson (2000), holding a religious belief or focusing on one's spirituality increases a sense of meaning and positively correlates with mental wellbeing. In line with the findings of this study, Plaas (2007) also reports on how NICU mothers turned to a higher power in times of uncertainty in the NICU. Although Plaas (2007) states that while selected mothers made reference to prayer, spiritual

feeling, or a belief in God or a higher power, it was clear that the presence of hope was dependent on religiosity.

Boss, Hutton, Sulpar, West, and Donohue (2008) found that parents in the NICU often based their decision-making on faith and spirituality. In the same study, many parents also reported that their baby's fate was in God's hands. These parents often found hope and comfort in reading spiritual passages and praying to God while in the NICU.

Green (2015) found that parents in the NICU were often so desperate that the only thing they had to hold on to was praying for a miracle. Brelsford and Doheny (2016) agree that when parents' worldview was based on faith and spirituality it seemed as if they were better equipped to deal with their infant being in the NICU. Faith and prayer were important sources of hope for Participant X during her NICU experience.

4.4.3 THEME 3: EXTERNAL RESOURCES OF HOPE

External resources of hope refer to significant others and external forces as agents of hope. These resources of hope are represented by the external contributions of family, peers and supernatural/spiritual beings or forces (Bernardo, 2010). The following subthemes were identified in this category: symbols of hope, caring medical staff, support from family and friends, improvement in Baby X's health and religious engagement.

4.4.3.1 Subtheme 3.1: Symbols of hope

Table 4.10: Symbols of hope

Definition	Hope being provided by something that serves as a representation of a particular instance of a broader pattern or situation (Nunberg & Newman, 2011)	
Indicators	References to the laughing toy, her deceased son's ashes, sensing the presence of the twin that passed away, hand- and footprints, photos or the symbol of the sparrow	
Criteria	Inclusion Symbols that provided her with hope within the NICU or hospital	Exclusion Non-symbolic resources of hope

Participant X often mentioned the symbolic sources of hope (see Table 4.10). She referred to her late son's ashes, a toy that starts laughing at random hours during the

night, sensing the presence of her son that passed away, the prints of her son's hand and foot, and the symbol of the sparrow. The symbol of sporrow is illustrated by photographs provided by the participant (see photograph 4.3, 4.4, 4.5, 4.6 & 4.7). This subtheme is presented by the following verbatim quotes from my interview with Participant X:

- ***Soos jy sien die foto'tjie wat ons daar gehang het met sy voetjies [afdrukke] en toe het ons hom [die ander tweelingboetie wat gesterf het] veras. Maar die ding is die verassing is nog steeds hier by ons … So hy bly by ons …*** (lines 326–329). *As you see, the photo we hung there with his feet [footprints] and then we cremated him [the other twin that passed away]. But the thing is the ashes are still here with us. So he stays with us …*
- ***En dan sit ons hom [die speelding] hier voor (wys na waar die speelding was) en dan hoor jy die ding lag … Dan sit ons hier en neem video's maar al wat jy sien is so donker wolkie*** (beduie donker wolkie se vorm) ***by dit maar dan is dit so wit om dit en dan is dit soos weet jy wat die kleintjie*** [die baba wat oorlede is] ***is hierso*** (lines 334–338). *And then we put it [the toy] up here in front (shows where the toy was) and then you hear the thing laugh … Then we sit here and take videos, but all you see is a little dark cloud* (demonstrates the shape of the cloud) *next to it, but then it's white around it and then it's like you know that the little one* [the baby that passed away] *is here.*
- ***En elke keer wat hy in die hospitaal was of in ICU was, was daar 'n mossie en as dit swak gegaan het het die mossie by hom*** [Baba X] ***gevlieg*** (lines 342–343). *And every time he was in hospital or in ICU, there was a sparrow and if it did not go well, the sparrow flew towards him* [Baby X]
- ***En elke keer as daar 'n mossie gevlieg het, het Baba X beter geraak. Ons glo die boetie van hom is in die mossie (glimlag)*** (lines 345–346). *And every time a sparrow flew by, Baby X got better. We believe his brother is in the sparrow* (smiles).
- ***… elke keer toe hy in daai saal was, was die mossie onder sy bed*** (line 356). *… every time when he was in that ward, the sparrow was under his bed.*
- ***Kyk die mossie sal daar sit en hy sal nie move nie*** (skud haar kop)***, dan is hy onder sy bed en dan klim hy op en dan is hy by sy kop en sodra hy wegvlieg, dan is daai kind fine*** (lines 357–359). *The sparrow will sit there and not move (shakes her head), then he is under his bed and then he*

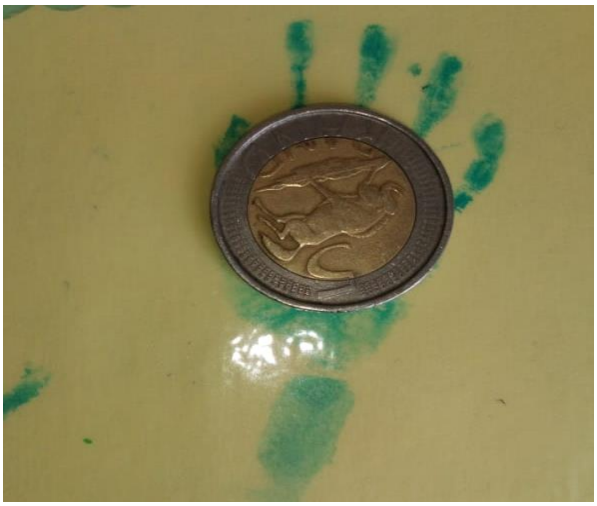
will climb up and then he is at his head, and as soon as it flies away, then this child is fine.

- ***So ons glo die boetietjie is in die mossie en dis hoe ons maar ons hoop het*** (lines 361–362). *So we believed that the little brother is in the sparrow and that is how we have hope.*
- ***Elke keer as die mossie daar is dan is hy gesond en dan geen probleme*** (lines 362–363). *Every time when the sparrow is there, then he is healthy and there are no problems.*
- ***Veral in ICU as ek daai mossie gesien het, my hoop het so hoog gegaan, ek dink nie dit kan hoër as dit gaan nie*** (lines 369-370). *Especially in the ICU if I saw that sparrow, my hope went so high, I do not think it can be higher than it was then.*
- ***… as daai mossie terug is dan weet jy daar is meer hoop. So die hoop het met die mossie ook gebou …*** (line 372–373). … *if that sparrow is back then you know there's more hope. So the hope was also built by the sparrow …*
- ***Daai mossie was, ek sal sê hy was die meeste wat die hoop vir ons gegee het eintlik*** (lines 375–376). *That sparrow was, I'd say he was the one that gave us the most hope.*
- ***So ons versamel nou die een sentjies en papiertjies wat ons versamel met die mossies op …*** (lines 394–395). *So we now collect the one-cent coins and papers with the sparrow on …*
- ***Sy foto's het ons nou omring, baie van sy ICU foto's met die mossietjies, wat ons weet hy baie swak was en die mossietjie was daar en hy het verbeter*** (lines 395–397). *His photos are now surrounded by it, many of his ICU photos with the sparrows, which we know he was very weak and the sparrow was there and he improved.*

Photograph 4.3: The presence of the sparrows in the NICU

Photograph 4.4: The presence of the sparrows in the NICU

Photograph 4.5: The size of Baby X's hand and foot compared to a R5 coin



Photograph 4.6: The size of Baby X's hand and foot compared to a R5 coin

Photograph 4.7: Participant X now collects one-cent coins that depict sparrows

Caldeira and Hall (2012) mention that parents sometimes place religious objects in their baby's incubator. Levick, Fannon, Bodemann, Munch, and Ahern (2017) found that NICU parents often feel a need for tangible memorabilia as reminders of to their NICU experiences. The infant's clothes, photographs, a lock of hair or other NICU

keepsakes can help them to overcome the trauma that they experienced within the NICU (Fanos, Little, & Edwards, 2009). Akard et al. (2018) found that, like the mother in this study, mothers generally found some hope and comfort in having symbols to remind them of their NICU experiences, such as the hand- and footprints of their NICU infant.

This links to the insight that was provided by Participant X on the role that symbols of hope played in her NICU experience. She mentioned many symbols, but the most recurrent symbol of hope, and according to her probably the most important, was the presence of a sparrow.

4.4.3.2 Subtheme 3.2: Caring medical staff

Table 4.11: Caring medical staff

Definition	An interpersonal process involving an emotional commitment to, and a willingness to act by an organised body of licensed physicians and other health care providers who are permitted by law and by a hospital to provide medical care within that hospital or facility (adapted from Medical staff, 2018; Miller-Keane & O'Toole, 2003).	
Indicators	References to advice received from nurses, quality care, encouragement and emotional support given by any medical staff member	
Criteria	<u>Inclusion</u> Any action by doctors and nurses or advice given by them that motivated and supported her	<u>Exclusion</u> Support from non-medical staff

Participant X stated that the caring medical staff (see Table 4.11) helped her more than she actually expected. They made her feel strong and she experienced hope when she saw how they cared for her child. Even when she thought her child had passed away, the nurse intervened. She stated that her hope was strengthened when her infant made it through with their help. When she cried, the nurse would comfort her, helping her to keep hope alive. The following extracts from the interview support this subtheme:

- ***Hulle het my eintlik baie meer gehelp as wat ek gedink het. Hulle het my eintlik laat sterkter voel*** (line 31–32)*. They actually helped me much more than I thought. They actually made me feel stronger.*
- ***So jy het eintlik baie hoop gekry om te sien. Hoor hier, hulle help jou en die kind raak beter*** (lines 36–37). *So you really got a lot of hope to see. Look here, they help you and the child gets better.*

- ***… van daar af het ons hoop weer bietjie meer gegroei waar die suster wys … die kind*** [Baba X] ***kan dit maak*** (lines 72–73). *… from there the hope started to grow a little more when the nurse showed … that the child* [Baby X] *could make it.*
- ***Daai suster het my goed gehelp daardeur. Elke keer as ek wil huil dan sê sy vir my: 'Nee, moenie huil nie, relax, smile'*** (wys met haar hande om te kalmeer) (lines 211–212). *That sister helped me a lot through it all. Every time I wanted to cry then she said to me no do not cry, relax, smile* (demonstrates with her hands to relax).
- ***Ek is so dankbaar vir daai suster, sy het my gehelp*** (lines 214–215). *I'm so grateful to that nurse, she helped me.*

Like Participant X, the mothers in Plaas' (2007) study felt that they were being supported by the NICU professionals, which increased their sense of hope in the NICU. The mothers in Plaas' (2007) study described the NICU staff as supportive, positive and capable of looking after their NICU infants, and reported that the staff had really helped them during the NICU experience and that they had provided information in a positive and helpful manner, which is in line with the findings of the current study.

Plaas (2007) states that nurses who appeared to increase the mothers' hope in the NICU encouraged participation in caring for the infants and took the time to involve other family members. She also reports that some of the biggest challenges to hope reported by mothers occurred when they felt that they were being neglected by the NICU staff and when nurses treated them rudely and insensitively.

According to other literature on the NICU experience, it is evident that parents spend a lot of time with the medical staff and derive support from nurses and physicians (Herbst & Maree, 2006; Labuschagne, 2015; Leonard & Mayers, 2008; Mabe et al., 2015). Gooding et al. (2011) looked at the role of the NICU staff in creating a positive environment and found that while they are in hospital, it is important for families to receive appropriate support from medical staff and a multidisciplinary team. The same study recommended that medical staff should be trained to attend to the parents' physical and psychological needs. The family-centred model for care in the NICU included in the study by Gooding et al. (2011) encourages open and honest communication with parents and also encourages medical staff to adapt the medical care to the family's structure and cultural beliefs.

When mothers in the NICU feel that they receive personalised care from the medical staff it increases their coping abilities (Cleveland & Horner, 2012). The mothers in the same study described personalised care as caring nurses that made them feel comfortable and shared personal information with them. NICU mothers in a study by Wigert et al. 2006) stated that individualised care and the provision of adequate information by the medical staff were very important to them. Their positive feelings increased when they felt that they were being included and were seen as unique individuals with unique needs.

As seen in my study, Participant X also described the important traits of nurses that enhanced her hope experiences in a similar way. She mentioned that they helped her to take care of her child, cared about her emotional wellbeing, encouraged her in the difficult times, kept her relaxed and positive and taught her how to focus on the moment and not to get ahead of herself. A new insight is that the nurses encouraged her to help and encourage other mothers, which possibly also enhanced the hope experiences of those mothers.

4.4.3.3 Subtheme 3.3: Support from family and friends

See Table 4.12 for the definition, indicators and criteria of Subtheme 3.3.

Table 4.12: Support from family and friends

Definition	Support: To prevent weakening or failing; an arrangement that helps keep something else functioning (Mosby's medical dictionary, 2006) Family: A group of people related by blood or marriage, or a strong common bond, such as those descended from a common ancestor, or a husband and wife and their children (Miller-Keane & O'Toole, 2003). Friends: The people you know, like and trust (American Heritage Dictionary of the English Language, 2011).	
Indicators	References to support from her fiancé, the grandmother and her family and friends	
Criteria	<u>Inclusion</u> Verbal, emotional and physical support and encouragement from her fiancé, family, extended family and friends	<u>Exclusion</u> Support from medical staff, other NICU mothers or any persons other than family members or friends

Participant X reported how her fiancé in particular, and also the grandmother, made her feel more hopeful. Messages of support and encouragement received from other family members and friends also helped to carry her through. The following quotes validated this subtheme:

- ***Die hoop was daar … veral die pa, hy het die meeste hoop gehad*** (lines 92–93). *The hope was there ... especially the dad, he had the most hope.*
- ***En dan kom hy*** [die pa] ***af en dan praat hy my weer hoop in … En die ouma ook, sy het ook altyd gekom en gehelp …*** (line 168–169). *And then he comes down and then he [the father] talks hope into me … And the grandmother too, she also came and helped.*
- ***… ons het baie familie gehad. Familie het my altyd gewhatsapp en gebel en gesê sterkte en stuur net soentjies vir die kleintjie en ons dink aan julle*** (lines 177–179). *... we had a lot of family. Family always whatsapped me and phoned me and said good luck and send kisses to the little one and we are thinking of you.*
- ***So ons het mense gehad van naby en ver wat ons daardeur gedruk het en veral die pa ook*** (lines 179–180). *So we had people from near and far who pushed us through and especially the father too.*
- ***Daar was baie oulike boodskappies en so het ons deurgedruk*** (lines 180–181). *There were many nice messages and so we pushed through.*

Plaas (2007) identifies hope and the role of others in encouraging hope as one of the core aspects of hope and emphasises the significant impact that the interest and concern of partners, family and friends has on the hope experiences of NICU mothers. This corresponds with what Participant X said about how much NICU mothers depend on emotional support from their partners and families, and how they appreciate encouraging messages. Grandmothers often helped NICU mothers by taking care of their other children at home. Plaas (2007) mentions that some of the mothers who participated in her study had felt distant from their partners during the NICU experience, and that this had affected their ability to remain hopeful. According to Participant X, it was her partner/fiancé who was the most hopeful and whose positive attitude increased her capacity for hope.

According to Cleveland and Horner (2012), family is an important source of social support for mothers in the NICU. Family cohesion and expressiveness correlates positively with mental wellbeing in the families of chronically ill children and cancer survivors (Fredrickson, 2000; Shaw et al., 2006). In a study by Cleveland and Horner (2012), the importance of familial support was identified in Mexican NICU mothers. It was found that the families provided the mothers with a tight-knit support system and a familiar environment. The importance of the support of family was also found to be crucial at the time of discharged. In the current study, the participant experienced hope when she felt connected to, and supported by the people around her.

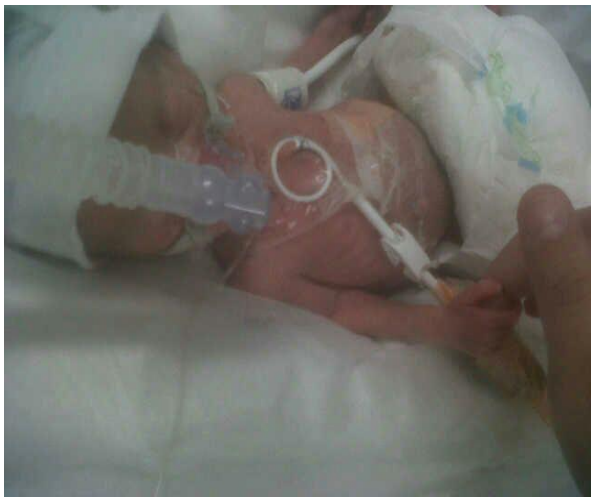
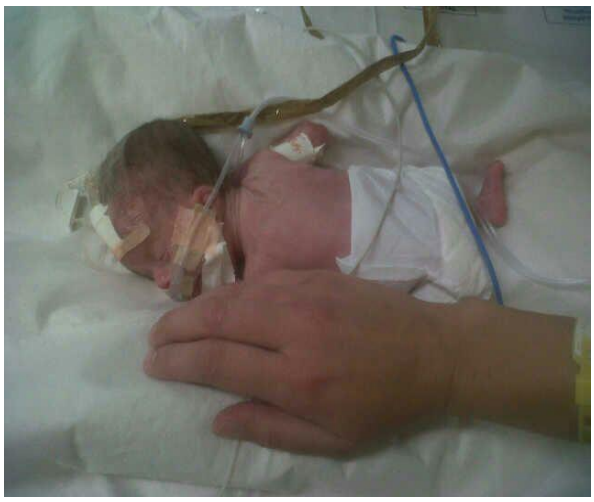
4.4.3.4 Subtheme 3.4: Health improvement

Table 4.13: Health improvement

Definition	Health: The state of being bodily and mentally vigorous and free from disease (Health, n.d.). Improvement: The act or process of making better (Improvement, 2018).	
Indicators	References to health improvement, such as receiving good news about her medical condition or being moved out of the NICU to the next ward	
Criteria	<u>Inclusion</u> Any reference to an improvement in her son's medical condition	<u>Exclusion</u> Any reference to medical regression or the improvement of the conditions of other NICU infants

Participant X described how she had become more hopeful after her infant's health improvement (see Table 4.13) and receiving good news about her infant's medical condition. It helped her to realise that her child was making progress. When she saw changes like his weight gain or the increased size of his feet, she was motivated (see photograph 4.8 & 4.9). She stated that she was the most hopeful when she was told that she would be moved out of the NICU to high care and from there to a regular ward.

- ***Elke keer as hy weer beter raak dan hoop jy hy gaan net sterker word*** (lines 13–14). *Every time he gets better you just hope he gets stronger.*
- ***So elke keer as jy die goeie nuus hoor dan weet jy jou kind vorder. So jy het hoop gekry. Na elke goeie nuus is die hoop net sterker*** (glimlag) (lines 23–34)*. So every time you hear the good news you know your child is progressing. So you received hope. Every time after good news, the hope is just stronger (*smiles*).*
- ***[Die hoopvolste oomblik gedurende die hospitalisering] was toe hulle vir ons gesê het ons gaan uit ICU uit en ons gaan High Care toe. En toe hulle sê jy maak reg ons skuif jou na Saal 4*** (lines 76–77). *[The most hopeful moment during my hospital stay] was when they told us we were leaving the ICU and going to High Care. And when they said: Get ready, we are moving you to Ward 4.*
- ***… partykeer is jy van: 'Kom boetietjie … tel net daai een of twee grampies op!,' so jy het hom altyd aangemoedig*** (lines 261-262). *… sometimes you're like: "Come on 'boetietjie,' just pick up one or two grams!," so you always encouraged him.*

	
Photograph 4.8: Baby X in the NICU	**Photograph 4.9: Baby X in the NICU**

Yam and Au (2004) note that a lack of improvement in their NICU infants' medical conditions can cause extreme distress in the mothers. According to Khoza and Ntswane-Lebang (2010), it is common for NICU mothers to feel uncertain and worried, but that once they see that their infants are gaining weight and are suffering fewer health complications, their fear changes to joy and affection.

Plaas also states that when infants recovered from surgery or near-fatal infections and respiratory failure, the mothers experienced a sense of hope. According to Plaas (2007), a mother would often set benchmarks for her child's improvement by using the current milestones to establish whether the infant has made progress or not. These benchmarks are resources of hope as they bring the ultimate goal, which is to be discharged, within sight.

4.4.3.5 Subtheme 3.5: Religious engagement

Table 4.14: Religious engagement

Definition	Religion is a multidimensional construct that includes beliefs and engagement in specific behaviours, rituals and ceremonies, and actions that include attendance of religious services, private religious activities like prayer meetings or Bible study, being reflective of greater religious commitment (Koenig, 2012).	
Indicators	Prayer or religious activities provided by the pastor	
Criteria	<u>Inclusion</u> References to religious ceremonies led by a religious leader	<u>Exclusion</u> Personal religious activities and prayers for herself and other mothers

Participant X mentioned the importance of the presence of a religious engagement (see Table 4.14) when her son's condition took a turn for the worst. She stated that once the religious leader had prayed for her infant, his medical condition improved within three hours and he was healthy. These extracts from the interview formed this subtheme:

- ***Ons het 'n dominee ook gehad op 'n tyd toe die tyd baie erg was met hom*** (lines 169–170). *We also had a pastor at a time when the time was very bad with him.*
- ***Toe hy 11 infeksies gehad het toe sê hulle vir my 'n uur tops dan is hy dood, want toe is hy op die ventilator en hy is op 100% [suurstof] en hy bly afgaan. Toe het ons 'n dominee gekry en hy het gebid en drie ure na die tyd kom die susters en roep my en sê: 'Weet jy wat, jou kind is van die ventilator af' … en toe is hy net so gesond*** (lines 172–175). *When he had 11 infections then they told me an hour tops then he'll be dead because he was on the ventilator and he is on 100% [oxygen] and he keeps on dropping. Then we got a pastor and he prayed and three hours afterwards the sisters came and called me and said: 'You know what, your child is off the ventilator' ... and then he was healthy just like that.*

Rosenbaum, Smith, and Zollfrank (2011) point out that medical care should not focus only on the physical needs of NICU parents, but should also incorporate their spiritual needs. Caldeira and Hall (2012) found that a pastoral counsellor would be an important asset in the NICU. According to Boss et al. (2008), parents are often not satisfied with the NICU conditions and if they do not feel supported they mostly turn to their spirituality in this time of need.

It is clear that in the case of Participant X, religious engagement with the pastor played an important part in her ability to deal with the challenges that she faced in the NICU. Faith seemed to play a crucial role in her ability to remain hopeful that her premature infant would recover. Caldeira and Hall's (2012) research showed that parents in the NICU often resort to religion as a coping mechanism.

4.4.4 THEME 4: SHORT-TERM CHALLENGES TO HOPE

Short-term barriers to hope refer to challenges that Participant X experienced during her NICU stay and which had a negative effect on her hope experiences in the hospital setting. These events occurred during her time of hospitalisation. Subthemes

included in this theme are: medical complications, adverse events during hospitalisation and physical exhaustion.

4.4.4.1 Subtheme 4.1: Medical complications

Table 4.15: Medical complications

Definition	A disease or injury that develops during the treatment of a pre-existing disorder. This complication frequently alters the prognosis (Mosby's medical dictionary, 2006). Any adverse or undesired result of disease management (Stedman, 2012).	
Indicators	References to the infant's medical condition and illnesses. Receiving bad news about her son's medical condition. Hearing that her son is not going to make it. Other medical treatments, such as operations and oxygen supply. References to her son's slow development in the NICU; an infection; thinking that he had died; not knowing whether her child was going to make it; his bleeding on the brain; heart problems; being worried.	
Criteria	<u>Inclusion</u> Any infection, illness or medical procedure performed on her infant during hospitalisation. Bad news from medical staff and infant's slow development in the NICU.	<u>Exclusion</u> Data linked to other infants' medical complications; medical progress; data relating to the child's current medical challenges outside the NICU; medical challenges and death of her baby's twin brother or other NICU infants

Participant X stated that she felt least hopeful when her infant experienced medical complications (see Table 4.15). She reported that at times her son was very sick and doctors warned her that he might not make it. Other medical complications that had a negative effect on her levels of hope were when he contracted a lung infection, when the medical staff told her that he had passed away, the times when his oxygen levels dropped and his heart did not grow as it was supposed to, and when he had bleeding on his brain. He was also operated on when he was only four days old and she did not think that he would survive the surgery. At one time he had multiple infections and was on a ventilator for a long time. The following quotes led to this subtheme:

- ***Dan sê hulle hy is dood en dan is hy weer lewendig. Dat hulle dit vyf keer gedoen het …*** (lines 6–7). *Then they said he was dead and then he was alive again. That they did that five times …*
- ***… elke keer dan huil jy, want jy weet nie of jou kind dit gaan maak nie*** (line 8). *Each time you cry because you do not know whether your child is going to make it.*

- ***So daar het jy al klaar gedink jou kind gaan dit nie maak nie*** (skud haar kop en kyk af na die vloer) (lines 57–58). *So there you already thought your child was not going to make it* (shakes her head and looks down at the ground)
- ***Dit was die, die, die ergste vir ons almal toe hy 'n groot infeksie gehad het, die bloeding op die brein en die hartjie wat probleem gegee het en die ventilator is op 100% en toe verklaar hulle hom dood klaar 'n halfuur daar …*** (lines 68–70). *It was the, the, the worst for us all when he had a major infection, the bleeding on the brain and the heart that had a problem and the ventilator was at 100% and they declared him dead for half an hour there ...*
- ***Ja, daar was 'n paar keer wat ons hoop verloor het soos as hulle gesê het die kind maak dit nie dan het ons hoop verloor*** (lines 100–110). *Yes, there were a few times we lost hope like when they said the child is not making it then we lost hope.*
- ***Partykeer die kind is so erg siek… dan verloor jy maar hoop…*** (lines 101–102). *Sometimes the child is so sick … then you lose hope ...*
- ***… maar mens is nogsteeds bekommerd gewees veral omdat hy so klein was*** (line 549). *... but one was still, worried especially because he was so tiny.*

Akbarbeglou et al. (2009) mention that mothers in the NICU find it very stressful to see their infants in pain, or to see them undergoing medical procedures, for example intravenous or tube feeding. Participant X found it very stressful to witness her infant's operations and seeing him on ventilators and connected to tubes. Cleveland and Horner (2012) confirm that parents are most concerned about the illness of the baby, providing in the baby's needs and knowing how to care for it.

As stated in Chapter 2, NICU parents may experience shock due to the physical condition and appearance of the baby (Ionio et al., 2016). Most of the infants in the NICU are very underweight and are constantly connected to ventilators, heart monitors, intravenous (IVs) and other tubes. This may cause mothers to be reluctant to interact with their infants. My participant described her son's physical appearance in detail, remembering that she could see the blood in his brain; that he did not have any ears or buttocks, but had long, tiny fingers, and that she could see that his breastbones were not connected. She often compared her child to the other babies in the NICU and she worried about the fact that he was smaller than any of the others.

4.4.4.2 Subtheme 4.2: Physical exhaustion

Table 4.16: Physical exhaustion

Definition	An overwhelming sense of tiredness, lack of energy (Mills & Young, 2008). Feeling weak, tired or rundown (Etzion, 1984).	
Indicators	References to being tired due to the strict hospital routine	
Criteria	Inclusion Challenges during the hospital stay that referred to physical exhaustion and the strict routine in the NICU	Exclusion Other adverse events during hospitalisation that were not related to physical exhaustion

Participant X referred to the challenge of physical exhaustion (see Table 4.16) a couple of times during the interview. She remembered how she had to get up every hour at night and that at some point she stayed awake for four or five days and just sat next to her infant, looking at him. When she had a chance to leave the NICU, she had to rush to pump out milk, have a shower and get dressed before rushing back to her son in the NICU.

- ***... ja, al daai nag-opstanery. Ek onthou hoe het ek elke uur moes opstaan …*** (lines 237–238). *… yes that getting up at night. I remember how I had to get up every hour ...*
- ***Ja veral as jy opstaan, dan is jy so moeg …*** (line 245). *Yes, especially when you get up, you are so tired …*
- ***… jy raak bietjie kortaf en moeg*** (lines 252–253). ***…*** *you become somewhat short-fused and tired.*
- ***… daar was 'n tyd gewees wat ek seker vir vier of vyf dae by hom geslaap het, wat ek nie eers bed toe gegaan het nie*** (lines 536–537). *… there was a time when I slept next to him for four or five days, when I did not even go to bed.*
- ***Ek het op daai stoel gesit en slaap en dan het die suster vir my gesê: 'Okay, gaan druk gou melk … dan gaan jy en dan gaan shower jy gou-gou en dan kom jy weer op'*** (begin vinniger praat). ***Dan het jy net daai halfuurtjie*** (lines 539–542). *I slept on that chair and then the sister told me to go and pump milk … then you go down to shower and then come up again.* (Starts talking faster.) *Then you only had that half hour.*
- ***Ek kan onthou daai vier dae wat ek so daar gesit het. Dan het ek vir vier dae nie geslaap nie. Dan sit ek so en kyk daai kind so*** (lines 534–545). *I*

can remember those four days I sat there. Then I did not sleep for four days. Then I sat there and just looked at that child.

A study undertaken by Boucher et al. (2011) found that it is common for mothers in the NICU to feel exhausted due to the constant care required by the NICU infant, and that they may also become exhausted if they have to constantly travel to the hospital for feedings. Labuschagne (2015) and Leonard and Mayers (2008) also report that mothers often feel physically drained during the NICU experience.

4.4.4.3 Subtheme 4.3: Adverse events during hospitalisation

The following table (4.17) states the definition, indicators and criteria for this subtheme.

Table 4.17: Adverse events during hospitalisation

Definition	Unfortunate surrounding events or incidents (HarperCollins, 2004) during hospitalisation that had a negative, harmful or unfavourable effect on the person (American Heritage Dictionary, 2011)	
Indicators	Being surrounded by death Seeing other mothers leave the hospital	
Criteria	<u>Inclusion</u> Data referring to negative events that occurred during to the hospital stay. Events around Participant X that included other NICU mothers and other infants.	<u>Exclusion</u> Data referring directly to her son's medical condition or her physical exhaustion

Participant X reported that she was very worried and stressed out when she saw how sick the other infants in the NICU were and then she often felt quite certain that her child would not survive. She also saw other NICU infants pass away and, surrounded by death, she was sometimes at a loss and did not know what to do. She found it challenging to see other NICU mothers come and go while she had to stay in the hospital. She stated that it seemed as if time was standing still. This subtheme was supported by the following extracts from the interview:

- ***… dan sien jy daai enetjie maak dit nie en dan stres jy sommer vir jou kind en dan is jy bang jou kind maak dit ook nie*** (lines 218–219). *… then you see that one will not make it and then you stress about your child and then you are afraid that your child will also not make it.*
- ***… jy sien dood om jou, die heeltyd, veral toe ek met hom daar was hoe baie babatjies het die heeltyd om hom doodgegaan en dan het hy erg***

siek geraak en dit het mens baie laat stres en jy het geworry (trek haar gesig) ***en dan sit jy daar en jy weet nie wat om te doen nie*** (lines 220–223). *… you see death around you all the time, especially when I was there with him, how many babies died around him all the time and then he got very sick and that made you feel very stressed and worried* (pulls her face) *and then you sat there and you did not know what to do.*

- ***Ja, veral as jy sien die mammas kom en gaan, kom en gaan en jy bly*** (line 257). *Yes, especially when you see the moms come and go, come and go, and you stay.*
- ***Veral soos die babatjies wat om hom doodgegaan het ...*** (lines 283–284). *Especially like the babies who died around him ...*
- ***… daai vier maande voel dit of jy twee jaar in daai hospitaal was, maar eintlik net vier maande*** (lines 532-533). *… those four months, you feel as if you were in that hospital for two years. But actually only four months.*

The birth of a pre-term infant with a very low birth weight (below 1,500 g) necessitates prolonged hospitalisation (Carvalho et al., 2009). Participant X in the current research gave birth to an infant with a birth weight of only 600 g, which led to a NICU stay of four months. She stated that it was hard to see other mothers being discharged while she still had to stay on. Prolonged hospitalisation can lead to psychological distress, feelings of powerlessness, and a feeling of being isolated from the rest of the world (Abad et al.; Carvalho et al., 2009).

Participant X also reported that she felt as if she was surrounded by death and that she constantly worried about whether her child would survive. In line with the findings of this study, Yaman and Altay (2015) state that parents in a NICU environment can experience constant fear of losing their baby. With uncertainty lingering in the NICU, the anticipation of a child's death is extremely stressful (Gooding et al., 2011). Plaas (2007) also states that feelings of uncertainty and powerlessness can be major challenges to hope in the NICU. According to Plaas (2007), mothers reported that the unpredictability of the situation in the NICU made them feel less hopeful. Participant X also reported that at times she felt very uncertain about her son's likelihood of survival and did not know what to do.

4.4.5 THEME 5: LONG-TERM CHALLENGES TO HOPE

Long-term barriers to hope refer to challenges that the participant experienced as a result of the long-lasting effect of the NICU experience. Although these barriers were not present during her stay in the NICU, the post-discharge barriers to hope were a

result of the time she had spent in the Unit. The following subtheme was included: post-discharge emotional challenges.

4.4.5.1 Subtheme 5.1: Post-discharge emotional challenges

Table 4.18: Post-discharge emotional challenges

Definition	Emotional turmoil or struggles after discharge from a hospital or other course of care (Dorland's medical dictionary for health consumers, 2007)	
Indicators	References to the participant's grief, vivid memories, feelings of regret and nightmares about her NICU stay and the death of one of her twins	
Criteria	Inclusion Any data that includes information about the death of her child and emotional challenges after the time of hospitalisation	Exclusion Data linked to challenges experienced during hospitalisation, or referring to her infant's post-discharge medical challenges

Participant X stated that she is experiencing post-discharge emotional challenges to hope (see Table 4.18). She stated that she still remembers the NICU experience in detail. She has vivid memories of the invasive medical procedures that her child had to undergo, and especially the death of the other twin. She still experiences regrets about not having been able to hold her other twin before he died. She remembers how he looked when he was born, and how she had thought that he would be the one to make it. She also remembers all the traumatic events surrounding the birth and his death.

She has nightmares and sometimes feels as if she is still in the hospital. She still struggles to cope and to get over the experience, and sometimes when she looks at her son she sees the other twin that passed away. Even though she tries not to think about it, she sometimes cannot help it and still goes to her room to cry. This subtheme was identified in the following verbatim quotes:

- ***Ek onthou dit presies, dis asof ek nou daar sit en ek onthou dit. Dit voel snaaks, want ek onthou elke ding detail vir detail*** (wys met hande)***. Hulle sê dit gaan maar vir altyd vir die res van my lewe my haunt*** (lines 281–283). *I remember it exactly, it's as if I'm sitting there now and I remember it. It feels funny because I remember everything detail by detail* (demonstrates with hands)*. They say it's going to haunt me for the rest of my life.*

- ***… partykeer word ek wakker en dan huil ek … 'Ek wou die enetjie*** [haar ander baba wat gesterf het] ***vasgehou het, maar hy is dood'*** (lines 291–

293). *… sometimes I wake up and then I cry … I wanted to hold that one* [the other baby that passed away], *but he died.*

- ***Partykeer dink ek nogsteeds hoekom, hoekom?*** (skud haar kop) (line 299). *Sometimes I still think why, why?* (shakes her head)
- ***Maar ja, dit voel nie so nie; dit voel of ek nou nog in die hospitaal is … maar dis nagmerries wat jy steeds nog kry. Dit gaan net nie verby nie …*** (lines 314–316). *But yes, it does not feel like that; it feels as if I'm still in hospital … but it's nightmares that you still get. It simply does not pass ...*
- ***Ek kan dit nog steeds nie verstaan hoekom ek hom nie net gevat het en vasgehou het nie. Dit sal mens altyd twyfel.*** (Skud haar kop.) ***Dis altyd 'n vraag wat ek myself sal vra, hoekom?*** (lines 425–427). *I still cannot understand why I did not just take him and hold him. You will have that doubt.* (Shakes her head.) *It's always a question I'll ask myself – why?*
- ***Maar dit raak beter, maar ek dink dit gaan maar baie jare vat voor jy, veral met die enetjie wat dood is …*** (lines 447–449). *But it gets better, but I think it's going to take many years before you, especially with the one that passed away …*
- ***Die ding is die probleem is mens sukkel om oor dit te kom*** (line 452). *The thing is the problem, one struggles to get over it.*
- ***So ek dink elke keer wat jy hom sien, dan sien jy die ander enetjie. En dan bring jy die wonde net weer terug*** (lines 458–459). *So I think every time you see him, you see the other one. And then you just bring back the wounds.*
- ***… maar partykeer kry jy daai dae wat jy sukkel … dan gaan sit ek in die kamer en huil so bietjie en dan kom ek en dan voel ek baie beter*** (lines 463-465). *… but sometimes you get those days when you struggle … I go to the room and cry a little and then I come and then I feel much better.*

In the last theme Participant X discussed the long-term challenges to hope. She still remembers her NICU experience in detail, sometimes experiences feelings of regret and suffers from nightmares. Mothers who had given birth to premature infants can experience depression, hopelessness, anger, loss of purpose and anxiety for up to between six and 18 months after the birth (Yaman & Altay, 2015). Participant X gave birth in 2015 and at the time of my research, in 2017, reported that she still sometimes struggled to cope. Wigert et al. (2006) found that NICU mothers still vividly recalled the birth and NICU stay as upsetting even up to six years after the experience. This is relevant to the findings of my study as the participant reported

that she still has vivid memories of the death of her other twin, the traumatic birth experience and the subsequent events experienced in the NICU.

The prevalence of acute stress disorder (ASD), posttraumatic stress disorder (PTSD) and postpartum depression (PPD) is higher among NICU mothers than among mothers who gave birth to full-term infants (Lefkowitz et al., 2010; Shaw et al., 2006; Yaman & Altay, 2015). Some of the challenges that Participant X is still experiencing can be indicators of possible PTSD.

4.5 CONCLUSION

In this chapter Participant X's definition of the nature of hope, resources and barriers to hope was discussed in detail. The five main themes were expanded by adding subthemes. After providing evidence in the form of verbatim quotes relating to each theme, I elaborated on the results in the different themes, and on how they related to or contradicted the findings reported on in the relevant existing literature in the form of a recursive literature review. I also mentioned the new insights that this study provided.

In the following chapter I will use my results to answer the research questions and expand on Plaas' (2007) Model of Hope in the NICU. The contributions and limitations of this study will be discussed and recommendations will be made for future practice and research.

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Chapter 5
Conclusion and Recommendations

5.1. INTRODUCTION

Chapter 5 commences with an overview of the previous chapters, followed by a discussion of my research findings and the extent to which I was able to answer the research questions that were posed in Chapter 1. I will then conclude the study by relating the findings back to my theoretical framework and discussing how my findings may potentially impact on Plaas' (2007) Model of Hope in the NICU. The limitations and likely contributions of this study will then be dealt with and recommendations will be made regarding possible future related research and practice.

5.2. OVERVIEW OF PREVIOUS CHAPTERS

❖ **CHAPTER 1: INTRODUCTION, RATIONALE AND OVERVIEW**

In the first chapter I provided the research rationale, stated the purpose of the research, the research questions and the potential value of the study. I also included an overview of this study.

❖ **CHAPTER 2: LITERATURE REVIEW**

Chapter 2 dealt with the literature review and previous research on hope in the NICU was compared and synthesized to provide a foundation for the current research. The Plaas (2007) model was also unpacked as the theoretical framework for my study.

❖ **CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY**

In this chapter the research methodology followed for this study, as well as the methods of data collection, the selection of the sample and ethical considerations were discussed.

❖ **CHAPTER 4: RESULTS OF STUDY**

Chapter 4 presented information on the process of data analysis, the layout and descriptions of the themes identified during the data analysis, and a synopsis of the findings combined with a recursive literature review.

❖ **CHAPTER 5: CONCLUSION AND RECOMMENDATIONS**

In this, the last chapter, the findings related to the research questions are discussed and a conclusion is reached. The limitations of this study and its contribution are also discussed and recommendations are made for future related research and practice.

In the following section I revisited my research questions and related the findings to each of the three research questions. As seen in Figure 5.1 below, Theme 1 (The nature of hope) may be linked to Question 1. Themes 2 and 3 (The internal and external resources of hope) may be linked to Question 2, and Themes 4 and 5 provide clarity to question 3.

5.3 ADDRESSING THE RESEARCH QUESTIONS

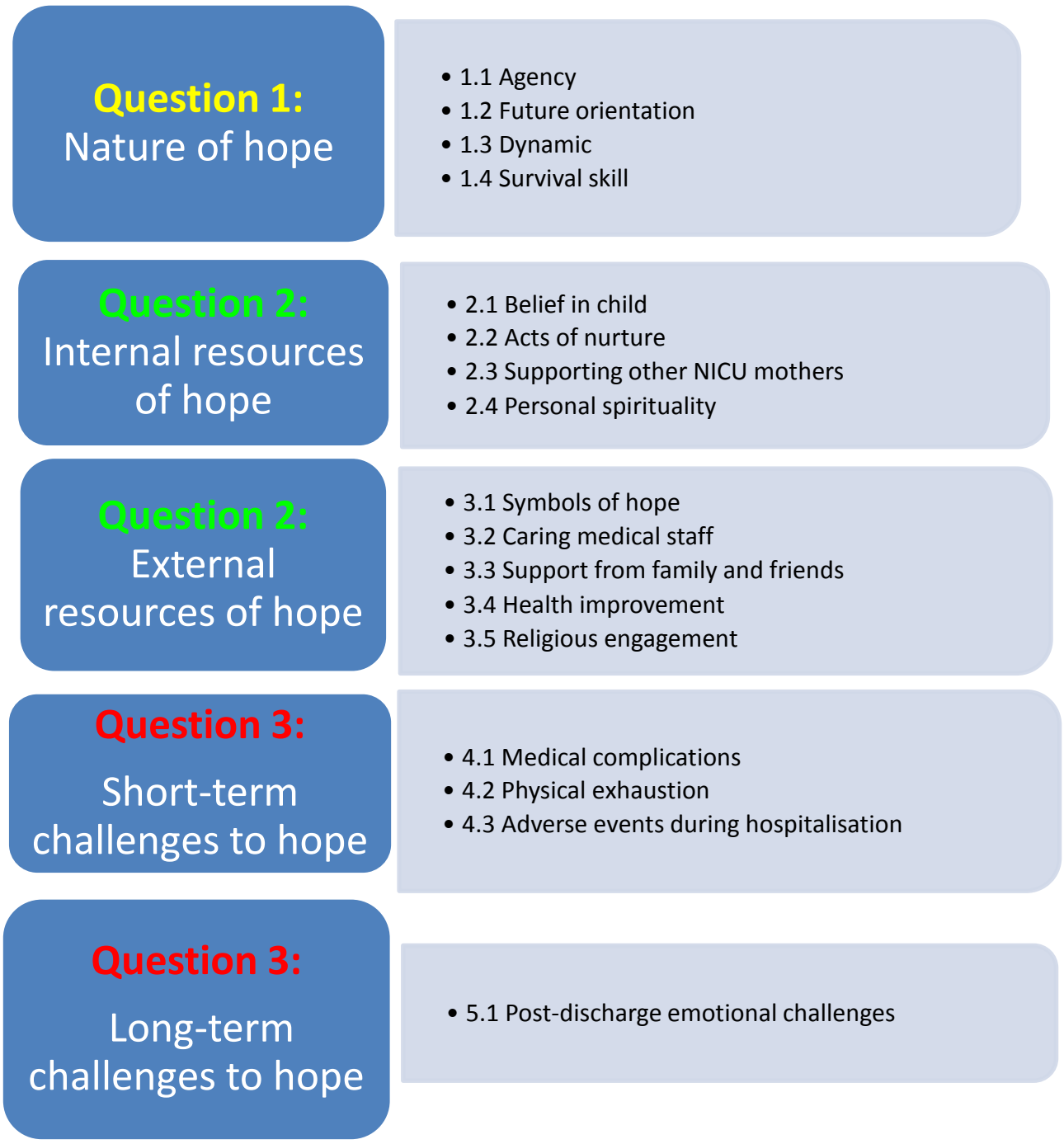

Figure 5.1: Summary of main data themes and subthemes in realtion to the research questions

5.3.1 CENTRAL RESEARCH QUESTION: WHAT WERE THE HOPE EXPERIENCES OF A NICU MOTHER IN A GOVERNMENT HOSPITAL IN SOUTH AFRICA?

The results of this study indicate that hope experiences in a South African government hospital are evident on the integrative cognitive, emotional, spiritual and intrapersonal levels. Hope experiences lead to increased motivation and mastery. Hope experiences are not only personal experiences, but are the result of collaboration between different role players in a caring social and professional environment. The experiencing of hope in the NICU was subject to change as it could be reoriented by in-hospital and even post-discharge events. Hope experiences are thus multidimensional in nature and are shaped over time by short- and long-term challenges and various internal and external sources.

I will now answer each secondary research question by providing a synopsis of the findings as they relate to the research question. These questions were asked in support of the primary research question and were used to elaborate in terms to enhance understanding.

5.3.2 SECONDARY RESEARCH QUESTION 1: WHAT ARE A NICU MOTHER'S PERSONAL UNDERSTANDINGS OF HOPE?

To answer this question, it was important to convey and appreciate Participant X's expanded understanding and personal definition of hope. The mother's understanding of hope was presented in the Theme 1: Nature of hope.

My findings indicated that hope was experienced as a feeling of agency, and that it could act as an emotional-motivational tool that could be used to achieve mastery. The desire to eventually be discharged from hospital with a healthy infant seemed to be another hope-driven motivator for mothers. Hope motivates mothers and enables them to push through the challenging NICU experience. Hope was further found to have been experienced in relation to mastery. The second most common theme identified in the conceptualisation of hope was its future-oriented nature.

Third, hope was found to be dynamic in nature, ever-changing, fluctuating between losing hope and building it up again. Last, remaining hopeful was a survival skill during times of great uncertainty about the outcome during the NICU experience. Hope may be described in the context of the NICU as emotional inspiration (motivation), or maintaining a dynamic positive future orientation in order to survive.

5.3.3 SECONDARY RESEARCH QUESTION 2: WHAT WERE THE RESOURCES OF HOPE THAT WERE DRAWN ON BY A MOTHERS IN THE NICU?

In this section I will address the second research question, which relates to the resources for the participant's hope experiences. Hope was provided by both internal and external resources. The internal resources of hope included the personal attributes, feelings and actions that led to hope experiences. Hope was experienced when the NICU experience was cognitively framed in a predominantly positive manner, by believing in her child.

When parents were involved in nurturing activities during their stay in the NICU, they tended to become more inclined to believe in the possibility of a good outcome. Personal interaction and time to bond with the infant therefore enhanced hope during the time of hospitalisation. Supporting, encouraging, training and praying for other NICU mothers also had a positive effect on Participant X's hope experiences in the NICU, as did personal spirituality. Prayer and believing that the events would make sense in the afterlife provided hope.

Hope was also experienced by relying on external resources. The most dominant external resources that framed hope experiences were symbols. Symbols of hope help people to cope with grieving and loss. In this study a particular symbol was found to have provided hope over time (during and after the NICU stay). This symbol served as a constant reminder of progress, healing and strength during and even beyond Participant X's stay in the NICU.

A major resource that contributed to Participant X's hope experiences in the NICU was the supportive care received from the medical staff. Advice, emotional support and encouragement received from the nurses seem to have had a positive effect on the nurturing of hope in the NICU. Hope experiences were also connected to the support of life partners, family and friends. Receiving encouraging messages from friends and family increased a sense of motivation.

Any improvement in the NICU infant's health was another external resource for hope experiences. Findings indicate that as the infant's health improved, the mother became more hopeful. Physical progress, like being moved from the NICU to the general ward, was described as the moment when hope really surged. The anticipation of improved health was based on hope and was in itself a catalyst of hope. Progression and improvement in the infant's medical condition therefore increased hope.

The presence and prayers of religious leaders were found to have played an important part in keeping hope alive. In this study it was clear that both personal and interpersonal resources were drawn on during hope experiences.

5.3.4 SECONDARY RESEARCH QUESTION 3: WHAT CHALLENGES TO HOPE DID A MOTHERS FACE IN THE NICU?

It is evident from the findings of this study that mothers in the NICU experience both short- and long-term challenges to hope. The short-term challenges include the difficulties that mothers may experience during their NICU stay. The infants' medical complications and lack of progress were found to be significant challenges to hope. Invasive medical procedures and the infants' physical appearance also had a negative effect on hope.

The findings show that hope is negatively impacted by exhaustion during the NICU experience. Exhaustion is often exacerbated by a lack of sleep due to half-hourly feedings required from the mother. Worries about the infant, combined with the strict feeding and medical care routines in the NICU, which contribute to the mother's physical, mental and emotional exhaustion, may impact negatively on a mother's hope levels.

Constant worry and stress were experienced when other infants passed away. Findings indicate that such events decrease hope levels and may lead to mothers beginning to have serious doubts about their own infants' chances of survival. Prolonged hospitalisation and negative events that are witnessed in the hospital environment, such as the death of other infants and seeing other mothers being discharged, can potentially diminish mothers' feelings of hope in the NICU.

The findings indicated that the NICU experience could have long-term effects on the hope of mothers and could still affect them long after the end of their NICU experience. Mothers may still experience feelings of regret, guilt, nightmares and vivid memories long after the NICU experience. Indications are that this may be a long-term challenge to post-discharge hope experiences. Although hope was experienced in the NICU, it was not always easy to maintain hopeful in that setting. The exploration of the challenges to hope also contributed to my understanding of the dynamic nature of hope.

5.4 RELATING MY FINDINGS BACK TO THE THEORETICAL FRAMEWORK

As seen in the literature control section, many of the findings in this study correspond to the findings of Plaas' (2007) study on hope in the NICU, which also served as the theoretical framework for this study (see Chapter 2). The findings of the current study seem to extend on Plaas' (2007) model and contribute to our understanding of the value of hope experiences in the South African NICU. This was made possible by exploring the personal definition of hope in the NICU and the resources and challenges that influence experiences of hope.

In discussing the findings of my study, it seemed appropriate to relate my themes back to the model for the theoretical framework. This is illustrated in Figure 5.2 below.

Plaas (2007, p. 42) states that hope is experienced in the "World of the NICU." In Plaas' model, hope is illustrated by a triangle consisting of three components: hope and the mother, hope and the infant, and hope and others. First, I included Participant X's 'personal understanding of hope' in the triangle. The dynamic nature of hope is plotted at the edge of the triangle to illustrate the changing nature of hope in the NICU. Second, I related each of the 'internal and external resources of hope' to the three components of hope. Most of the internal resources were categorised under hope and the mother, the resources of nurturing activities and health improvement were categorised under hope and the infant, and the external resources of hope were included under hope and others.

Third, the different 'barriers to hope' were included alongside Plaas' (2007) concepts of uncertainty and powerlessness. The diagonal line represents the time frame from birth to discharge. In the model, Plaas (2007) states that hope seemed to increase as mothers came closer to being discharged from the NICU. I extended the line after discharge to illustrate the long-term challenges and nature of hope. After discharge, hope is likely to remain dynamic in nature, based on the prolonged effects of the NICU experience, therefore I illustrated it with a zig-zag dotted line.

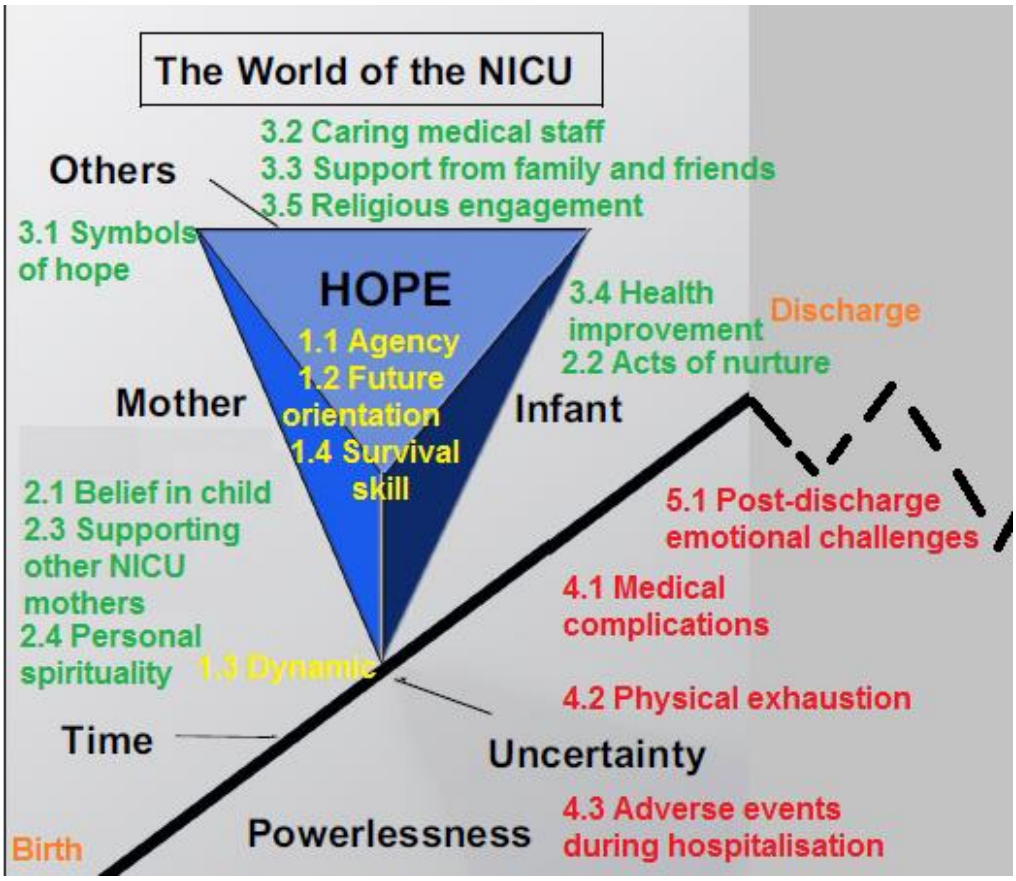

Figure 5.2: The findings of this study in relation to the theoretical framework (Plaas, 2007, p. 42)

5.5. LIMITATIONS OF THE STUDY

The first limitation to this study was the probability of personal bias as I had to carefully define my role as a researcher. As already mentioned repeatedly, I had been the Participant X's counsellor during her NICU stay in 2015, which meant that I had background knowledge of her NICU experience. At the onset and throughout the research I was able to manage my potential bias and to clearly separate my role as researcher from my earlier role as counsellor. I managed this limitation by informing the participant of my role as a researcher, setting clear researcher goals and procedures, conducting a comprehensive literature review, doing an inductive data analysis with verbatim quotes, using member checks, regularly consulting my supervisor and increasing my self-awareness by using a reflective journal (see Appendix F).

My previous involvement with Participant X might have had an effect on the data she provided during the interview. It is possible that she did not provide all the information as she may have assumed that I already knew her background and circumstances in

the NICU, or that she answered my questions according to how she thought I was expecting her to answer, which might have led to an optimistic explanatory style. I dealt with this limitation by encouraging her to share her honest and true perspective on the NICU experience. I asked a variety of open-ended questions and assured her that there were no incorrect answers, and encouraged her to be open about any negative experiences in the NICU.

A further limitation could be the fact that this study involved only one participant. While conducting my research in accordance with the ethical guidelines provided by the Faculty of Health Sciences, attempts were made to obtain a larger sample of NICU mothers; however, due to the sensitivity of this study and the difficulties experienced when attempting to locate the mothers, it was decided to conduct a single case study.

Lastly, the retrospective nature of the study could be seen as a limitation. Many of the questions were based on Participant X's past experiences. It is possible that during the time that had passed between the NICU experience and the study, she could have reframed the traumatic experiences or could even have forgotten some details of her experiences.

5.6. CONTRIBUTIONS OF THE STUDY

5.6.1 THE VALUE OF AN IN-DEPTH SINGLE-CASE STUDY

While recognising the limitations of having access to only one participant, I do believe that this participant contributed substantially towards developing an in-depth understanding of hope experiences in the NICU. Through this qualitative case study research design an improved understanding of the lived experience of a NICU mother crystallised (Niewenhuis, 2007a).

Therefore, although the findings of this study cannot and were never intended to be generalised to the greater population, it is still believed to contribute to the limited available literature dedicated to hope in the NICU context. Uniquely, it provides an in-depth glimpse into maternal hope experiences in the South African NICU context.

5.6.2 CHANGING THE VIEW ON NICU EXPERIENCES

As seen in Chapters 1 and 2, the NICU is frequently described as a difficult place to be in and NICU mothers are often portrayed as being depressed, anxious, guilt-

ridden and hopeless while facing multiple challenges. Findings indicate that the experience of having a pre-term infant has a profound effect on the mother's psychological wellbeing and hope. However, as seen in this study, the NICU is not only a place where hope dies, but can become a place for hope to grow and flourish.

The current study indicates that NICUs can be reframed as hope hubs in which we should value the nature and purpose of hope, treasure the dynamic nature of hope, explore and utilise the internal and external resources of hope and encourage mothers to become "champions of hope" (Bernardo, 2010; Cherrington, 2015, p. 47; Plaas, 2007).

5.6.3 INFORMING THE CONDUCT OF NICU MEDICAL STAFF

As seen in the literature study in Chapter 2 and the literature control section in Chapter 4, numerous studies have reported on the lack of quality care in NICUs and on how this could impact the hope experiences of NICU mothers. This study portrayed the medical staff as caring, compassionate, encouraging and supportive, which enhanced the mother's hope experiences. It also showed that supportive nurses can have a positive and long-lasting effect on how mothers frame their perception on the NICU experience.

The following key points, which may help medical professionals to provide quality care to mothers in the NICU, emerged from this study:

- Encourage bonding time with the infant and include mothers in caring for their babies.
- Use reassuring and positive language while working with NICU mothers.
- Encourage mothers to remain focused on their own infants and not to be disheartened by the regression of other infants.
- Allow NICU mothers to teach and train newly admitted NICU mothers.

5.6.4 HIGHLIGHTING THE IMPORTANCE OF POST-DISCHARGE CARE AND SUPPORT

As seen throughout the literature review in Chapter 2, many studies focus on the needs and experiences of the mother for the duration of the hospital stay. The fact that I had to change my research design from a focus-group study to a retrospective single-case study gave me the opportunity to explore and describe the possible lasting effects of the NICU experience on mothers. An unexpected finding was that more than two years after discharge, mothers may still be experiencing nightmares,

grief, vivid memories, feelings of regret and moments of intense sadness. This finding indicates the post-traumatic effects that may result from the NICU/premature birth experience. This finding highlights the importance of considering the need for improved post-discharge care and support.

5.6.5 CONTRIBUTING TO THE MULTIDIMENSIONAL VIEW OF HOPE

Through my research I aimed to contribute to the multidimensional view of hope. As seen in the findings, hope is described as much more than an individual process driven by agency (motivation towards a goal) and pathway thinking (ways to get there) (Snyder, 1995). Although in one of the subthemes hope was linked to individual agency and specific aims, it can be collaborative, as also suggested by Bernardo (2010), Plaas (2007) and Scioli et al. (2011). In this study it was evident that other NICU mothers, medical staff, life partners, family and friends can all contribute to a mother's hope experiences. It implies that hope is more than just a personal construct and is influenced by other people within the particular context (in this case the NICU).

This study also emphasised the dynamic nature of hope and confirmed Plaas' (2007) view that hope, especially in the NICU, is fragile and ever changing. Findings of this study connect with Farran et al.'s (1995) definition of hope, which describes hope on a continuum between hope and hopelessness. The current findings indicate that even having limited hope experiences makes a positive difference and does not equate to hopelessness.

5.7. RECOMMENDATIONS FOR THE FUTURE

The initial aim of this research was to explore maternal hope experiences in the NICU and to identify the different personal and external factors that lead to hope experiences. In my study I reported on the perspectives of only one participant. It is therefore recommended that hope experiences in the NICU be studied by using a bigger sample of mothers during their stay in the NICU. Hope experiences should also be researched in a variety of other medical fields and contexts.

Another recommendation is that future research should be undertaken to develop hope interventions specifically for the NICU. This current study has highlighted unique challenges and resources associated with the maternal hope experience in the NICU. Tailored interventions may be developed based on this, in order to support hope resources and overcome barriers to hope in this environment.

This study further highlighted the need for interventions and support for NICU mothers after discharge. NICU mothers still experience emotional challenges once they have left the hospital; therefore special care must be taken to continue offering them support. Counselling, support groups and psychological screening when NICU mothers go for their infant's check-ups or immunisations could help mothers to deal with post-discharge emotional challenges.

Lastly, care and support from medical staff could be an important resource for increasing hope in the NICU. It is recommended that NICU staff should take special care to support and encourage mothers during the NICU experience. Individualised care, involving the mother in caring for the infant, encouraging bonding between mothers and infants and emotional support from medical proffesionals are highly recommended. Further research can be conducted to establish specific guidelines and standards for medical professional to increase hope experiences.

5.8. CLOSING REMARKS

This study was an exploration of the hope experiences of a NICU mother, including her understanding of hope, her barriers to hope and hope resources from which she could draw in this context. This study was valuable as limited research has been undertaken on this topic, especially within the South African context. From the review of literature on hope it was evident that hope is a diverse construct, is drawn from different resources and has substantial and lasting benefits, especially within the context of adverse life experiences. It was apparent that these benefits would be valuable in the NICU context.

My description of the participant's personal understanding of hope provided a multidimensional personal definition of hope in this specific medical setting. This study was intended to contribute to a clearer understanding of the particular hope resources that the mother drew on during her stay in the NICU. The study acknowledged the ever-changing nature of hope and recognised that hope can be challenged by a variety of circumstances in the NICU context. Although the primary focus was on the participant's in-hospital experience, it was discovered that the NICU experience had a long-lasting effect on Participant X's hope experiences even long after her discharge from the NICU (see Photograph 5.1). The essence of hope experienced in the NICU context is well illustrated in the following remark by Participant X:

- *"Hope is the beginning of something greater that we sometimes don't understand, yet do not question … something beautiful in the future for our children" / "Hoop is die begin van iets groters, wat soms nie verstaan word nie, maar nie bevraagteken word nie … iets moois in die toekoms vir ons kinders."* – (Participant X, 2018 - Provided at the end of the study)

Photograph 5.1: Participant X and her older son holding hands with Baby X and her new-born baby

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APPENDICES

Appendix A:
Template of Consent Letter from the Participant

Appendix B:
Biological Information from the Participant

Appendix C:
Interview Schedule

Appendix D:
Transcribed Interview

Appendix E:
Fieldnotes

Appendix F:
Research Journal

Appendix G:
Audit Trail of Thematic Categories

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Appendix A:
Template of Consent Letter from the Participant

PARTICIPANT'S INFORMATION AND INFORMED CONSENT DOCUMENT

STUDY TITLE: Maternal hope in a South African Neonatal Intensive Care Unit

SPONSOR: None

Researcher: Mrs Charné Buissinne

Institution: University of Pretoria, Department of Educational Psychology

DAYTIME AND AFTER HOURS TELEPHONE NUMBER(S):
In case of an emergency you can contact the Ethics Committee:
Contact Person: Dr Ntho-Ntho Maitumeleng
Contact Number: (012) 420 5656

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

			:
dd	**mm**	**yyyy**	**Time**

Dear potential research participant

INTRODUCTION
You are **invited** to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

WHAT IS THE PURPOSE OF THE RESEARCH STUDY?
Having a premature baby in the NICU can be stressful and traumatic. Premature births can have a long lasting effect on the wellbeing of the mother and infants. Hope can help mothers to overcome the challenges that they experience while being in the hospital. I would like to know more about the experienced challenges in the NICU, what helped you to overcome these challenges, what hope means to you and what helped you to stay hopeful during this time.

DESCRIPTION OF PROCEDURES
I would like to invite you to take part in an interview about your experience in the NICU. I will ask you a set of predetermined questions. I will also be making observational notes. During the interview I will be recording the interview in order to capture your responses on the questions. The audio recording will then be transcribed for data analysis. After the interview and pre-luminary data analysis phase you will be requested to verify my findings. This will take place directly after the interview and during a face-to-face or telephonic interview or an alternative way suitable to you. I will give you my contact details if you have any concerns or queries later on. After the data has been analysed and interpreted, you will have access to a final report for approval. I will then either email you the report (if you have access to a computer) or you can collect a hard copy from the university.

Criteria to take part in this study

- You would have to have had a preterm infant with a very low birth weight (below 1,500 g) in the Neonatal Intensive Care Unit (NICU).
- You must be willing to participate in interview with me and talk about your experience in the NICU.
- You need to have adequate Afrikaans or English language abilities to understand and answer interview questions about your experiences in the NICU.
- You have to be 18 years or older.

DURATION OF PROCEDURES
The interview will last approximately 1–2 hours. If a subsequent interview is needed for unforeseen circumstances, I will inform you beforehand and arrange another meeting to continue the discussion.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?
This study received ethical clearance from the Faculty of Health and the Faculty of Education of the University of Pretoria and will be supervised by Dr A. H. Du Plessis.

This proposal was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, telephone numbers 012 356 3084/012 356 3085

and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013). A copy of the Declaration may be obtained from the investigator should you wish to review it.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS TRIAL?

Voluntary participation

The participation in this study is completely voluntary. You have no obligation to take part in this study. You are free to withdraw from this study at any time, without giving a reason. If you decide to withdraw from the study no information provided by you will be used in the study.

Confidentiality and Anonymity

As part of the informed consent all information that is discussed during the interview is confidential. You will remain anonymous throughout the research process. Pseudonyms or numbers will be given to you; hence your name will not be used in any form of data collection, analysis or the research report.

Incentives

No incentives (money or any other reward) will be given to any participant that chooses to participate in this study.

THE ROLE OF THE RESEARCHER

The topics discussed during the interview may include sensitive information about your stay in the hospital. Although I am a registered counsellor, and I was your counsellor in 2015 during your hospital stay, my role as a researcher states that I am not allowed to provide you any psychological services other than a debriefing session after interview. If the need for psychological services arises I will refer you Mrs Riana Visser, who is a counsellor that works with the non-profit organisation Counselling@. She worked as a counsellor in Hospital ABC's NICU during 2013–2014.

POTENTIAL RISK OR DISCOMFORT

During the interview we will discuss your experience in the NICU. This may elicit negative and traumatic feelings that you have experienced since your baby's birth and stay in the hospital. I am aware of the potential risks of in-depth interviews and will always aim to act in a sensitive you. If the need arises I will refer you to the counsellor mentioned above. You will not be exposed to any acts of deception in the research.

WHAT ARE THE BENEFITS TO YOU

You will get the chance to talk about the challenges and successes that you have experienced during your time in the NICU. You will have an opportunity to explore your own coping strategies and your personal and environmental assets. The topics in the interview will mainly focus on positive constructs like hope and meaning making of adversity. This may have a positive effect on your psychological wellbeing.

Questions and information

Please feel free to ask any questions at any time of the study. It is important to me that you understand the purpose and the process of the research. Please take the time to careful consider if you want to take part in the study. Feel free to contact me or my supervisor if you have any queries.

Thank you for your time and consideration in this matter.

Researcher: Mrs Charné Buissinne: 072 447 5309
Supervisor: Dr Alfred Du Plessis: 012 420 5503

Yours sincerely
Mrs C. Buissinne

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University of Pretoria
Cell: 072 447 5309
Email: charne_k@yahoo.com
Student number:10420747
HPCSA Student Psychologist: PS S 0138150
HPCSA Registered Counsellor: PRC 0027634

INFORMED CONSENT TO PARTICIPATE IN THIS STUDY
A research study of the University of Pretoria
Project title: Maternal hope in a South African Neonatal Intensive Care Unit

- I, _____ hereby confirm that I have read the attached information and understand the purpose and procedures of the study.
- The study has been explained to me by the researcher.
- I meet all the criteria to take part in this study.
- I understand the nature of the interview I will be involved in.
- I understand that I will be asked to share information on my experience in the NICU and hospital.
- I am aware that the interview will take place at a time and place which is convenient for me and the researcher.
- I understand that the information that I provide will be used as part of a research report and article.
- I understand that my participation is voluntary and that I can decide to withdraw from the study at any time.
- I understand that all information will be kept confidential and that my identity will be will remain anonymous by using code names.
- I give permission to the researcher to make use of an audio recording during the interview.
- I am aware of the possible risks that in-depth interviews may hold.
- I am aware that the researcher will not provide any psychological services but if the need arises she will refer me to a counsellor.
- I understand that I will not receive any incentives to participate in this study.
- I know I have access to all information obtained by the researcher.
- I have had sufficient opportunity to ask questions about the study.
- I hereby confirm that I will participate in the above mentioned research project.

Signed at _____ on this _____ day of _____2017.

_____ _____
Signature of participant Date

_____ _____
Signature of researcher: Mrs C.Buissinne Date

_____ _____
Signature of supervisor: Dr A. H. Du Plessis Date

VERBAL PATIENT INFORMED CONSENT (applicable when patients cannot read or write)

I, the undersigned, ……., have read and have explained fully to the participant, named ……., the study's information letter, which has indicated the nature and purpose of the study in which I have asked the patient to participate. The explanation I have given has mentioned both the possible risks and benefits of the study. The patient indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason.

I hereby certify that the patient has agreed to participate in this study

Patient's Name _____
(Please print)

Investigator's Name _____
(Please print)

_____ _____
Investigator's Signature Date

Witness's Name _____
(Please print)

_____ _____
Witness's Signature Date

(Witness - sign that he/she has witnessed the process of informed consent)

Appendix B:
Biological Information from the Participant

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Denkleiers • Leading Minds • Dikgopolo tša Dihlalefi

Maternal hope in a South African Neonatal Intensive Care Unit (NICU)

Biographical details of participant

Gender: Female

Age: 29

Race: White

Home language: Afrikaans

Second language: Engels

Home town: Pretoria West

Number of children: 2

Date of birth of NICU infant: 13 Mei 2015

Birth weight of NICU infant: 600g

Duration of stay in NICU: 4 Maande

Government hospital: (YES) / NO

Appendix C:
Interview Schedule

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Denkleiers • Leading Minds • Dikgopolo tša Dihlalefi

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Dissertation Title: *Maternal hope in a South African Neonatal Intensive Care Unit (NICU)*

Semi-structured interview schedule for the NICU mother

The participant will have a chance to answer questions on the following topics: her understanding of hope, challenges to hope in the NICU, resources of hope in the NICU and the influence of hope on her experience in the NICU. Follow-up questions on answers and probes will be used to elaborate on the participants' answers. Answers on these topics will be documented in recordings and transcriptions.

Semi-structured interview schedule:
1.3.1 Central research question:
What were the hope experiences of the NICU mother at a government hospital in South Africa?

1.3.2. Secondary research questions:

- What is the NICU mother's personal understanding of hope?
- What were the resources of hope that the mother drew on in the NICU?
- What challenges to hope did the mother face in the NICU?

- How would you describe the experience in the hospital?
- What challenges to hope did you experienced while being in the NICU?
- What helped you to get through these challenges (resources of hope)?
- Discuss things that provide you with hope in this time.
- Describe your definition of hope.
- How did hope help you to cope with your baby in the NICU?
- If you could give advice in relation to hope to other mothers in the NICU, what would it be?

Appendix D
Transcribed Interview

Nature or purpose of hope	Future orientated view Motivational and mastery Survival skill Feeling of excitement Dynamic in nature
Internal resource of hope	Belief in child Nurturing her NICU infant Supporting other NICU mothers Personal spirituality
External resource of hope	Improvement of NICU infant's medical condition Caring medical staff Support from family and friends Religious leaders and activities Symbols of reassurance
Short term challenges to hope	Medical complications or lack of progress Surrounding events during prolonged hospitalisation Physical exhaustion Emotional challenges during hospitalisation
Long term challenges to hope	Long-term medical challenges Post discharge emotional challenges

C: Okay as jy nou kan terug dink aan jou NICU experience hoe sal jy dit vir my verduidelik?
X: Dit was hartseer, traumatisering … dit was erg die belewenis was erg. (Kyk by venster uit) Alles wat mens daar deur gegaan het. Dit was emosioneel, veral met die kleintjie.
C: Wat het dit vir jou erg gemaak?
X: Wat vir my erg was was toe hy die groot longinfeksie gekry het, want hy kan dit nie deurdra nie. Dan sê hulle hy is dood en dan is hy weer lewendig. Dat hulle dit vyf keer gedoen (wys met haar hand) het en die heeltyd dink jy aan die kleintjie by die huis ook en hierdie enetjie en elke keer dan huil jy, want jy weet nie of jou kind dit gaan maak nie. Dan is die suurstof min dan is die suurstof weer reg toe het die, uhm, die hartjie wat nie toegroei nie en wat moet groter raak en dan die bloeding op die brein. So dit was bietjie baie erg, maar elke keer het jy maar net geglo en gebid en gehoop maar vir die beste. (Glimlag)
C: Was daar soms daar sommige tye in die hospitaal wat jy hoopvol was?
X: Ja daar was. (Wag vir 'n ruk voor sy weer begin praat) Elke keer as hy weer beter raak dan hoop wat hy gaan net sterker word. En as hy agteruitgaan dan het jy nogsteeds gehoop vir die beste en dan maar gewag.
C: Wat het jou gehelp om te hoop daar?
X: Ek het maar gedink aan die kleintjie wat hierso by die huis was en sy boetie die enetjie wat ons klaar verloor het saam met hierdie ene (beduie met haar hande) en mens het maar gehoop dat die een die vegtertjie sal wees dat hy vorentoe eintlik sterk sal uitkom en elke keer het hy elke keer bewys dat hy is sterker, hy het als oorwin. Die siektes en die elf siektes (skud kop) wat hy gehad het het hy deurgemaak en die hartkloppie wat so swak was en die

Commented [A1]: Medical complications or lack of progress

Commented [A2]: Personal spirituality

Commented [A3]: Improvement of NICU infant's medical condition

Commented [A4]: Belief in child

gaatjie het toegegroei, die operasies het hy vermy en die bloeding op die brein het weg geraak sommer na 5 dae. So elke keer as jy hoor die goeie nuus dan weet jy jou kind vorder. So jy het hoop gekry. Na elke goeie nuus is die hoop net sterker. (Glimlag).
C: So elke keer het dit geval, maar as jy hoor dit gaan bietjie beter kom die hoop weer.
X: Ja, dan kom die hoop weer. So jy het geweet half die goeie dae is daar en jy was so bly vir daai goeie dae, want dit help jou net. Dan is jy bietjie sterkter vir die kind self ook. (Knik kop)
C: En wat sal jy sê was die rol van die susters en die dokters in die hospitaal? Het hulle jou meer hoopvol laat voel of minder, watse rol het hulle gespeel?
X: Hulle het. Hulle het my eintlik baie meer gehelp as wat ek gedink het. Hulle het my eintlik laat sterkter voel. Want elke keer as die kind se bloed opgedroog is hy het nie bloed nie dan het hulle vir my gesê: 'Moenie worry nie!, kom sit hier!' (wys met haar hand) 'en kyk hoe doen ons dit'; so hulle het alles vir ons verduidelik en ons kon sien hoe doen hulle dit. So op die ou end dan sien jy hoe hulle met die kind werk en hoe raak die kind beter en alles. (glimlag) So jy het eintlik baie hoop gekry om te sien. Hoor hier, hulle help jou en die kind raak beter. Wys vir jou. As iets gebeur kan jy dit by die huis met jou kind doen. (wys met haar hande) So min of meer as jy uit die hospitaal uit kom dan weet wat om te doen, jy's eintlik voorbereid.
C: En hulle het jou self daar vir jou babatjie laat sorg?
X: Ja, self gesorg en die suurstof geoperate. Op 'n tyd het ek die neusie ook 'n bietjie geblaas. So ek het baie geleer by hulle. (knik kop)
C: So is daar nog goed wat vir jou hoop gegee het in die ICU soos experiences saam met die ander ma's of iets wat jy gevoel het binne jouself wat vir jou gehelp het, hoe het jy gecope?
X: Ek het elke keer vir hom gesing. So elke keer as ek vir hom vir hom 'n liedjie sing en goeters dan voel ek rustig. Dan begin hy ook rustig raak. (lyk verlig) So vir my was sing die beste. So hoe meer ek hom vasgehou het en gesing het, dit het my gehelp. Dit was maar ons sterkpuntjie saam. (glimlag)
C: Om na hom om te sien op die ou end van die dag?
X: Ja.
C: Dan … jy het al begin noem van goed wat jou hoop weg gevat het soos as dit slegter gaan met hom of … is daar nog enige iets anders wat jy aan kan dink? Soos jy't hoopvol gevoel en dan val dit weer …
X: Ja, soos toe hy gebore was alles was okay, die suurstof en die dokters het geweet hy is klein en so, maar toe hulle die operasie moes doen toe hy vier dagies oud was. Daai was vir daai twee ure bietjie scary gewees. Daai wat hulle mos gesny het met die pypies en als. So daar het jy al klaar gedink jou kind gaan dit nie maak nie. (Skud kop en kyk af na vloer)
C: Is dit toe hulle die sentrale lyn in gesit het?
X: Ja, en hulle het gesé daar was 'n 30/70 kans met hom gewees (begin harder praat) so daar het jy buite gesit en gehuil en gestres, maar op die ou end toe werk dit die beste uit, want die infeksies wat hy gekry het met daai pypies en alles en dan die suurstof is hy van pypie na pypie verander. Toe is hy nou na die nasal toe en dan raak jy mos excited (skuif vorentoe in stoel) want hy gaan nou die suurstof los, maar dan is die longetjies weer bietjie swak en dan is hy weer op die CPAP (Continuous positive airway pressure) (wys na neus) of met die infeksie was hy weer op die ventilator. So mens het maar baie geskrik veral as hy op die ventilator was. So daar was die scaryste tyd die meeste gewees; daar het hy ons gevang (skud kop). Dit was die, die, die ergste vir ons almal toe hy groot infeksie gehad het, die bloeding op die brein en die hartjie wat probleem gegee het en die ventilator is op 100% en toe verklaar hulle hom dood klaar 'n halfuur daar, waar ons op hom en die suster sê: 'Nee wag Sy skiet die voet (wys hoe suster se skiet aksie teen haar hand) toe begin hy wakker skrik, van daar af het ons hoop weer bietjie meer gegroei waar die suster wys skiet die voetjie die kind kan dit maak. Van daar af het als vir ons weer bietjie beter gegaan. Ons het die ups and downs gehad, maar die hoop daar was toe sterk. (knik kop)
C: En die oomblik wat jy die mees hoopvolste gevoel het in die hele stay?
X: Was toe hulle vir ons gesê het ons gaan uit ICU uit en ons gaan High Care toe (glimlag breed). En toe hulle sê jy maak reg ons skuif jou na Saal 4. Dit was vir my die excitingste deel gewees.

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Commented [A12]: Caring medical staff

Commented [A13]: Dynamic in nature

Commented [A14]: Improvement of NICU infant's medical condition

C: So goeie nuus het jou elke keer daardeur gehelp en nuus van die dokters en die susters, as jy gesien het dit gaan beter dan … wat is vir jou self as jy nou aan daai tyd kan terugdink, 'n definisie van hoop?
X: Ek sal se excited. (Feeling of excitement) (oë helder op)
C: Excited?
X: Ek kan dit nie as iets anders beskryf nie, jy was net excited. (Feeling of excitement) Want jy kan nie sê dis die sadness wat jou die hoop gegee het nie. (Skud kop) Jy's meer excited want jou mikpunt is om by die hospitaal uit te kom met daai kind. (Motivational tool) Dit het jou die hoop gegee vorentoe en jy het geweet daai kind gaan dit maak. Dit was my hoop gewees, vorentoe. (Future orientated view)
C: En toe jy ontslaan was uit die hospital uit, het hoop enigsins 'n rol daar gespeel?
X: Ja 'n groot rol. Want ek was so excited, want ek sien die kleintjie en ek sien die pa en ons kan die kleintjie vat en ons kan hom huis toe vat en vir die eerste keer vir almal wys. So dit was vir ons baie exciting gewees. Die hoop was daar … veral die pa hy het die meeste hoop gehad.
C: En sal jy sê dat hoop 'n groot rol gespeel het in die neonatale stadium wat jy daar was?
X: Ja.
C: Watter rol het hoop gespeel?
X: Jis dit het vir my en die kleintjie deurgedruk. Sonder hoop sou nie een van ons twee dit survive het nie.
C: Maar tog was dit ook soms maklik om hoop te verloor?
X: Ja, daar was 'n paar keer wat ons hoop verloor het soos as hulle gesê het die kind maak dit nie dan het ons hoop verloor. (kyk af na grond) Partykeer die kind is so erg siek en goeters en dan verloor jy maar hoop, maar jy bou hoop weer op. (beduie met hande)
C: Ja, en kyk waar is julle vandag. Ek het julle twee jaar laas gesien en kyk net. Dan wil ek jou vra as jy vir enige ma's kan raad gee in die neonatale ICU vir hoop, watse raad sal jy gee? Byvoorbeeld as jy nou hoor 'n vriendin van jou gaan daardeur, wat sal jy sê moet hulle doen om hoop te hou en wat sal jy van hoop vir hulle sê?
X: Ek sal sê glo in jou kind, glo in jou kind. Dis 'n miracle en hy sal daardeur kom (Begin trane in haar oë kry).
C: Ah X, eks jammer ek sit jou nou weer hier deur …
X: Toemaar ek's fine (vee trane af).
C: Maar dit is amazing om vandag weer hier te kan sit en hierdie conversation te kan hê oor hoop, want ek was daar gewees en waar jy net uitgeloop het en jy het gesê jy weet nie wat gaan gebeur nie en ek kan onthou hoe jy altyd … dis hoekom ek 'n studie daaroor doen, want ek dink aan mamma's soos jy wat daar gesit het met klein Baba X en hy was nog so klein en deurskynend gewees.
X: Ja, hy het nie eers 'n vel gehad nie ... (wys met haar hande en vryf oor haar eie vel)
C: En die lyntjie wat hulle hier moes insit
X: En al die tubes en CPAP, die breintjie, jy kon die bloed sien in die brein vassit en shame hy het nie boudjies gehad nie of oortjies gehad nie en die vingertjies was lank (wys hoe lank met haar vingers) en die bene was nog nie ontwikkel nie en dit was net vel en die borsbene was nog uitmekaar uit en ek onthou toe sê hulle nog twee, drie weke gaan dit bymekaar uitkom. So ek het alles gesien hoe ontwikkel dit. Gesien hoe gaan die melk by die pens af. (beduie met haar hande)
C: Waar gewone mammas dit nie eers sien nie, want die kind is nog in jou maag. Dan sien jy hoe daai kind fisies voor jou groei. Van 'n 600 g babatjie tot waar hy vandag is.
X: 11.2 kg nou. (glimlag) Dis 'n vordering.
C: Dit is. Wat sal jy sê was die … op daai tyd en nou langtermyn om 'n baba in die NICU te hê, watse uitwerking het dit op jou gehad as mens? Positief of negatief?
X: Dit het positiewe en negatiewe goeters. Soos daai tyd was dit negatief en dan kom dit positief. As die kind vorder. En dan het ons weer probleme gehad met sy magie. Hy gesukkel dat hy die stool kon afgooi so dit was onlangs, seker so drie maande terug wat dit nou eers verbeter het, maar dan was dit die epilepsie wat hy kry, gehad het en koors, veral met koors hy sukkel baie met koors. Die probleem is met tandesny. Hy was 'n jaar en 5 maande toe begin hy eers om tandjies te sny. En elke keer as hy tande sny dan slat hy verskriklik koors uit en dan moet ons hospitaal toe jaag, want ons kry nie die koors gebreek nie. So ons het

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Commented [A17]: Future orientated view

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Survival skill

Commented [A22]: Belief in child

Commented [A23]: Dynamic in nature

Commented [A24]: Long-term medical challenges

ups and downs nog steeds nou met hom, maar meer ups as downs. So hy verras ons eintlik. (knik kop)
C: En hy laat julle hoop voel?
X: Ja, hy doen eintlik. (kyk af en glimlag)
C: So sal jy sê dat hoop selfs na die twee jaar in ICU nog steeds vir jou belangrik is?
X: Ja, hy is verskriklik belangrik, want as ek nie in hom geglo het nie sou hy nie hier gewees het nie. (skud kop)
C: En dit het jou deurgebring tot waar jy vandag is met jou twee seuntjies en met die navorsing. Die mense weet nie noodwendig dat ek of hulle weet dit, want dit staan in my goed, maar hulle weet nie hoe baie ek in kontak met jou was in daardie tyd en hoe baie ons daar bo gesit het nie. So baie dankie dat jy vir ons 'n glimpse van dit gee en die rol wat hoop vir jou gespeel het in daai tyd. En dit was regtig 'n passie van my gewees, want ek het geweet daar is nie noodwendig baie in Hospitaal ABC wat jou help nie. En dis 'n donker plek en jy voel soms …
X: Ja, dis soos 'n donker kol, jy weet nie waarheen om te gaan nie, jy weet nie waar is die lig nie. (kyk af na vloer) Jy soek die lig, maar soos ek sê as jy in daai kind van jou glo hy sal daardeur druk. Hy gee vir jou die lig.
C: Die hoop op die ou end van die dag?
X: Ja. Jy sien die pad vorentoe vir die kind en hoe meer hy gesond raak hoe meer sien jy die pad en jy glo. (beduie met haar hand die vordering). En op die ou end gaan die kind daai pad. En jy wys eintlik vir die kind waar die pad na toe gaan. So dan kom hulle daar uit. So hoop is baie baie belangrik veral met sulke kleintjies.
C: Ja, want waarop ek my studie baseer is 'n vorige studie van oorsee en hulle teken die diagram wat wys die world of the NICU en dan is dit 'n lyn wat so op gaan wat wys vandat jy daar is tot aan die einde wat jy discharge word en dan gaan die hoop op. Maar hy is ook op die triangle wat wys hoop en jouself, hoop en die baba en hoop en ander. En hoe dit moet balance - so die eendag gaan die hoop met jou baba op, maar die ander dag moet jy meer op ander staat maak om vir jou hoop te gee en die ander kere kry jy in jouself hoop. Maar dit staan op die kleinste punt omdat hulle weet in die NICU wissel hoop van dag tot dag. Uhm, is daar mense in jou lewe wat jou ook in daai tyd gehelp het om hoopvol te bly?
X: Ja, soos my verloofde. Hy het partykeer vir my gesê ek is by die kleintjie en jy kan gaan sit by die ander een. Of die ander een is by die ouma so gaan relax jy net 'n bietjie. En dan kom hy af (wys met hande) en dan praat hy my weer hoop in en goeters. En die ouma ook, sy het ook altyd gekom en gehelp en goeters. Ons het 'n dominee ook gehad op 'n tyd toe die tyd baie erg was met hom. (vryf kop)
C: Ja.
X: Toe hy 11 infeksies gehad het toe sê hulle vir my 'n uur tops dan is hy dood, want toe is hy op die ventilator en hy is op 100% en hy bly afgaan (begin sagter praat). Toe het ons 'n dominee gekry en hy het gebid en drie ure na die tyd kom die susters en roep my en sê 'Weet jy wat jou kind is van die ventilator af' … en toe is hy net so gesond.
C: So godsdiens het jou ook daardeur gehelp?
X: Ja. (knik kop) Gereeld gebid en ons het baie familie gehad. Familie het my altyd gewhatsapp en gebel en gesê sterkte en stuur net soentjies vir die kleintjie en ons dink aan julle. So ons het mense gehad van naby en ver wat ons daardeur gedruk het en veral die pa ook. En dan kom hy en sê die en die sê dit en so en so … daar was baie oulike boodskappies en so het ons deurgedruk. So as hy eers kom en hy praat my moed in, want partykeer dan verloor ek baie moed en dan kom hy en sê moenie die moed verloor nie. Glo in jou kind en dit het ons gehelp. Elke keer wat ek net in hom geglo het het hy net beter en beter geraak. (beduie met hande)
C: So as van die ma's wat saam met jou daar was hoop verloor het, watter raad het jy gehad of wat kon jy in daardie tyd doen vir hulle?
X: Ek het baie saam met hulle gesit en saam met hulle gebid en vir hulle gesê moenie ophou bid nie. (skud kop) Partykeer as hulle nie geweet het nie dan het ek gesê, kyk my kind, hoe was my kind … omdat ek so lank gelê het … vier maande en hulle maar twee, drie maande daar; dan het ek gesê kyk hoe was hy, kyk hoe klein was hy, moenie dit [hoop] verloor nie. Kyk jou kind is dubbel my kind se size, groottes en lengtes, alles. (wys met hande die grootte)

Commented [A25]: Dynamic in nature

Commented [A26]: Belief in child

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Commented [A28]: Future orientated view

Commented [A29]: Support from family and friends

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Commented [A31]: Personal spirituality

Commented [A32]: Support from family and friends

Commented [A33]: Supporting other NICU mothers

C: Ja, Baba X was die champion daar, want almal het gesê as hy dit kan maak dan kan julle dit maak.

X: En so het hulle geglo op die ou einde en elke keer het die susters gesê: 'Wys vir hulle as hulle sukkel' en dan sê ek: 'Okay, bring gou die mamma' (wys met haar hande) en dan het ek vir die mamma gewys die kind en dan is hy so klein, jy het hom nie eers gesien in die bedjie nie, die lakens het hom als weggevat en ek onthou dan moet ek altyd vir die mamma wys hoe moet ek die doeke sny. Dan sny ek dit in die helfte en dan weer in die helfte sny (wys met haar hande) en dan het hulle so gelag (glimlag) en dan gaan hulle na hulle kind toe en dan sê hulle dit het hulle dag gemaak en so dan elke keer het hulle so positief geraak en hulle kinders het voor hom huis toe gegaan en baie van hulle was, hulle het my al laat weet, dankbaar vir alles en so en goeters. (kyk af)

C: En as jy kan raad gee vir dokters, susters of sielkundiges wat daar werk, watter raad sal jy vir hulle gee om die mammas se hoop beter te maak en hoe kan hulle die NICU meer hoopvol maak?

X: Ek sal eerstens sê luister na die mammas. Luister na wat hulle sê en goeters en dan probeer hulle positief hou. (knik haar kop) Veral as die ma positief is en sy hou die kleintjie vas, dan is die kind positief. Dan help dit die kleintjie ook. Want ek het so geleer by die susters in ICU, as jy positief is en jou kind is positief dan gaan jou kind ook vinniger gesond raak ook. Daai suster het my goed gehelp daardeur. Elke keer as ek wil huil dan sê sy vir my 'Nee, moenie huil nie, relax, (wys met haar hande) smile.' En elke keer as ek smile en ek hou die kind vas (sit hand op bors) dan het die kind se suurstof elke keer stabiel gebly en van daar af het hy begin gewig optel en hy het net beter geraak. So ek is dankbaar vir daai suster; sy het my gehelp. So ek sal sê luister vir die mammas en probeer hulle positief inpraat. En dit help hulle.

C: Ja, want julle is heeltyd omring deur hulle daarso.

X: Ja, en nie net dit nie. (skud kop) Jy sien jou kind hier is so klein en jy sien daar is 'n ander enetjie is so siek en dan sien jy daai enetjie maak dit nie en dan stres jy sommer vir jou kind en dan is jy bang jou kind maak dit ook nie. Want dis die heeltyd jy sien dood om jou, die heeltyd, veral toe ek met hom daar was hoe baie babatjies het die heeltyd om hom doodgegaan en dan het hy erg siek geraak en dit het mens baie laat stres en jy het geworry (trek gesig) en dan sit jy daar en jy weet nie wat om te doen nie en dan het die suster weer kom praat en dan sê jy suster dit en dan sê sy: 'Maar moenie dink aan daai kind nie' (skud kop), 'Dink aan jou laaitjie vorentoe' (wys met hand vorentoe). Kry die image vorentoe. Wat sien jy van jouself en die kind en so dan sit en dink jy wat sien jy vir julle en dit het ons deurgedruk. En dan sien jy elke dag. Dan sê sy ook moenie dink aan maande nie, dink aan dag vir dag en dit het my gehelp. Partykeer het ek aan uur vir uur gedink (beduie met hande stuk vir stuk). Dan stap ek elke uur op en dan gaan check ek en gee hom 'n soentjie en dan loop ek weer af.

C: En as dit dan net bietjie beter gaan dan voel jy net bietjie meer hoopvol.

X: Ja, dan voel jy so relaxed en goeters en dan los jy hom nie, jy wil hom amper nie terugsit daar nie. (skud kop) En dan as jy moet gaan melk druk of so dan wil jy dit nie eintlik doen nie. Jy wil hom net daar vashou en hom nie laat gaan nie, want so excited en jy kan dit nie beskryf nie, 'n trots in jou om die kind daar te hê so dis eintlik 'n goeie ding.

C: En dis al jou harde werk wat hom tot daar gekry het waar hy was.

X: Jissie ja al daai nag opstanery (skud kop en begin harder praat). Ek onthou hoe ek elke uur moes opstaan en toe later toe sit die suster vir my 'n stoel daar en sê: 'Sit net hierso, [wys met hand] ek gaan jou nou oor 'n halfuur wakker maak' en dan druk jy weer melk en toe op 'n stadium toe sê hulle: 'Okay, jy kan nou elke twee ure kom' en toe begin dit verbeter. Veral toe hy baie opgegooi het en die magie so begin swel (beduie met hand maag) het toe elke halfuur moes gaan melk gee. Dan was dit ook net 1 ml wat hy gedrink het, so dit was baie lank wat hy gesukkel het, maar dit het my deurgedruk.

C: Ja, daai bietjie meer, bietjie meer.

X: Ja, veral as jy opstaan, dan is jy so moeg, maar jy doen. Jy staan op vir daai kind maak nie saak hoe moeg jy was nie. (skud kop) So jy het opgestaan. Partykeer het ons een of twee verslaap en goeters, maar dan weet jy jy het klaar melk in die yskas vir die kind. En op 'n tyd kan ek onthou die suster het vir my gesê 'Druk nou vir my genoeg melk vir die volgende twee ure dat jy kan gaan slaap,' want dan het ek elke halfuur opgestaan om vir die

Commented [A34]: Supporting other NICU mothers

Commented [A35]: Caring medical staff

Commented [A36]: Nurturing her NICU infant

Commented [A37]: Caring medical staff

Commented [A38]: Surrounding events during prolonged hospitalisation

Commented [A39]: Caring medical staff

Commented [A40]: Future orientated view

Commented [A41]: Nurturing her NICU infant

Commented [A42]: Nurturing her NICU infant

Commented [A43]: Physical exhaustion

Commented [A44]: Nurturing her NICU infant

Commented [A45]: Physical exhaustion

Commented [A46]: Nurturing her NICU infant

kind melk te gee. En toe sê hulle vir my hulle doen dit nou deur die masjien so ek kan bietjie begin relax. Toe het hulle die masjiene begin inkry. So daar het dit ook begin beter gaan, want dan weet jy darem jy kry jou slapie in. Jy relax, jy's nie so kort af of so nie. Ja wat, jy raak bietjie kortaf en moeg. (vryf kop)

C: Ja, en veral as dit vir vier maande was soos vir jou.

X: Dis lank. (knik kop)

C: Sjoe, die bring nou baie memories terug.

X: Ja, veral as jy sien die mammas kom en gaan, kom en gaan en jy bly. En dan is jy soos: 'Kom boetiejtjie, groei nou!' (wys met hande asof sy hom aanspoor) En sy probleem was hy het nie gewig op getel nie en nou steeds sukkel hy met daai probleem, maar dit gaan die res van sy lewe wees omdat hy van geboorte al met dit gesukkel het. So ons weet dit, maar partykeer is jy van 'Kom boetietjie … tel net daai een of twee grampies op!,' so jy het hom altyd aangemoedig. (glimlag)

C: Hoe gaan dit nou met hom op die stadium in jul lewe?

X: Nou gaan dit baie goed, want hy is mammie-vas. So mammie kan niks doen sonder boetietjie nie. (skud kop) So as ek enige iets doen dan is hy by my en hy help my so (wys langs haar), maar ons het nog steeds ons ups en downs soos as hy siek raak, veral as hy verkoue kry en goeters. Dan moet ons maar hospitaal toe jaag, want dis omdat hy dit bietjie kwaai kry. Dan sukkel hy bietjie om asem te haal en goetertjies maar die dokter sê sy longetjies is actually nou fine. So hulle het vir hom drie maande terug weer steroids gegee om die longetjies … want hul sê die longetjies is maar nog bietjie klein. Dis nog nie 100% (skud kop) soos wat enige baba s'n moet wees op die ouderdom van twee nie. Syne is maar soos 'n eenjarige s'n so hulle boost hom nog nou en dan, maar hy kom daar. So ons het die ups en downs, maar dis meer ups as wat ons die downs het.

C: En dit is ook 'n definisie van hoop. As mens meer op die positiewe kan fokus as die negatiewe nè? En dis soos wat ek nou agterkom dis wat jy gedoen het en dis wat jou daardeur gekry het. Die hoop van die goeie. Al gaan dit sleg, hoop jy vir die goeie.

X: Ja, maar dis al wat jy kan doen is jy kan maar net hoop. Want as jy nie hoop het nie, . (skud kop) Die hoop is die belangrikste deel daarso.

X: Ja, dit het ook gebeur daar was 'n babatjie wat so siek geraak het en ook die ventilator gehad het en geopereer was soos Baba X en toe sy daar aankom toe is die kind dood. Ek onthou dit presies, dis asof ek nou daar sit en ek onthou dit (kyk by venster uit). Dit voel snaaks, want ek onthou elke ding detail vir detail (wys met hande). Hulle sê dit gaan maar vir altyd vir die res van my lewe my haunt. Veral soos die babatjies wat om hom doodgegaan het en goeters en sy ma het sy sussie ook verloor toe sy drie daggies oud was sy sê sy onthou dit nou nogsteeds en die meisiekind is al 44 jaar terug dood. Jy onthou nog presies die dag presies soos wat dit gebeur het. Sy sê dit gaan nooit weg nie. (skud kop).

C: Dis ook hoekom dit so belangrike studie vir my was, want baie keer dink mense sodra hulle uit die hospitaal uit is is dit verby, maar dis 'n lewenslange ding wat gebeur het en soos jy gesê het jy droom soms nog daaroor.

X: Ja, want partykeer word ek wakker en dan huil ek en dan sê ek: 'Die kind,' dan sê hy: 'Hier is die kind by jou,' dan sê ek: 'Nee, hy is in die hospitaal' en dan sê ek: 'Ek wou die enetjie vas gehou het, maar hy is dood' (praat hard en wys met haar hande). En toe kon ek hom nie vashou nie; ek verstaan nie hoekom ek hom vasgehou het nie, want toe is ek ook mos op die masjiene, want na die tweede enetjie het ek mos 'n keiser gekry en toe het my bloeddruk mos geval en die suurstof het geval (praat vinnig), toe sê hy: 'Maar die ding is jy was nie reg om die kind te kon gevat het nie,' - die tweeling, die tweede enetjie wat dit nie gemaak het nie, so ek het hom nie vas gehou nie. Partykeer dink ek nogsteeds hoekom, hoekom? (skud kop) En met Baba X kon ek hom mos vir 'n maand nie vasgehou het nie, want hy het mos nie vel gehad nie, en as jy aan hom gevat het dan het hy mos gebloei en dan moes hulle weer die masjientjie vat om die are weer bymekaar te kry (beduie met haar hande). Sulke goed onthou ek. Ek onthou dan vat ek aan die kind en dan is dit bloed en dan skree

Commented [A47]: Physical exhaustion

Commented [A48]: Surrounding events during prolonged hospitalisation

Commented [A49]: Long-term medical challenges

Commented [A50]: Improvement of NICU infant's medical condition

Commented [A51]: Dynamic in nature

Commented [A52]: Survival skill

Commented [A53]: Post discharge emotional challenges

Commented [A54]: Post discharge emotional challenges

Commented [A55]: Post discharge emotional challenges

jy: ‘Suster wat nou?’ (praat hard). ‘Moenie vat nie, moenie vat nie!’ Hy het nie ‘n vel gehad nie. Die susters het ons gewys. En die dokters: ‘Kyk hier hier is geen vel nie, die kind is gebore sonder vel en dis hoekom hy die kappietjie ook op die kop gehad het, dit was om die brein te beskerm’ (beduie met hande). Dit was nie om die CPAP te hou of om te keer dat dit hom seermaak nie. Dit was om sy koppie in plek te hou en die breintjie en goeters, want hulle sê die breintjie kon nog so bietjie flabber ook. Hy was nie vas nie. Ek onthou hy het net aan die kante by die ore kopbeen gehad, maar die ore het net gaatjies gehad. Dit was nie ore nie, hy het net daar twee kopbene gehad. (wys met hande) Jy sien hoe ontwikkel die kopbene en dis partykeer dan sien jy hoe ontwikkel dit. Dan sê ek vir hom: ‘Kom kyk hierso!’ Maar die kind is nie daar nie, hy slaap. Maar ja, dit voel nie so nie. Dit voel of ek nou nog in die hospitaal is. Dan sê hy: ‘Nee.’ Maar dis nagmerries wat jy steeds nog kry. Dit gaan net nie verby nie, partykeer raak dit beter en partykeer is dit bietjie erg. Maar as jy weer terugdink dan weet jy dis verby. Kyk waar is ons. (A sense of mastery) Dan sê ek vir myself: ‘Jy’s nie daar nie, jy is by die huis. Kyk hier is jou kind. Hy is groot - kyk watse wonderwerk is dit.’ So ja…

C: Ja dit is so. Selfs ek dink nog baie daaraan en ek was nie eers ‘n neonatale ma gewees nie. Ek was maar net julle counsellor gewees. Ons het nou gepraat oor hoop met klein ou Baba X, maar hoe het dit jou gehelp om … of het dit jou gehelp eerstens en hoe het dit gehelp om die gehelp met die hartseer sterwing van jou ander tweeling?

X: Dit is nogsteeds moeilik. Ons sukkel steeds om te cope met dit. Ons het nog nie regtig die way gekry om te cope met dit nie. Soos jy sien die foto’tjie wat ons daar gehang (wys na waar die foto hang) het met sy voetjies en toe het ons hom veras. Maar die ding is die verassing is nogsteeds hier by ons. Ons kry dit net nog nie dat ons hom kan laat gaan nie. So hy bly by ons en goeters.

C: Gee dit in ‘n manier vir jul hoop om hom hier te hou of …?

X: Ja, dit voel vir ons dit is ons closure. Ons het hom om by ons te bly en ons het agtergekom hy is eintlik nog steeds hier by ons (wys na haar hart). Ek het so speelding hierso en elke oggend drie uur, want jy moet hom slaan fisies dat hy lag. Veral vir Baba X wat klein is. En dan sit ons hom hier voor (wys na waar speelding was) en dan hoor jy die ding lag hy, elke oggend drieuur vir ‘n uur lank dan lag daai speelding uit sy nate uit en hy hou nie op lag nie. Dan sit ons hier en neem video’s, maar al wat jy sien is so donker wolkie (beduie donker wolk se vorm) by dit, maar dan is dit so wit om dit en dan is dit soos weet jy wat die kleintjie is - hierso. Dan voel ons rustig en dan gaan slaap ons. Dan hoor ons daai speelding soos hy afgaan. Al hoor ons die speelding, ons gaan slaap. Dan weet jy die kleintjie is hierso. En baie hier by ons. Hier is nooit mossies nie, maar vandat Baba X huis toe gekom het was hier ‘n mossie. En elke keer wat hy in die hospitaal was of in ICU was, was daar ‘n mossie en as dit swak gegaan het het die mossie by hom gevlieg. Ek weet nie of jy gesien het nie, maar altyd by die ICU afdeling in daai hoek het daar ‘n mossie gevlieg. En elke keer as daar ‘n mossie gevlieg het het Baba X beter geraak. Ons glo die boetie van hom is in die mossie. (glimlag)

C:’n Simbool van hom …

X: En toe ons elke keer toe hy epilepsie kry en dit so erg was. Want hulle het hom hierso gedrop by Medicross, toe jaag ons soontoe, en hulle het hom vyf drugs gegee net om rustig te kon kry. In die ambulans twee drugs gekry en toe kry hy weer die fits en toe ons net by Kalafong kom by die emergency afdeling toe jaag hulle deur met hom toe kry hulle dis verskriklik erg (trek gesig). Hulle het vir hom sewe drugs gegee, beenmurg getrek, brain scan gedoen, alles om uit te vind wat was dit, maar kon nie uitvind nie. Toe kom hulle agter die golwe van sy brein is baie vinnig, so epilepsie is daar, maar dis nie erg nie. Hy is daar, maar hulle kan dit verhoed. So gelukkig dit het,

Commented [A56]: Post discharge emotional challenges

Commented [A57]: Motivation and mastery

Commented [A58]: Belief in child

Commented [A59]: Post discharge emotional challenges

Commented [A60]: Symbols of hope

Commented [A61]: Symbols of hope

Commented [A62]: Long-term medical challenges

elke keer toe hy in daai saal was het die mossie onder sy bed. En dan sê ek vir sy pa: 'Kyk hier!' en ek neem foto's. (wys asof sy pa roep) Kyk die mossie sal daar sit en hy sal nie move nie (skud kop), dan is hy onder sy bed en dan klim hy op en dan is hy by sy kop en sodra hy weg vlieg, dan is daai kind fine en ons gaan elke keer huis toe. Elke keer dan gaan ons huis toe. Dan sê die suster: 'Jou kind is gesond. Jy kan maar huis toe gaan.' So ons glo die boetietjie is in die mossie en dis hoe ons maar ons hoop het. Elke keer as die mossie daar is dan is hy gesond en dan geen probleme en elke keer dan se ek vir my man: 'Sien, hier vlieg die mossie' en dan sien ons maar Baba X is gesond, niks fout nie. En dan sal hy hier op die vensterbank ook loop en op die stoep wees en Baba X is fine. So ons glo die tweede boetie is in die mossie wat na sy boeties kyk.

C: Dis amazing hoeveel hoop so simbool vir jou kan gee. As dit sleg gaan en jy sien net die mossie en dan weet jy al klaar dit gaan beter gaan.

X: Veral in ICU as ek daai mossie gesien het, my hoop het so hoog gegaan, ek dink nie dit kan hoër as dit gaan nie (skud kop). As ek daai mossie sien dan weet ek die kind gaan dit verder vat, hy gaan nou gesond raak. En as die mossie weg is dan weet jy hy gaan vir 'n ruk fine wees en die downs kom, maar as daai mossie terug is dan weet jy daar is meer hoop. So die hoop het met die mossie ook gebou, maar elke keer as daai mossie daar was ek kan jou nie sê nie, dan het ek en hy so gesit en kyk vir hierdie kind (sit op punt van haar stoel) en hy raak net sterker. Daai mossie was, ek sal sê hy was die meeste wat die hoop vir ons gegee het eintlik. (knik kop)

C: Daai mossie, daai mossie weet nie eers watse spesiale impak het hy op jou lewe nie en ...

X: Die susters sê hulle jaag hom nie weg nie (skud kop), want hy het 'n nes gebou by sy kop waar hy lê in daai bedjie. Net bo in daai hoek (wys na hoek) was sy nessie en daar was net een mossie. Daar was nooit 'n ander mossie nie. Net ene. En dan sou hy so op en af gevlieg het in ICU net bokant hom. En elke keer as hy so vlieg en rustig raak dan se die suster vir my: 'Weet jy wat? Jou kind verbeter, hy verbeter.' Dan sê ek vir haar dis die mossie. Toe sê hulle vir my hulle dink ook so. Toe sê ek vir haar van die ander boetie toe sê hulle dit kan wees. Die boetietjie is in die mossie in en hy wil 'n ogie hou oor sy boetie. So …

C: Dis amazing.

X: En partykeer dan sien jy daai mossies en dan dink jy weet jy wat … as ek Hospitaal ABC toe gaan vir sy checkups dan weet jy wat … kyk hier is die mossies en hulle loop na hom toe en dan loop hulle so verby. Hy kan hulle jaag, hulle vlieg nie. Dis vir ons amazing. (glimlag)

C: Dis nie iets wat ek geweet het daardie tyd … van die mossie nie wat so spesiaal was vir julle nie. En mag julle lewe omring word deur mossies.

X: So ons versamel nou die een sentjies en papiertjies wat ons versamel met die mossies op en goeters. Sy foto's het ons nou omring, baie van sy ICU foto's met die mossietjies, wat ons weet hy baie swak was en die mossietjie was daar en hy het verbeter. Baie van die fototjies is so omring met die een sentjies met die mossies.

C: Dis special.

X: Dis iets wat ons special nou maak vir hom. (glimlag) En partykeer kyk ons terug en dan sê ons: 'Kyk waar was ons en kyk waar is ons nou en weet jy wat ons gaan net verbeter.' (wys met hande) En so verbeter ons elke keer.

C: Jy't regtig 'n storie van hoop … waar julle was tot nou. Jy is 'n getuienis van hoop en waar hoop mens uitbring op die ou end van die dag.

X: Mens sal nie sê jy was daar en waar jy nou is nie. Ek sal nie enige iemand aanbeveel. Jy moet seker maak jy doen alles reg met daai swangerskap. Moet nie so vroeg kraam nie.

C: Maar soms kan jy dit ook nie help nie. Jou lyf gaan in kraam in.

Commented [A63]: Symbols of hope

Commented [A64]: Symbols of hope

Commented [A65]: Symbols of hope

Commented [A66]: Motivantion and Mastery

X: Maar soos met hulle ek het nie geweet ek was in kraam nie. Ek het net gevoel asof iemand my kielie op die pens en ek het sy ma laat weet, is dit normaal? Iemand kielie my pens. Toe sê sy dis nie normaal nie. En dis net op een plekkie waar hy jou kielie.
C: Hoeveel weke was dit omtrent?
X: Ses en twintig. Ja en ek het daar gelê en toe is ek bedlêend van die Dinsdag tot die Donderdag en toe Donderdag aand toe kom hulle. Ek het gedink Baba X was die een wat dood was, want hy was mos die kleintjie en hy was potblou. Hy was blou, blou. (kyk af) En toe sê hulle vir my: 'Nee.' En toe het ek mos die keiser. (wys na keiser oor maag) En toe sê hulle die enetjie is die een wat sukkel om asem te haal. Baba X het vir hom asem gehaal, vir die ander enetjie, toe het sy longetjies nie ontwikkel nie. En hy was maar 800 g gewees die ander enetjie nou.
C: Groter as Baba X, op die ou end van die dag.
X: Ja. En hy het 'n velletjie gehad en alles. Hy was complete babatjie gewees (wys met hande), maar net sy gewig en die longe. Maar hy was soos complete. Beentjies was gevorm en alles. Ek kan dit nog onthou. Presies soos was hy daar gelê het met daai groen lakentjie wat hulle hom mee toegemaak het en langs my gesit het en ek kon hom nie vat nie (kyk af). Ek kan dit nog steeds nie verstaan hoekom ek hom nie net gevat het en vasgehou het nie. Dit sal mens altyd twyfel (skud kop). Dis altyd 'n vraag wat ek myself sal vra, hoekom?
C: Ek dink ons almal probeer die beste ouers wees wat ons kan en op daai stadium is jy eerstens in skok en jy is getraumatiseerd en dis oraait dat jy die besluit daai tyd gemaak het. Jy moet net vir jouself sê dat dis wat jy gedink het op daai stadium wat reg was en jy't nie gedink hy gaan dit nie maak of so nie.
X: En onthou jy toe hy gekom het die vraag wat ek haar gevra het toe hy kom: 'Lewe hy?' En toe sê sy: 'Nee.' Toe sy sê 'nee' toe vra sy wil jy hom vashou toe sê ek vir haar: 'Nee.' Toe sit sy hom langs my neer. Toe vra ek vir haar is dit 'n seuntjie of 'n meisie en toe sê sy 'n seuntjie. Ek dink vir myself, ek sê vir myself elke keer: 'Hoekom ek hom nie gevat het nie?' Ek sou nie gecope het nie. (skud kop) Want hom het ek verloor en dan het ek nog daai enetjie wat ook lê en dan gaan ek heeltyd terugdink as ek hom moet vas gehou het, hy het dit nie gemaak nie en dan moet ek die enetjie … (kyk af).
C: Dit was jou manier om te cope op daai stadium.
X: Partykeer vra jy nogsteeds daai vra. Dis asof daar's nogsteeds 'n puzzletjie wat nie vir jou sin maak nie. Daai spasie. Jy wil daai deel weet. Maar ek sê vir myself jy sal dit nooit weet nie, tot jy eendag daar bo is dan sal jy weet. Die vrae, onbekende vrae wat niemand vir jou kan antwoord nie. Nie eers jy self nie, so niemand kan vir jou antwoorde gee vir daai vrae nie. Tot jy eendag daar bo is dan sal jy maar jou antwoorde kry. So mens cope in some way met dit. Jy gaan verby dit en dan gaan jy weer terug. Maar elke keer is maar 'n stappie wat jy gaan. (wys met hande) Maar dit raak beter, maar ek dink dit gaan maar baie jare vat voor jy, veral met die enetjie wat dood is, die cope situasie daar.
C: Dit is nog 'n rou wond. En al is dit 'n paar jaar terug, dis steeds 'n kind wat jy verloor het. En jy moet jou self daai kans gee om …
X: Die ding is die probleem is mens sukkel om oor dit te kom. Want hulle het vir my gesê hulle gaan nie identicals wees nie, want hulle was in twee aparte sakkies. (wys met hande) Maar toe hulle gebore is en as jy die foto vat van die boetie wat dit nie gemaak het nie …
C: Het jy 'n foto van hom?
X: Ja, ons het een op die computer en as jy na Baba X kyk hulle lyk steeds identical dieselfde (beduie met twee hande langs mekaar). So ek dink elke keer wat jy hom sien, dan sien jy die ander enetjie. En dan bring jy die wonde net weer terug. So dis

Commented [A67]: Post discharge emotional challenges

Commented [A68]: Post discharge emotional challenges

Commented [A69]: Personal spirituality

Commented [A70]: Post discharge emotional challenges

Commented [A71]: Post discharge emotional challenges

die probleem omdat ons so bietjie nog sukkel maar. Soos ek sê partykeer dink jy nou nie aan daai enetjie nie, want jy fokus net op die enetjie en dan nou en dan sal jy daai glipsie kry wat jy terug gaan en dan sien jy nou weer daai enetjie, maar dan weet jy nou min of meer hoe om dit te handle, maar partykeer kry jy daai dae wat jy sukkel. Dan het die pappa nou weer die enetjie en dan gaan sit ek in die kamer en huil so bietjie en dan kom ek en dan voel ek baie beter. So huil help vir ons ook. Partykeer dan sit ek dan huil hy ook, net om daai emosie bietjie uit te kry. (kyk na kamer)

C: En dan voel jy daarna …

X: Dan voel jy of jy duisende berge van jou skouers af het (haaal hard asem). Dan het jy so lus vir die lewe en dan fokus jy net weer op daai enetjie en alles. Partykeer sal hy saam met jou kom sit en dan huil hy saam met jou. Dan weet hy nie eers hoekom huil hy nie. En die ding is ons dink hy het sy boetie gevind in die ander ene, want hy is baie erg oor sy boetie. Hy soek min of meer die boetie, maar ons kom agter dis asof hy weet die enetjie is nie die een nie. Maar ons sal wanneer hy verstaan hom maar mooi verduidelik ook van die ander ene …

C: Ja, en ek glo in hindsight, even nou na twee jaar kan mens sit en kyk hoe het julle van dag een tot nou gekom en miskien oor ‘n paar jaar weer dan sien jy hoe het ek van vandag gekom tot twee jaar van nou af. En julle het ‘n amazing storie. En toe ek aan die studie dink het ek eerste aan jou gedink, want ek was amazed deur die proses waardeur julle was in daai vier maande en kyk waar is julle nou. En al is dit ups en downs ek glo regtig julle sal daardeur kom. En gee jouself tyd ook. Dis nie ‘n klap van die vingers en dis verby nie. Dit gaan altyd iets wees wat jy verloor het, maar it will be okay.

X: Ja, partykeer dan sal Baba X kom en dan wys hy vir my “boetie.” En dan kyk hy so en sê: ‘Ja, dis jou boetie’ en dis asof hy weet. Ek dink hy weet … (kyk uit by venster)

C: Hulle se mos tweelinge het daai band al van die baarmoeder af.

X: Ja.

C: Maar ek dink vir jare te kom sal Baba X steeds as die miracle baby wees.

X: Vir ons is hy ‘n miracle. As ons van hom praat dan praat ons altyd van die miracle baby. Van die familie ook … miracle baby. Hy is die enigste een in die familie wat so klein was, wat gebore was, wat so vroeg was en die enetjie wat die meeste siektes gehad het en dit alles kon maak het en nogsteeds. Enige siekte wat kom hy oorwin dit. Eintlik is hy baie sterk. Eintlik wys hy vir ons weet jy wat ek is ‘n sterk kind. So ons leer eintlik nog elke dag by hom ietsie. Nie hy by ons nie. So ons leer by hom eintlik.

C: Ek glo regtig hy is ‘n lopende simbool van hoop en wys wat hoop kan doen, want om jou woorde nou te gebruik … sonder hoop is daar niks.

X: Want jy weet nie waarna toe om te sien as jy nie hoop het nie. Want hoop is eintlik die sterk ding daar. As jy nie hoop het nie waarnatoe gaan jy dan? Die kind moet ook maar hoop hê. Want hy weet mamma hoop ek gaan sterker raak so hy weet op die ou einde gaan hy veg om sterker te raak. Daai hoop is eintlik die belangrikste. En ek glo dis wat ons deurgebring het … daai hoop. Daai verband wat ons gehad het met die hoop. (Motivational tool)

C: Wat ‘n voorreg om vandag hier te kan sit en ek sal graag vir Baba X kan sien en ontmoet, want daai lyfietjie was so klein toe ek hom ontmoet het die eerste dag.

X: Jy sal nie glo nie sy kop is nou die lengte wat hy was met geboorte.

C: Ja nee, dis hoekom ons moes daai footprints gedoen het en die foto’s geneem het om nou te sien hoe ver hy gekom het.

X: Veral noudat hy groot is en jy wys vir hom: ‘Kyk hoe klein was jy; kyk waar is jy nou.’

Commented [A72]: Post discharge emotional challenges

Commented [A73]: Post discharge emotional challenges

Commented [A74]: Belief in child

Commented [A75]: Motivation and mastery

C: Selfs as hy nou nog groter word gaan hy sien al my maatjies se babafoto's lyk so en myne lyk so.
X: Ja, so ons wil nou eintlik op twee jaar … want môre is hy eintlik eers fisies twee eintlik.
C: Wanneer hy sou gebore word?
X: Ja, dan wil ons nou môre die handjies en voetjies vat en dit dan saam met daardie sit en vir hom wys: 'Kyk!, gebore tot twee.' (beduie met hande)
C: Daai self is 'n simbool van hoop, om daai vordering te sien.
X: Ja ons het dit opgehad, maar toe was ons nog bietjie emosioneel (begin sagter praat) en toe haal ons dit maar af en bêre dit weer en toe se ons wanneer die tydjie reg is dan sit ons dit weer op en wys vir almal.
C: Jy sal weet wanneer die tyd reg is. Jy sal weet wanneer jy dit in jou hart voel.
X: Ons het dit juis opgesit omdat ons die boetietjie se voetjies daar gesit het, maar toe sê ons: 'Nee, dit bring meer die boetie se memories terug as wat …' (lyk of sy weer trane in haar oë kry).
C: Baba X. Ja, want jy het vir Baba X hier, maar om na daai te kyk laat jou terugdink aan daai tyd.
X: Soos ek sê elke dag raak maar bietjie beter, maar jy kry maar jou ups en downs en goeters, maar jy kom eintlik sterkter uit. Dit maak jou eintlik sterk.
C: Jy't 'n storie wat min mammas kan vertel en ek glo jy kan trots wees op daai storie al is dit hoe moeilik, waar jy vandag is kan jy op trots wees.
X: Ja, vir daai vier maande voel dit of jy twee jaar in daai hospitaal was, maar eintlik net vier maande. En die tyd het eintlik so vinnig gevlieg. Partykeer het dit net nie geloop nie. Ek onthou hoe het ek daar gesit en gedink: 'Kom nou tyd loop!'
C: Ja, want julle was dag en nag daar by hulle gewees.
X: Ja, daar was 'n tyd gewees wat ek seker vir vier of vyf dae by hom geslaap het, wat ek nie eers bed toe gegaan het nie.
C: Ja, op daai plastiek stoele.
X: Op daai stoel gesit en slaap en dan het die suster vir my gesê: 'Okay, gaan druk gou melk' en dan op 'n tyd het sy vir my gesê: 'Gaan druk gou vinnig melk en dan gaan jy af en dan gaan shower jy gou-gou en dan kom jy weer op.' Dan het jy net daai half-uurtjie. Dan moet jy shower, aantrek en dan weer vinnig opgaan (begin vinniger praat). Daar gat jy weer. Dan elke dag. Ek kan onthou daai vier dae wat ek so daar gesit het. Dan het ek vir vier dae nie geslaap nie. Dan sit ek so en kyk daai kind so (Maak of sy vir haar kind kyk).
C: Ja, jy's net bang as jy jou oë toemaak dan gebeur daar iets.
X: Ja, jy knip net jou oog en dan gebeur daar so iets dat jy vir die res van jou lewe worry. So jy het so gekyk. (rek haar oë) Maar daai vier dae was hy eintlik fine gewees, maar mens is nogsteeds bekommerd gewees veral omdat hy so klein was. Veral as jy sien almal se babas is groter as jou kind en hier kom die enetjie en hy is so teeny-weeny.
C: En op die ou end was hy groter as van die nuwes wat ingekom het en dan kan jy nie glo jou kind was so klein soos daai gewees nie.
X: Ja, en toe ons verlaat toe is meeste kinders in anyway groter as hy.
C: Ag shame, maar hy het 'n baie vroeë begin gehad.
X: Maar mens sal nie sê nie soos wat hy nou aangaan. Dis asof hy 'n normale geboorte gehad het. Behalwe met al die merkietjies nou wat nogsteeds daar is, maar …
C: As dit 'n paar klein merkies is dan het hy darem nie sleg afgekom van al daai ICU en al die highcare goed nie.
X: Ja mens vat eerder die merkies as wat jy hom verloor het. (kyk af)
C: Ja. Baie dankie. En nou kan ons vir hom gaan hello sê.

Commented [A76]: Post discharge emotional challenges

Commented [A77]: Dynamic in nature

Commented [A78]: Surrounding events during prolonged hospitalisation

Commented [A79]: Physical exhaustion

Commented [A80]: Physical exhaustion

Commented [A81]: Medical complications or lack of progress

Appendix E:
Fieldnotes

The interview took place at the participant's home in Pretoria West. It seemed as if she was very pleased to see me and could not wait to tell me all about her son's progress in the last two years. As we walked up the stairs of her apartment building so told me about her son and how big he has gotten. She said that she asked her neighbour to look after her son while we did the interview but that I was welcome to greet him afterwards. I was pleased of the opportunity of having the chance to see this young boy after I only knew him as a neonate in the hospital. As we sat down for the interview I went through the purpose of the study and the consent forms. I reassured her that although I am the researcher in this role, this interview will still be informal and relaxed. She seemed at ease. We read through the consent form and I gave her the chance to ask questions if anything was unclear. At the beginning of the interview she seemed very optimistic and positive. She gave me shorter answers and it almost seemed as the interview went on she remembered more and more detail. Her descriptions became more vivid and her explanations longer. When she said that she would tell other mothers to just believe in their child she became tearful. It seemed that at that moment she realised that she had always believed in her child and that although there was a whole NICU team responsible for her child's care, she as the mother had a big role to play in the whole process. At times where she spoke about the medical complications or all the medical procedures she would start to talk faster and she often described his physical size or his features with her hands. There were times where she would look out of the window or down at the ground, especially when she spoke about harder times or her other twin that passed away. But most of the time when she spoke about her son, his progress and hope, she smiled. She got specifically enthusiastic when talking about the symbol of the sparrow. She wanted to show me photos and made references to her deceased son's ashes and her NICU infant's hand and footprints. She offered to include photos of these symbols in the research. After all the questions I reassured her that if she found this interview as distressing or even if she feels in the aftermath of this research that she needs counselling or debriefing, I would refer her to a counsellor that also worked in the same hospital's NICU. She assured me that she felt fine and was excited to keep in touch. After the interview she went to call her son. As I sat there in her living room I was grateful and humble that this participant agreed to share her narrative of hope with me. She was radiant with pride as her son and I got a chance to meet.

Appendix F:
Research Journal

29 September 2017
Today I had my first interview with the participant. I was apprehensive of driving to Pretoria West for the first time in years. As soon as she invited me into her home I felt more relaxed. It was very nice to see my client as a research participant two years later. Although I am using past clients as my participants and it might lead to increased researcher biased I also felt that it had some advantages. We have already established a relaxed and trusting relationship. She was more open to share her triumphs and challenges with me because she knew that I was there when she went through those experiences. I felt a great amount of empathy when she started to get tears in her eyes but it seemed as if it was a significant moment for her to think of where they came from and where they are now. I sometimes found it difficult to formulate follow up questions that were relevant to my research questions. At times I felt as if some of my questions could be leading questions (which could also be because I know her past, what she went through and who supported her in that time). There were also times where I felt that I was repeating myself in questions to get richer information. Her descriptions of the events brought back a lot of memories of days in the NICU and it reminded me why I started this study in the first place. For my next interview I will go through the transcription and identify the relevant questions and those that lead to information that isn't relevant to my study. I will also translate the questions before hand. With this participant we both anticipated that she would be able to do the interview in English but we realised that she could provide richer information in her home language of Afrikaans. I suspect this will be the same case with my next participant. At the end of the interview I got the chance to greet her two year old son that I met as a 600g baby in the NICU and this was a very significant and special moment for me as her past counsellor but also as a researcher.

30 October 2017
Chapter 1, feedback 1

- Combine more statements that state the same concept.
- Look at sentence construction.
- There should always be a golden thread running through your paragraphs.
- Build the argument for research better.
- No need for a separate heading of problem statement.
- Expand on concept clarification that is specific to the study.
- Make sure that past tense is used throughout.

1 November 2017
I was supposed to meet my second participant today. We have rescheduled this interview many times. She works from 7 to 6pm thus I decided to arrange a meeting in her lunch hour. A few minutes before I was supposed to leave to meet her she informed me that the interview couldn't take place anymore because her boss was not at work that day. I found it frustrating that the interview was cancelled because it started to delay my data analysis process but I also had to remind myself that the participation was voluntary and that I couldn't force a participant into meeting me.

7 November 2017
Chapter 1, feedback 2

- Start with a more powerful statement.

- Explain concepts like preterm birth or NICU.
- Formulate a clear research problem and rationale.
- Don't use as many quotes and use more own words.

9 November
When first told my supervisor about not able to sample other NICU mothers, he told me to first do a preliminary data analysis before we decide if we had to get more participants. I found the data analysis with the resources and challenges much easier than the theme of what the mother's understanding of hope is. I found myself with overlapping themes and I wasn't sure for instance if positive expectations and motivation fell into one theme. At a point I was also not sure if it would have been easier to do a deductive analysis based on Plaas' model. So I decide to do the inductive analysis but I am considering not only doing a recursive literature review but also relating it back to Plaas' three themes. I found the different inclusion and exclusion criteria confusing at times and will consult my supervisor on this matter.

5 January 2018
When writing about my selection of participants, it took me back to my process of ethical clearance. At first I was set on having a much bigger sample and conducting a focus group in the NICU setting. After the long process of ethical clearance this proposal was amended and I was limited to having individualised interviews with my past clients. At first I thought that I would be able to get at least two to three participants, but as time went on I settled on one single participant. In conducting this single case study with one participant it made me think of all the pros and cons of this research design. The first thing that came to mind was with only one participant I could do a more detailed study on her unique experience, but would other NICU mothers be able to relate? Then I thought of the purpose of my study and remembered that it was not aimed at generalising her experience but rather giving her the chance to offer her narrative on the NICU experience. If I had a bigger sample I would have had a lot more data on different perspectives, but would the data have such rich descriptions on specific experiences in the NICU. When I did my proposal on the focus group design later gathered information on the individual interview it was clear that both methods do have their own advantages and disadvantages. When it comes to the data analysis and I subsequently do not have enough data to form themes I will deal with it then and make a plan to gather more information from my participant.

10 January 2018
Chapter 2, feedback 1

- Make it more of a review and do not just state what different studies contributed.
- Instead of the heading of "history of hope" replace it with "scientific roots of hope."
- Make sure to back up views with literature.
- Maybe uses of a table instead of lose statements at South African NICU research.
- Look closely at Snyder references.
- Start different sections with a clear overview and then unpack it in detail.
- It's not necessary to give all the details on each study only what is relevant to my research.

11 January 2018
I was anxious before this meeting because Chapter 2 was the most difficult to write. My supervisor gave me very good constructive criticism. One of the basic things that I learned in this feedback is a literature review must not only state literature but it should review it in the context of my study. After I mention a study I must say why it is applicable and helpful in this specific study. I also learned not to use secondary sources as much and that I should quote as little as possible. There was a part of my initial literature review that wasn't meant for Chapter 2 but could be better used in Chapter 4 in my recursive lit review.

10 January 2018
Chapter 3, feedback 1

- Make sure to start sections on paradigms or methods with what it is and how will I apply it.
- Explain diagram and insert arrows.
- Set clear boundaries for the case studied.
- Explain reason for sample of one participant.
- Clearly refer to different attachments.
- Use the interview schedule in an appendix and not in the chapter itself.
- Be clear on how different methods will be applied in this specific study.
- Change trustworthiness to quality assurance methods.
- Do more research on Silverman and what he said on generalisation of single case studies.
- Give details on ethical clearance process.
- Write less story-like and get to the facts quicker. Use bullet points as a guideline.

12 January 2018
In working on my Chapter 3 today I realised that I often repeat myself in different parts of the chapter. When working on a word document it is often easy to lose sight of the bigger picture or in this case the chapter. I decided today to print out my chapter to enable me to have a look at the hard copy and highlight different parts where I said the same thing, just in a different way. It starts to get harder when doing draft after draft because I often find myself losing sight of what I want to say and what I already mentioned in another paragraph or chapter. There is also so much information that one can put in about for instance the different paradigms, methodologies or strategies. I should concentrate more on getting to the point quicker and only to mention what is applicable in my specific case study. In writing information on a case study I also realised the importance of defining and bounding a case to a specific setting and participant. I thought I knew what my case specifically was, but when I had to define it in a few sentences I found it challenging. My participant's case is much complex than just having a premature infant in a NICU. She had twins and one passed away. Her NICU experience happened two years ago. I wondered how this would affect the definition of my specific case.

19 January 2018
While writing Chapter 3 today, I found myself writing in a very conversational manner. At times when you have been writing these chapters for days at a time you lose track of what academic language to use. I often found myself changing my writing styles from too informal to formal or vice versa. My supervisor advised me to start with bullet points. What is the core facts that you want to say, what do you want to get at?

Then take each of these bullet points and rewrite it in an academic but connecting way. He also taught me that I can often combine different statements into one so that it doesn't get dragged out or repetitive in nature.

23 January 2018
Chapter 1, feedback 3

- Make sure all the words participants are changed to participant.
- Adapt aims to be in line with Chapter 2 and 3.
- Give more facts that are up to date about premature birth and NICU.
- Make sure to use the same tense throughout.
- Do not make statements about what you found in other chapters or after analysis … this chapter was written before Chapter 2 or 4 where I discuss the data analysis and results.

24 January 2018
Initial member-checking process
Today I contacted my participant to verify my initial themes. I also sent her a photo of the diagram that illustrated the different themes. After explaining each theme to her she agreed with my initial results. She did not want to make any changes. I informed her that these themes could possibly change in the future and that I would inform her about it if it were to happen.

13 February 2018
Chapter 3, feedback 2

- Look at sentence construction.
- Be clear about aims of the study and make sure this correlates with Chapter 1 and 2.
- Combine criticism on qualitative and interpretive research.
- Personification: do not use sentences like this study made use of …
- Expand on use of the research journal.
- Make sure content in table is in past tense and written in the first person.
- Be more clear abou the role as a researcher.

14 February 2018
After another feedback session on Chapter 3 I realised that I have to make sure that what I say in my other chapters must mirror what I said in Chapter 1. If I aimed to do specific things in Chapter 1 I can't just add two extra aims in Chapter 2 or 3. My supervisor and I decided to include a section on criticism on qualitative research and the interpretivist paradigm to make it more transparent and apparent that I am aware of the pitfalls of my methodology. Writing this section was quite challenging in that during the whole duration of my research I defended and stated why exactly I chose these paradigms and now all of the sudden I have to write about the criticism and what I have to be aware of. When doing research on these criticisms on both qualitative research and the interpretivist paradigm I realised that the points made were very similar and that I once again felt as if I was repeating myself. My supervisor and I decided to combine these two separate sections as criticism on interpretive qualitative research. I also sated how I would address these challenges.

16 February 2018
After a consultation with my supervisor about my Chapter 3 draft I gain much more insight about common errors that I made in my writing. First of all he addressed my

personification in writing. I often implied that a study did something or that a paradigm took something into account. I realised that I had to mention specific authors more or that say that “it enabled me” and not the “study aims at/shows/provided.” In writing this Chapter I also often jumped to different tenses. Stating in one part that the perspectives used and then I will … my supervisor also highlighted that some of the statements that I made was too vague or loose standing. I had to make it clear what interpretivism was and how I applied it within my study. Just stating lose facts of how it has been used in the past is not sufficient. When explaining my research process I relied on a diagram. My diagram was also provided without context or an explanation. I learned that without an explanation a diagram means nothing. Another issue in my writing is that I often made used of direct quotes. I learned that most of the time there is a way to say the same thing in a different manner while not committing plagiarism. These quotes once again should also not be loose standing but should be integrated into the previous discussion. There should always be a golden thread running throughout my writing.

19 February 2018
Chapter 2, feedback 2

- Look closely at page numbers and only use it if you quote directly.
- Use possible resources of hope in recursive review when relevant.
- Be careful in using the word coping, the study is focussed on hope not coping.
- Explain diagrams and figures clearly in a paragraph.
- Explain the two main discourses of hope more clearly.

1 March 2018
Chapter 2, feedback 3

- Paragraphs should be in a more logical order.
- Make sure that all content under a heading is related to that topic.
- Integrate different parts to not repeat information already said.

10 March 2018
Today I recoded all my data for the third time. I found the process of reducing my verbatim quotes very challenging. During my first analysis of my data I found that I had too many quotes and that some of my themes overlapped. Another challenging part was that some of the verbatim quotes almost did not make sense when it was not mentioned in the context of the conversation. One of the themes where I am still struggling with finding the parameters of the theme is between mastery and motivation. In some parts the participant mentioned that her aim was to get out of the hospital but that hope also pushed her through. I will consult my supervisor on this matter and whether there is enough data to support the two different themes or if they can become part of one overarching theme. The overarching theme of “agency” is a possibility.

19 April 2018
Having an audit trail and a reflective journal came up in many of my research resources. The reflective journal is one thing, but the audit trial is something completely different. I found myself numerous times throughout this research process making notes and scribbling diagrams and thematic mind maps on paper. Highlighting things here and there, taking this out and putting that in and at the end of the day losing track of the process and what came before the other. Sometimes at

night I would also think of a new name or combination of names for a theme and the next day lose my line of thought of how I got to that conclusion. I want to use my hard copies of analysis and diagrams and try to put it over into a word document and include it an appendix in my research, as these thought processes and steps lead to very important decisions within my research. I decided that I would also include a table on how my themes were defined and adapted over time (see Appendix G).

3 May 2018
Chapter 2, Feedback 4

- Make sure aims correlate with aims in Chapter 1.
- Be careful of lose standing ideas.
- Rewrite section on the South African NICU contexts.
- Explain table on SA context and use full sentences to make it clearer.
- Be careful of personification. A study cannot do something, only a researcher can.

5 June 2018
Feedback 3 on Chapter 3

- Make sure about triangulation vs crystallisation.
- Include a short description on the process of member-checking.
- Number pages so that length of dissertation at this stage can be calculated.

18 June 2018
While writing my recommendations and contributions today, it took me back to my aims and purpose of my research. At this time in the research process I found myself questioning if my research actually made a contribution and if I reached my aims of my research. I remember in the beginning of the research process one of our lecturers mentioned that we should always have in mind that we are standing on the shoulders of giants. There are many pioneers of hope that have come before me and I have acknowledged that throughout my research. This research has taken so much time and effort in the past few years that is almost feels like an anti-climax to list my different contributions. Although I see my research as only a drop in the sea of hope, I hope that I was able to give insights into one person's view of hope. I watched Carte Blanche today and saw a segment on Dr Groopman's work and research on hope in children with cancer. I realised while listening to him that I have mentioned many of his key findings in my research. Although he has conducted research on hope on a much bigger scale it was quite interesting to realise that I have come to these findings through the experience of one mother who had no knowledge about hope theory and the benefits and resources of hope in the NICU environment.

30 June 2018
Final feedback on Chapter 3

- Make sure that the terms used in the headings and in the paragraphs correlates with one another.
- Mention the extra data source (photos voluntarily provided by the participant).
- Edit data analysis process. Do not only give information on thematic inductive analysis but mention the exact procedure that I used in my study.
- Change the word paradigm to perspective.
- Write the section on criticism on interpretivist and qualitative research in a more concise way: Focus on contextual nature of research.
- Change research methodology to research process.

16 July 2018
Final feedback on Chapter 4

- Include observations in research results.
- Clearly define the survival nature of hope.
- Change the theme of “Positive personal mind-set” to “Belief in child.”
- Reduce the number of verbatim quotes.
- Include a section on extending hope to others.
- Include more information in the recursive literature review on symbols of hope.
- Change “improvement of medical condition” theme to “health improvement.”

24 July 2017
Final feedback on Chapter 1

- Include a section on how this research relates to the field of educational psychology.
- Move personal interest in study to the end of the rationale.
- Rewrite the definition of hope in this study to allow for meaning making from the participant’s view of hope. This should be done due to the inductive nature of the data analysis.
- Move inclusion criteria to sampling procedures in Chapter 3.
- Include the assumption of hope being interpersonal and developmental.
- Elaborate on the gap in current research.

30 July 2018
Final feedback on Chapter 2

- State why South African studies are relevant to this specific study.
- Double-check different Cherrington sources.
- Be consistent in spelling of terms for example multi-dimensional vs multidimensional

11 August 2018
Final feedback on Chapter 5

- State the findings in a more general manner and less specifically linked to this participant.
- Make sure that the question order in Chapter 1 and 5 is the same.
- Include a discussion on the main research question before elaborating on the sub-questions.
- Write the conclusions more concise.
- Move the photos to Chapter 4 under each related theme

26 August 2018
Final member-checking process
After language editing and many feedback sessions on Chapter 4, I have established my final themes. Some of the themes have been renamed or combined after my last feedback with the participant. Today I contacted the participant to inform her about the final changes. I explained what each subtheme meant and included. She agreed with the changes and commented that it mirrored her narrative of hope experiences in the NICU.

Appendix G:
Audit Trail of Thematic Categories

Research questions	Themes after initial analysis	Second analysis	Third analysis	Final analysis
Nature of hope	• Future orientated • Believing in progress • Positive outlook • Motivational tool • Survival skill and coping • Being excited • Can fluctuate	• Future orientated view • Motivational mastery • Feeling of excitement (combine motivation, mastery, excitement into agency) • Survival skill • Dynamic in nature (already stated nature of hope)	• Future orientation • Agency • Survival skill • Dynamic	• Future orientation • Agency • Survival skill • Dynamic
Internal resource of hope	• Positive mind-set • Bonding activities • Supporting others • Religious believes	• Positive personal mind-set • Nurturing her NICU infant • Supporting other NICU mothers • Personal spirituality	• Positive mind-set • Acts of nurture • Supporting and encouraging other NICU mothers • Personal spirituality	• Belief in child • Acts of nurture • Supporting other NICU mothers • Personal spirituality
External resource of hope	• Medical improvement • Support from medical staff • Familial support • Symbols	• Improvement of NICU infant's medical condition • Caring medical staff • Support from family and friends • Religious leaders and activities • Symbols of reassurance	• Health improvement • Symbols of hope • Caring medical staff • Support from family and friends • Religious engagement • Symbols of hope	• Health improvement • Symbols of hope • Caring medical staff • Support from family and friends • Religious engagement • Symbols of hope
Short term	• Medical	• Medical	• Medical	• Medical

Research questions	Themes after initial analysis	Second analysis	Third analysis	Final analysis
challenges to hope	complications • Prolonged hospitalisation • Personal emotions	prognosis • Surrounding events during prolonged hospitalisation • Physical exhaustion	complications • Adverse events during hospitalisation • Physical exhaustion	complications • Adverse events during hospitalisation • Physical exhaustion
Long term challenges to hope	• Grieve, vivid memories, nightmares, regrets • Medical complications after NICU	• Trauma • Long-term medical challenges (not applicable to hope in the NICU)	• Post-discharge medical challenges	• Post-discharge medical challenges

---ooOoo---